Exploring the potential for public involvement in health research in Singapore

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EXPLORING THE POTENTIAL FOR PUBLIC INVOLVEMENT IN HEALTH RESEARCH IN SINGAPORE

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Lee Kong Chian School of Medicine

*A thesis submitted to the Nanyang Technological University in partial fulfilment of the
requirement for the degree of Doctor of Philosophy*

2020

*Caminante, son tus huellas
el camino y nada más;
Caminante, no hay camino,
se hace camino al andar.
Al andar se hace el camino,
y al volver la vista atrás
se ve la senda que nunca
se ha de volver a pisar.
Caminante no hay camino
sino estelas en la mar.*

Antonio Machado - Proverbios y cantares (XXIX)

Dans "connaître", il y a "naître".

Victor Hugo - Carnets intimes

其实地上本没有路，走的人多了，也就成了路 - 鲁迅

ABSTRACT

Despite growing evidence of the positive impact of public involvement, formally referred to as patient and public involvement (PPI), in research, this remains rare in Singapore. The potential of PPI in the Singapore-Asia context has to be explored.

I conducted a three-phased exploratory study aiming to: 1) set the background through a mapping review of published articles and grey literature, including media reports, 2) provide a national perspective through a qualitative study guided by thematic framework analysis and 3) provide a study perspective through a case study of involvement in a local biobank study using the Theoretical Domains Framework. An iterative research process was adopted throughout all phases, enabling findings from each phase to be integrated.

Phase 1 highlighted a shift towards patient-centeredness in Singapore, both in clinical curriculum and practices, and a desire to continue the road of patient activation and engagement. The shift for the clinical aspect could facilitate a shift in research-oriented tasks.

Phase 2 revealed that most interviewees (n = 40) expressed a lack of experience with PPI, which was perceived as a beneficial strategy, both by researchers and by lay members. Whilst highlighting both utilitarian and ethical reasons for implementing PPI, challenges specific to the Singapore-Asia context made involvement at an individual level less likely to be successful. Interviewees - researchers from diverse disciplines and levels of experience, and with roles in funding panels and ethics boards, and lay members of diverse background and ages - identified formal and informal strategies to overcome barriers, favouring an asset-based, more community-oriented approach.

In Phase 3 biobank researchers' attitudes were best described through the theoretical domains of knowledge, skills, professional role, professional identity, environmental context and resources, and goals. Sometimes, PPI was simply seen as a middle "nice to have" element, but not one to be considered before other priorities were resolved. Researchers' experiences of collaborating with the public during this case study were described as a motivation for further involvement.

A cultural reluctance of individuals to question perceived authority figures, such as health professionals, clinical scientists and researchers was noted in both Phases 2 and 3 of this study. It may be overcome by adopting an approach to PPI that is closer to local community values, and which facilitates patients and the public collectively engaging in research. Careful consideration needs to be given to issues of resource and support to enable members of the public to engage in meaningful ways that will deliver research best placed to improve patient outcomes.

The project's findings have been used to develop a useful framework to develop and support PPI in the Singapore-Asia context: the supported model of involvement. In the Singaporean context, the timeliness of involvement implementation will heavily rely on political opportunities, as central coordination and support appears to be a decisive factor for many. Despite not having a recipe for involvement, successful work with members of the public is more likely if adhering to four sets of basic principles: adapted to the local context, diverse & inclusive, timely & purposeful and reciprocal & respectful. Preparing fertile ground for collaboration will also require planning and early work building relationships and trust.

Statement of Originality

I hereby certify that the work embodied in this thesis is the result of original research, is free of plagiarised materials, and has not been submitted for a higher degree to any other University or Institution.

A handwritten signature in black ink, appearing to read 'Lidia', is written over a horizontal line.

10/07/2020

Lidia Luna Puerta

Supervisor Declaration Statement

I have reviewed the content and presentation style of this thesis and declare it is free of plagiarism and of sufficient grammatical clarity to be examined. To the best of my knowledge, the research and writing are those of the candidate except as acknowledged in the Author Attribution Statement. I confirm that the investigations were conducted in accord with the ethics policies and integrity standards of Nanyang Technological University and that the research data are presented honestly and without prejudice.

A handwritten signature in black ink that reads "Helen Smith". The signature is written in a cursive style with a long, sweeping tail on the "t" at the end.

12.07.20

Prof. Helen E. Smith

AUTHORSHIP ATTRIBUTION STATEMENT

This thesis contains material from four papers published in the following peer-reviewed journals where I was the first and corresponding author.

A refined version of Chapter 4 is published as Luna Puerta, Lidia, Bernadette Bartlam, and Helen E. Smith. "Researchers' perspectives on public involvement in health research in Singapore: The argument for a community-based approach." *Health Expectations* 22.4 (2019): 666-675.

The contributions of the co-authors are as follows:

- I designed the study and arranged and conducted all the interview work, including the literature review necessary in preparation for it and the creation of the interview guides. I also analysed the data.
- Dr. Bartlam analysed a sample of interviews to check for inter-coder agreement.
- Prof. Smith provided insights to the data analysis when both coders (Dr. Bartlam and myself) could not reach consensus.
- I prepared the manuscript drafts. The manuscript was edited by Dr Bartlam and revised by Prof. Smith.

A refined version of Chapter 5 is published as Luna Puerta, Lidia, et al. "Perspectives on public involvement in health research from Singapore: The potential of a supported group model of involvement." *Health Expectations* 23.5 (2020): 1074-1085.

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- Dr. Bartlam analysed a sample of interviews to check for inter-coder agreement.
- Prof. Smith provided insights to the data analysis when both coders (Dr. Bartlam and myself) could not reach consensus.

- I prepared the manuscript drafts. The manuscript was edited by Dr Bartlam and Prof. Smith and revised by Prof. Sun.

A refined version of Chapter 7 is published as Luna Puerta, Lidia, et al. "The reported impact of public involvement in biobanks: A scoping review." *Health Expectations* 23.4 (2020): 759-788.

The contributions of the co-authors are as follows:

- I proposed the review direction and drafted the protocol. I conducted the literature search and data extraction. I performed the synthesis of the data extracted and I prepared the manuscript drafts.
- Will Smith commented on the protocol. Thereafter he acted as second reviewer, performing the literature search and data extraction. He refined the synthesis of the data extracted and was a major contributor in writing the manuscript.
- Dr. Davies advised on the literature search and format of data synthesis.
- Prof. Ward guided the direction of the review and edited the manuscript drafts, revised together with Prof. Day and Dr. Davies.

A section from Chapter 8 and the text in Appendix 13 are published in Puerta, Lidia Luna, and Helen E. Smith. "The "PPI Hawker": An innovative method for Patient and Public Involvement (PPI) in health research." *Research Involvement and Engagement* 6.31 (2020).

The contributions of the co-authors are as follows:

- I formulated the concept of the "PPI Hawker". I was the coordinator of the "PPI Hawkers". I designed and conducted the three "PPI Hawker" sessions, and I analysed the comments coming out of it. I maintained the relationship with the PPI Facilitators and the researchers from the population-based research study throughout.
- Prof. Smith was a contributor in developing the evaluation of the PPI hawker and writing the manuscript.

10/07/2020

Lidia Luna Puerta

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ABBREVIATIONS

Abbreviation	Full name
PPI	Public involvement (formally Patient and Public Involvement)
NIHR	National Institute for Health Research
NHS	National Health Service (from the United Kingdom)
UK	United Kingdom
PAR	Participatory Action Research
ASEAN	Association of Southeast Asian Nations
PROMs	Patient-Reported Outcome Measures
PCORI	Patient-Centered Outcomes Research Institute
RCT	Randomised Controlled Trial
WHO	World Health Organisation
MOH	Ministry of Health
CJ	Citizens' Jury
TTSH	Tan Tock Seng Hospital
CBPR	Community-Based Participatory Research
CAB	Community Advisory Boards
NUS	National University of Singapore
KPI	Key Performance Indicator
IMH	Institute of Mental Health
LKC	Lee Kong Chian (School of Medicine, Nanyang Technological University Singapore)
ICL	Imperial College London
NHG	National Healthcare Group (Singapore)
PI	Principal Investigator
PO	Patient Organisation

INTRODUCTION

This thesis explores the perspectives of different stakeholders on public involvement in health research in Singapore and examines how public involvement could be implemented in health-research studies conducted in the local context.

Reasons to do this work

Since its City Council launched Decide Madrid, my home city of Madrid has become an example of digital democracy and public participation.^(1–4) Decide Madrid is a pioneer e-participation platform allowing citizens, associations, NGOs and companies to have a voice in the policy cycle of Madrid's municipality. Through it, I realised for the first time, that citizens can have a say in areas that until then, I thought were spaces for professionals only. For years, while I was enrolled in INSA de Lyon, an engineering school in France, I was an active user of Decide Madrid. So I regularly received email updates on proposals

and voting timelines that I closely followed. It enabled me to keep a strong connection with my city.

Thinking about a PhD topic, I felt the need to connect to Singapore, my adoptive city, and was reminded of the origins of participatory democracy in Madrid. This began in 2011 when Madrid was paralysed by a small group of residents camping out in the city's central plaza in the first days of the anti-austerity protests; this would quickly become an anti-establishment groundswell, and then a history-making popular uprising in which thousands of citizens protested and demanded better democracy: the May 15 Movement.⁽⁴⁾ Pablo Soto, one of the early protesters, described himself as “*an activist for democracy*”.⁽⁴⁾

Protestors spent months camping while thinking about the way societies are organised, planting the seeds to develop the first digital tools for “collective intelligence”. As the number of protestors grew, new forms of communication became necessary, and some protestors created their own communications software to exercise “true democracy”.⁽³⁾

In 2015, as corruption scandals were revealed nationwide and citizens' confidence in governing bodies decreased,⁽⁵⁾ a new coalition party, *Ahora Madrid* (Madrid Now), emerged, placing former protestors as councilmen,⁽⁶⁾ and bringing to the political arena the urgency “to build the tools for the people to be in charge”.⁽³⁾ As a result, Decide Madrid was launched.

With the ambition of ensuring transparency in the governance of the city, and to strengthen the public voice in decision-making and spending processes, its essential goal was expressed as “*empowering citizens, promoting transparency, and fostering open government practices*”.⁽²⁾ The platform aims to encourage citizens' voices by inviting them

to generate new ideas that could improve the quality of life of Madrid's citizens(1,7) through three principles: participation, transparency and open data.(8) With Decide Madrid, the public are involved in various stages of the policy cycle.(2,3)

To improve transparency, citizens have access to information necessary to inform their involvement (e.g. technical reports, proposals for public consultation and related information), and statistical information on participants' profile is made available.(1)

In 2018, Decide Madrid was awarded the United Nations Public Service Award in the Category "Making institutions inclusive and ensuring participation in decision-making".(1) The impact of Decide Madrid can be evaluated at three different levels: on the citizens of Madrid, on Madrid's policy and wider impact.

Citizens have directly benefitted from participatory budgeting, since they are the recipients of the projects they choose to fund. Also, the website has been designed to seamlessly unify their options for participation,(3) and consequently citizens of Madrid have voiced their satisfaction with the platform.(4) In its first three years, citizens have launched over 1000 initiatives and determined 2% of the municipal budget.(1) The most successful project to date was the renovation of *Plaza de España*, for which 26,961 citizens participated in the crafting and voting of ideas.(2) While 45,522 users took part in participatory budgeting initiatives in the first year, by September 2019 the platform gathered 460,000 registered users.(9) However, it is important to highlight that only 13% (n=60,630) of registered users voted in the early phases (10) and 7% (n=32,418) in the final phase of 2019 participatory budgeting.(9) In fact, just over half of registered users have verified their accounts and thus are able to participate.(9)

With regards to Madrid's policies, internal and external collaborations have been made more efficient and effective. Decide Madrid has revamped the organization of the

city council. All administrative units contribute to Decide Madrid by proposing topics and evaluating the proposals. Decide Madrid has also abolished barriers for citizens to participate, as the platform can be accessed anytime from anywhere.⁽¹⁾ Nonetheless, there is no proof that the website leads to improved decisions/decision-making or that enough people are taking advantage of the website.⁽⁶⁾ Whilst it has allowed citizens to give their input on drafting and modifications affecting Madrid, and many different citizens have commented on the ordinances and made suggestions for improvements, there is as yet no evidence that these processes have influenced any of Madrid's laws; neither is there evidence concerning the effect that this process has had on participants' attitudes about public issues, trust in the government, or sense of community identity.⁽⁶⁾ In fact, some members of the public have expressed discontent at how little information has been revealed on the progress of approved projects and on the impact of their inputs.⁽¹⁾

More widely, Madrid's City Council set a target of helping to expand the platform to 25 cities, as the Consul software is free to use. Strategies were in place to support other local governments wishing to initiate their own versions, providing technical, organisational and legal advice. Today, more than 93 cities and regions in Spain (Barcelona, Valencia, Oviedo, A Coruña) and beyond (Buenos Aires, Paris, Turin, Jalisco, Uruguay) are replicating the model of Decide Madrid.^(2,4)

Despite the apparent national and international impact beyond Madrid, I wondered why, even amongst my family and friends, I had never had a conversation about Decide Madrid, or any of the projects suggested. Were we prepared for it? Did we need it? I also thought that not much had been done over the years to raise awareness on Decide Madrid, so that only those who knew it from its start would be part of it. Moreover, I quickly realised some of its limitations, such as accessibility for those not 'tech-savvy' (including older and/or poorer people). I also wondered whether the initial aspirations of Decide Madrid had been realised and admired the accomplishments of other cities and even countries

who have pushed participatory governance even further; the most radical is the Icelandic case, where a new constitution was crowd-sourced through months of citizens' consultations and contains a provision for citizen-led initiatives to propose and alter legislation.(11)

When the time came to choose a PhD topic, I remembered Madrid's example and questioned whether the same eagerness to open up reserved spaces could also apply to health research. Whilst at that stage, I had never heard of public involvement in health research, a potential supervisor had some experience. Together, we decided to build up on my knowledge of participatory practices in Spain to explore the potential for public involvement in health research in Singapore. This would entail understanding the local context, gaining knowledge on the theory and practice of public involvement and hopefully, find answers to questions like the ones I had when thinking about Madrid.

Introduction to public involvement in health research

Public Involvement, formally Patient and Public Involvement (PPI), in health research has been recognised and endorsed since the 1970s.(12) Its aims are to increase democratic rights and public accountability, just like in the Decide Madrid case, and to improve health-care services and medical knowledge.(13) Since its inception, PPI has

progressed and developed, gradually becoming more mainstream in some, but not all, countries.

The evidence that PPI in health research carries a number of benefits for research, including the production of higher quality, more efficient and effective research, has been accumulated over the last 20 years.(14–28) During that period, PPI has become widely integrated into research in many Western countries, where some health research funders and policy makers make it a mandatory consideration, most notably the National Institute for Health Research (NIHR) in the United Kingdom (UK).(14,29,30) In North America, Australia and some European countries, such as Denmark and Spain, research commissioners and national organisations are also becoming increasingly aware of the importance of PPI.(31–40) An international network advocating for “a world where patient and public involvement is an integral part of health research” was launched in late 2017 and has been joined by 240 organisations and individuals worldwide.(41)

Although public involvement can be interpreted in various ways, the key principle of PPI is that the public is actively involved in the activities, organization and governance of health research, whether in specific projects or in research more generally.(14) It is defined as “research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them”.(31)

The utilitarian case for PPI(19,25,42,43) argues that by incorporating public knowledge and expertise, researchers can identify and develop user-centred research objectives and questions,(45,46) more appropriate research materials, enhanced recruitment strategies, user-centred interpretation of data,(47) enhanced cost effectiveness,(22,48–50) and optimize the dissemination, implementation and impact of research findings.(18,22,23,25,50) This is based on the premise that “*if the needs and views of users are reflected in research, it is more likely to produce results that can be used*

to improve clinical practice".(51) PPI can inform all aspects of research since patients *"know what it feels like to undergo treatments and their various side effects [...] they will have a good idea about what research questions should be asked [...] and how questions might be asked differently"*.(52) Involvement benefits everyone:(47) it can directly impact those participating, increasing self-confidence and knowledge,(53,54) and researchers can increase their experiential knowledge and communication skills through PPI interactions.(55,56) As a result, PPI is being embraced by commercial enterprises, such as those in the pharmaceutical industry, as well as public bodies.(48,49,57)

Balancing this utilitarian model, is the Kantian 'Categorical Imperative'. This argues that human beings are not means to an end(58,59) but rather ends in themselves, and that it is incumbent on people to always act as members of their communities, in which all other members are also ends in themselves. From this position, it can be argued that members of the public are legitimate and central stakeholders in research affecting the health of individuals and communities, who also contribute to the public funds often needed for its conduct.(25) Processes and strategies, such as PPI, can ensure good governance through supporting transparency and accountability in the use of such funds.(60) Linked to this are arguments on the importance and role of lay knowledge, which emphasise patients and members of the public as experts because of their 'lived experience', and them having responsibility to be meaningful partners rather than passive subjects and/or recipients of research.(61–64) PPI builds on the concept that knowledge extends beyond 'expert knowledge' to include the understanding that patients develop from living with their illness,(65–67) which can contribute to a broader understanding of the treatments that researchers study, improved knowledge translation, and more successful outcomes.(45,68) This emphasis on lay knowledge carries with it two challenges in particular:(25,61,69) first, the objectivity of the expert knowledge base; and second, a political challenge to the authority of experts in decision making policy. Lay knowledge and perspectives play a crucial role in opening up research evidence to public

debate. And the ethical argument suggests that PPI can rebalance power,(58,70,71) giving a voice to those whose knowledge is less heard in traditional academic and clinical settings.(61–64) PPI provides researchers with new perspectives from the public as ‘marginal knowers’ and yet ‘agents of knowledge’,(72) who can share their expertise.(45,73,74)

Tied to both the utilitarian and the ethical argument for PPI, is the consideration of research waste. In 2009, estimations by Chalmers and Glasziou reported that, despite the large sums of money being invested in it, 85% of all clinical research goes to “waste”.(75) Their study flagged four situations within current research practices contributing to waste:

1. Prioritisation of research questions that are irrelevant to health professionals and patients
2. Leading unnecessary or inappropriate studies or study designs
3. Failure to publish research findings
4. Selective reporting of research findings (75)

The most pernicious consequences of research waste, relating to research integrity,(76,77) are felt most by patients and members of the public. Indeed, if resources are wasted on a given endeavour, other health interventions, potentially more effective or future research projects based on the public’s priorities, might not be able to receive sufficient funding.

In response to 2009’s estimates of waste in research, in 2014 The Lancet promoted more consideration of research priorities,(78) improved research design, conduct and analysis(79) obtaining appropriate regulatory and governance approvals,(80) accessible research documentation(81) and appropriate research reporting(82) to target the major causes of avoidable waste.

A major step towards reduction of waste is the production of research relevant to its users, patients and other members of the public,(78) and thus the recognition and adoption of PPI in the design and conduct of research.(83,84) PPI leads to user-centred research that is more likely to be implemented, resulting in improved cost effectiveness of research is improved and minimisation of waste.(22,48–50)

PPI can occur at multiple stages of the research cycle.(85–87) Since PPI was introduced, numerous ways of involving the public have been proposed, from community involvement to patient-led research, through members of the public sitting in committees or management groups.(45,88–90) There is no one-size-fits-all approach, and the most appropriate method depends on the specific research question, health condition, population, and the available resources.(86,90) Nonetheless, numerous stakeholders, including journals,(45,91,92) advocate for PPI, and argue that, unless there is a valid reason not to, it should be the default approach of all research teams.

So far, the main PPI focus has been to encourage researchers to welcome members of the public as equal stakeholders in an environment for which experts have traditionally been the gatekeepers, while and incorporating lived experiences and knowledge into clinically scientific studies.(93–95) Efforts have also been directed at improving PPI reporting and evaluations of how different publics can add value to research,(96–98) whilst more conversations are required to understand the effectiveness of different methods, operations and best practices.(99) Although public involvement is often presented as a panacea, it does not come without limitations, particularly in the discussion of its impact. These will be presented in Chapter 1.

While much literature has explored the extent and impact of PPI in Western countries, there is little consideration of it through a non-Western lens and the evidence base for its use in Asian countries has not been considered before.

Introduction to Singapore

Western models of PPI tend to emphasise almost exclusively the contribution of individuals. To expand these models and make them context-specific, Singapore provides an interesting case study for exploring the potential of PPI within an Asian context. Indeed, it is perhaps amongst the most outward looking of members of the Association of Southeast Asian Nations (ASEAN) and a global research hub.

Reflecting its ethnic mix, Singapore has four official languages: English, Mandarin Chinese, Malay and Tamil. English was adopted as the first language in schools in 1966 and is today promoted as the ‘working language’.(100) Since its independence, first from Britain in 1959, and then from the Malay Federation in 1965, Singapore has experienced a dramatic economic and social change. In little over 60 years, it has risen from “Third World” poverty(101) to being an ‘Asian Tiger’, sitting alongside Hong Kong, South Korea and Taiwan.(102) In June 2020, Singapore had 1,351,800 foreign workers (that is 23% of its 5.69 million inhabitants of which 4.04 millions are residents),(103,104) of which 351,800 (26%) were work permit holders from the construction, marine shipyard and process sectors, 252,600 (19%) were work permit holders from other sectors, and 189,700 workers (14%) held an Employment Pass, which allows foreign professionals, managers and executives to work in Singapore. The drive to survive that powered this enormous transition has now transmuted into one that is focused on addressing the tension between its political and cultural position as an outward facing country and its geographical context, surrounded by traditional Asian cultures with a growing emphasis

on religious fundamentalism, including Indonesia and the Philippines.(105) Given these existential challenges, it is perhaps not surprising that Singapore is characterised by a strong government with a culture that privileges the collective rather than the individual experience.(106)

Singapore is an island city-state of only 722.5 sq. km.(107) With such scarce geographical resources and a rapidly ageing resident population that has increased from 1,886,900 in 1965 to 4,026,200 in 2019,(107,108) the Government has prioritised investment in knowledge capital.(109,110) Singapore prides itself on leading global rankings in education.(111) It has an education system structured to “foster a sense of national identity”(24) and Shared Values(106,112–114) to promote unity within the diverse population. Singapore workers are among the hardest working in the world, in terms of number of hours worked.(115) In addition, concerns are growing over affordable retirement as studies have found that retiree households living in public housing receive the bulk of their income from their children or relatives,(116) and that the majority of working adults in Singapore are financially unprepared for retirement.(117) This has implications for leisure time and availability for volunteering.

In 2016 SG\$19 billion (US\$14 billion) were invested in education and research.(118) Consequently, Singapore is rapidly becoming a world-class research hub, attracting international scholars and researchers.(109,119,120) Whilst this drive to innovation and excellence in research includes an emphasis on the advancement of patient care through translational clinical research, active involvement of patients and the public appears to remain rare beyond patient participation.

The collaboration between patients and researchers has been described as “*a fundamental paradigm shift in health and social care research, away from paternalism towards partnership*”.(92) As the effective engagement of all stakeholders across the

entire health system, including providers and patients, is required for large-scale health-care transformation,(122,123) PPI may be an mechanism to promote Singapore's further transformation of healthcare.

Aims of this Thesis

The aims of this thesis are i) to understand the perspective of different stakeholders in Singapore about public involvement in health research, and ii) to examine how public involvement could be implemented in health-research studies conducted in the local context. These research aims are exploratory and broad given the scarcity of existing research and the need to begin developing our current understanding.

To complete these aims, I am guided by the following research questions:

1. What are the existing uses, policy and drivers for public involvement in health research globally, and in Singapore (if any)?
2. What are the current models of patient involvement in health care related research in Singapore?
3. What are the views, preferences and experiences of local key stakeholders on public involvement in research?
4. What are the recommendations for research policy and practice in Singapore to move the public agenda forward?

Organisation of this Thesis

The central theme of this thesis is the exploration of the potential of public involvement in health research in the Singapore-Asia context. The first three chapters (1-3) outline the research context and the theoretical and methodological framework. Chapter 1 introduces public involvement in research, tracing its history, recalling different justifications and methods of involving, and presenting its impact. Chapter 2 reviews the role of the public and patients in Singapore in health care and research and beyond at the time this thesis started. This chapter introduces the reader to the cultural context in which this work took place. Chapter 3 elaborates on the theoretical and methodological approach chosen for this study, which is further expanded in the Appendices.

The second part of this thesis consists of three chapters,(4-6) addressing the qualitative study carried out to answer the third research question and outlining a national perspective on the potential for public involvement in health research in Singapore. Chapter 4 reports findings from interviews with researchers in Singapore, exploring their views and experiences of PPI and the implications for public involvement in research. Chapter 5 introduces the Singaporean public's perspectives on PPI and proposes a model for combining these with the previously reported perspectives of researchers in Singapore. Finally, Chapter 6 explores how the vision of Singaporean public and professionals relates to the 2018 NIHR Standards for public involvement in health research, reflecting on whether these could be used as a framework to build PPI in Singapore.

The third part of the thesis (chapters 7 and 8) provides a study perspective of the implementation of public involvement in research in Singapore, through a case study of the introduction of involvement in a local population-based study. This is done firstly through a scoping review of the impact of PPI in population-based studies, in order to appraise various methods and best practices of involving the public in such types of studies (Chapter 7). A case study is reported in Chapter 8, in which I reflect on the process of implementing public involvement within a flagship prospective cohort study in Singapore, using a novel approach to public involvement specific to the local context: the PPI Hawker.

In conclusion, Chapter 9 provides a concise overview and interpretation of the findings and a discussion of their implications for various stakeholders in the local context. Strengths and limitations of this thesis are also acknowledged, together with recommendations for further research.

The timeline of the research is summarised in Figure 1.

Figure 1: Research timeline

CHAPTER

1

BACKGROUND: PUBLIC INVOLVEMENT IN RESEARCH

This chapter provides an overview of the rationale and development of public involvement in health research. It introduces the role of the public thinking generally about research and evidence, rather than as individuals making decisions related to their own health and illness. I provide insights on what public involvement (PPI) in research is and provide a brief review of the evidence around it. I also examine the developments of involvement in research, locating it within related political, theoretical, and sociological debates. This leads to the rationales for involving the public, with a brief exploration of PPI at various stages of the research.

I begin by clarifying the terminology used to refer to lay involvement in research, providing a justification for the use of public involvement in this thesis. I will continue exploring the rationales given for the development of public involvement in research, with an emphasis on some key policies that catalysed its development globally, with a focus on the UK.

1.1. What is public involvement

1.1.1. The Meaning of Involvement

For over two decades, public involvement (PPI) in health research has been promoted within the United Kingdom at the highest levels. For this reason, this thesis will adopt the definition that is advocated in the UK.

INVOLVE, the National advisory group promoting public involvement (PPI) in the UK, defines involvement as research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them,(31) shown in Figure 2.

Figure 2: Schematic definitions of participation, engagement and involvement

Public involvement aims to empower individuals and communities to play a greater role in shaping health and research to maximise the benefits to both patients and society.(124) PPI refers to members of the public being actively involved in the research

process itself, rather than being passive participants or subjects of the research.(125) Patient involvement is hence opposite to traditional forms of research, where patients have been involved “passively” as subjects or trial participants, with patients and their representative organisations only rarely seen as partners in research practices.

Involvement includes patients, relatives, friends, and caregivers, who can use their experience of a certain illness to help shape research. During the process of involvement in research, the researchers consult, collaborate, or partner with members of the public at any stage of the research process to bring value to their work. Examples of involvement include defining research questions, planning and designing research studies or research materials (including the protocol, patient information, and informed consent), working with members of the public during the conduct of the research, disseminating research progress together, and designing and undertaking other involvement activities.

Involvement is part of a continuum together with public engagement and research participation.(126) The latter refers to patients or healthy volunteers taking part in the research. Participation occurs when patients contribute data to a study, and thus, research is being done ‘to’ them, rather than ‘with’ them (Figure 2). Research participants are essential parts of the research, as researchers rely on them to conduct their studies. For example, during clinical trials, new treatments are tested, refined and improved on patients and healthy volunteers before becoming commercially available.

On the other hand, engagement happens when information and knowledge about research are shared with the public (Figure 2). Engagement raises research awareness—for example, by providing patients with information about what it means to take part in a longitudinal study. Researchers must share the progress of their work and disseminate the results of their studies to members of the public, fundraising supporters, and the next generation of scientists to have an impact. Researchers can engage the public by

organising lab tours or research open-days, by writing blogs or by giving public talks and lectures.

The concepts of participation, involvement, and engagement are linked but distinct and complement each other.(127) Although there is no general formulation for involvement, there are two key differences between these three levels. Firstly, involvement requires the public is actively involved in the activities, organization, and governance of specific research projects or research in general. Secondly, a two-way communication takes place between the researchers and the members of the public during involvement.

Also, the construct ‘participatory research approaches’(128) is often used as an umbrella term which covers ‘participatory action research’ (PAR)(129,130), co-design(131,132) and co-production of research.(133,134) PAR unifies three basic aspects: participation (life in society and democracy), action (engagement with experience and history), and research (soundness in thought and the growth of knowledge). It is an approach to research in communities that emphasises participation and action. It seeks to understand the world by trying to change it, collaboratively and following reflection.(135,136) PAR was strongly influenced by the work of Paulo Freire(137) and South Asian social movements such as the Bhoomi Sena,(138,139) and draws on a wide range of influences both among those with professional training and those who draw on their life experience and those of their ancestors. Fundamentally, PPI, PAR and other participatory research approaches share a philosophy of valuing partnership and collaboration, encouraging lay people to take on the role of the researcher with a stronger voice to influence research planning, development and implementation. PAR potentially involves a substantial time commitment for the researchers and some of the key stakeholders, and extends beyond health research, involving whole communities on the topic of interest. Since it is public involvement that is promoted by health organisations in

the UK, which has served as a model in other areas of healthcare in Singapore, in this thesis I will focus on public involvement in health research.

As public involvement in research has grown in the UK, becoming a requirement for research projects and programs funded by some health and social care funders and strongly encouraged in all cases,(43,55) it has also been increasingly encouraged globally. Multiple understandings for engagement, involvement, and participation have emerged across and within countries, which is a challenge for reporting involvement and for creating a global body of evidence.(140) For example, PPI is referred to as ‘stakeholder engagement’ in North America,(32,141) while the same is called ‘participation’ in the Netherlands (142) and ‘consumer and community participation’ in Australia.(33) However, in all those cases, the ultimate aim remains to produce good quality research conducted with and by members of the public.

Finally, as the context of public involvement varies, so does the process. PPI interventions are now described as ‘complex interventions’.(68,90,124)

1.1.2. Who are the Public?

The same confusion applies when referring to the actors of involvement, the members of the public.(143) There is also no single definition of ‘public’ but instead a “plethora of publics”.(144)

Conklin et al. (145) performed a scoping review of public involvement in healthcare policy and found that definitions included representatives of patient organizations, ordinary citizens, community/local residents, and the community. Other terms used to describe individuals who can be actively involved in the research include consumers,

customers, stakeholders, partners, carers, citizens, clients, users and service users.(65,146)

Greenhalgh (147) developed a table with the common names for laypeople when involved in research, adapted in Table 1. The terms included are not interchangeable and are all different, specific to a particular context. For example, the term ‘consumer’ has now been abandoned due to its connotations of market ideology.(148) It was widely chosen in the literature of cancer research and was also used by INVOLVE and the Cochrane Collaboration before it was replaced by ‘public’.(149) Greenhalgh also noted that there is an overlap between the ‘public’ and ‘patients’, as we could all be both at times, concurrently.

Members of the public can be involved in the research process either individually or as a collective, as members of local, national, or international groups, as reflected in the taxonomy in Figure 3.

As we saw when introducing the different terms used to refer to PPI, different countries use different terms to refer to the public, and different people prefer different names too. In this work, as per INVOLVE’s definition, the ‘public’ includes patients, potential patients, carers and people who use health and social care services as well as people from organizations that represent people who use services.(31) The line of demarcation is thus between those that have a professional role in health and social care services and research (such as researchers, scientists, and other healthcare practitioners) and those that contribute on the basis of illness experience. I will refer in the following to ‘public’ or ‘members of the public’, or ‘lay’ as it is reflected in the health policy recommendations and INVOLVE guidelines.(16,89)

Table 1: Definitions of names for laypeople when involved in research. Adapted from Greenhalgh (147)

Name	Definition	When to use this name
PUBLIC	Everyone, especially in a defined country or geographical region	When talking about accountability to the public (e.g. whether something is a good use of people's taxes)
CITIZEN	Almost the singular of 'the public' (except some people, e.g. refugees, lack of full citizenship status)	When looking for someone to represent the public perspective, whose primary orientation is to the public good
LAY PEOPLE	People who do not have expertise or training in a particular field but who are nevertheless affected by it	When looking for the voice of ordinary experience and/or common sense (usually to balance a group otherwise composed of experts)
PATIENTS	People who are seeking or receiving healthcare	When looking for expertise in what it means to be ill and/or receive care (may be called 'experts by experience')
CLIENTS	People who are seeking or receiving social care and (sometimes) care from allied professions or therapists	As with patients, but in the social care/ allied health field
CARERS	People who help another individual look after themselves and access services	When looking for expertise in what it means to care for someone and/or on the wider impact of illness on the family
SERVICE USERS	People who use or seek to use a health or social service (including patients, carers, parents)	When looking for the user experience of accessing and using services
ADVOCATES	People who speak (and who have a mandate to speak) for a particular vulnerable person or group	When seeking the perspective of an individual or group who finds it difficult or impossible to provide that perspective themselves
CONSUMERS	People who make choices (and - usually - pay for them)	When information is being produced to inform a choice (e.g. by patients, service users or their families and carers)
RESEARCH PARTICIPANTS	Humans who take part in research	When undertaking research or seeking the perspective of those who take part in it
SUBJECTS	Animals on whom research is done	Not to be used when referring to humans

Figure 3: Taxonomy of public involvement. Source: Boote et al. (65)

While it is crude to categorise individuals, the distinction between the ‘public’ and the ‘professionals’ is necessary in the context of this study, as they each play different roles in research. While ‘professionals’ take part in research in a professional capacity, the members of the ‘public’ that take part in research give their individual voices from their experience of health services or ill health.(16) Both of these, together with funders and policymakers, are referred to as ‘key stakeholders’ in the following.

Representativeness in Public Involvement

Each individual shares a personal voice, and thus, all perspectives differ and are valuable. Individuals involved do not have to be ‘representative’ of a group. The complex role of lay members is understood in terms of their unique experiences and perspectives that increase the diversity of values and preferences of the research team. It is assumed that those involved will bring a “dose of ‘ordinariness’ or common sense” (147) to a group otherwise composed of researchers, clinicians, and other experts.

Instead of focusing on representativeness, at the centre of involvement is having different opinions around the table and making sure that decisions are made taking them into account. In fact, one of the six standards (98) for PPI advocated by INVOLVE in the UK is “diversity”, suggesting that the most effective involvement occurs when a wide range of voices are heard, as to encourage dialogue and enhancing trust and transparency for truly collaborative work. Diverse dialogues build legitimacy for the involvement exercises. Ultimately, involvement is an effort to diversify the decision-makers, and this effort would be hindered by limiting it to groups having to be heard through a single representative voice.

Using the chance to be part of research, members of the public seek to have their own genuine voice being heard, and individual experiences shared, rather than having a spokesperson. In this blog (150), a patient director from the UK highlights that currently, two problematic approaches are undertaken towards PPI: “feedback” and “representation”. The first approach limits what people can say, as the focus is merely on letting them share their experiences rather than giving them an equal role in the decision-making. As for the second, those involved are classified by the experts in groups to be represented, being reduced to an idea of them, that they need to perform to be kept in the conversation.

Finally, public involvement is distinct from patient advocacy. While the latter requires lay representatives, often designated from a disease-specific patient organisation, PPI aims for inclusive opportunities to invite the public to share their perspectives with the research team. Each individual has a personal voice and thus a unique perspective when involved, and a patient advocate represents the voice of all members of a specific organisation.(151) Patient advocates, representing both individual and politico-scientific issues, are also increasingly involved in research.(152,153)

On the other hand, not having a broad representation of individuals has its own problems. Those involved constitute a self-selecting sample that is, consequently, statistically biased. Three types of representativeness can be identified, as shown in Figure 4.

'Democratic' representativeness	'Statistical' representativeness	'Typical' representativeness
individual is elected by his/ her own peers (and thus is entitled to speak on their behalf)	individual is judged to be mathematically representative of a particular group (e.g. having acute form of a given condition)	individual is considered to share key characteristics and/or experiences with the group represented (e.g. user of A/E services).

Figure 4: Three forms of representativeness as defined by Barnes et al. (154)

Achieving these forms of representativeness has its own challenges. Regarding democratic representativeness, in order for someone to be 'representative' of any large and diverse group of people (e.g., patients who have diabetes), there would have to be a large number of people from that group choosing their representative. This person would then have to be in regular communications with them, updating them on the progress, and listening to their new concerns and experiences. This representative would have to be trained, and there would always have to be a highly organised group of patients and investment in user-led and other forms of grassroots organisations. There is a lack of resources and support to afford such a strenuous organisation. Also, the legitimacy of the spokesperson could be contested by other peers and by the experts. Finally, after having been trained and acquiring a semi 'professional' role of representative, it is unclear whether this person would still have the perspective of a member of the public.

Most commonly, researchers purposefully select members of the public with experience relevant to a specific study, tackling some form of "statistical and typical representativeness". As good involvement requires building reciprocal and meaningful

relationships as well as the investment of time and resources to train and support those involved,(19,155) researchers sustain relationships with a limited number of individuals that are already known to the team.(155,156) The experiences of these few members of the public are unlikely to represent the perspectives of all those that might be affected by the condition under study or by the outcomes of the study, and their opinion should not be generalized and considered to be representative of a unique “patient perspective”.(64,157) This would undervalue and silence the voice of other members of the public that might want to be involved and go against the rationale of involvement in research. Despite these issues, there are no guidelines for researchers regarding the rotation of members of the public involved for extended periods of time with the same group of researchers.

Finally, it is important to highlight that vulnerable groups are less likely to reach out and be heard. In this case, involvement would exacerbate existing inequalities.(143) Numerous efforts are being made to involve seldom heard voices,(158,159) and Canada and Australia have created regulations for the inclusion of indigenous groups and ethnic minorities.(160,161) More efforts need to be done to make sure that these groups have access to public involvement in research, and that some representation of their perspective exists.

Ultimately, two broad criteria have been proposed to guide researchers looking for members of the public to involve. Firstly, it is recommended to involve individuals or communities for whom the outcomes are of interest.(162,163) Secondly, it is recommended that those involved also display at least notable characteristics, particularly participatory behaviour.(164)

1.2. Involvement throughout the Research Cycle

To guide researchers when involving the public, the NIHR has developed a diagram of the research cycle, shown in Figure 5, highlighting roles for the public at each stage and illustrating some benefits that diverse perspectives can bring at each of its stages.(89,98,165,166)

Figure 5: The Research Cycle. Source: INVOLVE (166)

Deciding when to involve depends on researchers' motivations for involvement. Members of the public can contribute at specific stages or throughout the research cycle. Evidence suggests that the impact of involvement is greater when the collaboration between researchers and the public occurs at all stages.(167,168)

INVOLVE recommends involving members of the public as early as possible.(169) The commitment of those involved is greater when they are involved from the start, as it encourages a sense of ownership of the research.(170) Members of the public can be involved from the development of the research proposal and the formulation of research topics and questions.(171,172) In the UK, the James Lind Alliance, established in 2004, is a non-profit organisation that brings together patients, carers, and health professionals to create 'Priority Setting Partnerships'.(173) Academic researchers and industry use the outcome of these democratic exercises to plan future studies, and the top ten unanswered questions about treatment are made available to inform research funders.

As PPI becomes a requirement from funders, a project stands better chances of being funded (174) by demonstrating consistent and inclusive PPI throughout the whole project, including drafting the research proposal.(175) This is particularly the case when peer review is part of the process, and members of the public sit on the committee,(176–178) as these focus on the personal and social relevance of the research when making their decisions.(179) Researchers having involved the public support the benefits of including the public at this stage, such as avoiding wasting resources due to designs that do not work later on.(180) Truman and Raine reported difficulties when fully involving the public at later stages and concluded that “many of the problems we encountered might have been avoided if users had participated as fully at the beginning of the research as they did at the end”, and that “the quality and validity of our research improved as user participation increased.”(181) Within the design stage, the science Patient-Reported Outcome Measures (PROMs), i.e. “standardised, validated questionnaires that are completed by patients to measure their perceptions of their own functional status and wellbeing”, is a field by itself.(182) PROMs allow the efficacy of a clinical intervention to be measured from the patients' perspective and are central to the conduct of relevant research. The Patient-Centered Outcomes Research Institute (PCORI) is a United States-

based non-governmental institute created to fund research programme interventions including PROMs.(32,183)

Also, involvement of the public during the dissemination and implementation of findings is most effective if the public has been involved at other stages of the research process.(184) This could be because members of the public translate the aspects of research relevant to their local context, facilitating these findings to be embraced by other members of their communities and giving them the chance to discuss the implications on the research with researchers. Moreover, “building deep and enduring partnerships facilitates both these processes”,(184) suggesting that if members of the public involved in the dissemination are involved at other stages of the research, their impact at later stages is likely to be amplified.

Linked to this, long-term involvement has also been shown to be a facilitator and contributor to success.(180) During this time, those involved gain greater insights into research, and the relationship between them and the researchers develops, becoming more constructive and communication and learning occurring in both ways. For research advisory groups, maintaining continuity of members facilitates group cohesion and in-depth knowledge and contributions to the study.(185)

Regardless of the stage of involvement, it is important to seek active, inclusive, long-term, and well-coordinated collaboration with the public. It is also necessary to consider the purposes and circumstances of the involvement, e.g., whether you wish to initiate PPI to help with specific issues or problems arising during the course of a trial, or you wish to initiate it earlier in the research cycle or are even considering including a patient as a co-investigator. Overall, the evidence shows that the earlier involvement is initiated, and the longer people are involved in a study, the greater the research outcomes and its impact will be.

1.3. The Evidence for the Benefits of Public Involvement

The evidence base for PPI has grown over two decades. Despite the complexity of assessing PPI impact, there are examples demonstrating the potential benefits of involving the public in research.(186,187) As a result, PPI is being embraced not only by many public bodies but by commercial enterprises, such as the pharmaceutical industry.(48,49,57,188,189)

1.3.1. Overview of Impact

Today an increasing number of reviews highlight evidence demonstrating benefits of PPI to research outcomes in various research areas.(50,50,124,190–192) For example, there is strong evidence for public involvement in the field of mental health research,(22) as it enhances the quality of the research (24,26) and has a positive impact on those involved (193) and on the researchers.(124,194)

In an ambitiously structured literature review of the evidence of PPI funded by INVOLVE in 2009, Staley systematically gathered and reviewed the literature on PPI and found involvement can inform all aspects of research and has numerous forms impacts,(187) represented in Figure 6. First, involvement influences the research agenda— promoting the identification of user-centred research objectives and questions and funding decisions. Patients have lived experiences of conditions and their treatments and can comment on areas of uncertainty where research is needed. Secondly,

involvement has an impact on research design and delivery—influencing the project design, tools, and choice of method, recruitment, data collection and analysis, writing-up, and dissemination. Indeed, a utilitarian argument has been put forward (19,25,42,43) based on the premise that embedding the views and needs of patients in research is more likely to develop more appropriate research materials; enhance recruitment strategies; enrich data analysis; improve cost-effectiveness;(22,48,49) and optimise dissemination, implementation and impact of the research findings.(18,22,23,25,50,195) Illustrative examples of these are provided in Table 2 below.

Research ethics, such as consent process and developing ethically acceptable research gain from PPI. Moreover, PPI can also positively impact on all stakeholders, from the people involved to the researchers, through the research participants and even the wider community and community organisations, increasing self-confidence, knowledge and skills.(53–56)

Table 2: Examples of the impact of involvement on various stages of research projects

(Refining) research design	Patients were involved in a pilot RCT study aimed at exploring the effects of physiotherapy for people with Parkinson's; the feedback from this small pilot would be used for the design of the main trial.(196) Patients had the chance to comment on both practical and conceptual elements of the trial. This included making suggestions on the scheduling of appointments and reflecting on the inclusion criteria. Researchers had not previously realised how different times of the day could affect participants' symptoms, as these are affected by the time of medication intake. Researchers included this in the design and decided to tailor the appointments to the circumstances of each individual participating in the study. On the other hand, patients involved recommended including only participants who could benefit from the trial and could potentially improve. Moreover, patients involved also had a voice in the definition of outcomes. They considered that researchers were too focused on mobility while patients prioritised focus on Quality of Life elements, like sleeping patterns and sense of wellbeing. They highlighted that for patients with degenerative condition like Parkinson's not getting worse and keeping their current level of health is as important as improvement seems from the researchers' perspective. Consequently, the primary outcome would be maintaining mobility during the early stages of the illness.
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(Determining) ethical acceptability of research	<p>Patient and carer involvement was crucial in the design of a clinical trial of a new treatment for stroke issues, as it facilitated working around the ethical concerns of a trial with people affected by stroke.(197) Indeed, the treatment being evaluated would only benefit a narrow group of patients, and only if these were treated within a few hours of the onset of stroke. Also, the intervention could entail serious risks, as it could cause fatal brain haemorrhages in some. Finally, as patients with acute stroke are often unable to communicate, taking consent would be a challenge.</p> <p>Researchers organised a series of focus groups with stroke patients and carers and asked them for their views on the trial. These revealed that people were willing to take part and to accept the risks and provided feedback on useful consent procedures. For example, they suggested being more specific on potential risks and benefits and discussing with the next of kin. Researchers modified patient information documents and in hindsight concluded that feedback from patients helped them get through the ethical review process, and more quickly. PPI helped them to find acceptable solutions to the ethical dilemmas they were facing.</p>
(Facilitating) recruitment	<p>Researchers from a clinical trial for prostate cancer decided to explore public perspectives as recruitment for the control arm (no treatment) had only achieved 40% of the target.(198) A qualitative researcher from the team carried out an investigation (consisting of in-depth interviews with potential participants and listened to tape recordings of the recruitment appointments) to understand why people were declining to take part. The team found out that potential participants were not understanding the purpose of the study, that the different options were not presented equally and that members of the public had difficulty to understand the terms researchers were using. For example, researchers had referred to the control arm as ‘watch and wait’, which some men interpreted as ‘watch while I die’.(p.768) Researchers then changed the term to ‘active monitoring’, that implied that participants of the control arm would not be left but follow-up too, enhancing public confidence. With these changes the team quickly achieved a recruitment of 70%, with a more diverse sample. In other words, PPI allowed researchers to recruit faster and people that would not have taken part otherwise, proving that lay perspectives can be critical when working with “hard to reach groups” and that experts need to understand how to work better with these communities.</p>
(Improving quality) data collection	<p>The National Association for the Relief of Paget’s Disease (NARPD), a patients’ organisation was involved in a clinical trial looking into treatment of Paget’s disease (199). A member of the organisation sat in the Steering Committee of the study and others reviewed the protocol and overviewed the conduct of the study. From the researchers’ reflexions, involvement allowed ‘harnessing of a well-informed and interested population, who developed a sense of ownership of the trial’.(p.83) Participants understood what the aims of the study were, why it was important and how it would help patients, so they were motivated and committed to it, achieving a 98% response rate. Researchers also considered that involvement had facilitated recruitment and that in fact the massive response had improved the quality of the data collected.</p>

Appendix 1: The Impacts of Public Involvement provides a detailed review of the different forms of impacts of public involvement, with some illustrative examples.

1.3.2. The Challenges of Capturing Impact

This summary, like all other reviews and summaries of evidence and impact of involvement, is limited by a number of factors. For example, finding literature on public involvement in health research can be challenging because there are no standard search terms or language for describing what involvement means in each context. Moreover, when reported, PPI and its impacts are often not explained with enough detail, and authors fail to describe the rationale behind the chosen method of engagement or the actions taken as a response to the outcomes of involvement.(19,25,200) For these reasons, some reviews of the evidence and impact of involvement have noted that the evidence was generally not sufficiently robust.(201–204)

In the UK, the first efforts to measure the impact of involvement have focussed predominantly on three aspects:

- The ‘reach’ of involvement initiatives (the understanding of which people and communities have worked with researchers),
- the ‘relevance’ of involvement (the extent to which funding and activities reflect the priorities of the public), and on
- the ‘refinement and improvement’ (how much value involvement adds to research).(192)

A longstanding barrier to developing a stronger evidence base for public involvement from which to improve involvement practice is the under-reporting and sometimes poor quality of PPI in published papers. As of June 2016, less than 1% of published clinical trials included essential information on patients involved in the research.(200) Attempts to address this include the GRIPP-2 guidelines,(205) a framework for the reporting of different aspects of involvement, from the motivation to the impact and through the methods chosen. These are now recommended by several leading journals, such as the BMJ, though few currently make its use mandatory. For future

researchers to learn from current efforts of involvement, researchers need to incorporate more details of their experience, as well as evaluate them. Fergusson et al. (200) argued that the traditional format of publications, divided using the IMRaD (Introduction, Methods, Results and Discussion) structure, does not encourage authors to include details on their experience of involvement, as there is not a dedicated section.

The impact of public involvement has been underexplored through randomised controlled trials (RCTs), although Nilsen (13) showed that RCTs are feasible for building evidence around the impacts of PPI. His study reviewed six randomised controlled trials comparing different methods of involvement and found that most often PPI had a little or moderate impact on the selected outcomes, such as more relevant and readable materials, patients and informed consent forms, and satisfaction survey results. Nonetheless, the six RCTs included had a moderate or high risk of bias.(13)

Figure 6: Taxonomy of impacts of involvement. Source: Staley (25)

Secondly, the impact of involvement is bound to be somewhat unpredictable. When the partnership between researchers and the public starts, none of the parties ‘know what they do not know,’ and so they cannot anticipate all the challenges and benefits. Staley has described how those “missing links” between context and process influence the outcomes of PPI.(90) Moreover, as each case of involvement requires careful consideration of context and process to design the best strategy, while being able to learn from other experiences and adapting existing frameworks,(88) the impact of one experience of involvement cannot be generalised to all forms of involvement. Researchers can only hope to follow the standards for best practice and adapt them to their specific situation, while remaining flexible, to achieve the most out of involvement efforts.

Thirdly, linked to the fact that there is no one single method of involvement, and strategies are project-specific, there is not a one size fits all way to evaluate involvement. Indeed, PPI is not precisely defined through golden rules, and so the methods to evaluate it should not be.(68) Statistical evidence-based methods to quantify PPI impact are unlikely because at the core of involvement is dialogue and exchange of ideas, challenging assumptions, and experiential knowledge that cannot be measured. While some factors can be measured (e.g., recruitment and retention rates, time to complete the study, costs), focusing solely on those does not provide a complete picture of PPI impact, and only detailed accounts from researchers and those involved provide enough insights to be valuable learning from others. The study team should pick the measure of involvement that fits with their purpose and context, and the methodology to capture impact depends on the aims of the involvement process. As the rationale and method of involvement should be stated at the beginning of the research, it would be helpful to reflect then on the outcomes expected and to specify the strategies to achieve them. These expectations should be compared at the end of the process to what is ultimately achieved, in partnership between the researchers and the members of the public, to encourage a reflective research practice that can truly explore a holistic understanding of the impact of

involvement. Evaluating impact from the perspective of researchers only would contradict the original intentions of PPI.

Fourthly, what impact should be considered varies for each stakeholder, and the evaluation goals of all parties should be considered. While members of the public involved might want proof that their involvement made a difference, funding bodies might prioritize researchers' accountability. In fact, for a given study, each person in a study team might feel different impacts out of the same experience: as each person started with different knowledge and perspectives, the learning experience varies for each of them, and this the impact of involvement differs. The impact of involvement for people is materialised through reflective learning.(206) It is important that the evaluation process also constitutes a learning experience, and that the consideration of impact is done as a team.

Also, very few studies refer to the cost of doing research in partnership with the public,(207) and the tendency is often to report the positive aspects.(25,208) Oliver et al. distinguished five types of costs associated involvement, affecting the research itself, the research process, professional risks for researchers and stakeholders, personal risks for researchers and stakeholders, and risks to the wider cause of scholarship, and noted that often the literature available focuses solely on the positive aspects of involvement. Similarly, the Public Involvement Impact Assessment Framework (PiiAF) urges to consider also negative forms of impact, providing examples in terms of time and costs, or hindered data collection.(165) More evidence is needed on researchers' specific motivations to involve and the nature of negative impacts of involvement.

Finally, despite all the evidence available in favour of public involvement, it is important to remember that PPI is not a panacea, and its outcomes are affected by both context and process of involvement.(209) More research is needed to determine best involvement practices in different contexts, and more adequate reporting measures need

to be defined. The necessity to include PPI in some grant applications has generated concern that it has moved from being a desirable cultural shift to merely a tick-box exercise and some argue that the evidence for PPI should not be the focus when planning for PPI as public involvement can be understood as an ethical imperative in its own right,(55,210) as I will expand on in the next section.

1.4. The Arguments for Public Involvement

1.4.1. Early Influences

Social Emancipation Movements

From the late 1950s, different emergent social movements (black, anti-racist, feminist, lesbian and gay, mental health service users, and disability rights movements) coincided in demanding greater social rights by ending discrimination and oppression of minorities.(211) These groups aimed "to challenge and change their shared experience of oppressive policies and provision" (212) and aspired to be treated as equal citizens and to have access to welfare and other services that could finally meet their needs.

In particular, the feminist movement used the constructs of "standpoint theory" and "strong objectivity" (55,213) to justify claims of equality and respect and the need to respect and engage with minorities in their own terms. They argued that the voices of all groups, particularly marginalised ones, had to be captured to produce new knowledge, as "changing the knowledge producers will change knowledge itself".(55) "Unmasking of

new issues” (213) can occur when those that are not in power are listened to, as these function within the existing status quo while struggling for their own liberation.

For instance, the mental health survivors’ movement consisted in a collective campaign to challenge traditional perceptions of mental health conditions within the healthcare system and towards the general public.(270)

This parallels these civil rights movements, patient movements and public involvement’s ability to empower patients and have often been highlighted.(25,68,196,271) Ultimately, the development of public involvement, first in service development, is pinned to two major factors: *“public demands for a greater voice in decisions about health services, and demands from politicians for greater efficiency, quality of service and effectiveness in the use of public funds.”*(271)

The roots of PPI are multifaceted and account for a belief that public involvement enhances the accountability of health care planners and providers (including researchers) towards the community (18,25,272–274) and that the combination of various perspectives increases the likelihood of services (including research) to be relevant to the local context (275) and thus the legitimacy of interventions and strategies.(153) An in-depth explanation of lay knowledge, the perspective brought by members of the public to health research, is provided in Appendix 2: Lay Knowledge.

Arnstein’s “Ladder of Citizen Participation”

The “Ladder of Citizen Participation” was described in 1969 in Sherry Arnstein’s seminal article and since then has become a tool to understand different forms of community engagement practice.(276) The ladder conceptualised eight different degrees of participation ranging from active (higher levels) to passive (lower levels), as shown in Figure 7. "Manipulation" is situated the bottom of the ladder of citizen participation while

"citizen control" is at the very top, as this stage implies a redistribution of power. Levels are also grouped and categorised incisively. For example, the middle construct, "Tokenism", includes the levels of "information", "consultation" and "placation".(13)

Figure 7: The “Ladder of Citizen Participation”. Source: Arnstein (25)

This ladder relies on some assumptions that are not unproblematic. Firstly, it considers that the power is held by those interacting with patients. Secondly, it presumes that all patients want to be at the top of the ladder, while for some, being recognised and being invited to join the conversation on top may be enough. Thirdly, it ignores power differentials between patients.

Nonetheless, Arnstein's work is today viewed as a foundational paper in the development of community engagement, as it was timely published in a period of radical reform of many aspects of public life in the USA. By using the ladder as a metaphor for increasing access to decision-making power, it appeared as a deliberative provocative take on the relationship between the community and the government.

Arnstein's ladder has been extended to areas beyond politics, and the ladder has been used within social sciences to gauge the participation of citizens in decision-making as a democratic process.(281) The ladder is also often cited and expanded in current approaches to conceptualise PPI and its limitations.(282)

1.4.2. Global Developments of Public Involvement: the Policy Context

The UK Imperative for PPI

In 1983 the UK 'Griffiths Report' (271) recommended a NHS responsive to the needs of the public rather than a provider of interests. This is regarded as an early example of guidelines for greater public involvement in healthcare services.(65) In the United States, public involvement in peer-reviewed scientific research was encouraged from the mid-1990s by the Congressionally Directed Medical Research Programs.(271)

The NHS, a pioneer public involvement, acknowledges the potential of PPI to inspire a participatory model of healthcare and *"encourage[s] patient and public participation in the NHS, treat them respectfully and put their interests first. This allows us to develop the insight to help us improve outcomes and guarantee no community is left behind or disadvantaged"*.(88) Greater roles for patients, carers, and all members of the public is advocated across the UK.(178,283) In medical consultations, patients are expected to have the chance to participate in the decisions related to their own care with the clinician as the focus shifts towards shared-decision making, and patients are encouraged to express their preferences for treatment.(284) The commissioning of health services also involves the public in research decision-making groups (146,285,286) and similarly, health research decision making groups provide an opportunity for active involvement of the public in British health policy.(287–289) The 2006 document "Best Research for Best Health" states that: "patients and the public must be involved at all stages of the research process: priority setting, defining research outcomes, selecting

research methodology, patient recruitment, Interpretation of finding, dissemination of results”.(290)

A wealth of initiatives and organisations have spread in the UK to encourage and strengthen public involvement in research. These have been facilitated by higher education institutions (e.g., University of Bristol, University of Edinburgh), charities (e.g., Arthritis Research Canada, Cancer Research UK). Like INVOLVE, a national organisation funded in 1996 to support “active public involvement in NHS, public health and social care research”, they have produced a range of guidelines and resources, e.g. (291). INVOLVE, still almost unique of its kind, gathers expertise, insight and experience on PPI to make it an essential part of all stages of research.

In the last decade, PPI has become a requisite condition for securing funding in the UK’s NHS. The National Institute for Health Research (NIHR) was created in 2006 and is funded by the Department of Health “to improve the health and wealth of the nation through research”.(61,292) Researchers in the NIHR are expected to “actively involve the public in their research” (293) when applying for funding, and one of the strategic goals for the NIHR is that, by 2025, PPI is a “required part of high-quality research”.(294) PPI plans must be stated both in the outline and the full applications, and justification is required for its absence and funding bodies require evidence for PPI, clear plans and activities throughout the research.(295–298) The NIHR is perceived a PPI leader in an international context (294) and has stated that “[d]emonstrating PPI and the continued involvement of patients and members of the *public is a very important part of developing a successful grant application and is often a marker of quality research.*” (299)

In summary, PPI is increasingly recognised and legitimised in the UK and is now a requirement in both healthcare (e.g., legal duty to consult patients and the public in major service change in England) and health research (e.g., UK NIHR expects projects it funds to

include the public as partners as well as participants). This PPI imperative can be framed within a wider “participatory shift” in policy. Citizens have been encouraged to participate in democratic decision-making by contributing actively as partners, collaborators, and consultees in political processes.(296,297) In a broader scale, models of “new public governance” emerge internationally away from models of “government”. This is informed by a perceived need to address a purported “democratic deficit” as established representative democracies have been criticized for failing to match public expectations.(294,296)

Contemporary Policies Globally

Indeed, public involvement is becoming increasingly common (297) and an integral part of policies (300) internationally as it is widely acknowledged that “*patients’ experiences should be the fundamental source of the definition of quality*”.(295)

This redefinition of healthcare quality took precedence with the arrival of the 21st century. In 2001, the US Institute of Medicine published the report *Crossing the Quality Chasm: A new health system for the 21st century* (299) where good quality care was defined as safe, effective, patient-centered, timely, efficient and equitable. In 2006, the Organisation for Economic Co-operation & Development advised that Healthcare Quality Indicators include effectiveness, safety, and patient-centeredness.

In 2016, during the 69th World Assembly, the World Health Organisation concluded that “*integrated people-centered health services means putting the comprehensive needs of people and communities, not only diseases, at the centre of health systems, and empowering people to have a more active role in their own health*”,(301) echoing the principles of public involvement in health research.

Recently, the WHO has postulated integrated people-centered health services as *“an important new way to empower patients, fight health system fragmentation and foster greater coordination and collaboration with organizations and providers across care settings, to deliver health services that are aligned with the needs of people.”*(253) More effective, less expensive health systems can be built when the people and the communities are placed at their core, and with more health literate and engaged patients that can better respond health crises. Co-produced health services are claimed to be the “way forward” in healthcare.(302)

Public involvement in health research has steadily grown worldwide and is also well established in Western countries other than the UK.(300) PPI is recognised as best practice and is now an essential requirement to receive funding from many funders globally, including Netherlands, Canada, Australia, and the USA.(303,304) Also, like in England, in Nordic countries, the Netherlands and Canada, the provision of universal healthcare is associated with commitments to equity and expectations that health services engage with community organisations.(305)

In Canada, public involvement has been at the heart of the debates over the organization and governance of the health system.(35,257,258,262) Despite its long history, the legitimacy of existing forms of user involvement in Canadian health services continues to be challenged.(249) Like in England, members of the public on the boards of healthcare organisations is the primary form of public involvement.(263,264) On the other hand, Canada is seeking to develop its own models for public involvement in each province (265) and unlike INVOLVE,(89) which distinguishes between three PPI approaches (consultation, collaboration and user-led), Health Canada divides PPI into five stages: inform or educate, gather information, discuss, engage and partner.(258)

In the USA, the Patient-Centred Outcomes Research Institute (PCORI), an independent non-profit, non-governmental organization, aims to improve the quality and relevance of evidence available to facilitate better-informed decision making (32,183) and promotes public engagement in health research.

In Australia, the Statement on Consumer and Community Involvement in Health and Medical Research (266) proposed as a vision where “consumers, community members, researchers and research organisations working in partnerships, to improve the health and well-being of all Australians through health and medical research”. This is a commitment to the active involvement of members of the public “in all aspects of health and medical research” that moreover promises to be “encouraged and facilitated by research institutions and researchers”. This bold commitment has been grown over the policies for a decade,(33,266) with the support of programs such as the Consumer and Community Participation Program at the University of Western Australia’s School of Population Health, which began in 1998 and has published resources for researchers, for example, a series of Fact Sheets.(267) Members of the public also play an active role in guideline development, based on the assumption that “guidelines can only meet the needs of the population if they are developed with meaningful and authentic engagement with consumers”.(268) Nonetheless as public involvement is still not standard practice in research in Australia,(269,270) researchers are now encouraged to consider public involvement when applying for public funding.(33,259,270,271)

At a European level, The European Patients’ Academy (EUPATI) is a pan-European project of the Innovative Medicines Initiative, which works to involve patients in medicines research and development.(272) The project rallies multiple stakeholders from patient organizations, universities, not-for-profit organizations, and pharmaceutical companies and produces guidance for patient involvement in different domains around research(273,274).

Denmark, like the other Nordic countries, involves patients and the public in the health service through local democratic mechanisms.(225) Public involvement emerged in Denmark as a response to the growing concern around the development of future clinical trials due to failure in the recruitment of participants. A working group, inclusive of multiple stakeholders, for PPI was established in 2010 by the National Forum for Health Research, reporting to the Ministry of Health. Within a year, the group presented a report and recommendations aiming to raise awareness about PPI to a broader audience and to serve as a starting platform for the implementation of PPI among a number of actors. These were launched in May 2012. Currently, funding bodies are developing ways to integrate PPI into their decisions about funding and members of the public have joined councils to prioritise research needs.(38)

In the Netherlands, developments around public involvement place a greater emphasis on legislation than those in the UK.(261) The government shifted from a consultative to an enabling approach (i.e., creating the conditions to permit active involvement) (275) in an attempt to respond more efficiently to a complex and rapidly changing healthcare environment. The country has also developed a systematic approach to the implementation of PPI in research projects (276), and disease-specific networks have worked to encourage structural public involvement in related studies.(277)

Across these different healthcare systems, the varied approaches to user involvement illustrate underlying tensions in the relationship between professionals, public, and service users. While evidence of their success is mixed, only the Dutch and English systems incorporate a systematic approach to engagement with users, patients and the public in policymaking although in practice the outcomes are more mixed.(225)

Finally, PPI is increasingly embedded through international networks, as part of a global movement towards research co-production. The Cochrane Collaboration launched in November 2017 the #globalPPINetwork, an International Patient and Public Involvement Network aimed to become a social movement across different cultural, democratic, and political contexts strengthening PPI in its many forms and leveraging international change for research.(278) Australia, Canada, Croatia, Denmark, Eire, France, Germany, Italy, Kenya, Lebanon, Netherlands, Nigeria, Norway, Spain, UK, and the USA have joined this initiative that has not Asian representation yet. Also, the Wellcome Trust (UK) has been determined to support biomedical ethics and public engagement internationally, particularly in low to middle-income countries. A meeting in Kenya in 2016 gathered representatives from 60 countries, with some Asian representation (Cambodia; Myanmar; Thailand and Vietnam). Some of the conclusions from this event were the fact that many aspects and challenges of public engagement have global resonance.(279)

Motivations for Public Involvement

As a growing number of experts acknowledge that most clinical research is not useful and is in need of reform (75,280,281) as the “quality mark” promised by Evidence-Based Medicine has been misappropriated by other agendas.(282) PPI offers an opportunity to help address some or all of these failings if context and history are taken into account to design strategies suited for the specific needs of each healthcare system.

Nonetheless, if those are ignored and there is a failure to properly evaluate the motivations for involvement,(210,283) PPI risks to become an end by itself. Public involvement draws first on ideas of accountability and democratisation of research, rather than evidence-based practice.(284) As PPI has become a requisite for research in a growing number of Western countries and the evidence of its impact on research studies has grown, an instrumental view of public involvement has become dominant. Authors

have urged to consider the ethical and theoretical underpinnings of PPI processes and practices, as well as its impact on people.(25,68,210,285)

Ives et al. (285) suggested a dual model for public involvement, underpinned by two distinct motivations, summarised in Table 3. This conceptualisation of PPI emerged from what they called the “professionalisation paradox” within PPI, which stresses the tension between the moral and pragmatic motivations for PPI understanding and operationalisation. Researchers are increasingly adopting PPI in order to recruit more, rather than as a way to respect the democratic rights of the public to be involved.

The first rationale is outcome orientated and pragmatic. Public involvement is justified insofar as patients, and the public brings unique perspectives to research, making it more appropriate to their needs and the needs of health-care services,(18,25,286–288) promoting more reliable, relevant research (289) and materials’ (167) ‘usefulness’. This is due to the fact that often patients and clinicians do not agree on treatment preference,(290) and the same goes in terms of research priorities.(291) This pragmatic rationale can be ultimately defined in terms of producing better quality research.(13)

The second rationale can be outlined as ideological or process orientated. This motivation stems from broader social and ethical concerns around democratic representation, transparency, accountability, responsibility and the redressing of power imbalances.(225,292–294) In this context, PPI in research is underpinned by the notion that people who are affected by research should have a right to have a say in what, and how, research is undertaken.(25)

The ideological motivation builds on ethical commitments, fundamentally principles around respect for autonomy. Indeed, conducting research ‘on’ people rather than ‘with’ them was regarded as a breach of such principles starting from civil rights

movements, during which a “profound suspicion and distrust of constituted authority” (295) grew as citizens claimed rights to define their own interests and speak for themselves.

This second rationale is entrenched in political ideologies and confronts institutions, agencies, and organisations by making a case for self-determination and inclusion.(296) Public involvement can be promoted as a motor for social change and power redistribution at a macro level, while also challenging the politics and equalising power relationships of research processes at a micro level.(285)

Table 3: Rationales for public involvement. Source: Ives (285)

	PPI AS ‘MEANS TO AN END’	PPI AS ‘END IN ITSELF’
MODEL	Consultation by invitation	Partnership/alliance
APPROACH	<ul style="list-style-type: none"> ▸ Top down ▸ Pragmatic ▸ Outcome orientated 	<ul style="list-style-type: none"> ▸ Bottom up ▸ Rights based ▸ Process orientated
PURPOSE FOR RESEARCH	<ul style="list-style-type: none"> ▸ Increases the relevance of the research ▸ Increases the quality of the research (adds insight to the design, methods and findings; assists in dissemination and implementation) 	<ul style="list-style-type: none"> ▸ Representation of community values and preferences ▸ Transparency and accountability ▸ Equalising elitist and exclusionary power imbalances between the public and the academic community
NATURE OF INVOLVEMENT	<ul style="list-style-type: none"> ▸ Information giving about decisions made ▸ Invitation to respond 	<ul style="list-style-type: none"> ▸ Encourage new ideas and joint decision making
RELATIONSHIP	Transactional	Cooperative

The Risk of Tokenism

Positive outputs of involvement for the research as well as for the people are limited by the lack of universal framework, as involvement cannot be approached with a “one-size-fits-all” model.(88) Moreover, numerous authors have highlighted the confusion on the purpose and function of PPI.(192,297) Combined to the fact that PPI is a policy requirement, tokenistic practices endure globally.

In 2016, a narrative review of evidence related to PPI in 2016 described significant barriers for achieving genuine, greater, and better involvement, overcoming tokenism.(298) This study proved that the current models for PPI are too narrow and that the principles of empowerment and inclusive involvement are often overseen, pursuing direct, pragmatic benefits for the research. In this context, PPI is criticized for its deficiencies, linked to exclusivity and tokenism.

PPI is a process requiring significant resources, and its inclusion needs to be justified and purposive to get the most out of it.(160,299,300) Educating researchers in the rationale for involvement and encouraging them to define their own motivation to work with the public and be transparent about it when designing and reporting their studies could be a solution to this problem.

The next chapter provides an introduction to the health and research context of Singapore. The understanding of individual-level experiences requires insights into the socio-political, cultural, time-specific, and diverse contexts.

CHAPTER

2

REVIEW OF RESEARCH PRACTICE, POLICIES AND ANECDOTAL EVIDENCE ON PUBLIC INVOLVMENT IN SINGAPORE

In this chapter, I will address the first question, ‘what are the existing policies and practices around PPI in Singapore?’. This chapter maps the existing policies on the role of the public in health care research in Singapore. It comments on the extent to which public involvement in research has Singapore evolved from the beginning of the study started, in January 2018, to May 2019 using a combination of systematic bibliographic search, hand-search of various annals, grey literature sources and a collection of anecdotal evidence. This chapter also sets some background to the healthcare and clinical research context in Singapore, necessary to understand a possible shift in participatory methods used locally more broadly. Additionally, this chapter serves to start considering the question: ‘What are the needs of researchers and members of the public in Singapore that PPI could satisfy?’.

2.1. Mapping Review: the Policy and Practice of PPI in Singapore in 2018

The first phase of this program of work consisted of a scoping review of existing policies encouraging user involvement and research having used public involvement in Singapore, found through 1) a systematic bibliographic search, 2) hand-search of the annals of three main journals focussing on research produced with members of the public, 3) INVOLVE Evidence Library, 4) the annals of three journals publishing research conducted locally and finally 5) grey literature (see Figure 8 later in this chapter).

2.1.1. Methods

2.1.1.1. Definitions of Terms and Scope

The review used as a guide INVOLVE's definitions of 'the public' and 'public involvement in research',⁽³¹⁾ and the three main levels of public involvement in research that have been identified. INVOLVE defines the public as, "patients and potential patients; people who use health and social services; informal carers; parents/guardians; disabled people; members of the public who are potential recipients of health promotion programmes, public health programmes and social service interventions; organisations that represent people who use services". Public involvement in research is conceptualised as "doing research 'with' or 'by' the public, rather than 'to', 'about' or 'for' the public". Three main levels of public involvement in research have been differentiated:⁽⁶⁵⁾

1. consultation (where researchers seek the views of the public on key aspects of the research);
2. collaboration (an on-going partnership between researchers and the public throughout the research process);
3. 'publicly led' (where the public designs and undertakes the research and where researchers are only invited to participate at the invitation of the public).

In recognition of the different terminologies used to refer to the public shaping the direction of research studies in different cultural contexts,(127) I included papers that hint to active roles for the public in health research, even though the term “involvement” is not used. The focus is indeed on the meaning of public involvement rather than on the terms used to refer to it.

2.1.1.2. Searching for Evidence

Firstly, in January 2018, a systematic bibliographic search was performed in 5 major databases (shown in Table 4) spanning a multitude of disciplines around health sciences and psychology. The search terms were grouped into three categories: actors (public, patient, lay, citizen), action (involvement, engagement, participation, input, representation) and subject (health research). Searches were limited to publications in English from 2001 to 2018. To build a comprehensive search, it was necessary to use a range of search terms, recognising that no consistent terminology exists for indexing PPI in literature. The detailed search strategy can be found in Appendix 3: Search strategies for the mapping review.

Table 4: Databases included in the systematic search for mapping review

Database Title	Domains of interest
MEDLINE	Medicine
EMBASE	Medicine
PsychINFO	Psychology and psychological aspects of related disciplines, such as medicine, psychiatry, nursing, sociology, education, pharmacology, physiology, linguistics, anthropology, business and law
PsychArticles	Psychology
CINAHL	Professions Allied to Health

Secondly, the past editions of six journals were screened based on the titles of the publications in the archives. When a title included words related to participatory research methods or an Asian context, the abstract was searched to check for relevance before searching the full-text version. The annals of three journals with particular emphasis on research conducted with members of the public (*Research Involvement and Engagement*, *Health Expectations* and *Research for all*) were scanned for papers published from groups in Singapore where participatory research methods were used. Additionally, the annals of the three major health research academic journals in Singapore (*Singapore Medical Journal*, *Proceedings of Singapore Healthcare* and *ANNALS Academy of Medicine Singapore*) were searched for studies that used public involvement in research or editorials, commentaries and opinion letters that discussed participatory research methods. Additionally, the INVOLVE Evidence Library was also examined following the same method.

Thirdly, other sources from the grey literature were scanned (in January 2018 and May 2019) for information on the role of the public and extent of public involvement in health services and research in Singapore. When the titles and headlines included words related to participatory research methods (e.g. ‘engagement’ or ‘collaboration’), data on the details of participation were extracted from the full-text. A list of the sources consulted can be found in Table 5. This search aimed to find material that is not formally or commercially published (grey literature). These could be produced on all levels of

government, academics, business and industry, and charities and non-profit organisations and were available in electronic format.

Table 5: Grey Literature included in the mapping review

Title	URL Link	Description
Academic Medicine Research Institute	https://www.academic-medicine.edu.sg/amri/	Official website of the SingHealth and Duke-NUS Academic Medicine partnership.
Agency for Integrated Care	https://www.aic.sg/	Official website of the Agency of Integrated Care. AIC seeks to create a vibrant care community enabling people to live well and age gracefully. AIC coordinates and facilitates efforts in care integration to achieve the best care outcomes for clients.
Agency for Science, Technology and Research (A* STAR)	https://www.a-star.edu.sg/	The Agency for Science, Technology and Research (A*STAR) drives mission-oriented research that advances scientific discovery and technological innovation.
ANNALS Academy of Medicine Singapore	http://www.annals.edu.sg/	The Annals is the official medical journal of the Academy of Medicine, Singapore.
Centre for Health Services and Policy Research	http://blog.nus.edu.sg/chspr/	CHSPR was established in April 2014 as a Centre for organising health services to meet the health needs of a population.
Clinical Research	http://www.clinicalresearch.org.sg	This website gathers useful information on clinical research being carried out in Singapore.
Elderly Healthcare	https://www.moh.gov.sg/content/moh_web/home/policies-and-issues/elderly_healthcare.html	This website offers information for the caregivers of older people.
Eldershield	https://www.moh.gov.sg/content/moh_web/eldershield.html	ElderShield is a severe disability insurance scheme that aims to provide basic financial protection to

		Singaporeans who need long-term care, especially in old age.
GIVING	https://www.giving.sg	Volunteering Portal for Singapore
Health Promotion Board, Singapore	https://www.hpb.gov.sg/	Official website of the Health Promotion Board. Established in 2001, the Health Promotion Board (HPB) is a government organisation committed to promoting healthy living in Singapore.
Health Sciences Authority	http://www.hsa.gov.sg	Official website of the Health Sciences Authority, a statutory board of the Singapore Ministry of Health leading innovative authority protecting and advancing national health and safety.
Health Service and Outcomes Research	https://hsor.nhg.com.sg/Pages/home.aspx	The Health Services and Outcomes Research (HSOR) unit was established in 2005, as part of the National Healthcare Group.
Jurong Health Services	https://www.juronghealthcampus.com.sg/	Official website of Jurong Health Services.
Khoo Teck Puat Hospital	https://www.ktph.com.sg/	Official website of the Khoo Teck Puat Hospital and Alexandra Health System.
Ministry of Health, Singapore	https://www.moh.gov.sg	Official website of the Ministry of Health, Singapore.
Ministry of Health, Singapore: Press Room	https://www.moh.gov.sg/content/moh_web/home/pressRoom/pressRoomItemRelease.html	An archive of press releases from the Ministry of Health, Singapore.
National Cancer Centre Singapore	https://www.nccs.com.sg/	Official website of the National Cancer Centre. The National Cancer Centre Singapore (NCCS) is Singapore's only comprehensive cancer centre. It engages in research on cancers that are common among Asians.

National Healthcare Group	https://corp.nhg.com.sg	Official website of the National Healthcare Group.
National healthcare group Research	https://www.research.nhg.com.sg/wps/wcm/connect/romp/nhgromp/home	Contains information (grants, ethics, training...) for those doing research with the NHG.
National Medical Research Council	http://www.nmrc.gov.sg	Official website of the National Medical Research Council.
National Skin Centre	https://www.nsc.com.sg	Official website of the National Skin Centre, Singapore.
National University Health System	http://www.nuhs.edu.sg/	Official website of the National University Health System.
Primary Care Pages	https://www.primarycarepages.sg	An initiative by the Agency Integrated Care (AIC), Primary Care Pages aims to support General Practitioners by being a one-stop resource hub. It contains up-to-date information on schemes and new primary care initiatives.
Proceedings of Singapore Healthcare	http://journals.sagepub.com/home/psch	Proceedings of Singapore Healthcare is a peer-reviewed open access journal that publishes quality research on all aspects of healthcare and the biomedical sciences, with an emphasis on research of direct clinical relevance.
Saw Swee Hock School of Public Health	https://www.sph.nus.edu.sg	The Saw Swee Hock School of Public Health (SSHSPH), National University of Singapore, was established in October 2011 as Singapore's first and only national public health tertiary education institution. The School is also a member of the National University Health System (NUHS).
Singapore Association for Mental Health	https://www.samhealth.org.sg/	Official website of the Singapore Association for Mental Health.
Singapore Eye Research Institute	https://www.seri.com.sg/	Established in 1997, SERI is Singapore's national research institute for ophthalmic and vision research.
Singapore Medical Association	https://www.sma.org.sg/	Singapore Medical Association (SMA) has been the representative voice of the medical profession in Singapore through their combined efforts since its establishment in 1959.
Singapore Medical Journal	http://www.smj.org.sg/	The Singapore Medical Journal (SMJ) is the monthly publication of Singapore Medical Association (SMA). The Journal aims to advance medical practice and clinical research by publishing high-quality articles that add to the clinical knowledge of physicians in Singapore and worldwide.
Singapore National Eye Centre	https://www.snec.com.sg	Official website of the Singapore National Eye Centre.
Singapore Population Health Studies	http://blog.nus.edu.sg/sphs/	The Singapore Population Health Studies (SPHS) is a population-based health research initiative of the Saw

		Swee Hock School of Public Health, National University of Singapore.
SingHealth	https://www.singhealth.com.sg	Official website of the SingHealth Group.
SingHealth – Health Services Research	https://research.singhealth.com.sg/Pages/Health%20Services%20Research%20Institute.aspx	The SingHealth Duke-NUS Health Services Research Institute (HSRI) aims to provide leadership, strategic direction and coordination for HSR between SingHealth and Duke-NUS, and to serve as a bridge between SingHealth and Duke-NUS HSR groups.
SingHealth Academy	https://www.singhealthacademy.edu.sg/	SingHealth Academy, as the education arm of the largest healthcare cluster in Singapore, is committed to providing high quality clinical training and education to nurture a multidisciplinary team of committed, competent and capable healthcare professionals and leaders.
The Straits Times	https://www.straitstimes.com	The Straits Times is an English-language daily broadsheet newspaper based in Singapore currently owned by Singapore Press Holdings.
Today	https://www.todayonline.com	TODAY is a Singapore English-language digital news provider under MediaCorp Press. It was formerly a national free daily newspaper.
Tomorrow's Medicine	https://www.singhealth.com.sg/TomorrowsMed/Pages/Home.aspx	SingHealth Academic Journal

Figure 8 presents an overview of all the sources of evidence included in this review.

During the search in academic journals, titles of papers and abstracts were scrutinised for possible inclusion.

Public involvement would not have to be the study authors' primary research question. Publication dates were restricted to the interval between January 2001 to January 2018.

I would include studies where public involvement would be integrated as a component of other stakeholders' involvement: this is expected to be common practice in some contexts, such as members of the public being part of a biobank steering committee. These other aspects of involvement will be referred to as 'non-public involvement components' of involvement.

Figure 8: Diagram of sources of evidence used in the mapping review

For the grey literature, the annals of the publications or the tabs and links in the website were explored to find evidence of active roles for members of the public, either existing or projected.

Inclusion/ exclusion criteria

I was searching for experimental and observational studies qualitatively commenting or quantitatively reporting public involvement in health research in Singapore. I also decided to include editorials, comments, and letters written from Singapore and about Singapore since those would have useful insights to map public involvement locally.

Studies that involved patient advocacy groups, as well as studies that involved the community at large, were included since those are generally formed by patients and members of the public representing particular communities.

As this review focused on identifying examples of public involvement in Singapore, the following types of paper would be excluded:

- Reports of surveys;
- Studies describing educational/ awareness campaigns;
- Studies focussing on public attitudes towards research;
- Studies focussing on issues around representation and diversity of research participants;
- Studies focussing on different ethical models of individual consent without public involvement;
- Studies not conducted in Singapore.

Indeed, those would provide evidence on the views of the public on research and participation in research but not on the extent and types of participatory research methods in Singapore.

2.1.2. Results

2.1.2.1. Systematic Search

The search in the four databases returned a total of 9659 results. After removal of duplicates, 6318 publications were screened from the title and abstract.

No studies in Singapore were found from the publications found through systematic bibliographic search, in any of the annals of the six journals, nor in the INVOLVE Library, indicating no published research studies completed in Singapore having involved

members of the public in research. Similarly, no editorials, commentaries, and letters discussed this topic in a Singaporean context.

2.1.2.2. Findings from the Grey Literature

Based on the total lack of evidence on involvement in research in Singapore in academic journals, I turned to the grey literature to find examples of research conducted locally with members of the public and of policies encouraging involvement.

Although a wide range of sources were included, only SingHealth's "Tomorrow's medicine" blog had been consistently engaged in commenting on the changing health care landscape in Singapore. Consequently, most of the evidence provided in the following is sourced from articles published there.

2.1.2.3. Overview of Health Care and Research in Singapore

Singapore possesses the world's 4th best healthcare infrastructure.⁽³⁰¹⁾ Ranked in 2016 as the second most efficient healthcare in the world,⁽³⁰²⁾ while spending less than 2% of GDP,⁽³⁰³⁾ Singapore is an example of the successful transformation of healthcare.⁽³⁰⁴⁾

The country inherited a British style, largely tax-based, and publicly provided healthcare system at independence in 1965. Subsequently, healthcare became a fundamental aspect of Singapore's plans for improvement and development. Basic services had to be ensured, and clinics and outpatient dispensaries were built to serve a growing population. As Singapore's economy improved in the 1970s, the standard of living of Singaporeans became higher, with the provision of better healthcare services. Polyclinics replaced outpatient dispensaries and provided a wider range of healthcare

services such as medical check-ups for babies. From the 1980s a number of regulatory frameworks were introduced to ensure the quality of health services, and quality assurance committees became mandatory in all hospitals.(305–307)

In parallel to these shifts in healthcare infrastructure, Singapore has experienced an epidemiological transition in Singapore from infectious to chronic, non-communicable diseases, which have created different challenges for its public health system.(308,309) Today, a population-based strategy dominates, which emphasises primary prevention, through the promotion of a healthy lifestyle. Moreover, the government has deployed strong measures to detect chronic conditions early through screening and optimal treatment of the disease,(310) as these remain prevalent in the context of a rapidly ageing population.(311) Cancers and cardiovascular diseases are the major conditions affecting Singaporeans today,(311) accounting for more than half of all deaths.(312) This is a radical shift from the 1950's and 1960's when infectious diseases like tuberculosis and gastroenteritis were among the top five leading causes of death in Singapore.(309) While antibiotics provide an effective solution for the treatment of such infectious diseases, predominant non-communicable diseases necessitate long-term, continuous lifestyle changes. As these rely on changing people's behaviour or increasing preventive behaviour, PPI could be a useful approach to understand how best to approach initiatives that impact on the social, emotional, physical and even psychological aspects of life.

Today, holistic and integrated care is guaranteed with 26 hospitals and three specialty centers,(313) in a mix of public and private healthcare facilities. The Ministry of Health (MOH) coordinates the sector, through a range of regulatory, organizational, fiscal and information complementary strategies.(314)

With respect to research, since its independence, the country has also aspired to become a world-class research hub, as the Government has prioritized investment in

knowledge capital.(109,110) In 1994, the National Medical Research Council (NMRC)(315) was established to oversee the development of medical research, and in 2016, SG\$19 billion (US\$14 billion) was invested in education and research.(118) Singapore is now rapidly becoming a research leader, attracting world-renowned scholars and researchers.(118,121)

2.1.2.4. Current Challenges

Today Singapore is confronted with a rapidly aging population, rising prevalence of chronic diseases and increasingly complex care needs such that healthcare spending is exponentially increasing, expected to triple by 2030.(316)

The challenges that Singapore faces resemble those of other developed countries: provision of health services to aging populations, tackling long-term conditions including dementia, antimicrobial resistance, and understanding how best to address revolutionary changes to healthcare such as the rise of genomics. As the expectations from patients and the public are increasing, public health is a key focus for governments. Clinical research is then a “necessity” to overcome rising challenges faced by public healthcare.(317)

Lim analyzed the necessary transformations that Singapore healthcare would need to meet those challenges.(305) Particularly, he postulated the introduction of a ‘tripartite model’, involving not just the government and providers but empowered consumers. In this model, the government would loosen its role as a provider, allowing other providers to compete and cooperate, building together a higher value healthcare system. He also outlined the need for healthcare policies to be better informed by health policy research. Today, the philosophy of shared responsibility prevails as the centerpiece of the local system. Exemplified since the beginning in the financing of healthcare, where costs are shared between citizens and the government, today this is reflected in the aspirations to

educated 'activated' patients to become more proactive in taking charge of their care, working closely with healthcare professionals, whereby doctors are encouraged to educate their patients so they can share the responsibility of making decisions for treatment.(318)

While the quality of healthcare has profoundly changed in Singapore, the expectations also have increased. From 2016, it became clear that doctors are no longer practicing medicine in a 'black box', shielded from lay scrutiny.(319) Today principles of transparency reach all disciplines and care is "at least becoming translucent".(305) Unlike some developed countries, the drive for change did not come from public pressure, but the Government. Singapore citizens did not pressurize the system for hospitals to be accountable for the quality of care. Rather the paternalistic government of Singapore, as the regulator, purchaser, and public provider, triggered the transformation "on behalf of Singapore's non-vociferous, law-abiding citizens."(305) Providers are audited by the government, which is itself accountable to the people.

Singapore's healthcare has improved significantly over the years and keeps evolving to face new challenges. Today, a focus on aspects relating to preventive and person-centered care, especially in collaboration with community partners, is the new dynamic of healthcare in Singapore, while individuals start to have a more active role in their own health care.

A new "Healthcare 2020 Masterplan", summarized in Figure 9, was introduced in 2012 to make quality healthcare more accessible, more affordable for all citizens in the future. This plan relied on two main ideas: the evolutions of a two-cluster system into Regional Health Systems, and the expansion of the Primary Care Partnership Scheme into the Community Health Assist Scheme.(320) In the same year, a The Healthy Living Master Plan Taskforce was formed "to look into making healthy living accessible, natural, and

effortless for all Singaporeans”.(321) This task force represented a shift in the policymaking of healthcare in Singapore, as for the first time whole-of-government and whole-of-society effort, with representatives from various public agencies and the community, were united in a collaboration. This was continued in 2012-2013 by the initiative “Our Singapore Conversation”, in which the public could share views on the Singapore they envisioned for 2030. Health care was identified as one of the top concerns for Singaporeans, and the community as a place for action, with citizens as main actors for change.

Figure 9: Healthcare 2020 Masterplan. Source: Public Service Division (320)

Unveiled in March 2012, the Healthcare 2020 Masterplan features measures to enhance the accessibility, quality and affordability of healthcare, to better meet the needs of Singaporeans.

A few years earlier, Lim(305) had suggested a progressive empowerment of lay people, as the new demographic reality relies less on a benevolent government wielding regulatory powers on their behalf to ensure the quality and safety of their health. Indeed,

society's "acceptable" level of authority is a dynamic process and very much a function of social and economic change,(322) and in times of disruption, the status quo is expected to tip towards more distributed power between the experts and the citizens.(323)

Singapore is indeed a fast-changing country, and its socio-political context has also experienced a degree of transformation. Over the years, since first arriving to power in 1959, the ruling People's Action Party (PAP)-led government has made efforts to shape a more inclusive and participatory style of leadership, a sharp contrast to the authoritarian posture seen following independence. Singapore's society is more heterogeneous and differentiated social and political values must be taken into account. A well-functioning economy does not suffice for Singapore's middle class, especially the young and educated, that increasingly demands greater political space and a more participatory environment.(322)

Moreover, recent events have contributed to a gradual deterioration of the trust of the public in its healthcare system.(324,325) The most remarkable has been the SingHealth data breach (July 2018), in which the personal particulars (names, National Registration Identity Card (NRIC) numbers, addresses, gender and race information, and dates of birth) of 1.5 million specialist outpatient clinics and polyclinics patients were stolen, together with 160,000 prescriptions.(326–329)

To address these new complex health and societal challenges, Singapore and its Ministry of Health are rooting for innovative solutions that fulfil citizens' needs and expectations.

2.1.2.5. The Case for Translational Medicine

Translational medicine aims to align research and administration, bridging the gap between research and clinical applications. This gap is known as the “valley of death”.(330) Prof Wong Tien Yin, Research Group Director at SingHealth, professor and vice-dean at Duke-NUS Graduate Medical School (NUS), and deputy medical director of the Singapore National Eye Centre, argues that Singapore is behind other developed countries such as the US, in the integration of academic research with improved healthcare. Singapore needs to introduce biomedical research innovation to provide better care to patients and thereby create “Singapore Medicine 2.0”.(331)

In Singapore, even though the needs of patients (defined from statistical data of healthcare services use) serve as a guideline in developing the strategies for translational medicine, patients are not yet involved in defining them. This is reflected in Professor Salvatore Albani, Director of SingHealth Translational Immunology and Inflammation Centre, words: *“Even though administrators and researchers may be, and most likely are, very different, they can be driven by the common vision of changing the face of medicine for the good of patients.”* Here patients are not seen as actors in research projects but rather as beneficiaries of experts’ work.

In this context, collaborative research, away from the traditional silos of medicine and academia, is seen by some as the solution to face the increasing complexity and cost of care. Collaborative work has been suggested as a way to develop a comprehensive database of patients for care and research.(332) While the question “How will the patient benefit?” must be kept at the center of new systems and processes to enhance access to care and increase research impact, there must be avenues for the patients themselves to answer that question and to work with professionals to find solutions.(332)

Stephanie Teo, Chief Nurse of SingHealth Polyclinics, also acknowledged the contribution that patients can bring to research.(333) Indeed, to her any “like-minded people who share a similar passion for research” can be a source of inspiration, and to learn from and work with people from different backgrounds can make the experience richer.

2.1.2.6. From a Paternalistic Doctor-Patient Relationship

A shift was nonetheless mentioned in information pertaining to the clinical environment. Patients are put at the ‘heart’ of medical practice and research, as it is reflected in new forms of doctor-patient relationships. Caring, compassionate and knowledgeable caregivers have the power to make a positive impact out of hard times. To create a different experience and better outcomes, doctors are not only encouraged to push boundaries and develop new paradigms of care, but also to put themselves in the “patients’ shoes”.(334–336)

In Singapore, a new generation of medical professionals is making efforts to establish a connection with the patients and the families, to shift the relationship from a “very professional one”, where, the patient is a passive agent, as in the old way of providing care: “I give you medicine, and you take it”.(335) It is believed that patients treated by empathetic physicians feel more comfortable, being, and have more positive health outcomes.(334) In medical school, students are educated on how important it is to be empathetic and are even taught empathetic statements to say.(337,338) Students are asked to remain committed to medicine’s core values of compassion, integrity, and collaboration, practicing active listening and learn and learn “to appreciate illness and healthcare from the patient's perspective”.(337) The ability to understand a patient’s needs, values, and feelings, and to effect helpful actions based on these, should lead to

better and more holistic care for patients.(334) Young doctors in Singapore are now taught the importance of taking feedback from patients and reflecting on it.(339)

2.1.2.7. ... to Patient-Centred Care...

Following this trend to welcome the voice of the patient is the affirmation that “The time is ripe to deliver patient-centred care that focuses on choice, dignity, and respect”, in the words of Palliative Care Consultant Dr. Rosalie Shaw.(340) This quote suggests that the doctor-patient relationship in Singapore is not mature yet, as care is still provided in a paternalistic manner whereby patients are recipients of it, and providers do not always share the decision-making.

The move towards patient-centred care is now seen as a necessary response to the general dissatisfaction with care, an increase in medical specialisation, the loss of the general physician, rising healthcare costs, an aging population, and disillusioned healthcare professionals. This new care paradigm entails the shift of focus from disease to the individual person, as it is about being responsive to individual patient preferences, needs, and values.

Moreover, it would lead to additional pragmatic, positive results: it can reduce the number of diagnostic tests and referrals and enrich a medical practitioner’s life and clinical practice.(340)

As medicine today is sophisticated, specialized, and disease-focused, the best possible treatment outcome should embrace the real needs of patients who yearn for compassion and patient-centered care. Communicating with full attention, listening, noticing and responding allows the physician to approach each individual patient giving him choice, dignity, and respect, ensuring that patient values guide all clinical decisions.(340) For skeptics about this new form of providing care, Dr. Shaw added that

patient-centered care is different from “assuming that patients are the best judge of what is needed and leaving decision-making to them without adequate information or guidance”.(340)

Some of the steps that Singapore has taken in the road towards genuine patient-centered care are improved continuity of care across different settings (integrated care) and new methods of training clinicians. Above all, clinicians are encouraged to “stop measuring things that do not matter to the patient” and to “create more patient contact time”.(340) Rewards to healthcare providers for patient-centered practices have also been mentioned as useful approaches in this journey.

Moreover, patients are achieving positions in healthcare institutions beyond receiving care, for example through the role of “patient navigators”.(341) This scheme, introduced in 2014 in SingHealth group and followed in 2018 by the National University Health System (NUHS), aims to plan post-discharge care for patients with complex health and social issues to help them transition home smoothly and to prevent repeat incidents that will land the patient back in the hospital.(342) These are nurses who are specially trained. Nurses can also make care arrangements for patients based on their preferences and needs. This initiative was introduced due to the uncertainty in the transition from healthcare to the community and the referral process. A key worker and continuity of care seemed the best way to satisfy the patients’ and caregivers’ needs.

Patient activation

Within the paradigm of shared responsibility and patient-centered care, the concept of patient activation was also mentioned in the grey literature. An ‘activated’ patient is “one who is well informed, motivated, and actively engaged in improving personal health”.(343) Indeed, today’s patients are expected to take charge of their own health and are accountable for it.

Following those principles, Tan Tock Seng hospital holds the Singapore Patient Activation Conference to make patients “truly engaged, empowered and activated” and show how “co-sharing, co-ownership, co-creation, and co-participation can lead to better care outcomes and experience”.⁽³⁴³⁾ Healthcare today is planned towards achieving greater self-reliance of patients, who are educated in their own healing process. Patient activation is expected to be “no longer an elusive ideal, but a reality”.

Another example found was the case of a Down syndrome patient who was encouraged by her clinical team to join in an advisory role in the Down Syndrome Association Singapore. Through these conversations with her, a multi-disciplinary team recognized that they could achieve a smoother, less disruptive process for care provision.⁽³⁴⁴⁾

The importance of different levels of knowledge and types of experience was highlighted by Professor Chay, Chair of SingHealth Academy’s College of Clinical Medicine (CCM), who mentioned that “[p]rogress of technology and medicine [...] has been so remarkable, so rapid that all of us have a lot to catch up on. Each one, even the younger ones, will bring new knowledge that we can learn from. So really, if you are ready to learn, there are many opportunities around. You just need to open your eyes and ears for it.” It can be expected that the traditional body of expertise will be expanded to include other forms of knowledge based on everyone’s experiences, and thus that the perspectives of the public will start to be valued.

2.1.2.8. ... and Towards Public Involvement in Research

Although the sparse evidence found in academic journals suggests that public involvement in research has not reached Singapore, some of the literature reviewed suggests that public involvement is emerging.

Prof Wong Tien Yin claimed that the “engagement of the public as a stakeholder” is a critical requirement for the success of the new medicine that Singapore needs.(331) He highlighted that in the US, institutions create a sense of legacy and tradition that is lacking in the high- quality health-care system and our biomedical research Singaporean landscape. For that reason, public engagement as a stakeholder in their healthcare, research, and teaching journey could be a solution awakening people’s gratitude. A sense of ‘ownership’ in the general community could attract any curious individual to research, joining young aspiring Singaporean doctors, researchers, patients in Singapore Medicine 2.0. Professor Wong Tien Yin proposes to start involving any laypeople interested in offering free science activities with advertisements similar to those in the Boston subway: "No prior knowledge necessary".(331)

2.1.3. Summary

While the drive to innovation and excellence in health care and research includes an emphasis on the advancement of patient care through translational research and patient-centered care, the results of our search suggested that the role of the patient remains limited to participation in research. While the doctor-patient relationship has shifted, and the expectations of the public changed, the organization of health is still geared in a top-down fashion.

The rhetoric has also evolved from the paternalistic discourse as leaders voice the need to work in partnership with members of the public in research. But for the moment,

these intentions have not been translated into policies that encourage an active role for the public in research. Consequently, studies are still conducted ‘for’ the members of the public rather than ‘with’ them, and public involvement does not happen in research practice locally.

2.2. Anecdotal Evidence Collected in 2018 and 2019

Due to the scarce evidence published in the literature, both through bibliographic and hand search, on the policies and extent of public involvement in health care in Singapore, I decided to attempt to fill in these gaps with anecdotal evidence collected during my doctoral studies.

This body of anecdotal evidence was collected opportunistically, and recorded in daily memos I compiled (more details in the discussion of reflexivity in my thesis), reflecting on the context of my thesis and linking thoughts emerging from my lived experience to my topic of interest. Some encounters contributed more than others, and thus in the following, I present those more in-depth.

2.2.1. 2018 Singapore Health and Biomedical Conference

Since 2002, the Singapore Health and Biomedical Congress has provided health professionals, clinicians and academics, industry experts, and other stakeholders a

platform to present their ideas and develop the frontiers of healthcare for Singapore. It is perhaps the largest and most important healthcare and scientific congress organized locally, with 3500 delegates attending in 2017. Delegates come not only from Singapore but from other Asia-Pacific countries (e.g., Japan, Korea) and Europe.

The most recent congress (October 2018) focussed on “Back to Basics: Adding Years of Healthy Life”, reflecting the strategies adopted by the National Healthcare Group, namely patient-centric, accessible and seamless care for patients.

In the 2.5 days program, a session particularly caught my attention, as it was centred on “Patient-centred care models, empowerment & practice”.

The synopsis and premises for the sessions revolved around the argument that existing models of care do not adequately meet the needs of patients and that the ever-increasing healthcare challenges require a rethink of the current model of care delivery. Both patients and providers should be further empowered to meet those needs, for example, through patient activation via shared decision making with healthcare providers. Such patient-centric require adequate patient engagement and thus necessitate changes in workflow, training of healthcare providers, and new business models.

In the midst of a biomedical dominated programme, and within numerous stands of exhibitors from the healthcare industry showcasing the latest medical technologies, I was very positively surprised to find such a session, where new and active roles for patients would be discussed by local doctors, nurses, allied health professionals, and researchers.

However, at the beginning of the 3.5 h session, the chairperson noted that the program had been slightly modified and the conversations would rather focus on care

models and the road in decision-making, alleging that those were the urgent priorities of Singapore at the time and thus were more worthy of being discussed.

The concept of “engagement” was boldly removed from the afternoon, and what may have been a proof of the shift and a step towards a rebalance of the roles of patients and professionals, stayed as yet another presentation of the struggles around the existing status-quo in the clinics.

2.2.2. Learnings from the Singapore Patient Conference

When scanning the sources of grey literature, the initiative that caught my attention the most was the Singapore Patient Conference. This was because traditionally, patients and members of the public have been excluded from academic circles such as conferences, and it was surprising to see an event that was dedicated to them. For six years, the Singapore Patient Conference distinguished itself for having “patients, caregivers, volunteers, community partners, and healthcare professionals come together to share their healthcare journeys, and to spark new ideas in co-creating a better healthcare system for all”.(343)

For this reason, in April 2018, I got in touch with the organizers of this event, and the manager offered to set a meeting. Shortly after, I met her and one of the event volunteers at Care Connect in one of the major public hospitals. I learnt that the Singapore Patient Conference is a platform co-created with volunteers.

Evolution of the Singapore Patient Conference

The theme of the conference changes every year to reflect a leading shift in society in Singapore in the previous year. 2017’s theme, “Volunteerism – powering change in

health and social care” was an opportunity for reflections on the blurred lines between health and social care, while 2018’s, “Active aging for life!”, would advance conversations on the aspirations to promote active aging in local communities. The hospital was thought to be an optimal place for this, as from 2018, the Ministry of Health and not the Ministry of Family and Social Development would be managing all Senior Activity Centres across Singapore.

Initially, the aim was to bring together patients, families, and caregivers. After a couple of conferences, the team realised that health professionals also had to have a role in it.

Another innovation that the conference introduced in its third year was to organise events in community spaces rather than in the hospital, following the government’s strategy of bringing health “beyond the hospital to the community”(345) and preventive medicine.(346,347) During the conference, clinicians meet members of the community in their space and organise health talks.

However, the conference still has some limitations. In 2017 the talks and booths were all in English, except for one in Mandarin. No clinicians attending the conference could speak Malay, Tamil, or Chinese dialects, making the event inaccessible to some, particularly older generations less fluent in English. Moreover, their work also concerns only Singaporeans from the Central Region of care. A similar supported and unified strategy is not present in the two other health regions, perhaps suggesting the sparser volunteer spaces in different and isolated centres.

The conference organizers are figuring out ways to capture the impact of the Singapore Patient Conference, and they acknowledge that this question is a cause of concern. In fact, they recently started collaborating with a nurse doing research in Patient Activation and are looking for other partners to solve the challenge of impact evaluation.

At the moment, the focus is measures of process, such as attendance to the conference and number of volunteers, rather than impact. In the future, the team wishes to develop an index of patient activation measurement. There was no doubt about how proud of their work both were, given the accomplishment of having created the first hub for patient engagement and activation in Singapore.

The strength and impact of volunteerism

The organisation of the conference has been possible thanks to the strong culture of volunteerism that Tan Tock Seng Hospital (TTSH) has cultivated over the years. To date, 1000 Singaporeans are registered as volunteers, and almost half of them are active. Progressively, volunteers have wanted to be more active (“not just distribute blankets in waiting rooms”). Their demands have been responded to some clinicians who have developed volunteer training programs in different fields, and now volunteers can engage patients while they wait. Each volunteer training program has a Clinical Lead (healthcare professionals) and Program Leads (administration contacts from each service). Support and resources have also been implemented in response to their requests. Moreover, an internal conference for clinicians is organised, where volunteers are introduced to the doctors. There have been efforts to promote the creation of a solid volunteer community, and for the recognition of volunteers in the hospital. For example, there is now a corner for volunteers in the staff canteen. Within TTSH, it seems volunteers are progressively being immersed in the expert ‘sphere’ and have effectively been empowered over time.

The volunteer cited different reasons amongst her peers to volunteer. These ranged from motivations to help others, like bringing joy and happiness to patients in need, to finding chances to make bonds with others, and meet new friends. Through Care Connect, people with similar interests come together feel more empowered to continue their volunteer journeys when surrounded by peers. They get the chance to socialise and talk about their experiences that become then more fulfilling.

Many volunteers are former patients whose own experience enables them to truly understand those they are helping. This reflects one of the motivations for public involvement in research, as it echoes the value of the lived experience that patients can bring to research studies. Other volunteers are students that need to earn points for community work as a requirement for their studies.

On the other hand reasons why volunteers decide not to continue include life changes (e.g. exams, need to take care of grandchildren or parents) or unfulfilled expectations. She knows colleagues that have left due to frustrations such as lack of training and support: volunteers have demanded more structured training opportunities and more chances to learn and connect. Finally, in her opinion, those who mention lack of time are simply trying to find an excuse and have other reasons they do not want to disclose.

Care Connect and other hospital initiatives

This meeting was also a chance to discover the Care Connect centre, that was created with the intention of providing value for patients and their families and to provide as space to develop partnerships between medical professionals and members of the community. This space was launched in 2013 following the model of Cleveland Clinic (USA), pursuing its efforts in patient engagement. It is a dynamic space where patients and clinicians connect and engage at a different level. The centre is now working on the Engage in Life model from Stanford University to encourages clinicians and patients to meet in new informal environments, promoting sharing of anecdotal lived experiences. With this program, clinicians become familiar with the real issues experienced by patients and forge engaging relationships with them. The hospital also recently launched (in October 2017) the Centre for Health Activation, a platform aimed at engaging patients by building confidence, knowledge, motivation. The objective is to educate patients to take

charge of their own health and consequently decreasing the burden on acute care services, leaving room for improvement in the treatment for those really needing it. In May 2019, the hospital opened the Centre for Healthcare Innovation, a vibrant hub open to the community to innovate the future of healthcare together. During the inauguration ceremony, Mr. Gan Kim Yong, Minister for Health, stated that this centre would allow “industry players and the academia to brainstorm, co-learn and co-create solutions, while harnessing the collective wisdom of the community”, but did not specify what the active role of the public would be.(348)

In terms of clinicians’ attitudes to these new platforms and services that bring the hospital to a new dimension other than the traditional understanding of healthcare, the manager thinks most of them still do not realize the benefits of these innovations. There is, however, a growing appreciation for the Singapore Patient Conference as professionals are more enthusiastic about volunteering in the training programs.

Shift in culture

We touched on the power dynamics between volunteers and health professionals. Both agreed that attitudes have greatly shifted since the Patient Conference started. Some health professionals still see volunteers as hurdles that “hinder their job” because they are not familiar with the environment and their work. It is a majority thinking along those lines, and some also thought that volunteers would threaten their work, thinking that “they are here to take my job”.

However, it is more frequent now for professionals to see volunteers as “assets for the healthcare system”. The manager went on insisting on the fact that volunteers belong to the healthcare “family” in their own right and that their presence allows a “bridging of talents.

The manager illustrates the shifting power dynamics with the story of a volunteer who got in touch with their program after filing a complaint on the care provided by the hospital. She was called for a focus group discussion aiming to improve the services, and due to the quick action of the hospital, she suggested collaborating on a long-term basis, helping them improve things further. Today she is the Co-Chairman of Care Connect.

Reluctance towards research

In hindsight, the most striking realisation from our conversation was the total reluctance towards health research that both of them showed. They grimaced every time I mentioned it as if it had been a threatening activity I was suggesting. The volunteer would become unengaged in the conversation and would have to be prompted to join in again when jumping to a different subject. None of them was familiar with clinical research, and both struggled to consider the impact that research could have on people's lives. When I suggested jointly organising a booth on patients' and the public's roles in research, including active roles as in public involvement, the manager of the conference even added that patients would not be concerned about research as it is an activity with no direct impact on people. The volunteer comments that the community is currently not even aware of the nature of research, and the conference manager adds working towards greater health literacy, and awareness of the health challenges are far more important. From this account, confined to a Patient Conference organiser and a volunteer, it appears that research is not a priority to the patients nor to the managers, whose efforts are directed to improve clinical outcomes through patient activation.

Discussion

The Singapore Patient Conference and the Care Connect centre are excellent examples of the move towards patient education and activation, and also shows a shift towards community engagement. The conference was co-created with volunteers and has risen as a flagship yearly event, that improves every year. Moreover, the hospital has built

a strong culture of volunteerism, and the volunteers have progressively raised concerns and have demanded greater responsibilities. The hospital has been responsive and has expanded the programs for them, providing training and support so that volunteers like the one I met have been empowered. Other initiatives launched reflect an aim to transform doctor-patient relationships, building trust, and providing more autonomy to patients. These initiatives are all aligned with the definition of involvement, as professionals are indeed starting to work ‘with’ patients rather than ‘for’ them. Nonetheless, at the moment, this progress is limited to clinical practice and does not seem to be expanding to other fields like health research.

2.2.3. SkillsFuture

SkillsFuture is a national initiative addressed to all Singaporeans to develop new skills and open new doors at any stage of their lives, following the trend of lifelong learning.⁽³⁴⁹⁾ This was launched with the intention of giving people the chance to adapt within a disruptive country in a rapidly changing world, and to push the limits of the local economy while building an inclusive society.

The program is innovative in that it defines skills beyond ‘marks’ and considers it as a compound of “knowledge, application, and experience”. Moreover, as shown by the rhetoric used in the description of the program “Your skills. Your asset. Your future.”, it encourages people to be active citizens and regain control their own lives, departing from the paternalism Singaporeans have grown up with.⁽³⁵⁰⁾

Courses cover all sectors and are offered by the purposefully created Future Economy Council, education and training providers, employers, unions. There were, in the spring of 2018, no courses available on research skills, and I thought that this could be a great platform to launch courses similar to those established by INVOLVE and UK

universities to introduce public involvement both to researchers and members of the public.(351,352) This could also be positive for researchers that would not have to spend extra time and resources to find and train members of the public and serve as a motivation for members of the public as they could be directly linked to projects as a sort of ‘final course project’. A centralised form of training would thus benefit all parties and optimise the process.

I got in touch with the deputy director of *SkillsFuture* and briefly introduced him to PPI and the outcomes that some training could have for the public, such as to join the research teams as co-researchers. I introduced the idea of developing courses for adults and older adults on research as part of *SkillsFuture*.

A reply came very quickly after, and the director asked for clarification on what new opportunities and careers the students of such courses would benefit from.

I then listed some of the skills attendants would practice, for example, research methods such as an outline of health research methods, ethics, difference between qualitative and quantitative data and interview techniques, and the roles that members of the public can have in health research projects such lay advisors or co-researchers.

This time he answered that there was no intention to have a course centred on providing the public with research skills. The reasons were varied: such courses would not be generic enough, so people would not be attracted to register; such courses could not be recurrent, happening once a year (although this could have happened) and most importantly, *SkillsFuture* courses are expected to open the door to new jobs, and thus they would prefer to keep them industry related, as they considered this would not be the case for research.

This example brought light to a certain lack of understanding and interest in health research from policymakers who saw research confined only to academic spheres and not directly ‘useful’ and concerning the citizens. This mentality, if also present among the public, could have direct implications for the feasibility of public involvement in research in Singapore.

2.2.4. Government Efforts to Involve Citizens

2.2.4.1. Citizens’ Jury in the ‘war on diabetes’

As the problems with diabetes rapidly grew, innovative strategies to fight the disease became urgent and the “war on diabetes” was launched in April 2016 during the Health Ministry’s Committee of Supply debate.(353)

In 2016 a new Diabetes Prevention and Care Taskforce was established to wage the War on Diabetes.(354) A team including representatives from Government agencies, the private sector, and patient advocacy and caregiver groups would seek to implement, monitor, and evaluate an action plan to fight diabetes in Singapore, engaging and mobilizing the public and the healthcare sector. Three workgroups were formed: Healthy Living and Early Detection, Disease Management and Public Education and Stakeholder Engagement.

Mr. Gan, Minister of health, voiced the need for community engagement in this initiative: “The key to winning the war on diabetes is for all Singaporeans to be engaged in the battle. We can also play a part in encouraging and helping others to do so”. Policy-makers acknowledged the need to shift mindsets to sustain the success of public health interventions, by mobilising the efforts of diverse local stakeholders.(355)

A public engagement exercise was launched by the Diabetes Taskforce from September 2016 to February 2017 to seek diverse Singaporeans' perspectives on potential initiatives that could be adopted in the War on Diabetes.⁽³⁵⁶⁾ This exercise was designed from the belief that “citizens can contribute meaningfully to the co-creation and co-delivery of approaches on issues of significance to them” and the community.⁽³⁵⁵⁾

Key public and private stakeholders were included, such as local non-government organisations, F&B industry players, and academia. Those living with diabetes and their families and caregivers were also consulted to identify their challenges and understand how MOH could better support them to control their condition and live well with diabetes. The views collected during the engagement sessions were collated as community-based recommendations on how to better prevent and manage diabetes as a nation, to include the feasible proposed measures into the Diabetes Action Plan. A summary of the process is represented in Figure 10.

Figure 10: Summary of public consultations on the ‘war on diabetes’ from September 2016 to February 2017

The first Citizens' Jury was conducted in Singapore between 25th November 2017 and 13th January 2018,(357) which represented a milestone for community involvement locally. Ms. Ngiam Siew Ying, Deputy Secretary (Policy) at the Ministry of Health (MOH), declared: "To properly engage, we had to look at different ways to interact with the public on issues". She acknowledged that today the public has wider expectations of the government so that "approaches such as deliberative engagements and proactive engagement before any programme or policy development were the way to go." (358)

Seventy-six selected individuals (Singaporeans and Permanent Residents), who represented a diversity of views, experiences, and backgrounds, deliberated, discussed, and achieved consensus on the next strategies for the 'war on diabetes'. Participants included diabetic patients (n=26), their caregivers (n=17) and healthcare providers (n=13), and people in the diabetic patient's secondary circle of influence (n=10). A small group of people without any experience with diabetes were also included (n=10). The participants were diverse in terms of their gender (54% females), age (2.6% below 21, 36.9% aged 21-39, 47.4% aged 30-59 and 13.1% more than 60 years old), education (12.1% up to secondary education, 34.2% with a university degree, 32.7% with a university postgraduate diploma/degree) and ethnic background (69.7% Chinese, 15.8% Malay and 14.5% Indian), so that different perspectives would inform the discussion.(359)

Four sessions were held on Saturdays, spaced by at least seven weeks. Twenty-one academics, healthcare practitioners, or members of volunteer welfare organisations shared resources and experiences about the management of diabetes. The event was facilitated by 16 volunteer facilitators from the MOH Facilitators' Network.

A summary of the process is represented in Figure 11. Participants were presented with expert views and data about diabetes in Singapore during the first two sessions.

During the third session, experts and academics from the healthcare industry and social services joined in to comment on the participants' recommendations and help broaden their perspectives. During the fourth session, citizen jurors presented their recommendations to be piloted in a report to the MOH.

Figure 11: Summary of the Citizen's Jury for the 'war on diabetes'. Source: (360)

After the event, 90% of participants indicated in a post-event survey they were keen to contribute more actively to whole-of-society efforts in the War on Diabetes, and that they would encourage their friends and relatives to do the same. 86% also felt that they had a better understanding of the challenge to compromise needs based on finite resources with the goal of developing solutions for the benefit of all Singaporeans after being part of the CJ. Indeed, the Citizens' Jury had a large and long-lasting impact on the

members of the public involved in it, beyond the potential impact for all Singaporeans based on their recommendations.

This event had implications for the approach the government has to policy-making, as it proved that members of the public could co-create solutions useful for Singapore, leaving the door open for more community-based solutions in the future. The Citizen's Jury was a novel experience for policy-makers in Singapore who are used to working in a top-down manner. This time, in the words of Ms. Ngiam, "[e]ssentially we [were] ceding control and ceding that space to the participants whom we invited to look at issues with us", (358) so the new level of trust was the greatest challenge for the experts.

Moreover, it was also a confirmation that Singaporeans, when given the opportunity, are willing to be more actively involved in issues of relevance to them. Participants were committed, despite the time and effort required during and in-between sessions. The Citizen's Jury was thus a milestone that built reciprocal trust and materialized a new way for policy-making in Singapore.

Their recommendations have been taken forward by the government, through a website dedicated to the Citizens' Jury.(361) Here one can find an illustration summarizing the recommendations (see Figure 12) as well as updates on how these are being responded by the ministry of health and regular updates on their implementation stage (see example in Figure 13, for recommendations on the domain "Enhancing skills of healthcare providers and caregivers", the third out of five). The Ministry of Health has since accepted, facilitated, and implemented some of these recommendations, for example, by facilitating exchange between the participants of the CJ and organisations to conduct healthy cooking demonstrations in community settings and at workplaces, as well as to promote the healthier option of home-cooking.

Figure 12: Illustrated recommendations of the CJ on the Singapore War on Diabetes.
Source: (361)

<div> <h3>3 ENHANCING SKILLS OF HEALTHCARE PROVIDERS AND CAREGIVERS</h3> </div>		
CJ's recommendation	MOH responses	Status update as of 1st April' 19
Communication-focused Diabetic Care Clinic that may adopt motivational interviewing as an approach to influence positive behaviour	Support	In progress
Expand the role of Singapore Association for Counselling (SAC) to include clinical communication and chronic disease counselling	Support	In progress
Expansion of the responsibilities of the Association of Diabetes Educators Singapore (ADES)	Explore	In progress

Figure 13: Progress status of recommendations from the CJ on the domain “Enhancing skills of healthcare providers and caregivers”. Source: (361)

This portal dedicated to the CJ, combined with the press releases and speeches available in the Ministry of Health website, provides an account of the impact of the Citizen’s Jury from the perspective of policy-makers. On Jan. 16th 2018, Dr. Amy Khor, Senior Minister of State for Health, acknowledged the efforts of the members of the CJ, and expressed satisfaction of the success of an event that she had embraced hesitantly, as she wondered whether such a methodology, that she had first got to know in Australia years earlier, could be implemented in Singapore.(362) The effort was later conceptualized as a “bold step” by Dr. Lam Pin Min in November 27th 2018.(355) Indeed, the CJ departs from the traditional top-down and controlled ways of working because it was participant-led and though could lead to unexpected outcomes. In the same speech,

Dr. Lam emphasized that the “CJ process was a tremendous success”, leading not only to implementable recommendations but also to a positive impact on people.

These joint efforts of multiple stakeholders were renewed in November 2018 when the minister highlighted the need to “better integrate, coordinate and scale up efforts”,⁽³⁶³⁾ for example by consulting the citizens.^(363–365) Public consultations were planned to be held in the first months of 2019 to “explore ideas that harness the power of community”.⁽³⁶⁴⁾ The public was also able to submit online their “helpful ground-up ideas on promoting active and healthy lifestyles”.⁽³⁶³⁾ Indeed, two of the key objectives had the public at the centre and sought to give them more autonomy in the management of their own health and that of all Singaporeans, namely “empowerment of individuals through technology” and “engagement of our communities”. This is because, in the words of taskforce chairman Amrin Amin, “Improving the health of all Singaporeans is a massive effort that cannot be solely undertaken by any single agency. It also needs the support of the private sector as well as the community”.⁽³⁶⁵⁾

One of the aims of greater collaboration with community partners (for e.g., volunteer welfare organisations) is to reach the lower income, vulnerable groups, that remained at the margins of the programs launched the previous years.⁽³⁶⁶⁾ Greater community engagement was thus defined as part nation-wide efforts for the reduction of inequalities and step towards the empowerment of all.

Nonetheless, communities and members of the public kept being excluded from wider programs. In November 2018, a Ministerial Conference on Diabetes, bringing together “international government leaders, stakeholders, academics and thought leaders”,⁽³⁶⁵⁾ was announced. Although numerous stakeholders would share best practices and insights, the perspectives of the community would not be present at the

occasion. Similarly, a report published by the Diabetes Taskforce had no mention of an active role for the citizens in its recommendations for the future.(367)

The ‘war on diabetes’, particularly the Citizen’s Jury, show that new methods are being employed for health policymaking, that strengthens and nurtures active citizenry. To tackle complex problems such as the diabetes epidemic, the government is seeking creative strategies that require empowered members of the public

Other government-led initiatives to harness the voices of the public

Despite the novelty of the Citizen’s Jury, as a formal method of public deliberation, there have been earlier informal government-led initiatives to harness the voices of the public.

For example, from 2016, the Singaporean government has sought to provide opportunities for public debates around the budget. Nonetheless, these were not followed-up by citizens, as the Speaker of Parliament Halimah Yacob lamented in April 2016. The press noted that citizen participation is lacking in Singapore and examined different reasons for it, for example, the lack of awareness amongst citizens on the possibility to debate issues like the budget.(368) Other reasons are citizen’s lack of knowledge on the topics to debate, the impression that their opinions are not wanted, general apathy, complacency as well as “cynical attitudes towards government programmes”. Moreover, this article also highlighted recommendations for the future that align with the recommendations for public involvement in research, such as seeking the public perspectives early on in the process, as well as “a two-way deliberative communication, rather than simply one-way information sharing”.

Similar efforts to consult the public were also deployed in 2018, as the Ministry of Health sought feedback on a new Healthcare Services (HCS) Bill from 5 January 2018 to

15 February 2018 (369) and on the proposed amendments to the Infectious Diseases Act (IDA) from 27 June to 7 August 2018.(370)

Finally, on May 30th 2019, Dr. Khor, Ministry Of the Environment & Water Resources and Ministry Of Health, aimed for a “whole-of-society approach” rallying “Singaporeans from all walks of life” to enhance an action plan on lifelong health, beyond the government efforts, and announced a public consultation in late 2019 to co-develop an updated plan with various stakeholders, including our seniors, community and business partners.(371) Moreover, she highlighted older adults’ desire to and passion to “give back”, stressing it is the governments’ responsibility to support them in achieving this goal by “help[ing] them find roles that give them continued meaning and purpose in this phase of life”.

These examples highlight the governments’ intentions to support citizens and communities in being active collaborations in future policy-making by harnessing their individualities, valuing their social and economic potential, and celebrating their contributions.

2.2.5. 11th Singapore AIDS Conference

In December 2018 took place the 20th Singapore AIDS Conference, where findings would be presented and discussed around medicine, social science, and local community action in the fight against HIV. In the opening speech Dr. Amy Khor, Senior Minister Of State, Ministry Of Environment and Water Resources and Ministry Of Health, described the conference as a “forum for healthcare providers, public health experts, the community and other stakeholders” to share and discuss not only research but also engagement strategies.

I attended a public session entitled “Community-based Participatory Research – The New Way Forward for Public Health” to explore ways in which Singaporean researchers are working with stigmatized communities to do their work and face this public health challenges.

The session was divided into three parts: first, a talk by Professor Judith D. Auerbach from the University of California, San Francisco (UCSF) on her extensive work with communities since the early moments of the fight against HIV, followed by a panel discussion with two local researchers using community engagement in their work with stigmatized populations.

NB: as discussed previously, in the United States, ‘community engagement’ is equivalent to ‘public involvement in research’. In the following section, which reports conversations with a US researcher, the expression ‘community engagement’ will be used.

‘Nothing about us without us: Community engagement in HIV research’

The title of Prof. Auerbach’s talk, ‘Nothing about us without us: Community engagement in HIV’, referred to the phrase used by those engaged in the advocacy of disability rights in North America through the HIV epidemics from 1981.

The talk presented a stark contrast of epistemological knowledge of professionals and the experiential knowledge of the community. It was a brilliant example of how both groups need to partner to produce the desired research and health outcomes. In the ’80s, those infected by HIV had to start advocating for themselves: they judged that their government was not doing enough, and the general public was apathetic to their cause since only those from stigmatized communities were affected by the mysterious epidemic. Activist groups, formed by regular people from the community, had to educate themselves

and became scientific experts “as credible participants in the process of knowledge construction”.(372)

The story of early HIV research served as an illustration of the emergence and challenges patient advocacy in research, community engagement, and wider Community-Based Participatory Research (CBPR) methods. Working partnerships with the community are especially relevant when working with communities aside from the general public, as gatekeepers are often required to establish sustainable relationships, and collaboration is expected from all stakeholders.

For example, community engagement in trials allows us to identify, recruit and retain the right participants, and Community Advisory Boards (CABs) can serve to relay information between the community and the researchers in both ways. When collaborative research is done with a CAB of members of the community being researched, the study becomes not only relevant but also sensitive and respectful of the characteristics of each community. In particular, Professor Auerbach highlighted the importance of ethical community engagement and presented benchmarks for collaborative partnership.(373)

The cycle of research, education, and action was described as the differentiating element of CBPR, coupled with the involvement of community members, research, and organisations in all aspects and steps of the research process.(374) This requires the use of frameworks backed by evidence (375) but also flexibility: in collaborative research, the path is always different from what is initially intended to. Finally, awareness of the power relationships within the community was highlighted to be of critical importance for successful CBPR.

The presence of community members all along the research process also enhances the implementation of the findings and translation of the science behind for a wider

audience. Consequently, the public understanding of science is enhanced. Prof. Auerbach then encouraged the audience to understand the public, research being a two-way learning process. The public has a democratic right to be informed, and the academics should be interested in the creation of meaning from the outcomes of their work and, conversely, incorporate the new type of knowledge that the public presents to modify their research.

She gave the example of the social movement U=U (undetectable = untransmittable), that made available a scientific finding to the society and has been liberating for thousands of people infected by HIV. This anti-stigmatizing finding had not been communicated to people, and after becoming a social movement, it has reached the policy context, as the premises are now endorsed by the Canadian movement.

Panel discussion

One of the panel discussants was a professor (medical anthropologist in the Saw Swee Hock School of Public Health, NUS) recently arrived to Singapore from Hong Kong, and with research experience in the United States and Korea. His aim to introduce here the field of CBPR with the lessons learnt over the years on the fields, focusing on the determinants of health inequalities and on vulnerable groups, such as homosexual sex workers. This professor emphasized the importance of the 'action' step within the cycle of CBPR. Research had to be implemented locally as a policy or translated into some other action. He saw CBPR as an interplay between the body of knowledge held by the experts and the knowledge of the body held by the public, as shown in Figure 14.

Figure 14: Conceptualisation of the transfer 'knowledge' within CBPR

CBPR had to start by asking the community of interest for their needs, followed by a dialogue to understand their values and preferences. Active listening and feedback from both groups would permit shared ownership of the study. Being available for members of the community was part of getting their buy-in and trust.

The second panel discussant was a PhD candidate from the Saw Swee Hock School of Public Health, NUS, whose work centred around migrant and sex workers in Singapore. He reflected on his dual position as a researcher and as a member of the community, and on the great moral challenge that this represents for him and for the members of the community he is working with. In his case, the power disparities became obvious from the start, and this presented challenges when nurturing relationships. He has worked with a social enterprise, sharing his aim of empowering people, building connections with the members of the community he is working with, and gain their trust.

The panel discussion revolved around the fact that in Singapore, the professionals are still seen as the only source of epistemic authority, while the patients and the society at large accept the *status quo*. Attendants highlighted the dominant positivist paradigm to research, that limits the nature and the content of research being carried out, while CBPR and similar approaches are marginalized.

A great part of the discussion was dominated by the barriers for involving the public, particularly older people, as they are the greatest challenge to health care. Another challenge cited was the recruitment of members of the community to engage in research. Attendants lacked practical insights into how to recruit and also in knowing would be the best persons to include. Different strategies were suggested, from a general call to community members, snowball sampling, and importantly, using the formal and informal networks of researchers and community gatekeepers. In terms of who to include, the most important aspect was seen to be maximizing the diversity of perspectives, forming a group

of people with a different set of characteristics. Moreover, attendants discussed the degradation of trust of the public towards experts, particularly in healthcare and research, after the data leak that occurred in the summer of 2018, and the registries of over a million patients under the care of SingHealth were stolen. Linked to this, some members of the public explained that this distrust towards the research community could partly be due to the long history of patients being simply ‘subjects’ of research. A long-term commitment with community members gives them the opportunity and the confidence to use their own experience and expertise to inform science, rather than, at best, only receiving its results. The discussion finished with consensus on the fact that new strategies need to be put in place to ensure that both worlds, the expert and the lay, meet within the frame of CBPR and that this would need institutional and structural changes to happen, including the provision of resources and training.

Another concern that delegates had was the fact that research funding is tied to a particular research question, and thus it would not be possible to define the question with members of the community. In other words, the public cannot be involved from the early stages, including the definition of research aims and questions, if the study does not exist (not funded) yet. Solutions given were to work with foundations and social enterprises to gather enough initial funding to establish connections with a community, define the question with them, and then apply to formal public research funding. The final research objectives should then be a balance between the needs of the public and the interests of the researchers.

The topic of health literacy and the need for more education followed. Speakers then highlighted their role as drivers of CBPR, to bridge gaps between the public and policymakers. Nonetheless, some suggested a paradox in the local context: due to historical reasons and the socio-political context, in Singapore, the gatekeepers between

researchers and the public are the policymakers themselves, as often community organisations stem from the government.

The broader socio-political context itself was seen as a tension point for CBPR. Some attendants thought it would be difficult to create spaces for constructive dialogue and reverse the top-down organization of society, leaving space for bottom-up initiatives.

In response to this, changes in the way plans are laid in Singapore were cited, also within the Singapore Ministry of Health (MOH). Attendants highlighted that policymakers seem to understand now the need to focus on communities and are moving forward towards greater collaboration with the public. The taskforces for the ‘War on diabetes’ were cited as the best example of new partnerships, where all stakeholders, including some members of the public, work together and present and discuss findings with policymakers. Another indicator of the shift being experienced by research in Singapore is the fact that one of the Key Performance Indicators (KPIs) of the newly funded (2018) Society of Behavioral Health is involving the community in their program of work, and this will become a condition for future funding.

It would seem then that policymakers have acknowledged that often all work with the same goals and have created spaces for other voices to be heard. Nonetheless, at the moment, participatory initiatives laid by the government are limited to consultation with the public and to participatory expertise and often constrained to non-sensitive areas. Attendees noted that the value of collaboration with the community is critical in areas that are culturally sensitive, and that the eyes of researchers and policymakers should be on the communities concerned by those. Nonetheless, some attendants highlighted that for that research remaining at the margin, new innovative solutions can be applied, that requires another level of partnership with the public. Indeed, one attendee had previously used crowdfunding to fund research with stigmatized communities, when the funders did

not see the value of this research. In his opinion, this added an extra level of accountability with the public and strengthened the bonds between the civil society and researchers.

The audience pointed out multiple times that, at the moment, Singapore is not a participatory setting and reflected on how to build capacity for community engagement locally. Different strategies were discussed, from putting more demands on funders to training community volunteers to conduct research. For the former, researchers considered that CBPR should be made mandatory for some types of research. Other strategies pertaining to the funding included using community peer-review for proposals and dissemination, and the inclusion of markers of community engagement in researchers' KPIs.

Another concern was how to support community members that wish to be involved in the research. At this point, the need for funding to advance their educational aspirations became obvious. Other advice included sharing the research milestones with them, by including them as authors, and writing and disseminating research in an accessible language, to shift both the public and the policy discussions. Finally, attendees agreed that locally creative ways would be needed, balancing funding, training, and accountability.

Linked to this was the fact that today researchers work in silos and are disconnected from the community. For researchers, the success and impact of their work should be two-dimensional and include the impact on people besides all factors involved in the KPIs. The majority of attendees wished for other researchers to acknowledge that they do not work in the vacuum but relate to others within the society, and thus for a wider dialogue outside of academia, with fellow citizens. Only then would the public have an understanding of science and a tie with scientific work so that a new relationship between the community and the researchers is possible.

Discussion

This session allowed me to reflect on the parallel between the beginning of community engagement in research in the US, in the early '80s, in the UK around the same period and Singapore today. In all cases, it all started with stigmatized populations, minorities, whether that of those infected with HIV (US), users of mental health services (UK), or immigrant workers (Singapore). Despite a common thread of stigma, a critical difference applies: in the Western cases, the stigmatized were often educated and could organize themselves to advocate for rights and treatment, while here in Singapore, the populations are the most vulnerable and uneducated. Community engagement in Singapore will not stem from the people because it will need support from the civil society and be driven by the interest of the researchers if it has to happen. For community engagement to happen, not only greater health literacy and research awareness amongst members of the public would be needed, but also researchers would need to become 'community literate' and learn 'soft' research skills to have functional collaborative relationships with members of the community.

Another conclusion from this conversation was the fact that Singapore is simply not and is not prepared to be a participatory setting. The biomedical field particularly is dominated by an entrenched, hierarchical system where knowledge is reserved for the certified expert. Also, funding requirements include constraining KPIs and visions pre-defined by research institutions that do not suit the needs of flexibility and trust for community involvement in research. Importantly, as the second discussant noted, there exists in Singapore a negative correlation between the autonomy and the strengths of community organization. This will be a challenge for public involvement to truly empower people if it is mediated by organisations that are governed in a top-down manner.

Finally, attendees could not come up with a solution on how to implement CBPR in Singapore, besides the certainty that a translation of its principles to the local context would be needed. New strategies need to be put in place to ensure that both worlds, the expert and the lay, meet within the framework of participatory research methods. This would need institutional and structural changes to happen, and also the creation of new structures for knowledge translation that are setting specific.

2.2.6. A New Life for the Community and the Rise of Volunteering

The second search, in May 2019, highlighted the rise in government and healthcare institutions' interest in harnessing the skills and efforts and the community to sustain their programs, as well as Singaporeans' interest to volunteer in different causes. Due to the diabetes challenges, Singapore is learning from other Asia-Pacific countries, such as Brunei, Japan, Malaysia, and Tonga to collaborate with local community networks to educate and empower the public to improve their health, and to co-create solutions to tackle public health challenges.(376)

Policymakers are advocating for broader and deeper collaboration with all stakeholders, including citizens and communities, to maximize the efficiency and impact of their work. In March 2019, Grace Fu, Minister for Culture, Community, and Youth, acknowledged the “strengths of communities”(377) and in October 2018 Mr. Chan Heng Kee, Permanent Secretary, Ministry Of Health, highlighted the need to collaborate with organisations and individuals sharing the same goals to increase the impact and sustainability of initiatives deployed by policy-makers.(378) This recognition was also acknowledged a month later by Mr. Gan Kim Yong, Minister For Health, who declared “we need to involve all stakeholders by being inclusive in our actions”, stressing the role of the government in strengthening and ensuring the sustainability of programs through “better community participation and engagement through a whole-of-society approach”.(379)

Healthcare institutions are following the government's efforts to educate and engage the public. For example, the National Cancer Centre (NCCS) organizes roadshows and public education activities in the heartlands, where people live, based on the belief that empowering the public with the knowledge and skills helps citizens to care for themselves and those around them. Similarly, the Singapore Hospice Council is resolved to work with member organisations and other community partners with the hope of generating conversations in the community, building meaningful relationships with older people in the community. Dr. Amy Khor, Senior Minister Of State, Ministry Of Health, encouraged in June 2018 other Voluntary Welfare Organisations and Family Service Centres to follow their example.(380)

Equipping the community with the necessary skills and confidence to make sure new central initiatives are implemented represents a “significant paradigm shift”(381) to the way healthcare and policy have been conceived before. The government and healthcare institutions are radiating out, beyond their own comfort zones, to “harness the immense wealth of knowledge and experience”(382) of citizens, particularly the older ones, who can continue to contribute to society while also improving their own experiences in later life. For them, active aging is being promoted through Community Networks for Seniors (CNS), an initiative that brings together voluntary welfare organisations, grassroots, government agencies, and community partners.(383)

Volunteers are the key to community resources, and the government has deployed social mobilization efforts to reach them.(376) As the limits of mass communication have been unveiled in a society that craves personalized messages, targeted messages are being used to reach diverse demographics, empowering them to take ownership and action of their own health. In 2018, 15000 volunteer Health Ambassadors and Health Advocates, of different backgrounds, had been gathered by the Health Promotion Board to raise health awareness in the communities, sharing knowledge and skills.(382) In an

effort to centralise the community engagement strategies and to oversee volunteers, in March 2019, the parliament appointed seven selected community-based organisations as Volunteer Centres, “to actively recruit, manage and develop a pool of volunteers” so that these work as “central coordinators” across various sources of volunteers and volunteer programmes.(377)

Regional Health Systems (e.g., the National University Health System), hospitals (e.g., Tan Tock Seng), health centres (Singapore Eye Research Institute) and disease-specific associations (e.g., Singapore Association for Mental Health) include in their website a section with information for the public to volunteer. As Singaporeans have become central elements of the “culture of care”, the number of volunteers in public hospitals is rising (about one in three Singaporeans volunteered their time in 2016, up from just one in 10 in 2000),(377,384) as they are offered new types of roles in healthcare (see Figure 15 for an illustration of the four roles offered by Tan Tock Seng Hospital), expanding and supporting the lack of workforce in the field.(384)

Figure 15: Tan Tock Seng Hospital Volunteer programmes. Source: (385)

2.2.7. Dealing with Funders when Intending to do PPI

In this section, I will provide examples of two grant applications submitted by my own department (both with local and UK researchers) where public involvement was included in the proposal, and reflect on how the current research funders understand the aim of public involvement.

2.2.7.1. Planning for Co-Researchers

The first example introduces a grant application submitted by my research group, where I would be part of the public involvement strategy. The feasibility study's objective was assessing household health literacy as a potential enabler to treatment adherence and lifestyle management in primary care patients, and we aimed to identify the range of health literacy within households in Singapore.

We also wanted to incorporate public involvement at all stages of the research, from design through to interpretation of data, and dissemination of study findings, and we decided, so a secondary aim was to test the feasibility of training members of the community to work as co-researchers within the three main ethnic groups in Singapore.

We submitted the first application in mid-2018, where the idea of having members of the community as co-researchers was introduced. Later in 2018, in response to queries from the reviewers, a full grant application was submitted, including an in-depth description of the process of co-research with community members.

Identifying co-researchers

We would recruit and train four members of the public of three local communities as PPI collaborators (two Chinese, one Malay, and one Indian). Those should be part of the local communities we are interested in and demographically similar to those with

whom they will be working. They would be English speaking with high school education (to ensure basic literacy and numeracy) and over the age of 21 years (age of consent to participation in research without also needing consent of parents).

The role of co-researchers

This study aimed to give co-researchers an experience of the research process. They would:

- Advice on the development of participant facing documentation (recruitment materials, information leaflet, consent form, etc.)
- Identify and assist in recruiting households to the study
- Support the RA during research encounters and data collection
- Document their experiences of working on the study (recruitment, access, administering the questionnaire, etc.) in the form of contact summaries and observational data
- Contribute to the interpretation of findings
- Support the dissemination of findings (co-author publications and papers)

Valuing and supporting co-researchers

Co-researchers' experiences and observations would be expected to be a central part of the study, as they were expected to generate a comprehensive understanding of individual and household circumstances, and social and cultural contexts. Co-researchers would be trained and expected to complete with the RA a contact summary report of each individual encounter at a household, as to provide the basis for more extensive observations and reflections. Moreover, two focus groups were planned: one at the start of the study, before the training programme, to introduce the study team, to confirm the design of the study and to identify what would need to be included in the training; and a second one at the end of the study to identify implications for future research, enhancing

data analysis with the public perspective and to gather co-researchers' reflection on the research process and the experience of collaborating.

Due to funding regulations, it will not be possible to remunerate co-researchers appropriately. Nonetheless, efforts to value and support their contribution were reflected in the application. A detailed one-day training programme for co-researchers was included in the funding application. This programme would include the rationale and overview of the study, a review of research ethics and legal requirements, exercises to provide qualitative research skills and a Study Handbook (with details of the study and protocol processes, and key contact details). Also, refreshments were budgeted at the training day and for the focus groups, as well as appropriate travel costs within their communities and to the university. Finally, the co-researcher's contribution would be acknowledged in publications, or they could be included as co-authors if they wished to push the collaboration further, and also would be funded attendance to a local conference to co-present study findings.

These actions are in accordance with the guidelines provided by INVOLVE for payment and recognition of public contributors, beyond payment.(386) Still, INVOLVE recommends that at least "all out of pocket expenses should be covered for members of the public"(31) and acknowledges that a fixed rate for involvement cannot be defined, since the tasks public contributors are asked to complete can be very diverse. In the UK, each organization has particular payments and expenses policies, and generally, rates vary from £25 for involvement in a brief task requiring little preparation to £150 for involvement in all-day activities.(387)

Expected impact of the study

With its emphasis on public involvement, this feasibility study aims to provide an example of practical ways to include lay perspectives in health research in Singapore, by

putting patients at the centre of the work. The study could indeed provide a basis for a more extensive incorporation of the public's perspectives in health research in Singapore.

This study also aims to build community-based collaborations that could support future programs of research. Finally, for the co-researchers in this study, we would hope that exposure to the research process in this way would foster their interest in further collaborations. This proposal was finally accepted by the funding body.

2.2.7.2. Funding a Lay Advisory Panel

The second example is a funding application being reviewed by the Research Administrative & Support Services in early 2018. In this case, the group wanted to involve two members of the public to form an advisory panel for the study. Over a year, the panel was expected to meet four times, and remuneration for the attendance to these meetings was costed in the original application. When the reply arrived, in May 2018, the reviewers asked to revise the budget for the panel as this was deemed as “non-fundable. It seems to equate to consultancy service”. The reviewer had not understood the goal of having patients advising the study and rejected funding it.

2.2.7.3. Discussion

I just provided two examples of grant applications submitted by my own department in Singapore by UK researchers, where public involvement was included in the proposal. These had two very different outcomes: while in the first case public involvement was accepted, it needed a very thorough review, as if the co-researchers were participants in the study; in the second example, funding for a lay advisory panel was rejected because it was understood as a service in the form of an external consultancy.

Both cases evidence that research funders and regulators lack of an understanding of theoretical and practical public involvement, and the impact it has on researchers' ability to include it in their studies.

Due to this unfamiliarity, funding applicants have a critical role in educating funding bodies on public involvement in research. Researchers have a responsibility to take the lead on it and make a case for public involvement, not assuming that there will be automatic "buy-in" from the funders.

If public involvement is to become the norm in research in Singapore, awareness of policymakers and funders need to be raised, and training should also be provided to them to fully understand this methodology and its impact on research.

2.2.8. Encounters with Researchers Speaking about Participatory Methods in Research

In the spring of 2018, a Singaporean doctor came to the university and delivered a seminar entitled "Patient Participation in Healthcare" where the concepts behind public involvement in health services and research were introduced. The doctor had acquired and practiced these concepts during a stay in Australia.

In summer of 2018, a conference organized by the newly formed Society of Behavioural Health, Singapore gave me the opportunity to attend a talk delivered by a PhD candidate social participation amongst older adults in Singapore. Using Participatory Action Research methods, she could complete her study in collaboration both with the community, with foundations, and with government organisations such as grassroots from the neighbourhood. Members of the community were involved as co-researchers to encourage thinking on community issues and thinking together on the best solutions for

them. They acknowledged the fact that focusing first on initiatives that would directly help the community would be of mutual benefit in the longer term. Volunteers became program leaders after undergoing training. She mentioned challenges to introduce community-based research methods to the grassroots, as these structures are geared for top-down work. At the start of the project, older people had voiced their feeling of lack of agency, while the grassroots were supportive. She then decided to open a dialogue between both groups to achieve more individual empowerment of community members. This brought to light a tension between the need for social cohesion (maintained by the grassroots) and the aspirations to have an autonomous, active, and empowered citizenry. During her talk, she highlighted other challenges to sustain public engagement in research and in other fields within the current mindset and socio-political context, for example, the fact that local NGOs are replaced by Voluntary Welfare Organisations that are also controlled from the top, which challenges true empowerment of the civil society.

Also, in autumn 2018, a panel of examiners included a professor who highlighted some interesting initiatives around public involvement in Singapore. This professor is a physician-researcher focusing on the design and evaluation of integrated care systems, and on the role of social innovations in health.

In the National University of Singapore, the Saw Swee Hock School of Public Health published a job offer for a Research Associate in Rehabilitation and Community-based Research and has a Professor using community-based research models. Moreover, the School had welcomed international speakers using community-based research methods.⁽³⁸⁸⁾ Similarly, the Centre for Health Services and Policy Research also has a Research Fellow whose research interests revolve around community-based research.

2.2.9. Community Engagement

During this study, conversations with colleagues have led me to recent efforts by research departments of public hospitals and universities to engage the public, raising awareness in research, and educating the public.

Since August 2017, the Institute of Mental Health (IMH) runs a 'Caregivers' Roadshow' every month (alternating English and Mandarin).(389) This initiative is coordinated by IMH Medical Social Work department to reach out to caregivers of persons with mental illness, community partners, and members of the public. In each event, a team of multi-disciplinary mental healthcare professionals (including doctors, pharmacists, and occupational therapists) unravels specific mental illnesses, explaining available treatments and therapies, psychiatric medications and their side effects. Moreover, those are used as an opportunity to provide information on community resources and practical tips for caregiver coping.

NTU has a Local Community Engagement Office that actions its commitment to building capacity of and creating a positive impact on the community of the South West of Singapore. In 2018 a monthly talk series, 'Did you know', started to be held on the last Friday of every month.(390) All members of the public are welcome to discuss with NTU experts emerging research topics and trends affecting the society.

Other examples of anecdotal evidence of the shift of the role of the public beyond health research are provided in Appendix 4: Other Examples of Anecdotal Evidence.

2.3. Summary

In this chapter, I examined the current models of patient involvement in healthcare-related research in Singapore using a review of published and grey literature, including research policy and patient group websites.

Although the systematic search did not yield any result on patient involvement in research in academic publications, anecdotal evidence collecting along this study showed good examples of the shift towards patient-centeredness both in clinical curriculum and practices, and a desire to continue the road of patient activation and engagement. This shift in the mindset for the clinical aspect can facilitate a shift in research-oriented tasks, and some researchers are already considering introducing active roles for members of the public in their studies. Similar transformations are occurring at a wider scale in parallel to the ones in the clinical arena, and people in Singapore, like the students, seem to be increasingly encouraged to have an individual voice.

Moreover, new complex health challenges have pushed the Ministry of Health to look for innovative solutions that have included greater levels of collaboration with the public and the necessity empowerment of all individuals. Community engagement methods have been used by policy-makers in the health domain since 2016 to find innovative ideas to tackle the 'war on diabetes' and these events have built reinforced the trust of the citizens on the government and have demonstrated to the policymakers the power of public involvement. Tackling non-communicable diseases heavily relies on changing people's behaviour or increasing preventive behaviour hence increasing the need for PPI to understand how best to approach these strategies in Singapore.

A shift within the researchers' community, for researchers working with vulnerable and marginalized groups, was also widely discussed. These have already started to establish relationships of equals with the communities they are working with and are slowly figuring out how to adapt Western participatory research methods to the local research culture and socio-political context. Other efforts to increase public awareness on diverse research topics were briefly presented, showing the increasing realisation of the importance of community engagement with research.

This chapter has illuminated a shift in health services, the government, and learning institutes towards a greater appreciation of the voices, perspectives, needs, and values of citizens. Public involvement is thus not to be a dormant field but an increasingly popular one that, although still in its infancy, will inevitably reach the wider health research domain as well. Also, this chapter demonstrates the willingness of Singaporeans to be involved, debunking the supposed apathy of the youngest generations of Singaporeans. Politicians have noted older people's strong desire to give back and have a sense of purpose in later life. As noted in the *Youth Conversations*, the youth want to be active and make a difference but need to be engaged through innovative challenges compatible with their lifestyle.

In the following chapters of this thesis, I will explore using qualitative research methods the perspective of the research community and of the public on what is needed for participatory methods to flourish in Singapore, and will examine their own motivations, views of barriers and challenges, and ideas for implementation. In the next chapter, an overview of the study design is provided.

CHAPTER

3 STUDY DESIGN

In the previous chapters, I presented a review of the literature on public involvement theory and uses as well as an overview of the landscape in Singapore to support the development of my research questions. In this chapter, I discuss the methodological approach that I have taken. This includes the justification and introduction to the methodology used and the research design. Also explained in this chapter are my own theoretical position and values about this research.

3.1. Restating the Research Questions

The aims of this thesis were i) to understand the perspective of different stakeholders in Singapore about public involvement in health research, and ii) to examine how public involvement could be implemented in health-research studies conducted in the local context. These research aims were exploratory and broad, given the scarcity of existing research and the need to begin developing our current understanding.

To complete these aims, I was guided by the following questions:

1. What are the existing uses, policy and drivers for public involvement in health research globally and in Singapore (if any)?
2. What are the current models of patient involvement in health care-related research in Singapore?
3. What are the views, preferences, and experiences of local key stakeholders on public involvement in research?
4. What are the recommendations for research policy and practice in Singapore to move the public agenda forward?

This chapter illustrates how I designed the research to answer these questions and its methodological underpinnings.

3.2. Ontology and Epistemology

There is no ideal theoretical framework or method for conducting qualitative research, nor a theoretical position and set of values that should be prioritised. However, it is of critical importance to match methodology and research questions and to acknowledge the choice of methodology and methods as positive decisions.

Using a method appropriate to the data is as important as stating researchers' epistemological (and other) assumptions if the aim is to produce research that is both theoretically and methodologically sound.⁽³⁹¹⁾ The choice of a theoretical framework carries a number of assumptions about the research endeavour and the nature of the data obtained, what they represent of the *world*, *reality*, and *truth*.

In this section, I state my philosophical position, what influences have shaped my ontology and epistemology, and thus my rapport with this research.

3.2.1. Limitations of traditional schools

Research methodology has traditionally been approached from three major schools of thought (positivism, interpretivism, and social constructionism), which are opposed in their views. Positivism has been the dominant philosophy since the natural sciences were positioned as the gold-standard of scientific research inquiry. Interpretivism is positioned at the other extreme and has been the heterodox approach until being surpassed by social constructivism. Generally, social scientists position themselves within one of these methodological frameworks.

Positivism, interpretivism and social constructionism present differing views of the social reality (social ontologies). While the first considers that both natural and social entities are “phenomena” and “objects of experience”,(392,393) interpretivists establish a boundary between both, arguing that the social reality is constructed through language.(394,395) Finally, social constructionism sees no distinction between natural and social entities, both being linguistically constructed.(396,397) In fact, within social constructionism, the natural sciences are positioned as a part of social life.

While the positivist standards are still used as the norm in many spheres of science (such as engineering and neuroscience, areas I have previously focused on), adhering to its ontological frameworks conflicted with my understanding of social reality. By no means can I imagine that my work aimed to find “general” or “universal governing laws” to predict and control the impact of PPI. Such laws are needed to develop an understanding of

fundamental sciences, and the methods used for it differ from those needed in my research.

On the other hand, I consider that social life also follows some laws and cannot be limited to meanings brought by language and context (which social constructivism posits). The way reality is understood affects our approach to it and thus our ability to unveil *truths* (imperfect because not immutable) by performing empirical experiments. While our interaction with the world is thus linguistically mediated, there is more to reality than what we are able to explain and predict through our thoughts and language. In order to interpret and understand the social reality my thesis addresses, my work assumes the existence of mechanisms driving a reality.

To account for the apparent differences between the physical entities and social structures, and to work within a common ontology, I had to look beyond these three dominating paradigms.

Critical realism, sitting between the two traditional poles of theoretical frameworks, intersects with my considerations of what exists. The “critical” instance refers to the acknowledgment that human language and social power inevitably affect (if not determine) our rapport to all human activities, including science. Critical realism refuses to reduce the social to the natural. Secondly, because the approach to the natural sciences is “mind-independent” and assumes “condition of possibility”, this philosophical framework is described as “realist”.

3.2.2. Introduction to Critical Realism

Critical realism, originally developed by Roy Bhaskar in the 1970s, represents a relatively new approach to research. Now established as a stand-alone school of thought,

critical realism is characterised by a confrontation of the central concerns of both natural and social science regimes.(398–400)

In practical terms, the critical research method focuses on evaluating the data and suggesting appropriate changes to address a problem. For example, the critical research method would ask why some groups are less engaged in research, and what can we do to fix this issue, leading to practical recommendations. Critical realism offers a novel approach to research(401,402) that can reunite the complex theories postulated to explain complex social phenomena with the challenges of healthcare systems and scientific research.(398,403–405)

The philosophical framework postulated by critical realism has its own ontological and epistemological departure points(406,407) that researchers of all fields can use as a basis for rigorous exploration, with particular implications for their work.(398,408) In the following sections, I briefly describe the ontological and epistemological aspects of critical realism and examine the application of critical realist principles to qualitative research.

3.2.3. Ontology

Ontology is concerned with the understanding of what is, what exists, and what is real.(408,409) Only those entities considered real within a particular philosophical framework can be the focus of inquiry of researchers,(398). It is the chosen ontology of the researcher that limits the possibilities for creating knowledge.(410)

Critical realism owes its characteristics to a very particular ontology, as it posits a unique approach to the classification of ‘what is’.(398,411) It distinguishes three ontological domains (illustrated in Figure 16) and considers the relationship between causal laws and observable events.(412)

Figure 16: Iceberg metaphor for critical realism's ontology. Source: Fletcher (413)

As represented in Figure 16, what lies in the actual domain is a subset of the real domain, and similarly, what lies within the empirical is a subset of the actual. All three domains lie within the same reality and are connected.

This stratified view of reality can be translated to my field of research, as Figure 17 shows. The research landscape in Singapore represents the 'real' domain. In this domain, generative mechanisms exist that activate events. These take place amongst researchers working in a particular research institute in Singapore. A specific research institute represents the 'actual' domain. Not all events generated in that institute will be known to each of the researchers working there, or to the research participants in research being conducted there. However, even if a particular individual is not aware, those events are still happening. Within my research files, there are documents (e.g., memos, transcripts, and manuscripts) containing the data for my study, and these represent the "empirical" domain. Even though these are arranged in one way today, my interpretation of the data has changed over time; they have been updated as my understanding has evolved, and new evidence was gathered. From the critical realism perspective, data interpretation and the recommendations that I have formulated from it are "fallible".

Figure 17: A visual representation of the three layers in the stratified ontology of critical realism applied to my study

In summary, critical realism is different from other ontologies in that it acknowledges the existence of an independent and wider reality beyond what is known to the researcher. In contrast, other philosophical frameworks only acknowledge the “mind-dependent” strata; thus, the researcher is limited to recognising and identifying phenomena in the “empirical domain”.(399,411) Critical realism offers researchers the possibility to unveil and understand complex social phenomena in particular. They can then formulate theories or practical recommendations on the generating phenomena arising in other strata which affect the reality under study.(403,410,414)

3.2.4. Epistemology

Epistemology is concerned with the nature of the relationship between the individual that can know (i.e., the ‘researcher’) and what can be known to that individual.(415) It also concerns the assumptions of the world where the individual is situated. Indeed, epistemology refers to how a given philosophical framework considers that knowledge is generated, what knowing means, and what the process of thinking

represents.(407,408) While ontology examines what exists, epistemology examines the ways we can know about what exists.

Within critical realism, scientific statements aim to illuminate the context or circumstances leading to the generation of a particular event, or to clarify when an existing explanation is valid.(403,416) Critical realism uses abductive inference,(403) i.e., it starts from empirical observations and then seeks the simplest and most likely explanation, or generating mechanism, accounting for the observations. The researcher draws upon his own experiences and perceptions arising from the empirical domain, rather than trying to find an unattainable mind-independent perspective.(402,403,417,414,400)

Importantly, critical realism notes the fact that the reality we know is a social construct, as only events that have been experienced and that we are aware of can be considered.(418) The real world, with its generative mechanisms that interact to produce actual events, is much broader than the reality we believe to be in.(419) For this reason, what we call the *truth* of our body of knowledge is contextual. Consequently, the “*advancement and validation of scientific knowledge claims are thus a matter of clarifying the contingent circumstances under which a particular explanation is likely to hold*”.(403)

Critical realism offers new perspectives for the social sciences and is an increasingly popular framework in social-based research.(414,420–422) It highlights an inherent complexity to all phenomena, and in particular, to social phenomena. The recourse to multiple strata, perspectives and approaches is particularly relevant for the qualitative exploration of events and experiences.(403,423)

The ontology and epistemology of critical realism provide new perspectives for the approach to the topic of this thesis. Public involvement bears significant relevance to the natural sciences (due to its relationship to health research) and social sciences (due to its

application in a specific new cultural context like Singapore). Because it brings together both of them, critical realism is particularly interesting in the study of public involvement in health research. Also, critical realism emphasises the context-dependence of causal explanation,(414) which will be useful to fulfil the aims of this study.

While I chose critical realism as the philosophical framework guiding my research, to understand public involvement in research, it is also useful to approach the subject in terms of a knowledge framework.(424) In my thesis, I started from the standpoint epistemologies related to critical disciplines such as feminism.(425) These encourage the active participation of those who benefit from healthcare services and allows the incorporation of their experiential knowledge(426) (or service user knowledge(427)). Standpoint theories examine and challenge prevalent and generalising understandings of health, consequently opening and democratizing research.(428) In these frameworks, knowledge based on experience, amassed through personal approaches to mind and body, contrasts with codified, academic knowledge learnt through formal education,(429) introducing a diverging discourse to the healthcare context.(15,430)

3.3. Study Design

This section gives an overview and a justification for the study design and research methods chosen. A more in-depth insight into the methods used for data collection, analysis, and interpretation is given in each specific chapter of findings.

3.3.1. Characteristics of Exploratory Research

Research always begins with curiosity and the desire to create new knowledge; all research is, by definition, a type of exploration. However, it is often stated that for research to be sound, a set of rules (or formulas) needs to be followed. Research is a social process that comes to fill gaps in the wealth of knowledge by putting together what one learns in the process of conducting research from initial loose ideas and hunches.

Not all research is exploratory. Exploratory research favours flexibility and pragmatism following the researcher's initial interest on a specific unexplored topic, contrasting with traditional positivist approaches to research that expect it to be conclusive, descriptive, and explanatory.(431) Keeping the research open is the main concern of exploratory research.(432)

The aim of exploratory research is to use preliminary information to define gaps and problems and suggest hypotheses(433) in new and unexplored topics and/or contexts.(434) The objective is to explore the boundaries of a research problem instead of offering final and conclusive results.(431) For this reason, a preliminary stage of exploratory research is required for all emerging research process,(435) where discovery is always possible, and a broad and non-specialised content provides useful insights. The future direction the researcher takes is influenced by the findings of the exploratory phase.(436) Exploratory research requires above all flexibility,(432) and when done efficiently, exploratory research is instrumental in the definition of the conceptual framework(437) and in the design of future studies, including sampling and data collection methods.(432,438,439)

Because exploratory research often lacks formal structure, it permits a flexible and emergent research design, as the boundaries of the topic are defined alongside the process. This flexibility may attract criticism. The methodological rigor is often questioned

compared to conclusive studies, and the sample size is often far smaller. However, an exploratory study can be conducted with methodical rigor(439) and it is particularly well-suited for qualitative research.

Indeed, exploratory research is especially attractive in the social sciences,(432) where all aspects of life are interconnected. Social sciences "*seek to find out how people get along in the setting under question, what meanings they give to their actions, and what issues concern them. The goal is to learn 'what is going on here?' and to investigate social phenomena without explicit expectations.*"(440) Their study requires accurate representations of holistic processes, which cannot be achieved through narrow rule-bound frameworks.

Following an exploratory methodology, the research question remains open. This allows approaching research topics that present high levels of uncertainty, covering problems that are not very well understood (i.e., the literature is scarce on the subject matter).(434) Qualitative methods can be used to find tentative answers to the "why", "how" and "when" of the phenomenon explored.

Figure 18: Key characteristics of exploratory research

My study firstly aims to clarify and define the nature of public involvement in Singapore rather than generating a description, explanation, and conclusion. The topic presents high levels of uncertainty, as the issue of public involvement in local health research is not well understood (i.e., very little existing research on the subject matter),

and the boundaries of the subject are not defined at the start of this study. Based on the characteristics summarized in Figure 18, an exploratory methodology was appropriate to start with. Only such an approach would permit the identification of factors or variables of relevance to the understanding of involvement in Singapore.

3.3.2. The Choice of a Mixed Methods Approach

Critical realism has been described as a “*powerful middle way to create knowledge through intensive and extensive research methods, that when used in conjunction, can come closer to achieving a much needed systematic understanding of the relationships, structures, and mechanisms constituting the material and social world.*”(400)

Critical realism encourages the use of numerous research methodologies and methods.(413,441) It is for this reason that it has been described as the “*least restrictive perspective, insofar as it is maximally inclusive as to causally relevant levels of reality*”.(442) In particular, critical realism is helpful when using mixed methods,(400,403,414) since it highlights the fact that the observable changes noted empirically need to be approached via multiple levels.(422)

3.3.3. Overview

This project was designed as a mixed-methods, inductive, and iterative three-phased study, as shown in Figure 19. The first phase consisted of a literature review of the uses and policy drivers for public involvement globally, the different models of participation, and the evidence for lay involvement in research. Qualitative semi-structured interviews with researchers and members of the public in Singapore were conducted in the second phase, which concludes with a commentary of qualitative findings based on foreign guidelines for best practices in public involvement. Finally, a

case study of the operationalisation of public involvement in a developing research project in Singapore was conducted for the third phase. The case study was a biobank, and this was complemented with a systematic review of the impact of public involvement in such studies.

Figure 19: Diagram of the study design in three phases

The first phase focuses on the first research question expressed above. The second question is addressed through phases 1 and 2. The second phase in particular, and partly phase 3, provide answers to the third research question. Finally, all phases contribute to the last research question.

3.3.4. Data integration

This project was exploratory, and an iterative research process was needed throughout all phases of data collection and analysis, enabling findings from each phase to be used to inform future work. Findings from Phase 1 were used in the development of the interview topic guides for Phase 2 and the case study conceptual framework for Phase 3. Themes obtained in Phase 2 informed the operationalization of public involvement in

the case study. Findings from Phases 1 and 2 laid the foundations for the case study evaluation. Finally, findings from Phases 1 to 3 were integrated and final themes were used for discussion and recommendations for research, policy and practice.

3.3.5. Choosing qualitative research

Public involvement is a complex and poorly defined field, which is highly dependent on context and the process for various reasons.(90) For example, as discussed in Chapter 1, there is not a precisely defined, standardised action that can be defined as public involvement. To study such a wide topic from the perspective of various stakeholders, I chose qualitative research methods. These are preferred when examining how broad structural, historical and cultural conditions influence people's perspectives, experiences and choices.

Qualitative studies help to describe the context in which the phenomena of interest takes place, giving access to new meanings for barriers and facilitators and stakeholders' perspectives around it.(443,444) To understand the potential for public involvement in Singapore, conducting a qualitative study can give answers to the questions listed in Figure 20.

A qualitative exploration of different strata of reality is encouraged by critical realism. The aim is to research beyond particular concepts and aspects of reality previously identified(420) to understand the power underlying social objects, behaviours, and relationships (generative mechanisms).(414)

Figure 20: Types of questions approached through qualitative research

The ethical frameworks considered in the context of qualitative research are detailed in Appendix 5: Ethical Frameworks to Consider in Qualitative Research.

3.3.6. Aligning methodology and methods

Critical realism is used to explain social events and suggest practical recommendations, thanks to its comprehensive philosophy of science and its characteristic search for causation.(445) While traditionally critical realism has emphasized the explanatory power of researchers, researchers working within that framework have highlighted a lack of methodology to apply its principles to empirical research.(446,447)

Critical realism is not tied to a single type of research method but rather supports an extensive variety of methods that are chosen according to the type of the project and the aims of the study.(400,403) While critical realism is useful (valid and flexible) for guiding social research inquiry, it does not provide specific guidance on which research

methods to apply.(413) For this reason, the number of authors having demonstrated the contribution of critical realism ontology and epistemology to their research (design, data analysis, and findings) is scarce.(413,414) On the contrary, because critical realism can accommodate a wide variety of research methods, mixed methods research is facilitated within it.

Qualitative interviews

Although the use of critical realism in empirical research is limited,(446,447) examples of its use in qualitative interviews can be found. This is the case of in-depth interviews, as those conducted by Fletcher,(413) Parr(448) and McEvoy & Richards(401) in the healthcare field.

Qualitative interviews are particularly geared for research within a critical realist framework.(443) This is because critical realism supports the idea that individuals' social and physical contexts have a causal influence on their beliefs and perspectives. Thus, a realist perspective provides a better framework for understanding the relationship between individuals' perspectives and their actual situations.(414)

Because of the availability of empirical examples and the suitability of qualitative interviews for research using critical realism, qualitative semi-structured interviews were my preferred choice for the major component of this thesis (Phase 2, a national perspective). Through those, I aimed to identify the views, preferences and experiences of local key stakeholders on public involvement in research.

Qualitative interviews are widely used in health research(449) and have become almost “*synonymous with qualitative research*”.(450) They entail complex interactions with the participants, across a range of communication settings, open to numerous types of analysis and interpretation. They are the only recommended method for collecting data

when seeking to understand the perspectives of individuals conceptualized within their own story and/or experiences.(443,451) Indeed, while the researcher directs the content, participants lead the conversation shifting it towards new but related directions. This method permits the identification of themes and higher-order patterns; the researcher can then explain those and draw recommendations from them.

Semi-structured interviews are the most popular primary data collection method in exploratory studies. This type of interview is moderately standardised. The process is structured around a topic guide (to ensure the conversation remains relevant to the topic of interest), which facilitates comparison between participants, while also allowing flexibility and ‘spontaneity’ for the participant.(443) This is reflected in critical realism’s notion that prior theoretical ideas are necessary to guide and ground the research in the existing body of knowledge.(452) Another advantage of this approach is that it adds an extra dimension to the analysis, as one can explore *how* the participant responds to each particular question. For example, participants might require prompting and explanations during the interviewing process, before providing a full answer to the question listed in the guide.

Other research methods used

For the other phases of this study, I used evidence synthesis and observation.

Scoping studies are a "*form of knowledge synthesis that addresses an exploratory research question aimed at mapping key concepts, types of evidence, and gaps in research related to a defined area or field by systematically searching, selecting, and synthesizing existing knowledge.*"(453) In Phases 1 and 3, scoping reviews of peer-reviewed studies were conducted to map the use and policy drivers of involvement globally as well as to record the preferred methods and impact of public involvement in biobanks.

The second stage of Phases 1 and 3 included observational methods. The first project sought to explore the local landscape and the role of patients in health services and research and members of the public more broadly at the start of my doctoral studies. The second observational project, detailed in Chapter 9, explored the implementation of public involvement in a recently commenced local research study. Informal dialogues and other forms of communication (e.g., email) were also considered. Critical realism has been proposed as a coherent, novel, and helpful approach to observational and case studies.⁽⁴⁰²⁾ It has been recommended particularly for case studies that focus on bounded but complex phenomena such as organisations and the relationships within those; this will be the case in this thesis.⁽⁴⁰²⁾ In this context, critical realism facilitates the understanding of the social phenomenon by recording and analysing the associated events that take place as a result of the actors acting. In my case, adopting an observer stance allowed me to study the barriers and facilitators for public involvement adoption within a group of researchers without having direct influence and assistance in the team dynamics.

3.3.7. Reflections on Methodology and Methods

Researchers need to assess the fit between method and purpose.^(444,454) For me, the need to use a qualitative approach, despite my quantitative background, was determined by the research question and purpose of my thesis, rather than my prior experience. Indeed this project required a detailed understanding of processes and experiences. The boundaries and characteristics of the topic in the Singapore context were not clear, and a big part of my data would come from participants' perspectives from in-depth semi-structured interviews (i.e., non-numerical data). I gathered vast amounts of information aiming to explore a seemingly novel topic in the context of interest.

Since the beginning, I was challenged by my own - and most of the local researchers' - lack of understanding of qualitative research. I was forced to immerse myself in the literature to be able to answer and argue for my case and to conduct research with rigor and confidence. My approach to qualitative research methodologies evolved from a stage of conscious incompetence wishing to be consciously competent, to a level that cannot be refuted.

Critical realism seemed to unify my belief in science to understand the natural world, that I nurtured in my training as an engineer, while acknowledging the limitations of this to cover the social world. Critical realism deviates from both and unifies the seemingly opposed positivism and constructivism and offered me an epistemology to work within.

3.4. To Make Sense of the Data

3.4.1. Choosing Thematic Analysis

Regarding the application of critical realism to data analysis, the literature is also scarce and, when described, the processes are vague. Fletcher(413) mentioned the interest of using a flexible coding process and recommends the use of NVIVO software to map the connections between codes and to organise and rationalise them. In NVIVO one can check the list of existing codes, as it appears at the side of the screen. This prevents the development of new codes that are very close to existing ones - a challenge encountered when working on hard copies of transcripts and long paper lists. Greater insights into the rationale for using NVIVO are provided in Appendix 6: Using NVIVO as a Computer Assisted Qualitative Data Analysis.

The method chosen for this thesis is thematic analysis, as it is a flexible and useful approach to data analysis and provides a fundamental understanding of qualitative research for a novice qualitative researcher like me. Appendix 7: Introduction to Thematic Analysis and the Coding Process provides an introduction to the operationalisation of thematic analysis and the coding process in this thesis.

Thematic analysis has been qualified as a ‘foundational method’ for qualitative analysis(455) amongst a rich, complex and nuanced range of qualitative approaches.(391) Despite the fact that at its core is the search for ‘thematising meanings’(391) like in all other approaches of qualitative analysis, thematic analysis can be a method by itself, and not simply a tool to be used in other approaches, as some have argued.(456,457)

Braun and Clarke(455) warn that only by following a series of clear guidelines can thematic analysis be flexible and useful while responding to the ‘anything goes’ critique(458) that any qualitative researcher must face. Indeed, since thematic analysis is based on the unifying principle of qualitative research, thematic analysis is a flexible method that can be employed under the umbrella of most methodological approaches. In my case, because of an apparent lack of agreement in the how-to of thematic analysis,(456,459,460) I have adapted the 6-phase approach to thematic analysis suggested by Braun and Clarke (familiarization with data, generating initial codes, searching for themes among codes, reviewing themes, defining and naming themes, and producing the final report) (455) and Smith and Firth(461) and used NVIVO to organise the analysis process.

3.4.2. Ensuring rigour in research

"[The quality of qualitative research] cannot be determined by following prescribed formulas. Rather its quality lies in the power of its language to display a picture of the world in which we discover something about ourselves and our common humanity"(462)

Even though rigour is a challenge for any piece of research, due to its specific epistemological basis qualitative research faces greater challenges in demonstrating its rigour. Indeed, as the previous quote argues, unlike for the natural science, where prescribed formulas exist to measure the reliability and validity of research,(463,464) qualitative research lacks of a formal universal tool to assess its rigour and its value seems to belong elsewhere than measurable outcomes. However, some strategies and standards do exist to avoid "anarchy"(464) and ensure the rigour of qualitative research.

For a piece of exploratory research to be of good quality, the concepts of reliability (or credibility), validity,(464,465) and trustworthiness (466) are often stated. In this section I will discuss some of the strategies I put into place to ensure the rigour of the research was maintained all along.

Reliability

Reliability or credibility can be achieved by using multiple data sources that together create a holistic and contextual account.(467) In my case, I explored multiple perspectives around a same phenomenon, by gathering the voices of researchers and lay participants, and greater heterogeneity within the group was sought as well. Finally, global perspectives around involvement were gathered through the review of the literature.

Secondly, the quest for consistencies and variances and for contradiction of expectations and assumptions by disconfirming data will provide more rigour to the study

and a better understanding of the specificities of local research. Indeed, searching for confirmatory or refuting evidence for ideas and thematic frameworks within and across cases is another way to increase the credibility of research.(465)

Reliability in the analysis was also achieved by having two persons working on the same transcripts allowed to compare views and ideas between different researchers. Indeed, the process known as inter-coder reliability brings credibility to the interpretation as:

‘...reliability refers to the degree of consistency with which instances are assigned to the same category by different observers’(468)

Reliability refers also to the replicability of the research findings.(469) Often qualitative research is criticized for its “anecdotalism”,(464) arguing that the findings cannot be replicated. I will thus provide examples of original data and of the process of data analysis, which will give the reader a chance to assess the quality of the source and of the interpretation.(470) A process of analytic induction through rigorous thematic analysis of interview transcripts was supported by adequate evidence of systematic coding scheme materialised in a codebook also provides an argument for the generalizability of the findings.(464)

Finally, the writing of memos that encourages a reflexive endeavour that reinforces the credibility of the research.(471) A reflexive diary gave me a space to reflect on the influence I could be playing on the research design and outcomes and on the development of the research.

Validity

In qualitative research validity refers to the “appropriateness” of the tools, processes, and data (469) with respect to the research question and epistemology, amongst others.

I have previously illustrated my ontology and epistemology, placing myself within the research and stating my understanding of the nature of knowledge, and delved into the match between those and my methods to address the topic of validity. In the earlier sections of this chapter, and in the final reflection of this thesis, I provide an explanation of the recruitment methods, the data collection and analysis strategy and reflect on the limitations of my methods.

Reflecting on the methods and progress with regards to the research questions in journal memos was another way to judge whether the work done was sufficient to answer these questions and what alternative strategies could be needed to do it.

Rigorous and systematic thematic analysis, supported by the use of NVIVO, helped to developing more inclusive theories to account for the data enhancing the validity and representativeness of the findings.(464)

Moreover, I reflected on the cultural and contextual variables affecting my research, acknowledging the fact that any research must be situated within a temporal, spatial, social and situational conditions in order to be valid.(472)

Trustworthiness

While quantitative research is concerned with issues of 'truth' or 'value', a non-positivist understanding of qualitative research suggests the need of 'trustworthiness' instead. For Sandelowski qualitative research 'becomes a matter of persuasion whereby the scientist is viewed as having made those practices visible and, therefore, auditable'.(826, p.2)

Trustworthiness is thus a relatively abstract concept that has been defined in the literature from different approaches and is bound to issues of credibility (internal validity); dependability (reliability), transferability (external validity); and confirmability (presentation).

If trustworthiness is seen as the ability of the researchers to account for the research accurately and transparently, trustworthiness of the research arises then from data being recorded objectively and comprehensively, by levels of analysis being tracked at all times. Earlier in Chapter 3: Study Design I highlighted the methods I followed in this work and in Chapters 4 to 8 I thoroughly reported an account of research findings. Finally, the Appendices provide with in-depth details of supplementary information to inform the trustworthiness of my work.

Finally, Seale argues that because the aim of qualitative research is to have an accurate and "authentic" understanding of people's experiences, qualitative research prioritizes the use of open-ended questions and techniques such as interviews. For this reason:

"Authenticity rather than reliability is often the issue in qualitative research."(464)

Such that trustworthiness of data collected, and findings ultimately depends on the ways in which judgements are made about the content of the data and by making sure that the findings are inductively produced to reflect accurately the voice of the participants. The role of the researcher is then to reflect on people's experiences so as to generate additional data and insight.(474) Reflexivity along the process such as writing memos and a research journal has then allowed me to maximise the authenticity and trustworthiness of the research.

3.4.3. Reflexivity

Without some degree of reflexivity any research is blind and without purpose.(475)

When approaching any piece of qualitative research, it would be a mistake to overlook the role of the researcher. Indeed, for qualitative research, it is difficult (and some might even consider it wrong) to put a distance between the researcher and the body of research. In this case, the researcher becomes both an instrument and a piece in the research, in "*a process of on-going mutual shaping between researcher and research*", by zooming in and out from the field.(476) However, numerous authors caution that the researcher must be aware that rigour of the research is to be maintained throughout, such that the work is not merely a 'confessional' work.(477) I have previously presented how I put into place to ensure the rigour of the research was maintained during my doctoral studies.

This thesis is a social construction of my own interpretation, and at times emotions,(478) of the narratives imbued within the literature, the interviews conducted, and my observations. This thesis and its appendices are provided to demonstrate the rigour with which my research was conducted. While established methods were used to minimise bias, all stages of the research process, from design and data collection to the

final stage of writing, were influenced by my own disposition.(479) The style of this thesis is commented on in Appendix 8: Style of the Thesis.

To maintain a reflexive approach to my research, I kept a research journal, in the form of memos written in a dedicated folder in NVIVO. Writing about the research process gave a space to practice prospective reflexivity by becoming aware of the impact that I, as a researcher, was making on the research.(480) I recorded events and happenings that could have an impact on the research. Some examples of questions guiding my reflection were:

- Why are you doing this project?
- What do you think it's about?
- What are the questions you are asking?
- What do you expect to find and why?
- What have you observed so far?

Further insights into the importance of memo writing during my doctoral studies are provided in Appendix 9: The Importance of Memo Writing in this Study.

I have previously stated my motivations for undertaking this research project, and I introduced my ontology and understanding of the social world and science, and my position in it. Throughout this thesis, I have balanced an objective third person with my personal views expressed in the first person to express my voice and share my reflections. Finally, at the end of this thesis, I will reflect on my overall experience and provide a summary of my thoughts and findings from this research, and I will provide an account of the effect of this project on myself, as part of the retrospective aspect of reflexivity.(480)

In this chapter, I have outlined the methodological framework within which my research needs to be read and understood. I have provided a justification for the

theoretical orientations and recounted their implications on the methods chosen to gather rich data and answer the research questions. Finally, in this chapter, I have highlighted some of the strategies I used to deal with some of the common criticisms often identified for qualitative research.

In the next chapters, a description of national perspectives on public involvement is provided through a qualitative study. The views of researchers on public involvement in health research will be reported first.

CHAPTER

4

RESEARCHERS' PERSPECTIVES: THE ARGUMENT FOR A COMMUNITY-BASED APPROACH

4.1. Introduction

“To be a citizen is to participate in the civic affairs of the community where one lives, extending outwards to the nation.”(481)

The evidence that Patient and Public Involvement and Engagement (PPI) carries several benefits for research, including the production of higher quality, more efficient and effective research has grown in the last 20 years.(14–28) During that period, PPI has become widely integrated into research in Western countries, where some health research funders and policymakers make it a mandatory consideration, most notably the National Institute for Health Research (NIHR) in the United Kingdom (UK).(14) Although patient involvement can be interpreted in various ways, the critical principle in PPI is that the public is actively involved in the activities, organization and governance of health research, whether in specific projects and/or research more generally.(14)

The utilitarian case for PPI argues that by incorporating public knowledge and expertise, researchers can identify and develop user-centered research objectives and

questions, more appropriate research materials, enhanced recruitment strategies, user-centered interpretation of data, enhanced cost-effectiveness,(22,48,49) and optimize dissemination, implementation, and impact of research findings.(18,22,23,25,50) As a result, PPI is being embraced not only by public bodies, but by commercial enterprises such as those in the pharmaceutical industry.(48,49,57)

Balancing this utilitarian model is the Kantian ‘Categorical Imperative’ which argues that human beings are not a means to an end(58,59) but rather ends in themselves, and that it is incumbent on people to always act as members of their communities in which all other members are also ends in themselves. From this position, it can be argued that members of the public are legitimate and central stakeholders in research affecting the health of individuals and communities. Linked to this are arguments on the importance and role of lay knowledge, which emphasise patients and members of the public as experts in their ‘lived experience’ both entitled to be, and having the responsibility to be, meaningful partners rather than passive subjects and/or recipients of research.(61–64) This emphasis on lay knowledge carries with it two challenges in particular:(25,61,69) first to the objectivity of the expert knowledge base; and second, a political challenge to the authority of experts in decision making policy. Lay knowledge and perspectives play a crucial role in opening up research evidence to public debate.

4.1.1. Singapore

Western models of PPI tend to emphasise almost exclusively the contribution of individuals. There is little consideration of the concept from a non-Western lens, and the evidence base for its use in Asian countries is virtually non-existent. Singapore is perhaps amongst the most outward-looking of members of the Association of Southeast Asian Nations (ASEAN). It provides an interesting case study for exploring the potential of PPI within an Asian context.

Singapore has four official languages reflecting its ethnic mix (English, Mandarin Chinese, Malay, and Tamil), with English adopted as the first language in schools in 1966. Since its independence, first from Britain in 1959, and then from the Malay Federation in 1965, it has experienced dramatic economic and social change. In a little over 60 years, it has risen from “Third World” poverty¹ to being an ‘Asian Tiger’, sitting alongside Hong Kong, South Korea and Taiwan.(102) The drive to survive that powered this enormous transition has now transmuted into one that is focused on addressing the tension between its political and cultural position as an outward-facing country and its geographical context, surrounded by traditional Asian cultures with a growing emphasis on religious fundamentalism, e.g. Indonesia and the Philippines.(105) Given these existential challenges, it is perhaps not surprising that Singapore is driven by a strong government with a culture that privileges the collective rather than the individual experience.(106)

Singapore is an island city-state of only 722.5 sq. km.(107) With such scarce geographical resources and a resident population that has increased from 1,886,900 in 1965 to 3,994,283 in 2018(107) and which, moreover, is one of the most rapidly aging in the world,(108) the Government has prioritised investment in knowledge capital.(109,110) In 2016 SG\$19 billion (US\$14 billion) was invested in education and research.(118) Consequently, Singapore is rapidly becoming a world-class research hub, attracting world-renowned scholars and researchers.(118,121) While this drive to innovation and excellence in research includes an emphasis on the advancement of patient care through translational clinical research, PPI remains rare beyond patient participation. This chapter reports findings from interviews with researchers in Singapore, exploring their views and experiences of PPI and the implications for public engagement in research.

4.1.2. Study Aims

Our study aims were to explore:

1. The extent to which those working in health research understand the principles, role, and scope for involving patients and the public in health research
2. The challenges and opportunities for implementation of PPI in Singapore.

4.2. Methods

4.2.1. Research Design

Data were collected through face-to-face semi-structured interviews, designed to offer the opportunity for participants to reflect on their experiences and produce their own narratives, being guided rather than lead by the interviewer.(482,483) The topic guide was informed by the literature and adapted iteratively during and after each interview to explore emerging themes in-depth (Appendix 10: Interview Topic Guides). In addition, brief personal and professional data on each individual were also collected to contextualise their accounts and experiences (see Table 6). Potential participants were identified from the websites of different research institutions in Singapore (in order to reach both early career a mid-late career researchers as well as biomedical versus clinical versus public health/social researchers) or by a participant's recommendations.(443) In approaching subsequent participants, purposive sampling(484) was used to ensure as wide a range of perspectives as possible (see Table 6). Participants were invited via email with a study flyer attached. Where people responded positively, a study information sheet and a consent form were sent as part of the process of arranging the date, time and location of the interview. All participants were given an SGD15 voucher as a token of appreciation for their time. Data collection took place between April and July 2018.

Informed consent was obtained before beginning the interview and checked again at the end. Immediate reflections post-interview were documented by way of contact summary forms (Appendix 11: Contact Summary Forms).(485) All interviews were audio-recorded, transcribed verbatim, cleaned, and anonymized before analysis. Participants were assigned a code in replacement of their identity, consisting of the letter 'R' followed by a two-digit number in order of sequential recruitment (i.e., R01, R02, etc.), which was applied to their personal and professional data also. Finally, all data were stored securely in line with Nanyang Technological University's (NTU) requirements for safe data storage.(486) Participants were eligible for inclusion if they were involved in ongoing health and social care related research in Singapore and were able to communicate in English.

4.2.2. Analysis

Socio-demographic and professional data were summarized using descriptive statistical analysis. Qualitative analysis was supported by NVivo 10.(487) A thematic analysis(455,488) was undertaken in six stages (see Figure 21). To ensure reliability, a process of inter-coder consensus was adopted, in which two of the authors (LLP and BB) independently coded a random selection of six transcripts. A coding framework was then developed and applied to the remaining data by LLP. More details on the coding process and how thematic analysis was used can be found in Appendix 7: Introduction to Thematic Analysis and the Coding Process.

The analysis process was both iterative and concurrent with data collection,(489) repeatedly moving from the concrete reality of data to potential models and recommendations.(490) Consequently, data saturation was not based on informational redundancy but rather inductive thematic saturation.(491)

Figure 21: The six stages of coding, adapted from Braun and Clarke (455)

Finally, within the critical realism perspective adopted for my doctoral studies, in this study the term empirical domain reflects data collected (the interview transcripts and reflective memos), the term actual domain reflects the mechanisms in place in the context in which the study took place (such as the *Shared Values*), and the real domain captures the findings discussed in this study.

The study was reviewed and approved by NTU Internal Review Board, April 2018 (ref: IRB-2018-02-028).

4.3. Results

A total of 36 potential participants were identified and contacted; 26 (72%) replied; 20 (56%) were interviewed. The average interview lasted approximately one hour. The total amount of audio data was 22 and a quarter hours.

4.3.1. Participants

Just over half of the participants were women (n=11) and half had more than 10 years' experience, with a range from less than one to 20 years. Five people were completing their doctoral studies, four of whom were practicing clinicians with previous experience of research. Nine individuals were working at the professorial level. Two individuals were involved in research administration, including recruitment, rather than working as researchers themselves. See Table 6 for the full details of participants' characteristics.

Table 6: Details of researchers' participants

	Gender	Ethnic Group	Position	Research Experience (years)	Research field
R01	Female	Chinese	Research Fellow	6 - 10	Pregnancy & Parenting
R02	Male	Caucasian	Doctoral Researcher	1 - 5	Older adults
R03	Female	Chinese	Doctoral Researcher	1 - 5	Neurology
R04	Female	Caucasian	Doctoral Researcher	1 - 5	Pregnancy & Parenting
R05	Male	Chinese	GP Researcher	<1	Family Medicine
R06	Male	Indian	Assistant Professor	> 10	Chronic conditions
R07	Male	Chinese	Doctoral Researcher	1 - 5	Psychiatry
R08	Female	Caucasian	Associate Professor	> 10	Chronic conditions
R09	Male	Chinese	GP Researcher	1 - 5	Family Medicine
R10	Male	Chinese	Research Manager	> 10	General population
R11	Male	Chinese	Assistant Professor	> 10	Older adults

R12	Female	Indian	Adjunct Associate Professor	> 10	Psychiatry
R13	Female	Chinese	Research Manager	< 1	General population
R14	Male	Chinese	Associate Professor	> 10	Physiology of ageing
R15	Female	Chinese	Professor	> 10	Neurology
R16	Female	Chinese	Professor	> 10	Older adults
R17	Female	Chinese	Doctoral Researcher	< 1	Chronic conditions
R18	Female	Chinese	Occupational Therapist	6 - 10	Physiology of ageing
R19	Male	Malay	Assistant Professor	> 10	Chronic conditions
R20	Female	Chinese	Associate Professor	> 10	Patients with cancer

Three major themes emerged: reasons to adopt PPI, adoption challenges and opportunities for implementation. In what follows, we present details of these themes using illustrative quotations, before turning to look at the implications.

4.3.2. Reasons to Adopt PPI

Interviewees recognized two key reasons to adopt PPI. The first was rooted in a belief that PPI would facilitate the research process: *“The process becomes easier, things will be smoother... the research will be more fruitful” (R10/M/Chinese/Research Manager/>10)*. The second was its potential to increase research relevance, mainly by aligning research to patient and public priorities.

Participants identified several reasons for including PPI, of which the most frequently mentioned was making their research *“easier”* by either optimising the design and/or enhancing recruitment:

“They [the public] could actually help the research to be more efficient, to recruit much easier if they're involved.” (R15/F/Chinese/Professor/>10)

Part of this notion of efficiency was the potential for PPI to enhance the use of resources, starting with financial resources:

“And [PPI would] probably save a lot of money for the grant bodies.”

(R06/M/Indian/Assistant Professor/>10)

Linked to efficiency in research was the notion of how PPI could inform participant retention:

“Because they [the research team] can understand the public better... to ... bring these people, participants, back again and again, year after year to continue the study.”

(R09/M/Chinese/GP Researcher/1-5)

PPI was also seen as a way to avoid potentially costly and avoidable mistakes:

“If I don’t do this [PPI] it might also lead to a lot more problems later ... you know, you do it very quickly and then you come up with a design that is not good. Then you actually have to do a lot of patchwork to try and solve the problems.”

(R16/F/Chinese/Professor/>10)

Interviewees also saw PPI involvement as a way to increase impact:

“I think it will be more helpful because you have one additional perspective that will help you, later on, to translate it much easier than if you didn't have it.”

(R15/F/Chinese/Professor/>10)

The voice of the patient was seen as an intrinsic element of this:

“A patient’s voice is generally more powerful than a physician’s opinion.”

(R06/M/Indian/Assistant Professor/>10)

PPI was seen to offer a complementary perspective to researchers’ knowledge:

“In my view, it is a mistake that we just look at the evidence...sometimes, as researchers... you no longer hear right what people are saying... We think we know, because we read

what our peers publish in the journals, but do we really know?"

(R08/F/Caucasian/Associate Professor/>10)

PPI was also seen as an advantage when applying for grants:

"Because if we are talking about translational research and that's your area of study, showing that your study is centred around your patient is the number one criteria."

(R14/M/Chinese/Associate Professor/>10)

This was seen as of particular importance in longitudinal studies, where ensuring sustainability over time is critical:

"I think it would be definitely more sustainable. We would probably get more support from everybody else. And even probably better, more sustainable funding". (R09/M/Chinese/GP

Researcher/1-5)

Aligning research to patient and public priorities was also identified as a reason for involvement:

"We want to make sure that whatever we are designing or whatever we are coming up with needs to, first of all, meet the needs of patients, and needs to be something they want. So, I think for sure, in clinical and health services research, patient and public involvement is critical, is important and critical." (R20/F/Chinese/Associate Professor/>10)

Linked to this was the recognition of the need for an inclusive approach to health services planning and research strategies:

"So there is room for the top-down approach, but then at the same time we need another set of research coming up, participator from bottom-up. To say: ok, yes it is strategic, but if you want programs that are going to be effective, we need to engage these real people to tell us what's going to be effective for this cohort, for this group."

(R18/F/Chinese/Occupational Therapist/6-10)

4.3.3. Adoption Challenges

Participants highlighted a number of challenges, that can be grouped into three sub-themes: (i) lack of understanding of PPI theory and practice, (ii) management time and resources in research and (iii) the broader socio-political context of Singapore.

The overarching challenge to the adoption of PPI was the evident lack of understanding of its role and function on the part of most participants, which could engender anxiety:

“Maybe also a certain amount of anxiety or fear, because they have never done it before...” (R17/F/Chinese/Doctoral Researcher/<1)

This lack of knowledge extended into how to incorporate PPI methodologically:

“If I was gonna organize it by myself for future studies I wouldn’t know how to go about it.” (R02/M/Caucasian/Doctoral Researcher/1-5)

The lack of understanding of PPI for some participants was linked to their perceptions of the status of patients within the research process:

*“Absolutely not necessary... it’s your paper, not their paper... They are subjects.”
(R05/M/Chinese/GP Researcher/<1)*

Such attitudes and beliefs were seen as key:

“If I believe in user-centred design I would do it, but if I don’t believe in user-centred design I will not do it.” (R16/F/Chinese/Professor/>10)

Related to this, some participants felt that the research community might struggle to have confidence in the contribution of PPI:

“At the back of their minds would be whether or not this member of the public has enough knowledge or sophistication, or understanding to be able to give you useful input, rather than just say anything they like.” (R10/M/Chinese/Research Manager/>10)

Time and resources also emerged as a potential challenge, linked to the lack of experience:

“I have time limits as to how long I can involve in my project. So that makes it very difficult. There is also cost of involvement, because... I would very much want to involve feedback. But it was not possible; it was the time limits, and also the cost. I did not factor in the cost. So, it’s very hard.” (R01/F/Chinese/Research Fellow/6-10)

The understanding of the ethical dimensions to PPI also emerged as a challenge:

“I think that there is a great barrier in terms of ethics. It’s because we are very used to the traditional forms of ethics application where participants are involved in a certain research project and then there are boundaries as to what they do and what they do not do. So, I don’t know whether giving ideas to researcher on the research, whether it is within the boundary or outside of the boundary. I really don’t know. I don’t know where it would come under, in terms of ethics.” (R02/M/Caucasian/Doctoral Researcher/1-5)

Linked to this, the broader socio-political context of Singapore was also seen as a potential challenge:

“I think it probably has to do with Singapore still being a more traditional paternalistic society where you are still seen, as a healthcare provider, as the owner of the truth and the one that kind of delivers that truth to the patients. I think the relationship is still not of equals.” (R04/F/Caucasian/Doctoral Researcher/1-5)

This broad cultural context was reflected in how patients were seen by the researchers to position themselves as passive recipients within the practitioner-patient dyad:

“Because of the culture patients just don’t speak up about what they need... [they] rarely question doctors.” (R06/M/Indian/Assistant Professor/>10)

This inequality in the relationship was also apparent within the research context:

“It’s been a bit difficult for us to engage people because when they hear ‘research’, you know they take part and all that [in the survey], but when they hear that we want them to come in and be interviewed, they feel a bit overwhelmed because they feel ‘I am not that educated’ or ‘who am I to talk’.” (R12/F/Indian/Associate Professor/>10)

Linked to the view of patients as ‘subjects’ of - rather than partners in - research, participants identified a potential sense of vulnerability:

“In taking part in research they feel very much like experiments or they feel like a laboratory rat or a guinea pig ... that disempowers them.” (R03/F/Chinese/Doctoral Researcher/1-5)

Consequently, researchers reported that if they asked members of the public to be involved in their research, people would turn down the opportunity because of feeling *“incapacitated to offer insight.” (R08/F/Caucasian/Associate Professor/>10)*

Related to this a cultural reticence on the sharing of personal information and trust in authorities:

“Asian cohorts tend to be a little bit more conservative in nature, so they would not like to share their personal information.” (R07/M/Chinese/Doctoral Researcher/1-5)

Reliance on traditional understandings of health, and health literacy, was also seen as particularly influential:

“There’s still a lot of this kind of folklore, cultural passing from grandparents to parents to... traditional thinking, that even today is very prevalent for things.”

(R04/F/Caucasian/Doctoral Researcher/1-5)

Interviewees spoke about the implications of low literacy more generally for PPI:

“Sometimes some of this research is very scientific stuff. I think it’s just a bit too much sometimes. Public people will not understand.” (R13/F/Chinese/Research Manager/<1)

Finally, challenges around engaging older people in PPI were identified, including mobility and language:

“Challenging to get very old subjects... they may not be ambulant ... older people that might be lower educated people, that would only use their mother tongue.”

(R10/M/Chinese/Research Manager/>10)

4.3.4. Opportunities for Implementation

Despite these challenges, interviewees also highlighted characteristics of Singapore that could facilitate involvement locally. These included current demographics, Education and raising awareness among both experts and members of the public and the strong government context of Singapore.

Participants identified several opportunities for developing and implementing PPI in Singapore. With a rapidly aging population, the need to move away from the pathologizing of old age was seen as offering a motive for engagement:

“Do we want to continue to see such reliance and dependency in future generations of older people?” (R11/M/Chinese/Assistant Professor/>10)

Education and raising awareness was seen to be crucial to implementing PPI:

*"I think [implementing PPI] through educating doctors [what it is] actually about...
because I do think people would generally feel it is a good idea."*

(R02/M/Caucasian/Doctoral Researcher/1-5)

Interviewees identified such education at two levels. Firstly, working with emerging researchers and health professionals so that the theories and concepts of PPI are normalised:

"When you teach research, it would be one of the things that you can consider, especially undergraduate education, all this. So, when you introduce research, you can bring this topic in. And after that, they would like to know [more]." (R05/M/Chinese/GP

Researcher/<1)

Secondly, strategies to update and engage existing researchers through continuous professional education, specific workshops and academic conferences:

"It could even be in courses where researchers are taught how to do a research proposal and stuff like that." (R09/M/Chinese/GP Researcher/1-5)

Participants also highlighted the need for public education and raising awareness:

"They [the public] just don't understand research. I think you would have to get that across." (R06/M/Indian/Assistant Professor/>10)

This lack of understanding was seen to have a direct impact on the willingness of patients and the public to become involved:

"I think it's more of public understanding about research and education, whether they want to be involved or not. Sometimes it's like you want them to be involved, but then they're not quite at that level of understanding, so it's difficult to get them to volunteer or donate the time." (R15/F/Chinese/Professor/>10)

PPI was also seen to offer the opportunity to build trust with the public:

“You have to earn trust first. You have to treat people as people first. To win trust first, to explain what you are doing, and to explain what you don't know about the research; and how they are contributing.” (R20/F/Chinese/Associate Professor/>10)

This would take time:

“Probably need some warm-up to really understand that there are no hidden agendas in what we are saying.” (R04/F/Caucasian/Doctoral Researcher/1-5)

Linked to building trust and understanding, and reflecting the notion of longitudinal, life-course learning for researchers, participants highlighted then the need first to raise awareness of research amongst the population at all ages and within different ethnic backgrounds:

“I would say the best way may be to start doing it in schools, maybe in young children, maybe in teenagers, those who are in secondary schools, and above, to let them know what does a research process involve, and what is good research and how can the public influence scientists and researchers and coming out with research directions and topics.”
(R09/M/Chinese/GP Researcher/1-5)

Interviewees also saw the current emphasis on lifelong education in Singapore as an opportunity to educate older adults on the principles of public involvement:

“We do have SkillsFuture in Singapore right now going on, so you could have a continuing education module on that [on research and PPI].” (R15/F/Chinese/Professor/>10)

The strong government context of Singapore was also seen as offering opportunities should policymakers adopt PPI:

“I think what we reward and what we don’t reward is important. So, you need to reward the right behaviour, you need to reward the right design and so on.”

(R14/M/Chinese/Associate Professor/>10)

Linked to this, participants considered that embedding consideration of PPI as mandatory in funding proposals would inevitably increase emphasis on the patient as the central to health research:

“To put it as a requirement that your research has got to involve this kind of people. It will help to bring it to be more conscious for people to focus more around the patient.”

(R14/M/Chinese/Associate Professor/>10)

The key was seen as integrating the principles of PPI into Singaporean culture itself:

“It’s almost like inculcating, developing, nurturing this kind of idea to be part of the culture. So, it’s not just educating, it’s like how do you make it part of your lifestyle?”

(R15/F/Chinese/Professor/>10)

4.4. Discussion

This qualitative study suggests that researchers in Singapore lack experience of PPI. However, the interview process itself provided an opportunity for reflection through which it was clear that they considered it to have potential benefits. With 85% of health research globally not being implemented, in part because of a lack of relevance to patients and the public,(75,281,492) opportunities were seen in the drive to increase effectiveness and efficiency of research, primarily motivated by the needs of Singapore’s aging population and the concomitant increasing demands on health services. Major challenges were identified as low awareness amongst researchers and the public, and the socio-

political context of Singapore with its emphasis on Eastern cultural notions of collectivism, rather the Western stress on individualism.(493)

Existing evidence, including that from countries where it is advocated by policymakers and funders,(494,495) indicates that PPI is not always embedded in research(496) because of a lack of real collaboration between PPI and professional researchers.(497) Reflecting on the findings of this work, previous reports highlight researchers' lack of knowledge, skills, and experience of PPI operationalization as a major challenges.(17,497–501) Despite a growing understanding and appreciation of the value of PPI,(190,297,502) the attitudes of researchers remained diverse.(297,498) For example, the report '*Going the Extra Mile*' in 2015 by the NIHR(14) concluded that, although the value of PPI was progressively realised, there were "*inconsistencies in practice and implementation*" of PPI in the UK and cited negative attitudes of researchers as a major barrier. In 2014, Boaz et al.(297) reported that researchers were still reluctant to share power and control of their work with patients and members of the public, who were often relegated to the role of 'thinker at the edges',(297,498) not least because of the inclusion of 'lived experiences' of health and illness challenges 'expert knowledge' in what remains a mostly positivist research paradigm.(503) This is closely related to the maintenance of a high level of professional paternalism.(504,505) Finally, researchers have been reported to experience feelings of apprehension and discomfort around involving the public, as also evidenced in our findings.(498,506,507)

As reflected in this study, PPI is sometimes seen by researchers as time- and energy-consuming, and as an added hurdle to developing and carrying out a research project,(17,502) opening the door for tokenistic involvement practices(502) and potential resistance to change.(19,42,506) Other practical challenges identified in the literature, and evidenced in this study, are a lack of clear roles for PPI amongst both the public and researchers, and concerns about possible public agendas that might be contrary to the

aims of the research. Finally, the perception by some researchers that contributions from the public will not result in useful input has also been identified as a barrier.(42,508–510)

The literature also highlights the ubiquity of hierarchies as a critical challenge to PPI.(508,509) Such hierarchies also exist in Singapore.(106,511) Respondents in this study considered that some patients may feel intimidated by the status of researchers' who are considered a source of epistemic authority by members of the public.(106,481) Such power imbalance may be deepened by a lack of understanding around research, low literacy, and poor English amongst those with the greatest health needs, particularly older populations who have not experienced the post-independence Singapore education system, with a consequent reluctance to speak out and/or engage with research. Linked to this was the notion that trust between the public and researchers needs to be strengthened. Strategies identified to address these challenges included education across the life-course both for researchers and the public, starting at school and undergraduate level and continuing into adult learning arenas. Careful consideration of language was seen as fundamental to such a process of raising awareness across different sectors of society, not only in the avoidance of jargon but also in developing resources to work with those for whom English is not a first language, and ensuring that people feel their contribution is valued regardless of their background or opportunities for formal education.

The socio-political context of Singapore offers opportunities to address these issues more strategically by translating the Western emphasis on the individual into one of the collectives, in keeping with the ethos of the nation-state. A possible approach is the World Health Organisation (WHO) Health for All 2000(512) emphasis on the centrality of communities in setting their own health priorities and resource allocation.(513) In addition to identifying and prioritising research questions, this participatory collective approach could be adapted to also include reflections on all stages within individual programmes of research, including data analysis and implementation.(195) Rather than

expecting individual patients and members of the public to come to universities and research centres, as is predominantly the case in Western societies, such a participatory approach would allow the voices of individuals to be heard within the collective safety of their own local communities, and on their terms. It offers a mechanism for traditionally received wisdom to be shared and to contribute to an inclusive dialogue of mutual respect and learning, building trust, and potentially leading to enhanced resilience and capacity to adapt within what is a rapidly changing landscape of health and health care. Such a dialogue could result in responsive and flexible guidelines and resources to support innovative and effective health research, reflecting Singapore's position as a leading global science hub.

Strengths and Limitations of this Study

This is the first study to explore the perspective of those working in health research in Asia on PPI. It identifies the potential for PPI in a non-Western setting, together with a number of challenges and opportunities that are culturally-specific. To do this, it drew on a range of views, from those with extensive research experience to those with very little. The majority were Singaporean and all three Caucasians had lived in Singapore for ten years or more. Only one researcher was Malay to reflect the ethnic disparities among researchers in Singapore. Although one individual with little experience did express particularly negative views (R05/M/Chinese/GP Researcher/<1), we found very little difference between the views of those more or less experienced.

A further strength of the study was the contribution of researcher reflexivity. In an attempt to limit the impact of implicit assumptions on the interview process, no participants were working colleagues. The study was undertaken as part of my doctoral research project by me, a non-Singaporean. An initial concern centred on the possibility of researchers giving limited data to someone they might perceive as inexperienced and an outsider. In fact, participants gave very generously, with 13 of the interviews running over

time. All of the interviewees commented that I was well positioned to critically evaluate the situation in a way that a Singaporean might not. In addition to detailed use of the contact summary forms and memo writing, this process of reflection also featured in analysis discussions with the other researchers (HES, BB). The process informed both data collection (refining the topic guide), and analysis.

A further strength of this research is its contribution to the growing body of evidence calling for a radical re-thinking of how PPI can be integrated into research in ways that are meaningful and which also maximise its potential impact.(210,285,514) It also supports the argument for clarification on the relationship between PPI, research and research ethics.

A first limitation to this study is the limited elaboration on critical realism as a framework for discussing the results. It was my intention to apply it to the interpretation of my findings and I did put it into practice, providing glimpses to the ‘actual’ and ‘real’ domain. For example, I alluded to the causal mechanisms, such as professional deference, and structures, such as the ‘Shared Values’ and broader socio-political context rooted in Confucian perspectives, leading to challenges for the implementation of involvement in Singapore. However, given the lack of clarity in empirical research accounts that have framed themselves as critical realist investigations, full elaboration from critical realism it may not have clearly emerged, as the presentation of most themes remained mostly on the ‘empirical level’, with limited elaborations on the ‘actual level’ and the ‘real level’. At the beginning of this doctoral work, I was foreign to qualitative research and I did push my practice as far as I could. Further research could take a deeper dive in the interpretation of all findings to connect all three levels of critical realism’s inquiry.

Member checking is commonly used in qualitative research as a means to maintain validity and credibility of results, by allowing returning the data participants to check for

accuracy and resonance with their experiences.(515) Participants' comments serve as a check on the viability of the interpretation, as they can critically analyse the findings and comment on them. Although during the interview process I often restated and summarised new information, and then questioned participants to determine accuracy, I did not complete member checking after analysis and interpretation of results. I worked with busy professionals who were generous of their time, and who emphasized during the interviews how busy they are. It was often challenging to find a slot for the interview, and it would have been very difficult to schedule a time to go through the final results with participants. Added to the extensive demands on the participants' time, members checking was not pragmatic given the resource and time constraints of my own doctoral work.

Whilst the study includes a diverse range of participants, in terms of research experience, Singapore is itself unique in Asia. The findings from this study, therefore, require more detailed examination in the context of other Asian cultures. Finally, and most importantly, this study focuses only on the views of health researchers; further work, presented in next chapter, explores the views of patients and the public.

4.4. Conclusion

The socio-political context of Singapore offers opportunities to translate the dominance of the individualism prevalent in Western notions of PPI into a more Asian culturally sensitive model of community-based involvement and engagement. Such a participatory collective model offers the prospect of developing sustainable mechanisms for dialogue to understand better communities, and what they can offer in addressing and

adapting to the health challenges facing the nation. Such an innovative model for PPI will still require engagement with many of the complex challenges identified in contexts where PPI is more established, including addressing understandings and appreciation of the role of lay knowledge and expertise.

The next chapter reports on the views of the public on public involvement in health research in Singapore.

CHAPTER

5

PERSPECTIVES OF SINGAPORE PUBLIC: THE POTENTIAL OF A SUPPORTED MODEL OF INVOLVEMENT FOR SINGAPORE

5.1. Introduction

In health research, public involvement (PPI) is defined as “research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them”.(31) Promoting PPI in health research in Western countries began over two decades ago.(32,55) In the UK, PPI is now a required component for publicly funded health research studies, whilst in North America and Australia, public engagement is strongly encouraged by research commissioners and national organisations.(31–35)

PPI can inform all aspects of research, from identifying and prioritising questions through to design, data collection, analysis and dissemination. Patients “*know what it feels like to undergo treatments and their various side effects [...] they will have a good idea about what research questions should be asked [...] and how questions might be asked differently*”.(52) Involvement can also directly impact those participating, increasing self-confidence and knowledge.(53,54) Researchers too, can increase their experiential knowledge and communication skills through PPI interactions.(55,56) PPI builds on the concept that knowledge extends beyond ‘expert knowledge’ to include the understanding that patients develop from living with their illness.(65–67) The ethical argument suggests

it can rebalance power, giving a voice to those whose knowledge is less heard in traditional academic and clinical settings. PPI provides researchers with new perspectives from the public as ‘marginal knowers’ and yet ‘agents of knowledge’(72) who can share their expertise. A utilitarian argument has also been put forward(19,25,42,43) based on the premise that *“if the needs and views of users are reflected in research, it is more likely to produce results that can be used to improve clinical practice”*.(51)

Founded in 1965, Singapore has a culture that privileges the collective rather than the individual experience.(106) Since then, Singapore has experienced immense economic and social change, rising from “Third World” poverty(481) to being an ‘Asian Tiger’.(102) It has a population that has doubled in 50 years and which is multi-ethnic, with four official languages,(107) while English is promoted as the ‘working language’.(100) Singapore prides itself on leading global rankings in education.(111) The education system is structured to “foster a sense of national identity”(24) and *Shared Values*(106,112–114) to promote unity within the diverse population. Singapore workers are among the hardest working in the world, in terms of number of hours worked.(115) In addition, concerns are growing over affordable retirement as studies have found that retiree households living in public housing receive the bulk of their income from their children or relatives,(116) and that the majority of working adults in Singapore are financially unprepared for retirement.(117) This has implications in terms of leisure time and availability for volunteering.

Singapore is an international research hub,(118,121) but PPI in health research remains rare.(516) This chapter introduces the Singaporean public’s perspectives on PPI and proposes a model for combining these with the previously reported perspectives of researchers in Singapore.(516)

5.1.1. Study Aims

Our study aims were to:

1. Investigate how the public in Singapore understand the rationale, role and scope for being involved in health research
2. Identify the potential, challenges, facilitators and strategies for implementing PPI in Singapore.

5.2. Methods

5.2.1. Research Design

5.2.1.1. Recruitment

Potential participants were identified in two ways. Information on the study was shared with a) members of local community groups, and b) participants in a previous phase of this work (516) were asked to invite potential participants to contact the researcher via telephone. The initial strategy was snowballing,(443) but as recruitment proceeded, purposive sampling was used to ensure a range of perspectives.(484) Once contact was made, participants were given information on the study and, if still agreeable, arrangements were made for an interview at a time and place convenient to them. To be included participants needed to be able to communicate in English. No other inclusion or exclusion criteria were applied given the study aims. As a token of appreciation, they received a SGD15 voucher.

5.2.1.2. Data collection

Data were collected through face-to-face semi-structured interviews, designed to guide participants to reflect on their experiences and enable them to produce their own narratives, privileging those issues most salient to them.(482,483) Interviews were

conducted in July and August 2018. The topic guide (Appendix 10: Interview Topic Guides) was informed by published literature on the scope and practice of PPI and was adapted iteratively to include emerging themes. It included some socio-demographic questions in addition to generally exploring views on research, any experiences of research, and views on PPI in a Singaporean context. Informed consent was obtained before the interview and confirmed again on completion. All interviews were audio-recorded, transcribed verbatim, cleaned and anonymized before analysis. Immediate reflections post-interview were documented by way of contact summary forms (Appendix 11: Contact Summary Forms).(485) Notes included unexpected themes warranting review in subsequent interviews.(517) Data were stored securely in line with Nanyang Technological University's (NTU) requirements for safe storage.(486)

5.2.2. Analysis

A structured thematic analysis (455,488) of the transcripts was undertaken in six stages (see Figure 22), supported by NVivo 10 data management and analysis software.(487) More details on the coding process and how thematic analysis was used can be found in Appendix 7: Introduction to Thematic Analysis and the Coding Process.

Despite English being the language of education in Singapore, Singaporeans commonly use fractured, ungrammatical English, locally known as Singlish.(518) Singlish is a cultural marker for many Singaporeans. Standard English has evolved due to the influence of the many dialects spoken locally. For clarity, the narratives reported in this chapter have been linked together with pronouns and verbs in [] so that the quotes transpose to coherent written text. For example: "I [would] go with anybody, helping; talking about this, that, everything... If there was someone to bring me out, chitchat with me, [it] would make me happy also".

The process of reflexivity, continued during the analysis, was in the form of memos. Analysis was iterative and concurrent with data collection,(489) repeatedly moving from the concrete reality of the data to potential models and recommendations.(490) Data saturation was based on inductive thematic saturation within topics.(491)

In this qualitative study, the real domain consists of the theoretical principles and the model suggested to move forward. The interview transcripts and memos are elements of the empirical domain, the building blocks to identifying the real domain.

Figure 22: The six stages of coding, adapted from Braun and Clarke (455)

5.3. Results

5.3.1. Participants

Twenty people participated (11 women; 9 men) with an average age of 47 years old (ranging 26-71 years of age). Six people were 60 or older, of whom four had been involved in designing a study to develop models of intergenerational support. Eleven people were Singaporean-Chinese, four Singaporean-Indian, and three Singaporean-Malay. Four were retired, 15 working and one was a housewife. Table 7 provides full details of participants' characteristics.

5.3.2. Emerging Topics

Four main themes on PPI in Singapore emerged from these interviews: potential contribution, challenges, facilitators, and potential strategies for implementation. Details of the themes are presented using illustrative quotations. Unique identifiers include participant number, age, gender, ethnicity, with previous experience of involvement in health research indicated by yes or no ('Y'/'N'). No differences emerged across the ethnic groups.

5.3.3. Potential for PPI

Interviewees recognized two key potential benefits of PPI. The first was rooted in a realisation of the need to improve of the power imbalances between the public and health research 'experts': *"it will move us forward, because after all research is meant for everyone, and not just researchers"* (P17/56/M/Chinese/N). The second was its potential

to improve research generally as this participant with previous experience reflected: *“You have to step into the community to do better research”* (P13/61/F/Chinese/Y).

PPI was perceived as beneficial in all phases of research, from preparation of funding applications, through to data interpretation and implementation of evidence: *“because whatever is done now, that really impacts them [younger public]”* (P02/34/M/Chinese/N). During the funding application, PPI could ensure the research was grounded in patient experience *“if you have the inputs of the people on the ground, it will probably be beneficial to the funding application”* (P18/37/M/Malay/N). It was anticipated that members of the public could enrich the interpretation of data and help reduce bias attributable to seeing things from only one perspective, referred to as the *“researcher’s lens”* (P19/30/F/Indian/N). In terms of implementation, PPI was seen to have the potential to influence policy and service stakeholders who would be more responsive to recommendations from a study with public collaboration: *“[The] general public, what they feel is very important for someone to implement something”* (P04/55/M/Chinese/N).

Table 7: Details of lay participants

	Gender	Age	Ethnic Group	Education Level	Profession/employment status	Participated in medical research before	Previous PPI involvement
P01	F	67	Chinese	Secondary School ¹	Retired (accountant)	Yes	No
P02	M	34	Chinese	PhD	Research Fellow (Materials Science)	No	No
P03	M	32	Chinese	Masters	Research Associate (Physics)	Yes	No
P04	M	55	Chinese	Primary	Taxi driver	No	No
P05	F	53	Indian	Undergraduate	Teacher	No	No
P06	F	32	Chinese	Undergraduate	Public Relations (PR)	No	No
P07	F	66	Indian	Primary	Housewife	No	No
P08	M	29	Indian	Secondary School	Journalist	No	No
P09	F	26	Malay	Undergraduate	Administration	No	No
P10	F	37	Caucasian ²	Undergraduate	Teacher	No	No
P11	F	60	Chinese	Masters	Retired (teacher)	Yes	Yes
P12	F	31	Chinese	Undergraduate	Marketing	No	No
P13	F	61	Chinese	Secondary School	Retired (quality control inspector)	Yes	Yes
P14	M	71	Chinese	Secondary School	Retired (stock clerk)	Yes	Yes
P15	F	64	Chinese	Secondary School	Third sector worker	Yes	Yes
P16	M	59	Filipino ³	Graduate (diploma)	Technician Engineer	No	No
P17	M	56	Chinese	PhD	Marketing research	No	No
P18	M	37	Malay	Graduate (diploma)	Business	No	No
P19	F	30	Indian	Undergraduate	Social worker	No	No
P20	M	37	Malay	Graduate (diploma)	Teacher	No	No

¹ Singaporeans are 15-16 years old when they complete Secondary education.

² Singaporean Citizen at the time of the interview.

³ Singaporean Permanent Resident at the time of the interview.

Interviewees emphasised the potential benefits of involving members of the public with characteristics similar to study participants. Interviewees not only saw the potential for PPI to improve research, but also expected it to have an impact on themselves and others taking part. Within this, some generational differences emerged. Younger interviewees considered it an opportunity to improve professional prospects and gain extra income: *"Students, it's very clear cut. They [we] want credit. They want to be able to put it on their resume like; 'I helped the researcher do that'. A bit of pocket money would definitely help"* (P08/29/M/Indian/N). The expectations on the part of older interviewees, however, centred more on self-fulfilment and the hope that it would *"stimulate [your] mind, make [you] work and think. [...] give you the opportunity to improve yourself [...] more confident"* (P14/71/M/Chinese/Y). As someone who had experience of PPI, he felt that he had gained skills and knowledge, and increased his self-confidence and self-esteem. Another interviewee described becoming *"more empowered"* (P11/60/F/Chinese/Y), whilst others mentioned it made them feel *"useful at this age"* (P15/64, F/Chinese/Y). PPI also enabled new perspectives on research: *"a different way of looking at researchers [and thought that] research can be very interesting"* (P11/60/F/Chinese/Y). This potential for increased fulfilment was summarised by one interviewee, who was physically disabled, and who highlighted the importance of resources to support PPI: *"I [would] go with anybody, helping; talking about this, that, everything... If there was someone to bring me out, chitchat with me, [it] would make me happy also"* (P07/66/F/Indian/N).

Linked to this, participants also saw benefits of PPI for researchers, beyond the more practical aspects of research, in its potential to influence attitudes and perspectives: *"It's easy to be caught up in your own circles, and it's not often that you see how what you do impacts the layperson"* (P08/29/M/Indian/N). Whilst interviewees felt that not all researchers are prepared to involve the public in their work, *"I don't know whether researchers have the luxury of the time to do it and even the skillset to do it [effective PPI]"* (P06/32/F/Chinese/N), they saw the development of such skills having positive outcomes

by enabling researchers to sensitively and appropriately work with diverse ethnic groups, with community members helping to identify culturally-specific issues and solutions: “[researchers] do not know that these are the sorts of cultural issues [...] involving people in the community helps [...] being able to reach out to more people able to give you inputs that you do not have” (P20/37/M/Malay/N). This was seen as particularly important in the context of Singapore, which has a substantial number of non-local researchers, for whom “it may help to have a Singaporean around to help” (P09/26/F/Malay/N).

5.3.4. Challenges to PPI

Participants highlighted a number of challenges rooted in Asian culture, particularly in relation to the high levels of deference to professionals and those in authority, which was reflected and reinforced through the education system. In terms of culture, it was considered that in Singapore, “human to human interaction and relations are probably not as open as it would be in other countries” (P09/26/F/Malay/N). It was considered that Singaporeans only come forward when certain they are right and will avoid potential humiliation: “social circles tend to be very tight. It’s very hard to get a Singaporean to open up [...] the kiasu ⁴ culture, then everyone is scared to lose face” (P12/31/F/Chinese/N). Interviewees described their compatriots as predominantly pragmatic: “they don’t like to talk about things, they are more Asian culture. They just live their life” (P03/32/M/Chinese/N). This had broad implications: “Singaporeans in general are apathetic about the issues of ethics, principles and conversations that go beyond bread-and-butter issues” (P08/29/M/Indian/N). Such pragmatism was embodied in practical issues pointing to the workaholic culture of Singapore: “[to] me time is money” (P06/32/F/Chinese/N); “in Singapore we are all busy with our own lives” (P05/53/F/Indian/N); “[people] cannot afford to help others, because they’re either

⁴ a Hokkien (local Chinese dialect) word that means a grasping, selfish attitude. The term can be translated into English as “afraid of being blamed” from ‘kia’ “afraid” and ‘su’ “problem”

working, or they're trying to earn more money, or they're trying to study so hard that they can score straight A's" (P19/30/F/Indian/N). Such a work culture was felt to potentially deter people from PPI, particularly when there was no personal benefit: *"It's always about money. If they cannot get anything about this except for the family that they need to help out with this research, they won't be able to give 100% of the time"* (P16/59/M/Filipino/N). However, it was also noted that time may sometimes be used as a convenient excuse *"I'm not sure if they are genuinely busy or if it's just an excuse"* (P19/30/F/Indian/N).

Underpinning this culture is the education system which participants consider generates high levels of literacy, whilst producing students who are required to show respect and not challenge their teachers. Consequently, critical thinking is often poorly developed: *"our school system kind of teaches people the mechanics of education but discourages people to think independently"* (P17/56/M/Chinese/N), resulting in what a number of participants described as the *"Asian mindset"* (P02/34/M/Chinese/N).

Linked to this, the education system was not considered to give students an understanding of research: *"we have some kind of programme which allows the students to research, but [...] it doesn't give them a real sense of what research is"* (P20/37/M/Malay/N). Indeed, research at the moment was perceived to be solely the domain of researchers, *"the individual researcher's piece of work. It doesn't involve public. It's very personal. There's nothing public about it"* (P11/60/F/Chinese/Y). For most, the public's role was confined to participation in research: *"[...] the white mouse'. For what? They do a test. It's like guinea pig"* (P14/71/M/Chinese/Y).

The culture of deference embedded within the education system was seen to lead to assumptions and beliefs around the status of researchers: *"A lot of Singaporeans think research is for people who are way up there. They have to have a very high pay; they have to be super smart and stuff like that"* (P09/26/F/Malay/N). This was seen to challenge a

genuine engagement with PPI: *“sometimes they [participants] see researchers as, ‘oh, he is so educated, right? How can I share with him because I feel very small?’ [...] they might not want to share with them because they don’t want to lose face”* (P10/37/F/Caucasian/N). Such deference could result in an unquestioning position: *“Because their qualification is very... They study about it. So, we don’t know about it, which is wrong, and which is right. What he says, we follow”* (P07/66/F/Indian/N). This could have implications for informed consent, as this participant reflects: *“[M]aybe I am a bit negligent [...] to me, well I didn’t really question them [the researchers]”* (P01/67/F/Chinese/N).

5.3.5. Facilitators for PPI in Singapore

Despite these challenges, interviewees also highlighted characteristics of Singapore that could facilitate involvement locally. These included current demographics, cultural shifts, and compliance to centralised initiatives.

Firstly, the rapidly ageing population was perceived as a catalyst for PPI adoption, particularly as the associated healthcare demands necessitate research focusing on efficiency and innovation. Older people were considered ideal candidates to be involved in PPI. The young thought that older people were *“less self-centred”* (P09/26/F/Malay/N), had more time and could use this opportunity as a way to remain active: *“it might be something they look forward to. It fills time, they feel helpful [...] [PPI]’s a good opportunity for them to do something that actually matters”* (P10/37/F/Caucasian/N). As a result of this, they *“might be more interested”* (P10/37/F/Caucasian/N). Moreover, these views were reflected in those of older people who perceived themselves as more valuable because of their life experiences: *“youngster just come out, so they know less than what the old people know”* (P07/66/F/Indian/N).

Some also saw the compensation offered to those involved in research as a small, although much-needed, source of income for later life. An older woman reinforced that *“[being paid for being involved] matters to me because once I retire, I don’t have any income”* (P15/64/F/Chinese/Y). Those older people who already had some experience of PPI had suggested it would give others a sense of purpose in later life. Linked to this, older people remember village life and the *“kampung spirit”*⁵ (P19/30/F/Indian/N), which gives them a sense of social cohesion, encouraging understanding and neighbourly compromise. Older people’s motivation to be involved was driven by a wish to reciprocate, *“[PPI] is a way I can use to help myself. I find it useful, so I can use it to help others”* (P11/60/F/Chinese/Y) and recreate the *“kampung spirit”* for future generations.

Secondly, while acknowledging a culture of pragmatism and self-centredness, interviewees recognised *“things are changing”* (P18/37/M/Malay/N) in a way that creates more opportunities for PPI. Interviewees highlighted a shift towards Singaporeans becoming less closed, *“learning to be more friendly”* (P15/64/F/Chinese/Y) and wanting *“to give back a little bit more”* (P06/32/F/Chinese/N). Others described increasing interactions with people from other ethnic communities, and across age groups, and how PPI could further nurture these new relationships. Indeed, improved openness, although in its infancy, is creating more room for broader perspectives: *“[authorities] are making moves towards doing that [giving people a voice], but they should be more radical in it”* (P08/29/M/Indian/N). Interviewees also discussed how Singaporeans are challenging convention, exploring ways to have their own voice, sometimes even *“demanding it”* (P10/37/F/Caucasian/N). In parallel to public endeavours for the expression of diverse perspectives, it was recognised that *“the government is trying to promote that”* too (P10/37/F/Caucasian/N).

⁵ A sense of social cohesion in a community where there is understanding and compromise among neighbours, even as preferences differ from household to household

Thirdly, although the “Asian mindset” (P02/34/M/Chinese/N) was seen as a challenge for PPI, other Singaporean characteristics were advantageous, such as the high level of education which could mean people “*should have more ideas*” (P11/60/F/Chinese/Y) when collaborating with researchers. Similarly, cultural norms, such as discipline and respect for authority were considered consistent with the systematic requirements of best research practice: “*because Singaporeans are very structured. People could follow up on research a little bit better because they like to follow rules*” (P10/37/F/Caucasian/N).

Finally, it was noted the small geographical size of Singapore could make centralized initiatives easier to implement and manage, “*I don’t think we are ready in that sense, at a snap of the finger, but we can be there [...] We’re a small country, it’s easy to control*” (P17/56/M/Chinese/N).

5.3.6. Strategies for Implementation

During the interviews, participants drew on their past experiences of campaigns driving change to suggest both formal and informal strategies to realise PPI in Singapore. Firstly, interviewees discussed the introduction of policies around PPI in health research. Given the culture of deference, most interviewees considered that PPI could be achieved by making it mandatory in research: “*that would make a whole world of difference and should be implemented right away*” (P17/56/M/Chinese/N). Interviewees considered “*the government is the one in the best position to make these fundamental structural changes*” (P08/29/M/Indian/N). Recalling the government’s recent strategy to tackle diabetes, “*within six months the pamphlets already appeared in every corner of Singapore, and you already had volunteers going around talking to people*” (P08/29/M/Indian/N), interviewees described the public’s readiness to engage as “*just one of the perks of being semi-*

authoritarian in Singapore because it works” (P08/29/M/Indian/N). Interviewees also described proactive attitudes towards health, because *“the government is sending messages about inclusion and special needs and being health conscious is being pushed a lot [...] everyone’s touching up on the message”* (P10/37/F/Caucasian/N). It was anticipated that if advocated in a similar manner, PPI could quickly become the new norm in research.

However, on the other hand, some were concerned that a top down approach would challenge the PPI principle of empowerment: *the government can advocate for it [PPI], but then, that would not empower the people*” (P17/56/M/Chinese/N). If led by politicians, some feared it could result in promoting only research topics considered *“no threat, in the social, political sense.”* (P17/56/M/Chinese/N).

Additionally, interviewees suggested various strategies to support PPI implementation. They noted that PPI implementation should begin with raising awareness, in particular within the community, and they frequently highlighted the power researchers’ community outreach initiatives. Raising research awareness and encouraging public’s curiosity were considered best achieved in public spaces through *“a guest session [...] where people who are interested to learn [could] sit down with researchers and whatever, and then they can volunteer”* (P06/32/F/Chinese/N). To reassure and build confidence, researchers need to use lay terminology, to be clear and honest about the research aims and the role of PPI: *“It sounds like a very scary thing. Rocket science. But, if you can break down to them, really, what research really is about, and how they can involve themselves”* (P19/30/F/Indian/N).

In this context, participants recommended linking PPI to community values, presenting it as a shared endeavour with the people: *“you have to start from the bottom up [...] we are still Asian [...] still quite collective at a certain level, even though we try to be*

individualistic” (P17/56/M/Chinese/N). Indeed, most interviewees thought that promoting PPI “*should be a joint effort between the community, the research institutes and the government*” (P08/29/M/Indian/N). Those with PPI experience recalled researchers using “*a very attractive, creative way of bringing us together*” (P15/64/F/Chinese/Y) by engaging with community organisations. Discovering about PPI in a familiar environment with opportunities to informally ask questions was considered desirable.

Finally, it was suggested that researchers could learn from community organisations that are already using bottom-up programs to transform their understanding of citizenship. Participants suggested that recent shifts have been encouraged by government policy and rooted in the community. An example of it is a new culture of shared identity, described as “*this desire of getting to know each other [...] Last time we just kept quiet, but now we interact here and there. So, there is this effort of wanting to know, to continue to maintain this harmony that we have*” (P15/64/F/Chinese/Y). Following these dramatic transformations, interviewees suggested PPI should be rooted in the same community spaces.

The community was seen as central to developing PPI, overriding any individual approaches: “*if you are talking about lay people, then you should try everybody. You can start with [community] organisations*” (P17/56/M/Chinese/N). Also, existing community leaders could be engaged to lead in promoting and supporting PPI: “*You need to find the leaders. You need to go to communities that you see that are very active in their monthly gatherings. Those are the people that might be willing to help you do this*” (P10/37/F/Caucasian/N).

Finally, interviewees suggested that outreach should include innovative ways to target all ages: “*if an app could be created, social media is being used, like a cool, attractive one, or something, then you’d probably get the younger generation*” (P19/30/F/Indian/N).

5.4. Discussion

This qualitative study suggested that although the Singaporean public may be unfamiliar with the concept of, PPI they recognized its potential benefits, identifying a range of ethical and utilitarian reasons for adoption. Interviewees also recognised benefits of PPI at an individual level, including personal development for the public and professional development for researchers. PPI was thought to offer the potential to generate public empowerment and to build new relationships and trust between lay people and academics and health professionals. Proposed challenges to PPI's success were rooted in the "*Asian mindset*", including high levels of professional deference, an educational system resulting high literacy and numeracy, but low critical appraisal skills, and a culture with a heavy emphasis on long-working hours to the detriment of community cohesion. Nonetheless, interviewees noted contemporary cultural shifts which could facilitate PPI adoption; these included in particular the revival of a "*kampung spirit*" with its emphasis on community support and inclusion. Participants identified formal and informal implementation strategies, including policies requiring involvement or awareness campaigns in the community. The role of experts and policy makers in supporting PPI was also highlighted.

5.4.1. Possible Ways Forward: A Supported Model of Involvement

In this context, an adapted version of the 'Supported group model'(519) may offer a useful framework to develop and support PPI in the Singapore-Asia context. Following this model (Figure 23), a partnership between researchers, the government and community organisations would allow for a progressive and sustainable involvement of

the public in research, drawing on the central role that the government and the community have in the lives of most members of the public. This model is aligned with the government's *Shared Values*(112,114) to harmonize life in the country, as well as the meritocratic nature of the society.(106,520) While the latter acknowledges the power of technical expertise, the former emphasizes the importance of the state ("*Nation before community and society above self*") together with the community ("*Community support and respect for the individual*").(114) These three contributors are represented in the 'Supported group model' for PPI, whereby researchers hold the technical knowledge, the community represents the members of the public and the government and other civil organisations form a mediator-partner host. Globally, PPI has been criticized for being dominated by authoritarian and expert-driven models(521) that do not mend the power imbalance between certified experts and experts by experience.(522–525) Previous studies have suggested that the method of engagement often determines who gets involved, together with the resultant empowerment.(519) It is recognised that, of the many approaches to involvement, not all of them yield empowerment or improve research.(508,526–528) This is the case for some patients who are not given a chance to speak up while sitting on study groups. On the contrary, the bottom-up model is advocated by those who believe that members of the public have a duty(229,529) not only to promote participatory approaches to research but also to contribute to a model for PPI that works for everyone. Only then can ethical practices be achieved from the beginning, promoting a rebalance of power and maximum return for everyone.

Despite the interviewees' limited awareness and experience of PPI, all identified potential tensions that adoption of PPI might pose, despite changing attitudes that would facilitate PPI by enabling Singaporeans to more readily express their expectations for research. Interviewees noted the inherent tensions between top-down and bottom-up approaches; the former may be effective but may not create the necessary cultural change for meaningful and sustained PPI, and the latter lacking the institutional structure and

support needed for change in Singapore. Thus, a combination of approaches would be required if PPI is to be compelling for all stakeholders in Singapore, as the supported model conceptualises. Interviewees expressed their need to be supported and reassured if they were to play an active role in PPI. Their ideas extended beyond formal strategies, such as policies and incentives for researchers to involve the public,(31–35) and also included role models and awareness of campaigns in the community that would lend themselves to reinforcing the importance of PPI and supporting community engagement.

Figure 23: Supported Group Model for PPI in Health Research based on Vegeris et al. (519)

The two critical requirements for PPI in research are that researchers are well educated on the necessity for PPI and are committed to its application in their work.(516) Additionally, the responsibility for devising methods of involvement should not be restricted to researchers but should include the public as well.(229)

Power imbalances with real or perceived different levels of knowledge and authority have been cited as major challenges for PPI in the Western literature.(530) However, in the Asian context these imbalances are exacerbated by a preference for “*consensus not conflict*”.(112,114) Existing literature describes Singapore's hierarchical society,(106,511) in which the public rarely challenges the perceived expertise and authority of professionals and researchers. Members of the public saw themselves as passive subjects of research and considered how difficult it would be for them to have a genuine voice that may challenge experts’ opinions. In the Singapore-Asia context, the term “patient” still denotes a passive recipient of healthcare, and in research, participants are “subjects” providing the necessary data. Both terms reflect an inherent imbalance of power, to which those inhabiting these roles are expected to comply.(531) In contrast, in the West, patients have often demanded partnership in research design and governance and are increasingly given opportunities to influence health services and policies.(83)

Singapore will need to consider the best model for involvement to suit the prevailing top-down organisation of society to go beyond traditional forms of consultation and information sharing. With PPI in its infancy, Singapore has the opportunity to learn from countries where it is more established. A flexible model would leave room for driving the PPI agenda forward while departing from the current top-down paradigm of research and healthcare.(532) Full and genuine participation of the public can only be achieved if their needs, wishes and aspirations are reflected in the research agenda.

Finally, it must not be forgotten that it is not only the process and methods of PPI that shape the outcomes, but also the context and values implicit to it.(68,533) Therefore, the development and implementation of PPI in Singapore requires a shift in the understandings of patients, the public, professionals and policy makers. All these stakeholders need to work in partnership, to develop research relationships that engender trust and meaningful understandings and that are based on mutual respect and collaboration.

5.4.2. Strengths and Limitations of this Study

This is the first study to explore the perspective of the Asian public on PPI drawing on a range of views, from diverse ages and ethnic backgrounds. It identifies promising opportunities for PPI in a non-Western setting, while also highlighting a number of challenges that are culturally specific.

To ensure reliability, a process of inter-coder consensus was adopted, in which two of the authors (LLP and HES) independently coded a random selection of six transcripts before developing a coding framework that was applied to the remaining data by LLP.

The study was undertaken as part of a doctoral research project by me, a non-Singaporean. There was initial concern that the public would be reluctant to share their views with someone perceived as an outsider; however, participants spoke generously, often commenting that they felt less constrained talking to a foreigner. Furthermore, the use of the contact summary forms, memo-writing and discussions with the other authors encouraged further reflection. This process informed both data collection (refining the topic guide) and analysis.

An obvious limitation of this study is that the interviews were limited to participants who could converse in English, as I don't speak any of the other official local languages. Although I completed purposive sampling to recruit as diverse range of participants as possible, and although English has been the preferred language in education for decades in Singapore, potentially whole groups were left out of this study. Further research, conducting interviews in Mandarin, Malay, Tamil and other dialects such as Hokkien, are required to gather a broader range of perspectives.

As in the previous chapter, a limitation of this study is the lack of members checking after the analysis and interpretation stage. This would have been desirable but not pragmatic, as I worked with lay people who were generous of their time, and who emphasized during the interviews how busy they are. Moreover, this added to the resource constraints of my doctoral work.

The application of critical realism to the interpretation of findings was also limited in this study, as the themes related mostly to the 'empirical level', with limited elaborations on the 'actual level' and the 'real level'. However, attempts were made to bring the latter to the discussion, illustrated for instance by the mentions to the 'kampung spirit' as a mechanism for community support and inclusion and by the inclusion of the supported model of involvement, as a structure that could help PPI implementation.

Lastly, whilst the study includes a diverse range of participants, the findings require more detailed examination in the context of other Asian cultures in order to understand their broader implications.

5.5. Conclusion

Findings suggest the need for a supported model of involvement, whereby the government and community organisations develop a community-based culture that encourages collaboration and participation in research. As part of this, careful consideration needs to be given to issues of resource and support, both educationally and practically, to enable members of the public to engage with researchers in meaningful ways that will deliver research best placed to improve patient outcomes.

Such a supported model of involvement offers the opportunities for partnership within the socio-political context of Singapore, combining the individual empowerment aspirations to a culturally sensitive model based on community values. In spite of PPI being a new concept, it deeply resonates with community-based initiatives currently being led in Singapore by diverse stakeholders, enabling the government and community organisations to establish the ground necessary for collaboration between experts and the public. Nonetheless, basic awareness of research is still missing, and a combination of formal and informal strategies will be required to drive PPI. Understanding local communities' aspirations and helping individuals become aware and confident of what they can offer to researchers' efforts will be the first challenge for the establishment of PPI in Singapore, and in Asia.

CHAPTER

6

CAN THE 2018 NIHR STANDARDS FOR PUBLIC INVOLVEMENT BE USED IN A SINGAPOREAN CONTEXT? UNDERSTANDING THE PERSPECTIVES OF SINGAPOREAN RESEARCHERS AND PUBLIC

6.1. Introduction

6.1.1. The 2018 NIHR Standards for Public Involvement

Since the creation in 1996 of INVOLVE, a national advisory group to support public involvement within the NHS,(31) public involvement in research has become the norm in health research in the UK, and more recently in many other Western countries including Canada and Australia.(160,257)

Progress has been made in developing different ways of involvement. Despite numerous organisations trying to provide guidance to investigators and research organisations, more than two decades after the introduction of PPI, there remained uncertainty about the purpose and implications of public involvement in research,(534), and a “*striking lack of clarity about what ‘good’ or ‘successful’ public involvement looks like*”.(300)

For these reasons, in July 2016, representatives of several major UK research funding bodies came together to form the Public Involvement Standards Development Partnership. The NIHR Standards (Figure 24) are designed to answer the question: “What does good public involvement look like?” illustrated by six core elements (Table 1).(98)

The first version of the NIHR Standards was published in March 2018 after a public consultation with nearly 700 responses. The standards have been written for all stakeholders who might need clarity on involvement, from individual researchers and research organisations to those who promote or conduct of public involvement in research, and also the public, community groups, and research funding agencies.(535)

Since the standards are guidelines for effective involvement, it is suggested that they are applicable to all research methods and all approaches to public involvement. Each standard contains between three to five indicators “*against which improvement can be monitored*”.(98) Within each indicator, there are three or four examples provided of how they can be translated into practice. This structure is summarised in Figure 25. The indicators were chosen to encourage approaches and behaviours supporting “flexibility, partnership and collaboration, a learning culture, the sharing of good practice and effective communications”; this approach was adopted to avoid generating rules and promoting fixed ideas about public involvement.

The Standards were tested during 2018/2019 in 10 pilot sites across the UK(535), with more than 40 organisations sharing their experiences to help refine them.(536,537) An updated version of the Standards is awaited. Insights shared by pilot organisations revealed that the standards work as a framework that encourages “*self-reflection and learning*” for all partners (98) they succeed in encouraging creativity rather than recommending particular ways of planning, conducting and evaluating public involvement

in research.(536) The standards emphasize the need to capture the process, context(90) and impact(25) of involvement, including the successes and challenges encountered, so that these can be shared to improve the purpose, quality, and consistency of public involvement more widely. By describing the best practice, the six core elements become the building bricks for creating good involvement. The pilot organisations' experiences found they could use the standards in ways that best suited their resources, needs and purpose.(536,538)

6.1.2. The Singapore Case

The Standards were expected to impact the future of health research in the UK,(300) but it was also envisaged that other countries could use them to develop their own policies for public involvement.(300)

In Singapore, public involvement in research is in its infancy;(516) a major challenge being the general lack of awareness of how to proceed, which is apparent even amongst researchers willing to involve the public in their work. However, being a late adopter of PPI does have advantages, as the lessons learnt by early adopters can be used to quickly develop a working framework tailored to the local context. Based on the intention that the 2018 NIHR Standards are "*adaptable to your own situation*",(98) we decided to explore how similar the perspectives of researchers and the public in Singapore are to the principles promoted in the standards and whether these could be used as a framework to build PPI in Singapore.

Figure 24: 2018 NIHR Standards for public involvement. Source: NIHR (98)

Figure 25: Structure of the 2018 NIHR Standards

6.2. Methods

For this research, we utilised existing transcripts from a the studies that had explored researchers and members of the public's understanding of the principles, role, and scope of public involvement in Singapore and to identify barriers and opportunities for implementation (reported in Chapters 4 and 5 respectively). As part of my doctoral thesis and as previously described, I conducted semi-structured qualitative interviews in Singapore between April and August 2018, with 20 researchers and 20 members of the public of diverse backgrounds. The earliest participants were researchers from NTU. These were contacted via email and had no previous relationship with me. Public participants were identified in two ways: through a) local community groups and b) participants in a previous study (516) who were asked to invite potential participants to contact the researcher via telephone. The initial recruitment strategy was snowballing,(443) but as recruitment proceeded purposive (maximum variation) sampling was used to ensure a range of perspectives.(484,539) Once contact was made, participants were given information on the study and, if still agreeable, arrangements were made for an interview at a time and place convenient to them (e.g. their workplace, their homes, or at the university). Interviews were a one-off encounter and lasted an average of an hour; as a token of appreciation, participants received a SGD15 gift voucher.

The topic guides were informed by published literature on the scope and practice of PPI and was adapted iteratively to include emerging themes from the analysis. These were designed to guide participants in reflecting on their experiences and views, and to enable them to produce their own narratives, privileging those issues most salient to them.(482,483) The detailed methods are reported in a previous publication.(516)

Detailed reflexive notes, in the form of contact summaries,(485) were made as soon as possible post-interview. The notes included observations about the quality of the interaction and any tensions, questions asked by the interviewee, and unexpected themes that might warrant checking out in subsequent interviews.(517) The process of reflexivity continued during the analysis in the form of memos.(540,541)

A structured thematic analysis(455,488) of the transcripts was undertaken in six stages,(516) supported by NVivo 10 data management and analysis software.(487) To describe the similarities of the interviewee's PPI perspectives and the NIHR Standards, thematic analysis revolved around each of the standards and indicators in the NIHR 2018 Standards for public involvement (i.e., each Standard was a main theme and each indicator a sub-theme in the coding tree), and our reflections were then structured based on those. When a topic was identified that was not considered in the standards this was noted and included in the coding framework. Thus, the analysis was both inductive and deductive, combining thematic and framework analysis,(542,543) allowing highlighting similarities and differences between the thinking about effective involvement in the UK and interviewees in Singapore (Figure 26). Data saturation was based on inductive thematic saturation within topics.(491) To ensure reliability, a process of inter-coder consensus was adopted, in which the two authors (LLP and HES) independently coded a random selection of six transcripts before developing a coding framework that was applied to the remaining data by me.

The transcripts were not returned to participants for comment and/or correction, and interviewees did not provide feedback on the findings. Although this is considered best practice to verify the accuracy of qualitative interview transcripts,(544) the added time was a threat to participant recruitment and outweighed the potential advantages.

Congruence was calculated by contrasting each indicator to the interviewees' perspectives. When some elements were included in the Standards but did not emerge as relevant in the interviews, no points were added, while when there was overlap, a point was counted. For each standard, the total number of points was added and calculated as a percentage of the number of points vs. the number of examples in each indicator of the Standard.

Figure 26: Schematic representation of the sources of data and aims of this analysis

6.3. Results

6.3.1. Characteristics of Interviewees

Thirty-six researchers were contacted; 26 replied, and 20 agreed to be interviewed. Out of 45 members of the public contacted, all of them replied, and 20 agreed to be interviewed. The main reasons stated to refuse the interview were lack of time and lack of health research knowledge.

Researchers had experience ranging from less than a year to more than 10 years, with the majority having at least six years' experience. Research topics and areas of expertise were also diverse. Fourteen researchers were Chinese, two were Indian, one was Malay, with three Caucasians, reflecting the ethnicity of Singapore. Members of the public included a wide range of ages, from 26 to 71. They were generally PPI naïve; however, four interviewees over 60 had been previously involved in designing a study to develop models of intergenerational support. Eleven lay people were Chinese, four Indian, and three Malay. Just over half of participants from both groups were women.(516)

6.3.2. Context

In general, the interviewees were willing to learn from other contexts, in order to implement PPI as smoothly and as efficiently as possible in Singapore. Nonetheless, they also cautioned against taking guidance from abroad without tailoring it to the local Asian context:

“Singapore, of course, we try to adopt good practices that are useful elsewhere. And rather than just copy, we try to adapt to the local situation. [...] And you need the key stakeholders to also agree and be willing to engage in this process.”

(R10/M/Chinese/Research Manager/>10)

Figure 27 below summarises the degree of congruence between the data from the interviews, and each example of each indicator of the six Standards.

6.3.3. Inclusivity and Collaboration

- Standard 1. INCLUSIVE OPPORTUNITIES: We offer public involvement opportunities that are accessible and that reach people and groups according to research needs (5 indicators)
- Standard 2. WORKING TOGETHER: We work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships (4 indicators)

Even with little practical experience of PPI, most interviewees spontaneously discussed the importance of inclusion and working together. Everyone highlighted the need for involvement opportunities to be widely accessible and for researchers to use tailored strategies to ensure the involvement of those who are meant to benefit from the research. Participants highlighted the satisfaction they would obtain from seeing their contributions valued and their wishes taken into account. Interviewees anticipated a transformation of the relationships between researchers and the public, with greater awareness, trust, mutual understanding, and goals.

There were lots of similarities between the characteristics envisaged for successful PPI in Singapore and the first two NIHR Standards, entitled Inclusive Opportunities and Working Together. We estimated a level of congruence of 85%, as 23 out of 27 NIHR examples were contemplated by interviewees. Only two examples of Standard 1, and two examples of Standard 2 were not reflected in their perspectives, and these are detailed below.

Standard 1: Examples that did not emerge from interviewees' perspectives

No interviewees mentioned making arrangements for people with special sensory needs, e.g., *“an involved member of the public who has a visual impairment can expect to take part in writing research plans”* (e.g. of indicator 1.1), but they did recognise that older people may have physical impairments that would have to be accommodated, for example, a lay respondent with arthritis suggested that transportation would need to be arranged.

None of our interviewees suggested that *“involved members of the public have the option to request ‘book ahead’ transport so that they don’t bear the cost upfront”* (e.g., of indicator 1.2). While the public noted that transport should be provided by the research team, they did not detail processes such as booking and reimbursement.

Standard 2: Examples that did not emerge from interviewees' perspectives

While the public expressed the need for their capacities to be considered when assigning tasks for them to undertake, and researchers recognised the need to be attentive to the roles the public could comfortably undertake. Still, no one discussed an iterative process in which public members would *“feel able to communicate how they find their role and adjust it if needed”* (e.g. of indicator 2.3).

While Singaporeans expected to communicate and share their experiences, and researchers wished to use best practice, neither group mentioned the public giving feedback on how well the researchers enabled them to be involved, as was described in an example of indicator 2.4; *“public contributors give feedback on their involvement such as whether they are able to contribute their ideas, and are involved in decision making”*.

6.3.4. Learning, Support, and Communications

- Standard 3. SUPPORT & LEARNING: We offer and promote support and learning that builds confidence and skills for public involvement in research (5 indicators)
- Standard 4. COMMUNICATIONS: We use plain language for timely, two way and targeted communications, as part of involvement plans and activities (3 indicators)

Our interviewees spoke about support and learning, and communication. Having realised their value, they questioned how these could be best promoted. Professional deference was seen as a major barrier, together with the time needed for laypeople to feel empowered and for researchers to be open to listening and supporting. Moreover, everyone highlighted the public's difficulties accessing information about research, due to the jargon of health research. Researchers and the public both proposed the need to improve communication strategies first, in preparation for subsequent involvement opportunities and activities. They indicated that two-way communication and plain simple language would be critical to ensure shared understanding.

Within the content of the interviews, we again saw high consistency with Standards 3 and 4. Congruence was calculated as 71%, as 17 of the 24 examples were spontaneously described by our interviewees. The four examples of Standard 3, and three examples of Standard 4 that were not reflected by our respondents are discussed below.

Standard 3: Examples that did not emerge from interviewees' perspectives

An example of Indicator 3.2, *"An involved member of the public who is housebound has access to video/phone conferencing hardware/software so that they can participate"*, did not emerge from our interviewees. One member of the public, who needed assistance to leave their home, identified the need for transport to PPI meetings, but they did not discuss involvement facilitated by technology.

Standard 1	INCLUSIVE OPPORTUNITIES: We offer public involvement opportunities that are accessible and that reach people and groups according to research needs
Indicator 1.1	We involve people affected by and interested in the research at the earliest stage
Example 1	✓
Example 2	✓
Example 3	✗
Indicator 1.2	We identify and address barriers to taking up public involvement in research
Example 1	✓
Example 2	✓
Example 3	✗
Indicator 1.3	We make information about opportunities for public involvement in research available, using different methods so that we reach relevant and interested people
Example 1	✓
Example 2	✓
Example 3	✓
Indicator 1.4	We have fair and transparent processes for involving the public in research
Example 1	✓
Example 2	✓
Example 3	✓
Indicator 1.5	We offer choice and flexibility in opportunities for public involvement in research
Example 1	✓
Example 2	✓
Example 3	✓

Standard 4	COMMUNICATIONS: We use plain language for timely, two way and targeted communications, as part of involvement plans and activities
Indicator 4.1	We develop and deliver a communications plan for our involvement activities
Example 1	✓
Example 2	✗
Example 3	✓
Indicator 4.2	We are inclusive and flexible in our communication methods to meet the needs of different people
Example 1	✗
Example 2	✓
Example 3	✗
Indicator 4.3	We gather, offer and act on feedback, which we then share
Example 1	✓
Example 2	✓
Example 3	✓

Standard 2	WORKING TOGETHER: We work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships
Indicator 2.1	We jointly define and record the purpose of our public involvement activity
Example 1	✓
Example 2	✓
Example 3	✓
Indicator 2.2	We develop public involvement plans and activities together
Example 1	✓
Example 2	✓
Example 3	✓
Indicator 2.3	We ensure there is shared understanding of roles, responsibilities and expectations, which may evolve over time
Example 1	✓
Example 2	✓
Example 3	✗
Indicator 2.4	We recognise individual ideas and contributions and uphold decisions together
Example 1	✓
Example 2	✓
Example 3	✗

Standard 5	IMPACT: To drive improvement, we capture and share the difference that public involvement makes to research
Indicator 5.1	We involve the public in the assessment of public involvement in research
Example 1	✗
Example 2	✓
Example 3	✗
Indicator 5.2	We record our agreed purpose for public involvement and its intended outcomes
Example 1	✗
Example 2	✓
Example 3	✓
Indicator 5.3	We collect information that will help us assess the impact of public involvement in research
Example 1	✗
Example 2	✓
Example 3	✓
Indicator 5.4	We reflect, learn and report the extent to which we have met our intended purpose and predicted outcomes
Example 1	✓
Example 2	✗
Example 3	✓

Standard 3	SUPPORT & LEARNING: We offer and promote support and learning that builds confidence and skills for public involvement in research
Indicator 3.1	We designate and monitor resources to ensure and support effective public involvement
Example 1	✓
Example 2	✓
Example 3	✓
Indicator 3.2	We offer a range of support to address identified needs
Example 1	✓
Example 2	✓
Example 3	✗
Indicator 3.3	We have a clearly identified point of contact for information and support
Example 1	✓
Example 2	✗
Example 3	✓
Indicator 3.4	We develop, deliver and monitor learning opportunities in partnership, for all involved in research
Example 1	✓
Example 2	✓
Example 3	✗
Indicator 3.5	We actively learn from others; we build on what we have learned and share our learning
Example 1	✓
Example 2	✓
Example 3	✗

Standard 6	GOVERNANCE: We involve the public in our governance and leadership so that our decisions promote and protect the public interest
Indicator 6.1	Public voices are heard, valued and included in decision making
Example 1	✗
Example 2	✓
Example 3	✓
Indicator 6.2	We have public involvement strategies and/or plans in place that we regularly monitor, review and report on
Example 1	✓
Example 2	✗
Example 3	✗
Example 4	✓
Indicator 6.3	Responsibility for public involvement is visible and accountable throughout our management structure
Example 1	✓
Example 2	✗
Example 3	✗
Indicator 6.4	We allocate money and other resources for public involvement
Example 1	✓
Example 2	✗
Example 3	✗

Figure 27: Degree of congruence between each example of 2018 NIHR Standards and the perspectives of researchers and the public in Singapore

A green tick represents congruence while a red cross represents examples that were not reflected in interviewees' perspectives

Interviewees did not mention the need for the research team to provide “*a named public involvement person and contact details (telephone and email) that are easy to find and accessible*” (e.g., of indicator 3.3). Lay people recognised that for successful collaboration, researchers would have to be accessible, patient, and friendly, but they did not advocate direct contact with researchers. The support systems they proposed a model relied on members of the public supporting each other.

No interviewee envisaged having “public contributors [as] partners in designing and delivering public involvement support and learning activities” (e.g. of indicator 3.4). Lay members were described in a passive role, as the recipients of training but never as contributors.

Singaporeans did not propose reviewing the involvement process, as suggested by “*involved members of the public are involved in any review of public involvement and research*” (e.g. of indicator 3.5). However, they did advocate that strengthening communication between researchers and the public would help refine and develop PPI processes.

Standard 4: Examples that did not emerge from interviewees’ perspectives

While the NIHR Standards encourage a “*research team [to] include a summary of its communication plan [...] in its funding application*” (e.g. of indicator 4.1), researchers did not contemplate having communication plans for their work. In relation to funding applications, researchers’ thoughts were focussed on the expectation that if PPI was mentioned in their funding application, there might be a greater chance of funding success.

None of the participants mentioned the need for information about the research to be “*available in different formats, such as easy read or large print, upon request*” nor for

there to be provisions for members of the public who are partially sighted as expressed as an example of indicator 4.2 *“easily access[ing] information in different formats for example for visual impairment”*

6.3.5. Impact and Governance

- Standard 5. IMPACT: To drive improvement, we capture and share the difference that public involvement makes to research (4 indicators)
- Standard 6. GOVERNANCE: We involve the public in our governance and leadership so that our decisions promote and protect the public interest (4 indicators)

NIHR Standards five and six on the concepts of impact and governance were more challenging for everyone to discuss and, when mentioned, tended to be in a hypothetical context. For example, a researcher described how uncertain the implementation of involvement in Singapore would be without clear governance:

“if it’s like it’s good to have public involvement in research and there is no funding body to do that and there is no people to sort of strongly encourage that it may be a ‘good to have thing’ and no, nobody will practice it” (R09/M/Chinese/GP Researcher/1-5).

Interviewees rarely discussed PPI beyond the present; those that did were aware of the importance of changing attitudes. Some also expressed the importance of governance, without which they anticipated little ongoing resources would be available.

While researchers highlighted the challenges of measuring and documenting PPI’s impact, all Singaporeans highlighted the lack of evidence for involvement, which they saw as a critical barrier for implementation. To drive the introduction of PPI, examples of the difference that the public could make are needed. This would encourage others to follow

and refine involvement based on past experiences. Although the public's role in governance was not discussed, the general opinion expressed was that the government and other institutions should construct the framework for involvement. Many envisaged the need for leadership and clearly delineated roles and responsibilities, encouraging transparency, accountability, and public trust.

There was less overlap between Standards five and six, and the content of our interviews. For these last two Standards, the congruence was 52%, as only 13 out of 25 examples were reflected in the thematic analysis of the transcribed interviews. There were five examples of Standard 5 and seven examples of Standard 6 that were not mentioned in any interview; these are discussed below.

Standard 5: Examples that did not emerge from interviewees' perspectives

None of the interviewees mentioned the public having a role as an advisor to a research organisation. As an example of indicator 5.1, the Standards recommend that *“a research organisation sets up a group of public advisors to work with them to assess whether intended outcomes and impact of public involvement have been achieved”*. Neither did they discuss a role whereby *“public contributors are part of the team that writes an annual progress report on the delivery of public involvement plans”* (e.g. of indicator 5.1).

Without any consideration of research organisation and their possible roles monitoring PPI it is not surprising there was no consistency with other examples in standard 5:

- *“a research organisation clearly states in their plans what they want to achieve as a result of public involvement in their activities”* (e.g. of indicator 5.2).

- “a research organisation [would] collect information about public involvement in both successful and unsuccessful funding applications, and review this information” (e.g., of indicator 5.3).

In addition, interviewees did not comment on the reporting of involvement within individual projects, e.g. “in publications, a research team writes about its public involvement activities and any impacts of public involvement and publishes this as well as using the learning from the project to inform future projects” (e.g. of indicator 5.4). However, some researchers noted that in recent years they had read journal articles that included a section on PPI, and a majority were open to that possibility.

Standard 6: Examples that did not emerge from interviewees’ perspectives

While the Standards encourage public contributors to “participate in senior-level decision-making groups” (e.g. of indicator 6.1), most participants envisaged members of the public occupying advisory roles. Indeed, a role in governance was not regarded as necessary for the public in Singapore, where decisions are made in a top-down fashion in most cases (106,511) and where the public rarely challenges the perceived expertise and authority of professionals or researchers (516), even where putting them at the centre is encouraged.

None of the interviewees proposed that “public involvement is a standing agenda item at senior management meetings” (e.g. of indicator 6.2). PPI was proposed as either a personal choice or something enforced top-down; it was never discussed as a formal collaboration. Continuous learning and evaluation of involvement, e.g., “a research team plans the public involvement in their project and then monitors and reviews what they do to learn and improve” (e.g. of indicator 6.2), was not contemplated. While they described PPI

as a “learning journey” and noted the need to learn from others’ experiences, systematic initiatives to monitor and review involvement outcomes were not mentioned.

None of the interviewees suggested that *“public contributors can identify who they should approach in a research team or organisation whether they want to raise a practical query or make a complaint”* (e.g. of indicator 6.3). While all voiced their ideas of what would be needed for involvement, no one considered a consultation on individual needs, e.g., *“public members are consulted about what resources might be needed to undertake public involvement effectively”* (e.g., of indicator 6.3).

Participants did not mention research teams keeping *“records of resources so that this information can be used for project review, and design and proposals of future research and public involvement”* (e.g. of indicator 6.4). Nonetheless, researchers did recognise the value of learning from others’ past experiences, inferring that they expect this sort of record to exist. Also, none of them suggested that *“public contributors are involved in decision making about the allocation of resources for public involvement”* (e.g., of indicator 6.4).

6.4. Discussion

6.4.1. Summary

The thematic analysis of 40 face to face interviews with researchers and laypeople about PPI in Singapore found that although they were unaware of the 2018 NIHR Standards there was congruence between the interviewees’ comments and many of the indicators described. Singaporeans spontaneously discussed elements they considered

essential, and these frequently coincided with inclusive opportunities (Standard 1) and working together (Standard 2). While interviewees realised the value of support and learning (Standard 3) and communications (Standard 4), they often questioned how these could be promoted in the Singaporean culture and context. Other elements, relating to the concepts of impact (Standard 5) and governance (Standard 6) were rarely mentioned, they were perceived to be examples of ideal involvement rather than pragmatic practices. Participants considered they could progress towards best practice if supported in their learning through engagement.

Where interviewees' offered perspectives that differed from the NIHR Standards, the reasons could often be attributed to contextual and cultural issues as well as their limited experience of public involvement. Differences arising because of context included interviewees not discussing the practicalities of attending PPI-related activities; perhaps because Singapore is compact and the public transport network extremely efficient, they only focused on the reimbursement of travel costs (Standard1). Other perspectives may have emerged from cultural differences, such as the roles of patients and members of the public being passive and professionals being paternalistic. The NIHR expectation is that research teams should have strategies in place and designated people (often members of the public) to train and develop those involved (Standard 3), but the Singaporean interviewees saw lay members as recipients rather than contributors to the training. Neither did interviewees envisage members of the public having roles in coordinating involvement, whether in the evaluation of its impact (Standard 5) or its governance (Standard 6). Finally, interviewees did not expand on the details and practicalities related to communications (Standard 4); most examples in this Standard were discussed by Singaporeans in a very general or hypothetical term, acknowledging the importance of communication, but not considering it necessary to plan for it to be two-way and targeted at this stage. They anticipated communication processes to emerge organically as involvement activities developed.

6.4.2. Perceived Problems with the Standards: Comparison with Existing Criticisms and Implications for Practice

Singaporeans expressed many and often critical questions about the rationale for public involvement in health-related research.⁽⁵¹⁶⁾ Unfortunately, PPI's evidence-base and cost-effectiveness were not addressed in the Standards documentation. Interviewees maintained that recommendations about how involvement should be undertaken could not be coherently formulated without some sense of why it should be undertaken. Previous critics of the Standards have also commented that they *"fail to address fundamental questions about when, why, and with whom public involvement should be undertaken in the first place"*.⁽³⁰⁰⁾ The standards would need developing to include the rationale for involvement if they are to optimise their impact on the development of PPI in an Asian context.

Other ways in which the Standards appear not to meet interviewees' expressed needs arose from insufficient detail of what good PPI looks like and how to implement it. For example, local interviewees considered at length who would count as a member of the public and who should be involved in particular projects. They warned against lay members being repeatedly involved and losing the lay perspective, mirroring the need for inclusivity and diversity as supported by Standards 1 and 2. They also noted that in some instances, people with lived experiences of a condition (either as a patient or as a caregiver) would be essential. However, while researchers wished to be guided and advised, the Standards simplify the definition of the public (encompassing patients, service users, survivors, carers and family members), failing to address how the rationale for involving patients in research might differ from the rationale for involving members of the general public. This critical aspect of involvement is ignored by the Standards, as the experiences, expertise, and interests of patients, caregivers, and other members of the

public differ.(300) Based on these challenges voiced by our interviewees, the Standards seem insufficient to overcome all their reservations for supporting PPI implementation.

The standards shortcomings highlighted here have implications for practice, as dilemmas evoked by interviewees would remain unanswered by simply using the Standards in Singapore. Since publication, the NIHR has made accessible supplementary “supporting resources”(545), which contribute to the contextual and environmental factors, increasing their utility. As Singaporeans wished to learn from other colleagues having undertaken PPI locally, the Standards presented as a framework encouraging “self-reflection and learning”(98) seem an appropriate start.

6.4.3. Strengths and Limitations of this Study

This is the first study to consider if the 2018 NIHR Standards could be used in Singapore, an Asian rather than a Western country, and one where PPI is still in its infancy. The relevance of the Standards were analysed by drawing on the views expressed by both the public and researchers about PPI potential and its challenges. This commentary has some limitations; in particular, the interviews were conducted with individuals, with no opportunities for researchers and the public to interact and share their perspectives. Secondly, the interviews conducted were not about the Standards; instead, this study was a secondary analysis of an existing data set on the patient and public involvement in future health research in Singapore. It is possible that discussion focussing on the Standards may have elicited additional issues.

A further strength of the study was the contribution of researcher reflexivity. The use of the contact summary forms, memo-writing, and discussions with the other authors encouraged further reflection. This process informed both data collection (refining the topic guide) and analysis. The study was undertaken as part of a doctoral research project

by LLP, a non-Singaporean. Initially, this led to concern that the public would be reluctant to share their views with someone perceived as an outsider. In fact, participants shared generously, often commenting that they felt less constrained talking to an outsider who might be better positioned to critically evaluate the situation in a way that a Singaporean might not. Consequently, being an outsider generated potentially richer data than might otherwise have been the case.

Our data source was rich, but important questions remain unanswered, such as determining what difference the Standards could make in practice in Singapore. In order to consider those aspects, more clarity would be needed on (i) how local researchers and members of the public envisage implementing the standards in practice, (ii) how roles and responsibilities might be assigned and to whom and (iii) what other sources of relevant guidance are available.

Finally, while this commentary is derived from the analysis of views expressed by a diverse range of participants, it may not be generalisable to other Asian countries. This is because Singapore is unusual in Asia; as an international research hub, it attracts globally-renowned scholars and researchers.^(118,121) In countries with different cultural issues, less research activity, and fewer international research collaborations, the utility of the Standards may be different and requires further exploration.

6.5. Conclusion

Although unaware of the 2018 NIHR Standards, this study illustrates many similarities between Singaporeans' aspirations for public involvement and the criteria. Overall, we conclude that although our interviewees came from a culturally different

environment, their perspectives indicate that the Standards could provide a broad framework for the implementation of PPI in Singapore. However, we noted that a weakness of the Standards for this audience is their failure to provide clarity on the rationale and evidence for best practice needed by our interviewees, to champion the implementation of PPI in the local context. In Singapore, where PPI is not yet widely adopted, supplemental resources specific to the local context are required.

Now that a national perspective on public involvement has been explored, the next two chapters focus on a study perspective of the operationalisation of public involvement in Singapore, through a case study of involvement in a population-based study.

CHAPTER

7

A SCOPING REVIEW OF THE IMPACT OF PUBLIC INVOLVEMENT IN BIOBANKS

7.1. Introduction

7.1.1. Biobanks

Biobanks are large genetic databases that combine genetic, medical, and other personal data. They entail the collection and storage of tissue samples, while often requiring additional personal data, such as genealogical and lifestyle information.

The growth of biobanks has been facilitated by the rapid advance of genomic technologies and data science, along with the quest for more personalised medicine. Biobanks represent significant research opportunities, “as a promising way to untangle the links between genetics and environmental factors and begin to understand the causes of common diseases”.⁽⁵⁴⁶⁾ The aims of biobank initiatives are varied, from improving scientific understanding of the aetiology of common diseases and developing the prescription of targeted pharmaceuticals, to securing valuable economic resources for countries seeking to compete in a global economy.

Biobanks can be classified according to tissue type, the purpose of use, and ownership. They are operated by a variety of actors, ranging from hospitals and research institutes to pharmaceutical companies and patient organisations. Two main designs of biobank exist. Population-based biobanks focus on the development of common, complex diseases for a specific community over time, commonly from the DNA of large numbers of healthy individuals representative of that community. Whereas disease-oriented biobanks study biomarkers of a specific disease.

The practice of biobanking presents a series of ethical, legal, and social implications (ELSI). These have been summarised by Haga (547) as “the fairness of collecting donations from vulnerable populations, providing informed consent to donors, the logistics of data disclosure to participants, the right to ownership of intellectual property, and the privacy and security of donors who participate”.

7.1.2. Public Involvement in Biobanks

Biobanks are increasingly employing public involvement and engagement strategies. Public involvement is seen as a means to obtain public trust and legitimacy, essential for the functioning of biobanks. Scholars have noted that the need to consult and collaborate with the public “is not surprising given they rely on them to donate genetic data freely, undergo physical measurements and tests, allow access to medical records and give other personal information by questionnaire or interview”.(548)

This trend to involve the public in processes of decision-making has occurred across the healthcare sector in recent years. Processes for involving the public are varied and context-specific. In the U.K., “public involvement” is mandated by the National Institute for Health Research and other research funders. In Canada, the Canadian Institutes of Health Research advocated for “proactive mechanisms for dialogue and

shared agenda-setting in decisions that affect Canadians as health consumers and citizens” (549), and has devoted increasing resources to make sure the public has resources to be meaningfully engaged. In the U.S.A., deliberative engagement strategies are commonplace, and, since 2012, the Patient-Centered Outcomes Research Institute funds health studies that cover research questions critical to the public.(32)

Despite their differences, public involvement practices share common features. For the purposes of this review, we understand involvement to mean “mechanisms whereby there can be meaningful and legitimate public input into a policy that involves a dialogue between relevant public with scientists, policymakers, and other stakeholders... [We are] not referring to unidirectional attempts to increase public awareness of certain aspects of science and technology; nor [...] to the measurement of ‘public opinion’ on certain controversial issues”.(550)

7.1.3. The Impact of Public Involvement in Biobanks

Investigating the *impact* of public involvement in biobanking is an important research question. There is a growing literature on the role of public involvement in the ethical, legal, and policy implications of biobanking.(551–554) However there are few published accounts of the impact that public involvement has had on the governance, design, and conduct of biobanks,(555) or on the public who are involved. The existing evidence as to what effect public involvement practices have on biobanking, or indeed health research in general, is contested and varied. There are cases where public involvement is reported to have improved the accountability or transparency of the biobank or the recruitment and retention of participants.(125,556) Other cases claim that public involvement makes no difference to research or describe such practices as harmful, providing legitimacy for pre-conceived conclusions. For example, public involvement has

been “criticized for “placating the public and speeding product development”,⁽⁵⁵⁷⁾ as mechanisms for “engineering consent”,⁽⁵⁵⁸⁾ and as framed by “narrow questions”.

The lack of clarity over impact arises because of the challenges of defining “impact”.⁽¹⁻⁴⁾ This stems from competing rationales for why impact should be investigated. To some, public involvement should be able to produce a demonstrable change in the research to justify its existence. To others, the impact is better conceived as a process of reflective learning between researchers and the public. For the purposes of this study, we adopted a broad definition of impact, which relied on self-reporting of the authors themselves in order to include a wide variety of perspectives on impact, both empirical and normative.

This review investigates the impact of public involvement on biobanks and their activities and explores how this varies with the context and nature of public involvement.

7.2. Methods

7.2.1. Definition of Terms and Scope

The review used INVOLVE’s ⁽³¹⁾ definitions of ‘the public’ and ‘public involvement in research’. INVOLVE has defined the public as, “patients and potential patients; people who use health and social services; informal carers; parents/guardians; disabled people; members of the public who are potential recipients of health promotion programmes, public health programmes and social service interventions; organisations that represent people who use services”. Public involvement in research has been conceptualised as “doing research ‘with’ or ‘by’ the public, rather than ‘to’, ‘about’ or ‘for’ the public”. We decided to include studies that involved patient advocacy groups since those are generally

formed by patients and their families and use their collective experience to campaign.(561–563)

Most papers do not define “involvement”. There are many different ways to label public involvement and approaches to it, particularly in the biobank context. As the term “involvement” tends to be U.K. specific, we are “concerned with mechanisms whereby there can be meaningful and legitimate public input into a policy that involves a dialogue between relevant public with scientists, policymakers, and other stakeholders”.(550) In recognition of the different terminologies used in different cultural contexts to refer to the public shaping the direction of research studies,(127) we included papers that suggest active roles for the public in biobanks, even though the term “involvement” was not used. Our focus was indeed on the meaning of public involvement rather than on the terms used to refer to it.

As this review focused on identifying examples of public involvement in biobank studies, the following types of paper were excluded:

- Documents with insufficient detail of the contribution(s) of the public to the biobank study;
- Studies describing educational/ awareness campaigns on biobanks;
- Studies focussing on public attitudes towards biobanks and public involvement;
- Studies focussing on issues around representation and diversity of biobank participants;
- Studies focussing on different ethical models of individual consent without public involvement;
- Studies describing a research activity other than biobanks;
- Viewpoint or general discussion papers on public involvement in biobanks.

These types of paper were excluded in accordance with our definition of public involvement, characterised by O'Doherty (550) as “mechanisms whereby there can be meaningful and legitimate public input into a policy that involves dialogue”, and our definition of biobanks described as “structured collections of biological samples and associated data, stored for the purposes of present and future research.”

7.2.2. Searching for Evidence

The systematic search followed the PRISMA statement. A literature search was undertaken in January 2019 of MEDLINE, EMBASE, and Web of Science databases, with the aim of identifying all peer-reviewed journal articles published on public involvement in the biobank study process. The search strategy combined keywords within three topic domains: biobanks, public involvement, impact. Further details pertaining to the search strategy are contained in

Table 8. In addition to the electronic database search, we searched the INVOLVE Evidence Library for any papers pertaining to public involvement in biobank studies, as well as the archives of three journals focussing on public involvement in research (*Research Involvement and Engagement*, *Health Expectations* and *Research for all*). A further comprehensive search of the reference lists of identified studies was undertaken to identify other relevant reports of biobanks that involved the public.

Table 8: Search strategy for the scoping review

	Search domain	Search terms
1	Biobank	biobank*.mp OR exp biobank as Topic/
2	PI	((consumer* or citizen* or client* or carer* or communit* or lay or patient* or public* or service user* or user* or survivor* or stakeholder* or family or families or relative* or parent*) and (involv* or collaborat* or engage* or partner* or consult* or advis* or emancipat* or empower* or advocat* or embed* or represent* or particip* or led)).ti.
3	PI outcomes	(impact* or effect* or adapt* or modif* or change* or develop* or design* or improve* or worse* or increase* or boost* or decreas* or reduc* or differ* or edit* or suggest*).ab,ti

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7.2.3. Identifying Relevant Evidence

On completion of the search, titles of papers and (where available) abstracts were scrutinised for possible inclusion in the review by the first and second reviewers independently. These inclusions were checked for accuracy by comparing the reviewers' lists. Disagreements and uncertainty about eligibility were resolved through discussion, and the opinion of a third reviewer could have been sought if discrepancies had persisted.

Evaluation of the impact of public involvement on the biobank study did not have to be the study authors' primary research question. We put no limits on publication date, but only studies in English, French or Spanish would be included.

The studies included did not have to be necessarily labelled or contextualised as 'public involvement' by the study authors (e.g., other accepted labels were consumer participation or community based participatory research). We included studies where public involvement was integrated as a component of other stakeholders' involvement: this was expected to be common practice in some contexts, such as members of the public being part of a biobank steering committee.

Based on previous reviews of public involvement in other types of research,(21) we foresaw that the two main reasons for exclusion are often: (1) the document does not focus on biobank research or reflect on the public involvement within a biobank and (2) (for reports of biobank research) no evidence is reported of the involvement of the public in the study.

7.2.4. Extracting Relevant Data from Studies Included

A data extraction table was developed to systematically collect relevant data from the studies included. Data were extracted relating to country where the biobank operates; type and size of biobank; method and stage of public involvement; tasks addressed by involvement; description of the public actively involved; the impact of public involvement; factors that influence the impact of involvement; challenges encountered and facilitating strategies and recommendations.

When extracting data pertaining to the impact of involvement, we iteratively adapted common categories of impact found in the literature (25) (e.g., impact on research design and delivery, impact on researchers, etc.), refining them to suit the emergent findings from the studies included (e.g., impact on research design became impact on biobank). Even when there may appear to be similarities in the methods of involvement, like between “community engagement” or “community-based participatory research”, we chose to record the methods as stated in the text, because we wished to avoid adding our own interpretation rooted in the UK language for involvement.

Data were extracted by both reviewers, LLP and WK, independently. Their tables were then compared. The reviewers then discussed the extracted data before independently creating categories for methods of involvement and types of impact, including a working definition for each category. Their lists were then compared: if the same category appeared in both, the category remained. If not, both reviewers discussed if a new category was needed, or whether the data could be included in an existing category. If there was a disagreement, reviewers discussed until consensus was reached.

7.2.5. Expanding Data on Studies Included

For the biobanks in the studies included, additional grey information was sought both through their official websites and a popular search engine. This was to find more detailed information on the context, process, and impact of the involvement.

7.3. Results

7.3.1. Characteristics of Studies Included in this Review

Our search results yielded 1,143 records. After excluding duplicates, two reviewers screened 1,030 titles and abstracts and assessed 82 full-text articles for eligibility. Following the PRISMA guidelines, 41 studies met the criteria for inclusion in the review (Figure 28). The publication dates for those studies ranged from 2002 to 2018 (Figure 29).

These 41 studies covered 31 biobanks (see Table 9). The biobanks concerned populations from 11 different countries across the world (Figure 30), mainly the United States (12 biobanks, 35.4%) and the UK (7 biobanks, 22.5%). 14 (45%) of them were population biobanks, while 13 (42%) were disease-specific (Figure 31).

Figure 28: PRISMA flow diagram of records/studies included at each stage of screening and in final stage of data extraction

Figure 29: Number of articles per year of publication

Figure 30: Number of biobanks included in this review per country

Figure 31: Number of biobanks included in this review per type of biobank

Table 9: Biobanks included in this review and characteristics extracted from the studies reviewed

Name of the biobank	Date established	Size	Type of biobank	Host organisation	Country or region	References
80 biobanks in Western Australia	proposed biobank		all	Department of Health WA	Perth, Western Australia, Australia	(564)
Association Française contre les Myopathies	1958		disease-specific biobank	AFM (Association Française contre les Myopathies) financed by Telethon	France	(565)
Alaska Area Specimen Bank (AASB)	1961	266,353 residual biologic specimens (serum, plasma, whole blood, tissue, bacterial cultures) from 83,841 persons who participated in research studies	Population biobank	Alaska Natives (Indian Self Determination Act (Public Law 93-638 (1975))	Alaska, USA	(566)
Avon Longitudinal Study of Parents and Children (ALPSAC)	1991-2		Population biobank	University of Bristol (Medical Research Council, the Wellcome Trust)	Bristol/Bath, UK	(548)

BC Biobank	2007		Population biobank	University Of British Columbia Department of Pathology and Laboratory Medicine, the Canadian Tissue Repository Network and the BC Cancer Agency	British Columbia, Canada	(567,568)
BC Biolibrary	2007		not a biobank, a network to integrate and improve access and quality of several provincial biobanks	University of British Columbia	British Columbia, Canada	(550,569,570)
CARTaGENE		Aims to recruit a random sample of 50,000 individuals between the age of 25 and 75	Population biobank	Sainte-Justine Children's Hospital University Health Center	Quebec, Canada	(571,572)
Centre for Alaska Native Health Research (CANHR)		30% of eligible individuals (5000 eligible?)	Population biobank	Centre for Alaska Native Health Research (CANHR)	Canada	(573)

Generation Scotland		large family-based cohort study (recruiting from age group 35–55) with the eventual goal of collecting blood for the purpose of extracting DNA from 50,000 individuals	Population biobank	Partnership - four Scottish universities & NHS Scotland	Scotland, UK	(574)
GHC/UW - Consumer-governed non-profit HMO	1994	1,200 living participants; 1,700 deceased	disease-specific biobank	eMERGE Network - National Human Genome Research Institute (NHGRI)	Seattle area, Washington, USA	(575)
Inherited Cancer Connect (ICCon) database	2013		disease-specific biobank	Inherited Cancer Connect (ICCon) Partnership - Cancer Council of New South Wales, Australia	Australia	(576)
International HapMap Project	since 1980s		Population biobank	International HapMap Consortium	USA, Japan, China, Nigeria	(577,578)
Kaiser Permanente - Integrated health care delivery system	2005	All diseases represented in patient population - 160,000	Population biobank	eMERGE Network - National Human Genome Research Institute (NHGRI)	Northern California, USA	(575)

Kilifi Genetic Birth Cohort (KGBC)	1989	aims to recruit 12,000 infants	disease-specific biobank	Kenya Medical Research Institute (KEMRI) - Wellcome Trust Research Programme + MalariaGEN Consortium	Kenya	(579)
Melbourne Genomics Health Alliance	2014		Population biobank	Partnership - 10 research organisations & hospitals	Melbourne, Australia	(259,580)
Metastatic Cancer Breast Alliance Biobank	proposed biobank		disease-specific biobank	Metastatic Breast Cancer Alliance	USA	(581)
Multisite keloid study	2005	4200 samples from participants from 103 families	disease-specific biobank	University of Connecticut Health Center (UCHC) General Clinical Research Center (GCRC) & LAUTECH in Osogbo and UCH in Ibadan	Ibadan (Oyo State) and Osogbo (Osun State), Nigeria	(582)

Nugene	2001	All diseases represented in patient population	Population biobank	Northwestern University - University medical centre - eMERGE Network - National Human Genome Research Institute (NHGRI)	Chicago area, Illinois, US	(575)
Nottingham Health Science Biobank	2011	The aim is to consent every patient at the time of first presentation at our hospital and those referred for surgery and treatment after diagnosis (ongoing)	Population biobank	Nottingham University NHS Hospitals Trust	Nottingham, UK	(125,583)
Patients' Tumor Bank of Hope (PATH Biobank)	2002	Approximately 7500 patients have consented to be donors with seven sample source sites across Germany (ongoing)	disease-specific biobank	PATH Foundation, Germany	Germany	(125)

Peninsula Research Bank (PRB)			Population biobank	PenCLARHC: Peninsula Collaboration for Leadership in Applied Health Research and Care - NIHR Exeter Clinical Research Facility (CRF)	Exeter, UK	(584)
Personalized Medicine Research Project (PMRP)	2002	All diseases represented in patient population - 20,000	Population biobank	Marshfield Clinic - Medical centre - eMERGE Network - National Human Genome Research Institute (NHGRI)	Central Wisconsin, USA	(553,575)
PXE International Blood and Tissue Bank	1995		disease-specific biobank	PXE International	USA	(585)
Roswell Park Cancer Institute DataBank and Biorepository			disease-specific biobank	Roswell Park Cancer Institute Alliance Foundation and NIH - National Cancer Institute (NCI)	Niagara Falls, NY, USA	(586)
Tasmania Biobank	hypothesized biobank				Tasmania, Australia	(587,588)

Telethon Network of Genetic Biobanks (TNGB)	2008	90,000 biological samples representing approximately 850 distinct rare genetic diseases	disease-specific biobank	a consortium of 11 Italian non-profits supported by the Telethon Foundation	Italy	(589,590)
The Breast Cancer Campaign Tissue Bank (BCCTB)	2010	8,230 samples	disease-specific biobank	Breast Cancer Now and 5 U.K. universities	UK	(583)
The Mayo Clinic Biobank	2009	The target goal is to obtain 50,000 biospecimens (ongoing)	Population biobank	Mayo Clinic, Rochester	Minnesota, USA	(125,555,575,591)
UC Biobank	hypothesized biobank			EngageUC (UC Davis, UC Irvine, UC Los Angeles, UC San Diego, and UC San Francisco)	USA	(592)
UK Biobank	2000	aims to enrol 500,000 participants aged 45 to 69 for a period of several year	Population biobank	MRC/Wellcome Trust	UK	(548,593,594)

Vanderbilt University - University medical centre	2007	All diseases represented in patient population	Population biobank	eMERGE Network - National Human Genome Research Institute (NHGRI)	Tennessee, USA	(575)
Wales Cancer Bank	2004	Currently 12,000 patients (ongoing)	disease-specific biobank	Cardiff University	Wales, UK	(125)
Not focussing on any specific biobank						(595–597)

7.3.2. Methods of Involvement

We identified 12 methods of involvement, with varying degrees of active roles for members of the public (Figure 32). 14 (45%) biobanks combined up to four methods of involvement. The most common forms were the creation of lay advisory panels (n=13, 41%) and focus groups (n=13, 41%), followed by deliberative exercises (n=9, 28%). Ad-hoc consultation and support, community-based participatory research, public representative(s) in biobank governance structure, and surveys were each used by four biobanks (12.5%). Three (9%) were patient-led biobanks. Two (6%) biobanks used community engagement. Finally, a formal partnership with a patient organisation or a public representative in the ethics panel was reported each in one biobank.

Figure 32: Forms of involvement

7.3.3. Tasks of the Biobank the Public is Involved in

Not only did biobanks adopt a variety of involvement methods, but they invited public input into varied aspects of the biobank organisation (Figure 33). Most commonly, the public had a role in the governance of the biobanks (n=18, 58%), and in promotional initiatives and recruitment strategies (n=13, 42%). Nine (29%) biobanks worked with

members of the public to determine the model of consent. Models of consent reflect different agreements between research participants and researchers. In some cases, studies adopt a model for strictly specified consent (e.g., for a specific study), while on the other extreme, a model of blanket consent sets no restrictions for the use of participants' samples regarding the purpose of the research.

Figure 33: List of aspects of the biobank the public is involved with

Members of the public advised in aspects pertaining to methods of sample collection, ways of sample storage, conditions of sample use and transfer, and possibilities of data sharing in seven cases (22.5%). Six biobanks (19%) involved the public in drafting operating policies and procedures and in the conversation around researcher access to specimens and five (16%) in consent forms and documentation, the return of results and research & future involvement ideas. Research protocols and PISs and commercialisation were aspects of focus in four cases (13%). Finally, three (10%) biobanks involved the

public in delivering public education and in overall project acceptability, while only one biobank engaged the public in the discussions around incidental findings and IT.

7.3.4. Types of Impact Reported

The impact of involvement reported in the studies included could be classified into three main categories, adapted from types of impact mentioned in the literature, based on *where* the impact is seen (a detailed classification is shown in Figure 34).

Figure 34: Classification of the types of impact of public involvement in biobanks

These were the impact (1) on the biobank, (2) on the people involved, and (3) broader forms of impact. Within each of these categories, we were able to extract more precise details impact.

The most common forms of impact on biobanks reported were changes to the models of consent and the design of consent forms (n=14, 45%). Other common forms of impact were new policies and regulations and new recruitment strategies and materials (n=12, 38%). Secondly, regarding the impact on people, a common form of impact was

the education of communities (n=10, 32%). In the third category, the most common broader forms of impact reported were claims of some form of lasting and trusting research partnership (n=14, 45%) and new issues being raised by members of the public involved (n=12, 38%). Also, nine of the biobanks reported that as a consequence of public involvement, they decided to do more public involvement.

Out of the 41 studies included, less than one-third (n=12; 29%) included members of the public as authors, or in the reporting of impact (e.g., through quotes).

The level of detail when reporting impact varied considerably, partly due to the challenges of capturing it. Bossert (596) used a traffic-light system to track changes to materials introduced by members of the public involved, in an attempt to be transparent and acknowledge the contributions of the public. The Wales Cancer Bank includes in its annual reports the projects undertaken and features written by its lay collaborators so as demonstrate the value of public involvement within the biobanks.(125)

Most of the biobanks also reported impact at a normative level. In these cases, authors simply stated that public involvement led to increased transparency, accountability, and lasting, trusting research partnerships (see Table 10), but did not provide specific examples on it.

It is difficult to explore the association between methods of involvement used and types of impact. For most of the methods, there are not enough cases. We also know that many of the biobanks use multiple methods of involvement and show multiple impacts.

7.3.5. Impact on the Biobank

7.3.5.1. Impact on Model of Consent

Many biobanks (n=14; 45%) had their models of consent shaped in some way by the public. Biobanks tended to either (a) give a public group a model of consent to review or (b) run a deliberative exercise to generate principles that should appear in a model. Molster (564) provides an example of the latter, where guidelines written with members of the public recommended that transparency, autonomy and communication should be at the heart of the consent process. Those involved also produced a list of topics to be communicated to potential biobanking participants, as part of an informed consent process. On the other hand, Forrest (576) provides an example of the first process, where the public is given a pre-designed model of consent to comment on. In this case, the process of querying the public about different aspects of consent is illustrated with the inclusion of quotes from attendants during the discussion around the management of participants' consent. For example, they "demonstrated consumers' acceptance of [...] waiver of consent".

7.3.5.2. Impact on Participant and Consent Materials

Linked to the impact of public involvement on models of consent, almost a third of the biobanks (n=12; 29%) reported the public had an impact on participant materials and consent forms, often simplifying the language and shortening recruitment materials. For this activity, the aim for public involvement is defined beforehand, and there is limited scope for those involved to suggest new ideas. Also, authors generally provide the reasons why some recommendations from members of the public could not be acted on. For example, Kimball (555) illustrates the process of involving members of the public in these tasks in the Mayo Clinic Biobank, shown in Box 1.

Box 1: Example of impact on participant and consent materials

Kimball (2014) illustrates the process of involving members of the public in these tasks in the Mayo Clinic Biobank. In this case, members of the biobank's Community Advisory Board (CAB) produced a series of recommendations to improve recruitment and consent materials. Their suggestions included: (a) to more clearly articulating why particular Mayo Clinic Biobank participants were being invited to participate in the RIGHT study; (b) to shorten recruitment documents to make them easier to digest; (c) to remove language from the recruitment documents that may contain an overly emotional, pro-participation message. This feedback was "used to revise recruitment and consent materials". Several recommendations from the CAB were acted on, including adding a hotline telephone number and modifying the language of the draft informed consent document and other accompanying informational material.

Table 10: Types of impact reported

Impact type	Biobanks
ON BIOBANK	
Governance	
Written agreement with patient organisations	AFM; Telethon Network of Genetic Biobanks
New policies and regulations	80 biobanks in Western Australia; AFM; Alaska Area Specimen Bank (AASB); BC Biobank; CARTaGENE; International HapMap Project; Mayo Clinic Biobank; Metastatic Breast Cancer Alliance Biobank; Tasmania Biobank; BCCTB; Telethon Network of Genetic Biobanks; UC Biobank
Standardisation of procedures across biobanks	AFM; CARTaGENE; Melbourne Genomics Health Alliance; PXE
Centralisation of biospecimens	BCCTB; Telethon Network of Genetic Biobanks
Agreement to share resources	BCCTB; Telethon Network of Genetic Biobanks
Operations	
Models of consent and informed consent forms	80 biobanks in Western Australia; BC Biobank; BCCTB; ICon; Mayo Clinic Biobank; Melbourne Genomics Health Alliance; NUGene; Nottingham Health Science Biobank; Personalized Medicine Research Project (PMRP); Tasmania Biobank; Telethon Network of Genetic Biobanks; The Peninsula Research Bank; UC Biobank; Wales Cancer Bank
Recruitment strategies and materials	BC Biobank; BCCTB; BioVU; CARTaGENE; International HapMap Project; Kaiser Permanente; Mayo Clinic Biobank; Multisite keloid study; Nottingham Health Science Biobank; PXE; Tasmania Biobank; Wales Cancer Bank
Support for members of the public (hotlines, newsletters)	Mayo Clinic Biobank; Melbourne Genomics Health Alliance; Personalized Medicine Research Project (PMRP); The Peninsula Research Bank

Access to specimens/ data	AFM; Alaska Area Specimen Bank (AASB); BCCTB; Nottingham Health Science Biobank; PXE; Telethon Network of Genetic Biobanks; UK Biobank; Wales Cancer Bank
Confidentiality	Telethon Network of Genetic Biobanks; BC Biolibrary; Tasmania Biobank; BCCTB; Mayo Clinic Biobank
Increased participation & retention	Alaska Area Specimen Bank (AASB); Avon Longitudinal Study of Parents and Children (ALPSAC); BCCTB; Melbourne Genomics Health Alliance; UK Biobank
Recommendations for return of research results	Mayo Clinic Biobank; Nottingham Health Science Biobank; PATH; Personalized Medicine Research Project (PMRP); Tasmania Biobank
Recommendations for sharing research results	BCCTB; CARTaGENE; Kaiser Permanente; Mayo Clinic Biobank; Nottingham Health Science Biobank; NUGene; PATH; Tasmania Biobank; UK Biobank
Funding	Melbourne Genomics Health Alliance
New issues raised by members of the public involved	80 biobanks in Western Australia; Avon Longitudinal Study of Parents and Children (ALPSAC); BC Biobank; BC Biolibrary; CARTaGENE; Generation Scotland; International HapMap Project; Kilifi Genetic Birth Cohort; Mayo Clinic Biobank; Personalized Medicine Research Project (PMRP); The Peninsula Research Bank; UK Biobank
Research design	
New research questions/ outcomes	AFM; BCCTB; ICCOn; International HapMap Project; PXE
Study design & methods	
<i>Proposal of strategies/ methods</i>	BCCTB; BioVU; International HapMap Project; Kilifi Genetic Birth Cohort; The Peninsula Research Bank; UK Biobank; Wales Cancer Bank
<i>Practicalities of participation</i>	AFM; BCCTB; BioVU; International HapMap Project; Multisite keloid study; The Peninsula Research Bank; UK Biobank
Establishment of biobanks	AFM; PATH; PXE

ON PEOPLE	
People involved	
Trust	AFM; Multisite keloid study; PXE; Telethon Network of Genetic Biobanks; Wales Cancer Bank
Education	AFM; Tasmania Biobank; Telethon Network of Genetic Biobanks
Skills	AFM; Nottingham Health Science Biobank; PXE
Personal	AFM; Avon Longitudinal Study of Parents and Children (ALPSAC); BC Biobank; Generation Scotland; UK Biobank
Further participation and involvement	AFM; BC Biolibrary; BCCTB; Nottingham Health Science Biobank; PATH; PXE; Wales Cancer Bank
Researchers & biobank staff	
Awareness of needs & expectations of the public	Telethon Network of Genetic Biobanks; The Peninsula Research Bank; BC Biolibrary; Generation Scotland; International HapMap Project; Kilifi Genetic Birth Cohort; Melbourne Genomics Health Alliance; PXE; Wales Cancer Bank
Understanding & conformity to guidelines	BC Biolibrary
Research participants	
Clinical referrals	Nottingham Health Science Biobank; PATH
Facilitated relationships with researchers	AFM; CARTaGENE; Melbourne Genomics Health Alliance; Multisite keloid study; NUGene; The Peninsula Research Bank; Wales Cancer Bank
Shift in thinking	Multisite keloid study; Tasmania Biobank; Wales Cancer Bank
Wider community	
Health promotion	AFM; Multisite keloid study; Nottingham Health Science Biobank; PATH; Wales Cancer Bank
Education	CARTaGENE; Generation Scotland; International HapMap Project; Kilifi Genetic Birth Cohort; Melbourne Genomics Health Alliance; Multisite keloid study; Nottingham Health Science Biobank; NUGene; Telethon Network of Genetic Biobanks; Wales Cancer Bank

Wider engagement with science and research	International HapMap Project; Kilifi Genetic Birth Cohort; Melbourne Genomics Health Alliance; Mayo Clinic Biobank; Multisite keloid study; PATH; Telethon Network of Genetic Biobanks
BROADER FORMS OF IMPACT	
Further public involvement in biobank	
Creation of Advisory Board	Alaska Area Specimen Bank (AASB); Mayo Clinic Biobank; Wales Cancer Bank
Creation of more opportunities for ongoing discussion with wider representation	Alaska Area Specimen Bank (AASB); Generation Scotland; Mayo Clinic Biobank; PXE; UC Biobank; Wales Cancer Bank
New agreements with patient organisations	AFM; PXE; Telethon Network of Genetic Biobanks
Participation in recruitment of new biobank staff	Avon Longitudinal Study of Parents and Children (ALPSAC)
Lasting and trusting research partnerships	80 biobanks in Western Australia; AFM; Alaska Area Specimen Bank (AASB); Avon Longitudinal Study of Parents and Children (ALPSAC); BCCTB; Kaiser Permanente; Kilifi Genetic Birth Cohort; Multisite keloid study; PXE; Tasmania Biobank; Telethon Network of Genetic Biobanks; UK Biobank; Wales Cancer Bank
Transparency and accountability	AFM; BCCTB; Multisite keloid study; Tasmania Biobank; Telethon Network of Genetic Biobanks; UK Biobank; Wales Cancer Bank
Public representation	80 biobanks in Western Australia; AFM; BC Biobank; BCCTB; CARTaGENE; Tasmania Biobank; The Peninsula Research Bank; Wales Cancer Bank
Contributions to knowledge	
Mentoring other biobanks/ advocacy groups	AFM; PXE
Media presence, manuscripts and conference presentations	AFM; International HapMap Project; Melbourne Genomics Health Alliance
Dissemination and further adoption of involvement methods in STPs	AFM; PXE

7.5.3.3. Impact on Governance

Eighteen biobanks (58%) involved the public in governance matters, with two-thirds of those (n= 12, 38%) reporting new guidelines and policies resulting from involvement. Level of detail reported for this varied. The area of “governance” included different domains that were not initially defined, and often the impact was not described or covered a wide variety of outcome measures to illustrate the tangible effects of involvement. Nonetheless, some authors provided examples of deliberative exercises that led to policies being created as recommendations. For example, Baldo (590) reported on a consortium of 11 Italian non-profits organising a biobank network. In this case, 34 events over nine years involving patient organisations resulted in the draft of biobank policies and procedures, including those concerning ethical issues (e.g., draft of comprehensive informed consent that became the official model adopted by all the biobanks in the Network). Another example is provided in Box 2.

Often, the impact of public involvement on governance is vague. For example, the public deliberation exercise in O’Doherty (550) aimed to focus on the “Governance of Biospecimens and Associated Data”. The article mentions that the personnel of the biobank had obtained “valuable input” from attendees that they could use to set up the governance structure of the biobank. The study does not provide details on what the input looked like. Another example of such vague reporting is detailed in Box 3.

Some authors provided detailed accounts of the outcomes of involvement. Terry (578) reports on dialogue sessions that developed policy recommendations, with the recommendations summarised in a table with details on each of those. These new policies were presented later on in a forum for researchers and the public, and then at a final stage to the wider community.

Finally, in a few cases, authors discussed in depth how public recommendations for biobank governance were acted on, as shown in Box 2.

Box 2: Example of thoroughly reported impact on governance

Molster (28) describes a deliberative exercise in Australia, aimed at understanding “citizen perspectives, shared values and acceptable trade-offs in public interests”. During the event 16 members of the public formulated 28 recommendations around broad areas (Rules and regulations, Oversight, Biobank participation, Access and use, Information, Benefit-sharing and Demise). These recommendations were contrasted with existent policy and authors note that “most of the deliberants’ overarching principles, issues of importance and recommendations were reflected in the policy”. For most of the recommendations that were not reflected yet, experts took them onboard and translated them into biobanking guidelines. The authors acknowledge that “a minority of deliberants’ recommendations were not incorporated in the policy”, as some outcomes (in this case establishment of a state governance body and a registry of biobanks maintained by this body) were “beyond the scope of the guidelines” and in other cases the suggestions could not comply within existing laws and regulation.

The guidelines were publicly released after the event. Since then, Western Australia government health agencies must adhere to them and the guidelines have a achieved recognition at other levels, including internationally. In this case, the authors considered that public involvement not only influenced policy but also “increased credibility among stakeholders”.

7.3.6. Impact on People

In terms of impact on people, we identified four main groups that the studies referred to (a) members of the public “involved”, (b) researchers and biobank staff, (c) research participants, and (d) the wider community. The greatest impact was reported in this last group, as just below a third (n=10, 32%) of the biobanks reported education of

the wider community as an impact, and eight biobanks (26%) reported “wider engagement of the community with science and research”. Public involvement was reported to facilitate a two-way learning process, nine biobanks noting that researchers gained awareness of the needs and expectations of the public. Involvement had an impact on trust, education, skills, and other personal aspects, respectively, in five biobanks (16%). The impact on those involved is vague, as the means to measure it are not stated, there is no supporting evidence, and as members of the public are rarely involved in the reporting of impact. Also, some authors highlighted the impact on wider biobank participants (n=7, 22.5%), probably as a result of having more appropriate participant materials. Finally, further participation and involvement were cited as an impact on those involved in seven biobanks (22.5%). For example, one of the attendees of public a deliberation exercise would join the Governance Oversight Committee of that biobank.(550)

Box 3: Example of vaguely reported impact on governance

Olson (30) reports a four day deliberative community exercise during which attendees reviewed Mayo Clinic Biobank policies. At the end of the event, community members made recommendations and suggested guiding principles around biobank procedures “including: the need for strong privacy protections, convenient recruitment, the importance of data sharing, limited options for return of research results, the importance of long-term community oversight, and an easy-to-understand consent document”. However, the authors of this study do not provide further information on how those were acted upon.

The impact on those involved is not only positive. Topics discussed are often very complex, undecided, and unclear (and maybe not up for negotiation), which can lead to dissatisfaction and frustration,(574) as shown in Box 4.

Box 4: Example of negative impact on members of the public involved

Haddow (1) conducted a series of focus groups with different ‘publics’ during the early concept phase of Generation Scotland biobank. The topics brought for discussion revolved around participation, access, feedback (general/specific), confidentiality, engagement and governance, and the authors report the difficulty of discussing issues that are not only vague and ambiguous, but also presented as “up for negotiation”. In this context, the paper highlights the public’s frustration at the moderators, as they were being asked for their views on hypothetical issues that they had never encountered before. The public expected the researchers to be more specific and present some sort of “plan” and also indicated their preference to be involved over time rather than in ‘one-off’ exercises that did not truly let them room to decide and make a difference.

7.3.7. Boarder Forms of Impact**7.3.7.1. Impact on Time and Breadth of Involvement**

For ten biobanks (32%), an impact of involvement was further sustained involvement. This happened in four distinct forms: (a) one-off involvement became a sustained form of involvement (e.g., the creation of Advisory Groups to ensure public perspectives are shared at all stages of the biobank), (b) involvement started with a small group of people was then formalised with Patient Organisations (POs) to create a community with wider representation and to optimise resources for research on rare conditions, (c) in user-led biobanks for rare diseases, wider collective action on the part of users was organised to advocate for research and treatment of those diseases, and help was provided to other developing advocacy groups and (d) new PPI topics to be discussed in the future, raised by those involved.

In three cases,(125,552,566) initial collaborations led to the establishment of lay advisory boards. In the Wales Cancer Bank, an initial steering group composed of 28 stakeholders, out of which three were patients and one a relative of the patient, evolved into a larger Lay Liaison and Ethics group (LLEG).(125) Its chair is a full member of the Executive group so that public voice has progressively become an integral part of biobank governance structures. The LLEG has expanded its influence beyond the biobanks, forging relationships with patient groups, hospitals, and organisations (e.g., the international service organisation Rotary), widely strengthening the biobank profile. In the case of the Mayo Clinic, a Community Advisory Board (CAB) was created with the aim of keeping diverse community interests present. This was following the recommendations of a community engagement event “to facilitate community influence in the development and governance of the biobank” (552) at its early stages, which included the need for ongoing community guidance and involvement in biobank governance.(125,552) The CAB is co-chaired by a member of the public and although its recommendations are “not binding, they are viewed with considerable respect and are often incorporated into policies, actions, and decisions that leaders make”.(125)

In other cases, some forms of involvement led to the creation of more opportunities for involvement through formal agreements. For example, in the case of the Telethon Network of Genetic Biobanks (TNGB), the involvement of patients and families led to the formalization of various agreements between the TNGB and Patients’ Organisations (589). Opportunities for dialogue with the public (34 events aimed to explain the theory and practice of biobanks and for the public to voice their perspectives, needs, and concerns) were promoted through POs (590). In these arrangements, POs have multiple roles: they must (i) select a representative that updates associated families and referring clinicians on the Biobank’s activities and policies; (ii) promote the recruitment of patients and relatives, and (iii) organise shipment of biospecimens to the assigned Biobank (590). Successful involvement of POs led to formal collaboration with

other POs, resulting in a centralised catalogue of very unique samples and “sustained infrastructure” that encouraged more research of those “neglected” diseases.(589) This suggests that POs can be actively involved in those key areas of biobank research but also that they must be particularly active in the case of rare diseases because they are “instrumental in gaining a critical mass of samples essential for research”.(589) POs can create a strong community advocating for research on rare disease but can also have a broader impact by “raising awareness, trust and interest of the general public in Biobanks”.

The third type of impact is best reflected in what Rabeharisoa (565) reported as an early example of POs' impact on biobanking. In the case of the *Association Française Contre les Myopathies* (AFM) the self-help and the advocacy movements converged in their aim for “users’ empowerment” and illustrated the legitimacy and the ability of POs to organise collective action for advocating research and care for rare diseases. The AFM, through its unique biobank, also achieved a definition of the disease and its status. In the case of the AFM, POs made the case and rallied the scientific community, and it was their power that made progress possible for patients. In addition, POs can have an impact beyond their limits and impact other advocacy groups focusing on other rare diseases. For example, the AFM led the creation of the *Alliance Française des Maladies Rares* (French Alliance for Rare Diseases), an umbrella organisation currently grouping together 80 patient organisations. Similarly, Terry (585) provides an example of how patients and their families can form a biobank around a particular disease. In this case, those affected by PXE and their families formed a community that could represent their needs, and in return, those affected by PXE came forward to donate their samples. Success in the creation of the biobank encouraged the community to lead other research projects around PXE as the bonds with researchers were strengthened. Moreover, the experience developed in the creation of a user-led biobank was made purposeful by mentoring other advocacy groups and the creation of the Genetic Alliance Biobank, a coalition of over 600 disease advocacy

organizations, that use PXE's biobank infrastructure as a role model, sharing resources and methods.

Finally, the authors also mentioned often the new challenges raised by members of the public involved in 12 cases (38%). For example, Kimball *et al.* (555) provide a list of the questions raised by members of the community advisory board, including concerns regarding the recruitment and consent materials, the value of genomic research and its clinical utility; the risk of genetic discrimination; and personal ownership of genomic data and the distinction between indirect benefits to future generations and individual risk to research participants.

7.4. Discussion

7.4.1. Summary

This review conceptualised the impact of involvement in biobanks at four different levels (Fig. 8). The studies included focussed and discussed principally the class related to the public performing a functional task, leading to an understanding of impact in a 'functionalist' way. Moreover, the public was involved in exercises of idea generation within a pre-defined aim or procedure in other cases, leading to similar 'functionalist' forms of impact. Additionally, normative claims about the impact of involvement were made in more than a third of the studies included, while no evidence was included to support these claims. Finally, only in a few cases, the public had the capacity to go beyond pre-defined aims.

7.4.2. Definition of Impact (or Why Impact?)

The review has highlighted the vague reporting of the impact of public involvement in biobanks, particularly due to insufficient or incomplete efforts to assess it. There are a number of problems in the conceptualisation of impact which make trying to evidence it difficult.

First, many authors focus on **where** the impact has taken place, such as in the recruitment materials or the model of consent. Much less focus is placed on **what** the public is invited to do. Without such information, it becomes extremely difficult to answer questions such as whether the public has authoritative or advisory decision-making power or how pre-circumscribed the process is.

Secondly, with such few studies involving the public in considering the impact of their involvement, we are always likely to consider the impact from the perspective of the biobank. This makes it difficult to determine what impact there was on the public, including important outcomes such as their trust and legitimacy placed in the biobank.

Thirdly, there is a distinct lack of sense of **why** impact should be captured. To some, public involvement should be able to produce a demonstrable change in the research to justify its existence. To others, the impact is better conceived as a process of reflective learning between researchers and the public. This has consequences both for how involvement activity is then planned and how you would attempt to determine impact.

Fourth, involvement (particularly deliberation) involves persistent disagreement. Public involvement, particularly under the form of public deliberation, often results in *“the identification of points of resolution and recurring disagreement, providing invaluable information, from the many voices within society, for policy and procedure formation. The presence of end-users, particularly those in positions of power regarding policy formation*

and implementation, is important in generating trust as their presence validates the idea that participants' views are important and have some consequence." (587). It might also be the case that suggestions cannot be easily implemented. Kimball (555) highlights challenges to incorporate all suggestions made by community members because some were too "subjective" and "objective" evaluation would be needed.

7.4.3. Methods of Involvement

This review identified a variety of methods for involving the public in biobanking. Yet they fell broadly into two categories – (1) advisory groups or (2) deliberative exercises and focus groups.

Deliberative exercises are broadly issue-based and take place within a particular time-point of a project. They typically lack a formal connection to a decision-making process within the biobank. The inverse is true of advisory groups that are often convened across the life course of a project and have a connection to institutional decision making. Deliberation exercises often include a third-party mediator, which can contribute to balancing the power of the researchers with that of the public.

The review highlights several important considerations for meaningful deliberation. First, Walmsley highlights the dangers of deliberation methodologies that focus solely on consensus, arguing the importance of ensuring that conflict is possible within deliberation spaces. Similarly, Wilcox (583) asserts that "[w]e need to develop innovative ways of reporting agonistic deliberation as well as consensus – recording the frustrations, road-blocks, contested definitions and repeated questions that hamper attempts to reach "recommendations" and "outputs" as traditionally conceived" (583). Second, while biobank managers tend to propose topics that need to be discussed, there must be enough room for attendees to come up with their own too (so the agenda is not

rigidly determined by researchers, and aspects that might be relevant for the public but not considered by the experts can also be discussed). Indeed, this *“flexibility is required to ensure that participants are able to express the values they feel are most relevant to the issue. In imposing structure on deliberation, the event designers may have gotten it wrong, and a degree of willingness to be guided by participants is essential.”* (550) - also (578,583). Third, the sampling techniques often employed in deliberative exercises ensure they attract a diverse group of the public. This could be because the deliberations can be tailored to the needs of different communities (592) and be made culturally relevant, starting from the information provided at the beginning of the event to participants (generally in a booklet, see (569)). However, this is not always the case as Molster (564) notes that deliberation attendants were much less diverse than survey participants generally are, and Terry (578) that the project had limited effectiveness in engaging people with little interest in science and genetics.

McWhirter *et al.* (587) argued that public deliberation “surpasses other forms of public consultation because of its potential to develop trust in the process itself and in its outcomes. Participants feel heard, respected, and express confidence in the overall decisions made by the group.” Nonetheless, there are negative aspects to public deliberation, such as the fact that it is a resource-intensive method of involvement.(587)

Similarly, the review identifies important considerations for advisory boards. The creation of lay advisory boards is a method commonly used in public involvement in other fields of research.(598–603) Indeed, their flexibility makes advisory groups a suitable model in many areas of research, and within multiple organisations (584,603). Working with a consistent group of the public makes it easier for them to help at all stages of the research and feed into decision-making (576). Because of their periodicity, while also allowing for new members to join, advisory groups are described as a “consistent and

constructive framework” for involvement (584) that can “develop and strengthen an ongoing relationship” (552) between researchers and participants.(125,548,591)

The structure and content of advisory groups is varied. Kimball (555) advised a semi-structured guide to ensure that all topics on the agenda are covered and that the agenda can leave room for new questions brought by members of the public. Jenner (584) included a “lay member ideas” section on the agenda, as an “open forum” where members could bring their own concerns and interests to the table. These type of initiatives were suggested by Lemke (552) to build “a relationship of mutual learning and trust” (see also (553)).

The agenda can be jointly defined, “to encourage more equitable power dynamics”.(552) These measures attempt to overcome the limitations of advisory groups mentioned in the literature, as some studies claim that these can remain symbolic or tokenistic, and those involved can feel undervalued.(19,604) Watson (259) narrates the experience of panel members not feeling enough acknowledgment of their contributions and deciding to show the difference that an advisory group can make. On the other hand, the topics discussed are generally broad, but members can use them as a platform to become familiar with the research before getting more deeply involved in specific areas through other methods.(584) Also, to provide space for all the perspectives of the public, a moderator can facilitate the meetings.(555)

Nonetheless, some limitations of lay advisory panels cited in the studies included in this review are the small size of the groups (555,576) and the exclusion of certain groups based on language, since all attendants have to speak the same language.(576)

Finally, Terry (578) cites the concern of sustaining involvement through long-term relationships, suggesting the need to create processes to support continued interaction

between research institutions and the community. In this case, advisory boards afford the creation of long-term relationships, and thus sustaining the momentum needed for long-term impacts of involvement.

7.4.4. Involvement for Biobank Participation

The most commonly reported “impact” centred around the objective of ‘getting people to sign up’. This typically involved the public advising on the design and delivery of consent forms, recruitment strategies, and so forth. This was evident in the aspects of the biobank the public was involved with, where nine biobanks involved the public in promotional measures and recruitment strategies. As the role of trust is an important issue in the enrolment and retention of participants in biobank-based genetic research, particularly of minorities,(595) it is no surprise that the trust researchers claim to build thorough involvement is used by studies to get buy-in into their studies. This highlights a sense of tokenistic practice, where public involvement is being done in order to maximise the existing objectives of the biobank rather than to genuinely include the public’s needs, values, and concerns to shape and strengthen the study. In this context, involvement is considered by some as an extension to other programs of research, such as early large-scale consultations examining the public’s perception and understanding of biobanks.(1-7)

Some tension is inherent to trying to achieve involvement that is meaningful to all stakeholders. Involvement should be implemented in a way that it is possible for members of the public to contribute and share their perspectives, while also able to produce results relevant to the study and communities, and actionable and useful to institutions. This tension is first revealed in the challenges of organising complete and well-structured conversations (“biobank community engagement efforts need to have clearly defined goals” (552)), making the most of resources available, while giving the public a chance to

have a voice (“conclusions reached by deliberants should emerge from deliberation, rather than being pre-imposed by experts or policymakers in the form of pre-formulated options” (572)). This tension is also reflected in the limited aspects participants are asked to contribute to, while often, participants raise numerous other questions that they consider important to discuss. Terry (578) highlights that “participants in our project wanted fair and equitable access, and wanted a voice in the process”, which led them to expand the topics covered beyond those suggested by the researchers.

Also, participants contested the framing of questions in the materials provided to support deliberation exercises, and in some instances, these were changed by collective decision.(8) In fact, the studies included in this review had contrasting perceptions on the scope and level of detail of background and educational resources provided to those involved prior to involvement. Biobanking covers complex topics with wide implications, using its own jargon, and may be daunting for non-experts invited to the table. Consequently, Lemke *et al.* (9) cited the development of educational slides for the public as one of the greatest challenges encountered in the process of involvement. In O’Doherty *et al.* (569) a methodological innovation was used by introducing a workbook to structure the discussion around particular aspects of the biobank while not educating participants before, so as to bias them towards researchers’ agenda. Nonetheless, in this case, the workbook was also intended “to ensure that the deliberations and the conclusions eventually reached by participants remained within the parameters of recommendations that the Biolibrary was realistically capable of taking into account in their governance structure”, and thus the public was limited by the organisers in terms of what their involvement could achieve before the event took place.

Godard (571) highlights the “risk that the public will mistrust researchers and will simply not participate in sufficient numbers” if involvement is perceived by the public as another tool for researchers to achieve participation in their studies.

7.4.5. Normative

Although the extent of the impact of public involvement in biobanks had different degrees (Figure 35), many of the biobanks made normative claims that public involvement led to increased transparency, accountability, and lasting, trusting research partnerships. These tended to be poorly evidenced, and there seemed to be an assumption that involving the public meant good governance.

Figure 35: Extent of the impact of public involvement in biobanks

On the other hand, the narrow understanding of impact, also beyond normative claims, was contested in some of the studies reviewed. Walmsley (605) advocates for persistent disagreement as an output of involvement and writes that “we need to develop innovative ways of reporting agonistic deliberation as well as consensus – recording the frustrations, road-blocks, contested definitions and repeated questions that hamper attempts to reach “recommendations” and “outputs” as traditionally conceived”. Some authors were already working within this paradigm, and Molster *et al.* (10) recorded persistent disagreement in two topics (on the requirement of the provision of personal feedback by the researchers and/or biobank and on whether participants should benefit directly from the research that they have participated in). Nonetheless, reporting of

involvement by study authors is often limited to outcomes from the agenda of the researchers defined prior to involvement.

Public involvement in biobanks particularly relevant due to the ELSI issues around this type of research and in non-Western countries also to overcome the legacy of distrust in native communities, going through gatekeepers such as local tribes' councils. Indeed, *"The social and historical context in which donation is sought is crucial in understanding individual responses"*.(606) In some cases, such as biobanks working with ethnically and culturally diverse communities (e.g. research with American Indians and Alaska Native communities), engagement of those communities was noted to be an ethical obligation.(566,573) Parkinson (566) notes that guidelines to encourage indigenous community participation in health research have been agreed, which in return have *"contributed to the development of various tribal codes that aim to control health research conducted within tribal jurisdictions"* and, from the researchers' side, *"to the development of specific guidelines for policies regarding the collection and management of biological specimens collected during research involving indigenous peoples"*.

Marsh (579) notes the challenges of putting into practice community consultation in an African setting, *"illustrating the complexity of assessing information needs and levels of deliberation that are appropriate to a given study"* and in a given context.

7.4.6. Strengths and Limitations of our Review

This review adds to the scarce body of evidence of involvement in biobanks, and, to our knowledge, its results are consistent with previous studies that also highlight the focus on functional approaches to involvement.(556) Unlike other reviews, this study focused on the understanding of the impact and the forms of reporting it.

This review has some limitations. Firstly, the classification established for the methods of involvement is not self-categorised, but based on the methods stated in the studies included. As in different contexts, involvement and methods are named differently, it would have been more rigorous to create categories for each example of involvement. Nonetheless, this was not possible due to lack of details on the methods used, and instead, we chose to stick to the methods mentioned in each paper.

Secondly, the greatest impact was reported in the category of wider forms of impact, including education of the wider community and reported “wider engagement of the community with science and research”. However, none of the studies provided details on how these forms of impact were measured. This was the same for the impact on trust, education, skills, and other personal aspects. It is essential that in the future studies report in detail the types of impact if we are to grow the evidence base for public involvement. Researchers must be willing to spend the time and resources necessary to assess them methodically, and funders should expect detailed accounts of impact in the evaluation of research and public involvement.

Another limitation of this study is the predominance of US biobanks. It is possible that other biobanks have included the public, but our search strategy did not manage to capture those. It could also be that more biobanks involve the public in the US, and more research would be needed in this case to understand the reason for it.

Fourthly, involvement reported often concerned the early lifespan of the biobank, when the forms of impact are mainly functionalistic. This may be due to the challenges to evidence non-functionalistic forms of impact, that need long-term follow-up and probably require more time to change. For the latter, requiring more resources, careful planning, and long-term follow-up, the impact reported is consistently vague. For example, it was not possible to assess how national policies resulting from public deliberation changed

biobanking practices or how greater trust of the community towards biobanks was expressed in other studies.

Also, our study can only account for forms of impact that are reported in the literature and documents explored, limited in most cases to the perspective of the experts. It is very likely that involvement has led to other forms of impacts that have been reported otherwise or have not been reported at all.

Finally, and most importantly, the principal finding of this study is the vague, broad-brush reporting of the different forms of impact in the majority of the studies reviewed. For this reason, the forms of impact summarised here might only be a pale reflection of the reality, and more studies will be needed to capture all facets of impact in detail. Also, due to the lack of details, the review could not explore the impact of process and contextual factors that might also affect the outcomes of involvement (e.g. relationships between the experts and those involved, stages of involvement...).

7.4.7. Future Research and Conclusions

This review highlights that involvement and its impact are often reported in a very descriptive manner, centred in the process rather than the outcome. Moreover, involvement is often bounded by researchers' agenda, defined prior to the partnership. This might be due to researchers' limited understanding of involvement and its value as a technical process rather than as a radical transformation of the nature of knowledge and research. This narrow understanding limits the impact of involvement and its reporting, as the evidence and lessons learnt from the experience cannot be incorporated by future biobanks planning to involve.

This review is situated within a growing body of research that advocates for involvement as “*conversations that support two-way learning*” (206) in health and social care research. In this line, the focus should be placed in supporting researchers’ reflective learning based on their partnerships with the public. Best practices and guidance should be put forward to facilitate involvement, helping researchers to see its value despite their limited time and resources. Similarly, methods to capture more subjective forms of impact need to be developed to improve reflective two-way learning.

Moreover, there are several fundamental challenges to capture impact, that emerge from opposed rationales on why the evidence of impact is needed. This review invites not only to better practices and more resources to capture it, but more widely to a re-imagination of impact, that should be seen as a learning process.

We recommend experts to think ahead on the reasons and plan for involvement, focusing on *why* the public is involved rather than *how*. Moreover, further investment needs to be done to facilitate the task of accurately reporting and evaluating involvement, particularly for non-functionalist and wider forms of impact and long-term impacts.

The next chapter provides a case study of involvement implementation in a population-based study in Singapore, and provides a detailed view of the process and impact of involvement in this study.

CHAPTER

8

CASE STUDY OF THE INTRODUCTION OF PPI TO A POPULATION-BASED STUDY IN SINGAPORE

8.1. Aims

In this chapter, I will reflect on the process of implementing public involvement within a population-based study, using a novel approach to public involvement: the ‘PPI Hawker’.

The case study was the last phase of my doctoral program. In this phase, I introduced, advised and observed the development of PPI strategies into a developing biobank. I joined the team as an advisor on PPI and also sought permission to use my role to observe. My aim was to describe how public involvement was being implemented in the project, revealing the barriers and enablers. For this, I based my analysis on the Theoretical Domains Framework to identify the factors that might have influenced the behaviours, and the desired behavioural changes (that is, creating opportunities for PPI and embedding it into practice) in individuals working in the population-based study.

8.2. Introduction to the Research Study

This case study was about a population-based study, led by the Lee Kong Chian School of Medicine, and established in collaboration with the National Healthcare Group (NHG, Singapore) and Imperial College London (ICL, UK). The biobank has been designed to identify the genetic and environmental factors that underpin the development of complex conditions such as obesity, diabetes and cardiovascular disease in Singapore. Ultimately, the goal is to use this knowledge to develop novel ways for the predicting, preventing, detecting early and treating chronic diseases in Singapore.

The genetic and medical predispositions are different for each population, and to date, landmark studies have been done in the US, UK and Germany, but these exclude 60 per cent of the world population without European heritage. This biobank will facilitate the understanding of disease predispositions in South East Asians. The unique and extensive phenotypic measurements, collected together with biological samples and long-term follow-up, are hoped to illuminate the complex interrelationships between environmental, lifestyle and genetic factors on disease risk, and could influence future medical research in numerous fields (608–611).

This study will recruit 10,000 Singaporeans aged 30 to 84 from the three main ethnic groups (Chinese, Malay, and Indian) and others. Each participant will have a comprehensive health screening, including health and lifestyle questionnaires, physical measurements, and extensive physiological and imaging data. After the first visit, participants receive a report detailing any abnormal results. If necessary, participants will

be followed up long-term to identify changes in health status, including new onset diseases.

8.3. Methods and Underlying Implementation Theory

8.3.1. Methods

I observed the activities of this study for 24 months, from February 2018 to February 2020, joining some Steering Committee meetings and meeting one-to-one with team members. This ongoing involvement allowed me to understand how the researchers and key administrators understood and implemented PPI, with me as a catalyst but not undertaking PPI for them.

By reflecting on a study already in place, this case study gave me insights into how a study in Singapore might approach putting its principles in practice. Subsequently, by generalising the observations and using implementation theory to reflect on the experience, I was able to make suggestions for policy makers and researchers in Singapore to efficiently and sustainably implement PPI.

To carry this case study, I collected a combination of observational fieldnotes (similar to the contact summary forms of the interviews), email correspondence and

reflective memos, during the two years I spent in touch with some members of the population-based study. To systematically guide and reflect on the process, I used implementation theory.

8.3.2. Selecting an Implementation Theory

Implementation science is “the scientific study of methods to promote the systematic uptake of research findings and other evidence-based practices into routine practice, and, hence, to improve the quality and effectiveness of health services”(612).

In the last couple of decades, with the emergence of evidence-based research, there has been a growing enthusiasm in the validation and adoption of theories, models and frameworks, drawing on psychology, sociology and organizational theories, to guide successful implementation (613,614).

Previous research on implementation science (615,616) and on reporting guidelines for implementation studies (617,618) highlighted the importance of providing a rationale for the selection of specific theories, frameworks and models, and of giving sufficient background to the method finally selected. Therefore, in Appendix 12: Selecting an Implementation Theory, I detail the process of selecting an implementation theory to fulfil the aims of this case study.

8.3.3. Introduction to Implementation Theories

In my study, the use of implementation theories was adopted to facilitate reflection on the process of introducing public involvement to the research study; implementation theory was not used to guide the implementation. This approach was consistent with my

roles of both advising and observing how the plan unfolded within the study, in an exploratory manner, rather than evaluating the implementation.

As explained in Appendix 12: Selecting an Implementation Theory, I evaluated five popular theories and frameworks to choose the most useful one for this case study. A summary of the strengths and weaknesses for each of these theories and frameworks is provided in

Table 11 below.

Based on the comparative data in this summary table, my final choice was between the Theoretical Domains Framework (TDF) and the Normalization Process Theory. The latter had a clear weakness in my case as I did not plan to interview a particular researcher of the population-based study to base the analysis on his/her standpoint. On the other hand, a disadvantage of working with the TDF was my limited capacity to analyse data applying its extensive domains within the time constraints of my PhD. I weighed this as a minor disadvantage, as I could include this possibility in my research plan. Moreover, whilst I was familiar with the latter, the support of senior research fellow with the first seemed invaluable to me. Consequently, I settled for the Theoretical Domains Framework.

Table 11: Strengths and weaknesses of the most popular theories of implementation that could be used in this case study

	Theoretical Domains Framework (TDF) (619,620)	Normalization Process Theory (NPT) (621)	Consolidated Framework for Implementation Research (CFIR) (622)	Promoting Action on Research Implementation in Health Services (PARiHS) (623,624)	Implementation Climate = Implementation Effectiveness Model (625)
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Strengths	holistic and integrative framework used to analyse behaviour and motivations for change replacing individual behaviour change theories	results in a visual representation of the process of implementation, with direct understanding of the most challenging areas	consider barriers and enablers at different levels of the whole process of doing research	captures complexities of implementation process, at different levels	considers the impact of organization's climate on the effectiveness of implementation
	comprehensive as built by synthesizing 33 theories and 128 key theoretical constructs through expert consensus	can be used longitudinally to assess the changes in practice of PPI	clear	updated since its creation in 1998 and refined in 2015 for the quickly evolving healthcare field	
	includes personal values and also organizational dynamics as factors of implementation that are considered in a pragmatic and straight forward manner	constantly refined and updated, and numerous resources created by the authors easily available			
	coherent and comprehensive and can also be linked to a model of behaviour, which could be useful at later stages to suggest ways to move forward and drafting recommendations for future research studies willing to introduce PPI	applicable particularly to new health technologies and other complex interventions			
	developed for cross-disciplinary implementation				
	validity investigated by behavioral	the authors continually refine and test			

	experts sorting theoretical constructs using closed and open sort tasks	NPT to ensure its validity			
	a senior research fellow in my department who is able to support me is familiar with this framework and has previously used it in her work	I was familiar in the use of this theory, since I had attended a workshop on its use			
	quite straightforward to apply	easy to apply with use of specifically developed resources			
Weaknesses	can be time consuming to use for analysis – potential to overwhelm novice researcher given the 14 domains and 84 component constructs	need to choose a single standpoint (i.e. study team member) to consider each of the theory's propositions whilst the case study would focus on an organisational perspective	successful implementation as an outcome but I did not aim to evaluate the implementation per se, but rather to understand the process and infer recommendations for other research studies aiming to practice PPI	uses successful implementation as an outcome but I did not aim to evaluate the implementation per se, but rather to understand the process and infer recommendations for other research studies aiming to practice PPI	based on author's experience and does not synthesize previous frameworks to build the its constructs
			Has not been validated nor evolved over time since it was proposed in 2009	difficult for researchers not experienced in implementation theories to understand and apply	since first published in 1996, has not been updated nor validated
			may be difficult to digest language if new to area of implementation science		not particularly targeted for the field of health
					targets member's perceptions of the suitability

					of the strategy to be implemented for their values but, in my study, I would not know study team's members perceptions beyond my own observations as I did not conduct formal interviews
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8.3.4. Theoretical Domains Framework (TDF)

The revised TDF (620) was used to identify the factors (barriers and facilitators) that might have influenced the behaviours, and the desired behaviour changes (i.e. creating opportunities for PPI and embedding it into practice) in individuals working in the biobank. The 84 constructs, sorted into 14 domains, are described in Table 12.

Like many other theories, the TDF focuses on individual factors (e.g. beliefs and motivations), but also includes social and environmental factors. The TDF offers explanations of both behaviour and behavioural change in terms of:

- Motivational: theories to explain behavioural changes in people who have not yet established an intention to engage in a particular behaviour;
- Action: theories to explain the behaviour of those who are motivated to change; and
- Organisational: theories to explain change at a higher order social and systems level (626).

Table 12: Refined Theoretical Domains Framework. Source: Atkins et al. (627)

Reproduced from Cane, Connor & Michie, *Implementation Science*, 2012

Domain/Definition*	Constructs
Knowledge <i>An awareness of the existence of something</i>	<ul style="list-style-type: none"> - Knowledge (including knowledge of condition/scientific rationale) - Procedural knowledge - Knowledge of task environment
Skills <i>An ability or proficiency acquired through practice</i>	<ul style="list-style-type: none"> - Skills - Skills development - Competence - Ability - Interpersonal skills - Practice - Skill assessment
Social/Professional Role and Identity <i>A coherent set of behaviours and displayed personal qualities of an individual in a social or work setting</i>	<ul style="list-style-type: none"> - Professional identity - Professional role - Social identity - Identity - Professional boundaries - Professional confidence - Group identity - Leadership - Organisational commitment
Beliefs about Capabilities <i>Acceptance of the truth, reality, or validity about an ability, talent, or facility that a person can put to constructive use</i>	<ul style="list-style-type: none"> - Self-confidence - Perceived competence - Self-efficacy - Perceived behavioural control - Beliefs - Self-esteem - Empowerment - Professional confidence
Optimism <i>The confidence that things will happen for the best or that desired goals will be attained</i>	<ul style="list-style-type: none"> - Optimism - Pessimism - Unrealistic optimism - Identity
Beliefs about Consequences <i>Acceptance of the truth, reality, or validity about outcomes of a behaviour in a given situation</i>	<ul style="list-style-type: none"> - Beliefs - Outcome expectancies - Characteristic of outcome expectancies - Anticipated regret - Consequents
Reinforcement <i>Increasing the probability of a response by arranging a dependent relationship, or contingency, between the response and a given stimulus</i>	<ul style="list-style-type: none"> - Rewards (proximal/distal, valued/not valued, probably/improbable) - Incentives - Punishment - Consequents - Reinforcement - Contingencies - Sanctions
Intentions <i>A conscious decision to perform a behaviour or a resolve to act in a certain way</i>	<ul style="list-style-type: none"> - Stability of intentions - Stages of change model - Transtheoretical model and stages of change
Goals <i>Mental representations of outcomes or end states that an individual wants to achieve</i>	<ul style="list-style-type: none"> - Goals (distal/proximal) - Goal priority - Goal/target setting - Goals (autonomous/controlled) - Action planning - Implementation intention
Memory, Attention and Decision Processes <i>The ability to retain information, focus selectively on aspects of the environment and choose between two or more alternatives</i>	<ul style="list-style-type: none"> - Memory - Attention - Attention control - Decision making - Cognitive overload/tiredness
Environmental Context and Resources <i>Any circumstance of a persons' situation or environment that discourages or encourages the development of skills and abilities, independence, social competence, and adaptive behaviour</i>	<ul style="list-style-type: none"> - Environmental stressors - Resources/material resources - Organisational culture/climate - Salient events/critical incidents - Person x environment interaction - Barriers and facilitators
Social Influences <i>Those interpersonal processes that can cause individuals to change their thoughts, feelings, or behaviours</i>	<ul style="list-style-type: none"> - Social pressure - Social norms - Group conformity - Social comparisons - Group norms - Social support - Power - Intergroup conflict - Alienation - Group identity - Modelling
Emotion <i>A complex reaction pattern, involving experiential, behavioural, and physiological elements, by which the individual attempts to deal with a personally significant matter or event</i>	<ul style="list-style-type: none"> - Fear - Anxiety - Affect - Stress - Depression - Positive/negative affect - Burn-out
Behavioural Regulation <i>Anything aimed at managing or changing objectively observed or measured actions</i>	<ul style="list-style-type: none"> - Self-monitoring - Breaking habit - Action planning

*All definitions are based on definitions from the American Psychological Associations' Dictionary of Psychology (Washington: 2007)

As a framework, the TDF is useful in identifying and describing factors influencing a behaviour but cannot determine causality around the determinants of the behaviour in context and does not provide a series of conclusive testable hypothesis on those determinants.

In the following section, the data from the journey of introducing PPI in the population-based study was used to populate the domains in the framework with context-relevant information and behavioural observations. Then, the domains in the TDF served to identify those most relevant to the observations and suggest strategies to move forward in the Singapore context.

8.4. The Case Study

8.4.1. Aim of the Case Study

As the last phase of my doctoral work, the case study aimed to explore PPI in Singapore from a study perspective and to evidence the contextual and process factors impacting involvement implementation in a real research study. The objectives were to introduce, advise and observe the development of PPI strategies into a developing biobank in order to describe how public involvement was being implemented in the project, thereby revealing the barriers and enablers.

Moreover, the case study also aimed to develop a novel approach to public involvement specific to the Singaporean context that could fulfil researchers' expectations of PPI.

8.4.2. Overview of the Study Team

The overall structure of the study team is represented in Figure 36 below.

Figure 36: Population-based study team structure

The diagram indicates my relationship to the team. For the Principal Investigators (PIs), those affiliated to LKC are shown in purple, those affiliated to ICL are shown in blue whilst those affiliated to NHG are shown in red.

As previously mentioned, the population-based study is a shared effort between Lee Kong Chian School of Medicine, the National Healthcare Group (NHG, Singapore) and Imperial College London (ICL, UK). The study has six Principal Investigators (PIs), with two coming from each organisation - these are represented with different colours in Figure 36. As the study is based in LKC Medicine, one of the PIs from this institution effectively leads the study; he is referred to here as the Singapore-based PI. During this case study, a PI from NHG was appointed as a liaison between the PIs and me; he is referred here as the PI Liaison.

From the study team who works under the supervision of the PIs, Figure 36 only shows the two particular members who I had more contact with. The recruitment manager was often present in the meetings I attended to discuss my progress and I had a few one-to-one conversations with her, especially at the earlier stages. Finally, the most important relationship I had with a member of the study team was with the Operations Manager who would soon become the liaison between the study team and me. Referred to as Liaison, she is a post-doctoral researcher who worked with me to develop ways for the population-based study to hear and incorporate the public's perspectives into their research.

8.4.3. Stages of the Case Study

This introduction of a PPI strategy for the research study was divided into four stages (represented in Figure 37 below).

Figure 37: Diagram of the 4 stages of the case study

Stage 1	Baseline	<p>The first stage was initiated in February 2018 when, after discussion with my supervisor, I approached the Singapore-based PI and asked if they were willing to incorporate PPI to their research. For my thesis, this would be as a case study of how PPI could potentially be operationalised in a Singaporean context (e.g. identify practical challenges) for my doctoral studies.</p> <p>At this stage the communication was very informal and started through my supervisor. I was first directly liaised with the Singapore-based PI shortly after that month.</p>
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Stage 2	1 month	<p>Less than two weeks later the Singapore-based PI, my supervisor and myself met to discuss the forms that PPI had taken in other biobanks around the world and highlighted the popularity of Lay Advisory Groups as a method of involvement.</p> <p>Our meeting was brief (15-minutes) but I was invited to the Steering Committee, attended by all the six study PIs and the coordinators of biobank activities, a month later. I was assigned a 20 minutes slot which I used to briefly introduce public involvement to the committee together with an overview of ways other biobanks had involved the public in other countries (e.g. the UK, Qatar, Iceland and the USA). At the end of the presentation I suggested organising a Community Advisory Group (CAG) to move PPI forward in the study. The meeting ran 15 minutes late, so I was allocated 5 rather than 20 minutes to talk. I was asked to draft a costing for a potential CAG.</p>
	3-4 months	<p>The costing was shared in May with the Singapore-based PI, and I received a response a month later. The Singapore-based PI expressed concerns on how to justify the CAG to the school, a major funder of the study, to get permission from the Dean.</p>
	5 months	<p>The Singapore-based PI requested more details on workload for the member of study liaising with the CAG, and on the skills and knowledge that would be required from him/her. The Singapore-based PI suggested that only one member do that. It was suggested I work with the Liaison, who coordinates the biobank's daily work, to plan for the CAG (on consent and incidental findings) and with the recruitment manager, to plan for the recruitment topics for the CAG. I contacted both. The recruitment manager was poorly, but the Liaison was keen to meet the next day. I met with her couple of times after; we explored why doing a CAG and what the study could get out of working with the public.</p>
Stage 3	7 months	<p>In September 2018, I suggested to steer from CAG to a new strategy that I called the PPI Hawker (more details in Appendix 13: The "PPI Hawker": An innovative method for Patient and Public Involvement (PPI) in health research). This innovative method is simple and adapted to the local context. It would be a better way to have a first experience of PPI, with lower risks and potential to reach more people. I suggested to the Singapore-based PI to cover topics such as informed consent and incidental findings, which were issues the study had to solve.</p> <p>I drafted the idea with the Liaison, who had become the PPI lead within the biobank. After the Liaison and me worked a proposal for the PPI Hawker, mentioning the fact that two members of Imperial College would be here to support our work at the beginning of November (9 months), we sent it to the Singapore-based PI late this month.</p>
	8 months	<p>A follow-up email was sent early the next month, due to the short time left to organise a pilot for PPI Hawker in November. His reply came on two weeks after the initial plan was sent. Later that month, I was invited for a 30 minutes session to present the PPI Hawker to the Steering Committee. This time, at the beginning of the afternoon,</p>

		I received an email from the Singapore-based PI who invited me to join the whole afternoon session, so that I would be familiar with some progress too.
	9 months	The pilot for the PPI Hawker took place in early November (details provided in next section). The same month a summary report on the PPI Hawker pilot was sent to the Singapore-based PI.
	12 months	In February 2019, I was again invited at the Steering Committee. A 1-hour slot was arranged for my presentation on Community Engagement, during which I presented the outcomes of the PPI Hawker and we discussed the strategy for the future. During this steering Committee, the PIs expressed their intention to develop further the community engagement efforts of their study, and one of the PIs became a PI Liaison who would be planning a strategy with the Liaison and me. The PI Liaison and I met that month to introduce him to PPI and to develop a Community Engagement strategy for the biobank.
	13 months	I was invited to the study team building day, in March. An advance, a short form of the Community Engagement Plan was sent to the Singapore-based PI, after the Liaison suggested to create an overview for easy read. Later that month, when the plan was fully developed, it was sent to the Singapore-based PI for his feedback, and then, two days later, forwarded to all of the study PIs with the Singapore-based PI's comments. The Singapore-based PI suggested we carry on with refining the plan, but removing the name of the study, and referring to a generic population-based study.
Stage 4	14 months	When the proposal for the new PPI Hawkers and the Community Advisory Group (CAG) pilots were ready, a request to meet the Singapore-based PI to present and get his approval of the plan was sent. His assistant offered to meet him six weeks later.
	15 months	I met Singapore-based PI, the PI Liaison, the Liaison, the recruitment manager, PI2 and PI6. This meeting followed the study's weekly team meeting and started 40 minutes late and lasted 30 minutes. Attendants judged that the proposal for a CAG was too complicated; for example, they argued that discussions around incidental findings are very complex and require plenty of time. We agreed that I would simplify the outline for a CAG meeting including listening to participants' experiences of being participants, discussing the return of results and format of the report and brainstorming ideas for the engagement strategy. Discussion also focussed on how many people to involve in the CAG, trying to find a compromise between not having a big and diverse enough group and the challenges of managing a very heterogeneous group. We suggested organising three groups, one for each ethnic majority in Singapore, with six to eight people of different ages. The team agreed for those to be recruited taking part in the study at the School of Medicine. Finally, the Singapore-based PI concluded that although the study would

		<p>financially support the CAG, it came under my responsibility and thus I would take care of the ethical requirements and practicalities (recruitment, setting up compensation mechanism).</p> <p>On the other hand, all attendants of this meeting were enthusiastic with the plan presented for future PPI Hawkers aiming to engage the Malay and the Indian.</p> <p>After discussing the meeting with my supervisor, I decided to submit a formal IRB application to the school for the CAG to be covered in case the members of the collaborating biobank had any concern. At the end of the month the PI Liaison informed that he was too busy to continue supporting the community engagement strategy.</p>
	16 months	<p>The PPI Hawker Team conducted two PPI Hawkers successfully engaging the Malay and Indian populations.(628)</p> <p>At the end of the month the CAG got university ethical approval, and I informed the Liaison. We started planning for the CAG, including drafting an agenda for the conversation around return of results and format of the report, and an activity to determine whether participants could understand the distinction between research and clinical purposes.</p>
	17 months	<p>Early this month, I sent an email to the Singapore-based PI with a report on the PPI Hawkers and to inform that NTU IRB for the CAG had been approved. A week later, another email was sent to the Singapore-based PI, informing him that the materials for the CAG were ready and asking for advice on how to recruit to cause minimum disruption to the study team. The same day, the Singapore-based PI replied expressing his support and suggesting moving ahead, even if other PIs who did not attend the May meeting still were not aware of the plan.</p> <p>Shortly after, the liaison asked for the consent of the recruitment manager and the Singapore-based PI that I would proceed to recruit 40 potential CAG participants: i) on the spot in the study centre, requiring collaboration of the study's operations team and ii) past study participants using the existing re-contact workflow that has been approved by PIs. I started then identifying a diverse sample of potential participants based on the criteria defined in May.</p>
	19 months	<p>The Liaison asked the recruitment manager and the Singapore-based PI to forward an invitation letter approved by the ethics review board to 60 past participants I identified.</p> <p>Upon request from Liaison in preparation for her meeting with PIs, I shared (again but in a single folder): NTU IRB approval letter, NTU application form / study protocol and other files that had been submitted to NTU IRB (e.g. invitation letter and research abstract).</p>
	20 months	<p>PI2 informed via phone and mail that although "[study] is very supportive of helping get your study underway and was discussed at our PI meeting" and the IRB from NTU was obtained, the CAG would not move on as:</p> <ul style="list-style-type: none"> - "the IRB [would have to be changed] to one that focuses on population cohort studies in general with [study] as an example of one and not frame it as a [study] study. This gives you the flexibility

		<p>of expanding to other cohorts and more flexibility with the research directions.</p> <p>- to recruit from [study] participants - we will need to formally also inform / seek approval from [study] main IRB"</p> <p>I took this feedback onboard with my supervisor and asked the Singapore-based PI what the [study] main IRB stands for. I decided to submit an amendment to ethics to change "population health study" with "population health studies". Later this month, I informed the Singapore-based PI that the IRB amendment had been submitted to NTU adding "other emerging population-based studies" so that the CAG seems more general rather than [study] centred. The Singapore-based PI replied informing me that he would submit the amended documents to the study's IRB.</p>
	21 months	<p>About a month later we obtained ethical approval, and the official letter was forwarded to the Singapore-based PI. He then replied immediately after asking to start recruitment. On the same day, the liaison informed us that the planned recruitment method (email) was not valid anymore due to PI's decision, and that we would need to recruit by slow mail, more formal.</p>
	22 months	<p>From then until mid-December I prepared and sent out invitation letters to potential CAG participants, who had taken part in the study in the last three months and had agreed to be contacted by mail in the future. Over 120 invitation letters were sent out, asking those who were interesting to get in touch. As they called, I wrote down their name and preferences (timing, contact). Later on, I recruited through the phone other potential CAG participants, focussing on Malay and Indian.</p> <p>I updated the Singapore-based PI and the Liaison about the 15 past-participants recruited so far for the CAG (see</p> <p>Table 13). 5 more were pending confirmation. I also asked for guidance on booking facilities and on the payment for attendants.</p>
	23-24 months	<p>I worked with the admin of the study to set up the payment method with the finance department of the school, which was finally set up on 24 months in the case study. However, that month, the team agreed to postpone the CAG until after the covid-19 crisis is over.</p>

Table 13: Detail of recruited CAG participants

	Ethnic group	Recruited through...	Preferred method contact	Preferred meeting time
1	Chinese	Invitation letter	WhatsApp x2 Email/ WhatsApp Call/ WhatsApp	
2	Chinese	Invitation letter		
3	Chinese	Invitation letter		
4	Chinese	Invitation letter		
5	Chinese	Invitation letter		
6	Chinese	Invitation letter	WhatsApp	afternoons after 2:30

7	Indian	Phone call	Phone call	mornings
8	Indian	Phone call	Phone call	mornings
9	Malay	Phone call	WhatsApp	mornings
10	Malay	Phone call	Phone call	evenings
11	Chinese	Phone call	Phone call/ WhatsApp	evenings
12	Chinese	Phone call	Phone call/ WhatsApp	afternoons
13	Chinese	Phone call	Phone call/ WhatsApp	evenings
14	Chinese	Phone call	WhatsApp	mornings
15	Chinese	WhatsApp	WhatsApp	afternoons

To capture how attitudes and perceptions of the study members evolved with respect to PPI, a narrative summary is provided in the following. This summary includes observations on how the domains of the Theoretical Domains Framework (TDF) are expressed. The data that forms the basis of this analysis are email correspondence over the period of February 2018 to 2020, observational notes, meeting notes and minutes and presentations.

8.4.4. Introduction to the PPI Hawker

Building on the concept of the PPI Café used in the west we designed a “PPI Hawker” for Singapore. Here Hawker Centres rather than cafes are used frequently for eating and socialising, providing a one-stop destination for a wide section of society. The PPI facilitators approached people who were already sitting at tables (and thus not purposively invited) and joined them to discuss questions of relevance to a local research study. Observations and reflexive field notes were used to evaluate the “PPI Hawker’s” feasibility, acceptability and utility in the Singaporean community.

In three “PPI Hawkers” we approached 96 people and 72 (75%) engaged in discussions about the design of a population-based research study. The majority (75%) of participants willingly discussed all of the questions posed to them by the researchers, indicating the feasibility of PPI. The PPI participants came from the three major ethnic groups in Singapore and appeared to be broad in age, suggesting “PPI Hawkers” are easily

accessible. Both participants and researchers recognised the utility of the “PPI Hawker”, reflecting on people’s willingness to talk about the research issues, engaging in informative conversations and posing relevant questions.

The “PPI Hawkers” succeeded in engaging the public in conversations about a local population-based study. The public brought to the researchers’ attention a variety of previously unheard perspectives about the research. Each event fostered connectivity between professionals and the public, generating among researchers a more positive perception of the power of public involvement.

“PPI Hawkers” provide an opportunity for co-informed conduct of research studies with diverse members of the public. They create a focus within a community setting for researchers to engage with the public. The resources needed (costs and preparatory time) are relatively few. Not only do “PPI Hawkers” have potential in Singapore, but also for the rest of Asia.

The findings from the design and organisation of three PPI Hawker sessions have been published in *Research Involvement and Engagement* and are reproduced in Appendix 13: The “PPI Hawker”: An innovative method for Patient and Public Involvement (PPI) in health research.(628)

8.5. Principal Findings

Thematic analysis of the data collected revealed four themes and 8 subthemes:

1. Acceptability of research study shaped by PPI (subthemes: understanding PPI; researchers’ autonomy)

2. Impact on the research quality and outputs (subthemes: new relationships; conflict or partnership)
3. Implementing a participatory approach within traditional research (subthemes: fear of deviating from biomedical approaches; lack of confidence in the potential contribution of lay knowledge)
4. Practical concerns with PPI (subthemes: time pressure and resource limitations on research)

8.5.1. Principal Finding 1: Acceptability of Research Study Shaped by PPI

Sub-Theme: Understanding PPI

The first sub-theme was rooted in researchers' realisation that including Singaporeans' perspectives could help the design and conduct when supplemented by their own judgment and experience. This was noted throughout the two years of case study. From Stage 1 (baseline), the Singapore-based PI noted that they were "keen to work with the population" to expand the study design already in place. A year later, during Stage 4, the study PI Liaison in charge of developing the community engagement with me, stressed that they believed PPI is an "important component" of the study to "move forward", and reinforced that this opinion was shared by the Singapore-based PI.

Linked to this, researchers expressed willingness to incorporate their work decisions in line with the insights provided by members of the public, particularly around the definition of "future engagement strategies" (study PI, 8 months), around making the study more "attractive" (study PI Liaison, 12 months), and recruitment strategies. They considered the need to follow suggestions made by the public that could deviate from the strategy that researchers alone would have ordinarily followed, as long as the public suggestions were aligned with researchers' vision for the study - in this case, the consideration of public perspectives did not impose a transformation of conventional

research design and conduct. In my first conversation with one of the PIs (1 month), the tone shifted after an introduction to PPI. The ambitions they expressed drifted from collaboration to consultation, and the aims became more about “feedback” than just conversations and learning. The PI expressed that the members of the public involved could help in the areas where they have “trouble”, but they do not “need to be always there or aware of all [elements of the research study]”.

As researchers formed their own understanding of PPI, they conceptualised it not as a substitute for, but as an acceptable extension of usual research methods and current decisions. For example, after 15 months, I was invited to a study team meeting, where decisions were being made on the format of the report that participants receive with results at the end of their participation in the study. This was a topic that had been included in the agenda for a pilot of Community Advisory Group to be held later that year, as agreed with the study liaisons since 12 months in. At the outcome of this meeting, the study team agreed on a format for the report they would be following from then on. However, the team still wished to hear the perspectives on the public on this topic in future meetings of the Community Advisory Group to refine the model agreed upon by researchers.

When considered within the TDF, the theoretical domains of *knowledge*, *skills* and *professional role and identity* were especially suited to understand the aspects of the case study just presented. The members of the study team indicated positive *beliefs about the consequences* of using PPI with regards to strengthening the study as well as researchers’ current *knowledge* and *skills* for the research design and conduct. Nonetheless, they also noted that their professional expertise would remain at the core, hence the central element of the *researchers’ professional role and identity* would be preserved.

Sub-Theme: Researchers' Autonomy

Linked to their own understanding of PPI, researchers considered the impact of public involvement on their autonomy. There was a perception that public involvement would not substantially enhance researchers' decision-making regarding study design and conduct or of the interpretations of the study results. In this case, PPI was recognised as hindering researchers' autonomy; a position that could indicate researchers' consideration to the need to embed an increasing number of possibly contrasting voices, suggesting poor acceptability of PPI. During my first presentation to the study team (one month), one of the PIs asked if they would "have to say YES to all [that] lay people say or is listening enough".

The view was also expressed by PIs and researchers in the study team that design and the conduct of research and needing large resources were unlikely to be influenced by the recommendations made by the public. This was particularly the case for aspects with great ELSI implications, such as incidental findings; implying that some researchers did not always foresee positive additions coming from PPI, such as recommendations from a Community Advisory Group. At 15 months, during the team meeting, the main study PI suggested it would be difficult to get "informative answers" in the span of a single meeting. Another PI emphasized these topics were "too complex" for local citizens and asking them to discuss technical topics would be "assuming knowledge" from them. This prompted the Singapore-based PI to wonder what the "value" of involvement would be in approaching difficult topics and conversations. Nonetheless, they also noted that with larger groups of citizens and thereby listening to a greater number of voices, the insights collected could be more representative and, in particular, the study PI liaison considered that the voices would be more informative if coming from "knowledgeable people [from the public]". The concern of the educational level of those involved had been raised as an issue from the start, as already in the first study I attended at one month, one of the team members asked if only those with "high educational level [would be coming] to help".

The expectations regarding this second sub-theme were similar amongst members of the public who participated in the pilot PPI Hawker. They too, stressed the importance of researchers' judgment and experience, emphasising their lack of knowledge about research and technical issues they were asked about. Some of them commented that it was not their role to reflect on certain topics and expressed discomfort answering questions that they felt were too technical without enough information, such as those on data protection. While some of these answers may have appeared to be deferential, it is not entirely surprising that members of the public unfamiliar to the topic of data protection would feel uncomfortable commenting on it.

These observations suggest other theoretical domains from the position that public involvement would not considerably or meaningfully complement researchers' current *knowledge* and *skills* and might erode their *professional role and identity* because of threatened autonomy. These domains influence researchers' decision-making and perceptions of how public insights may inform decision-making for study design and conduct; as demonstrated in Figure 38.

8.5.2. Principal Finding 2: Impact on the Research Quality and Outputs

Sub-Theme: New Relationships

Relating to their expectations of PPI, some researchers felt that it could enhance the relationship between the public/participants and researchers. They also expected that the public would welcome research if it were more relevant to their preferences and needs. This would be achieved by promoting a two-way communication and encouraging partnership. The PI Liaison hoped, after 12 months, that the study would appeal to a "cohort of past participants [to be] engaged in the process", and that their sense of "altruism" and intention to "give back" would motivate them to be involved. He expected

involvement to create a "sense of belonging" and give them a "special status" beyond that of simply being participants. The PI Liaison envisioned the study as a new community and assumed that those involved would form new relationships with the researchers inspired by a “group support spirit”. This conversation reflected what PI 2 hoped for in March 2018, as PPI would create “a sense of belonging [for participants involved]” and the goal of “establishing trust with the public” set for the PPI Hawker during the Steering Committee at 8 months.

Figure 38: Researchers’ perceptions of the acceptability of a research study shaped by PPI

Schematic representation of the identified relationship between the theoretical domains identified above and how they relate with each other: ‘beliefs about consequences’ around PPI unidirectionally affect the domains of ‘knowledge’, ‘skills’ and ‘professional role and identity’; which successively influence the domain of ‘decision processes’

The view that involvement may lead participants and the public to feel positive about researchers valuing their insights and being aware of their needs, priorities and values was also evident in the PPI Hawker. The members of the public that we interacted with were willing to talk about the issues at length, curious about the research, and seemed to enjoy the experience, while asking questions to know more about the study and research efforts in Singapore.

Framing these findings within the TDF, a relationship between the domains of *beliefs about consequences, goals and professional role and identity* can be postulated. Indeed, the respective *roles and identities* of both researchers and participants could be examined from researchers' positive beliefs about the consequences of involving the public in relation to their goals (welcoming partnership and greater public participation). Both groups would become actively engaged in reciprocal communication, that could result in better research for greater public benefit and in increased participant satisfaction.

Sub-theme: Conflict or Partnership

The second sub-theme introduced the possibility for conflict to arise as a result of PPI, rather than partnership. A contrasting view was presented by PIs and other members of the study team that public involvement could impact negatively upon the relationship between the public or participants and the experts. One concern was that consideration of the public insights could impede upon the legitimacy of the experts that organised the rapport with participants. During a meeting early on, at one month, one of the study PIs went to present the ideas we had discussed on ways to involve the public with the team working in the clinical facility, attending participants needs. The researcher had been very keen to be transparent and to value those involved and suggested inviting them to a tour of the research facilities. Nonetheless, after talking to the clinical facility team, the PI was much more cautious with his words and was notably less interested in PPI. The researcher

mentioned that the staff refused to have someone “external” seeing how they work, and that they have all been “sceptical” with the ideas introduced about PPI and collaboration with the public.

Researchers also anticipated a potential for conflict if their choices and priorities were not in line with public’s inclinations and insights. Some were concerned that members of the public might bring their own individual positions and agendas, and thus they may have to work confined to those. Consequently, this was reason for anxiety for some researchers, who feared it could be difficult to bring forward appropriate study design and conduct, and who expected antagonistic encounters with the public. The study PI concluded that researchers “can listen [to the public] but do not need to follow their opinions”, after stressing the fact that PPI gives access to public’s insights, seen as “just opinions”.

For these researchers and members of the public involved, their *beliefs about consequences* raised concerns on involvement potentially undermining their *goal* of developing functional research methods and effective relationships between the professionals and the participants or the public. Threats to this relationship and to the rigour of the research were seen as having the potential to undermine key elements of the researchers’ and participants’ respective *roles and identities*. The relationship between theoretical domains with regard to the variation described within this theme can be represented as shown in Figure 39 below.

Figure 39: Factors influencing researchers’ perceived impact of PPI on the conduct of the study

Schematic representation of the identified relationship between TDF domains: ‘beliefs about consequences’ unidirectionally relates to ‘goals’ and ‘professional role and identity’; in turn these two might affect each other.

8.5.3. Principal Finding 3: Implementing a Participatory Approach within Traditional Research

Sub-Theme: Fear of Deviating from Biomedical Approaches

The first sub-theme was expressed as an inclination to stay within traditional biomedical approaches to research, with possible areas related to ELSI issues and optimisation of recruitment revisited to incorporate public insights. The biomedical model entails a need to optimise time and resources, resulting in little room for change. So that all necessary study procedures could hardly be revisited to match public expectations and that there are little resources and time for sustained dialogue with the public. References to this were made particularly in early stages of this case study, suggesting more widely that researchers see this as being part of the organisational culture of research. During the first presentation to the study team at one month, the questions centred around: the delay that gathering public insights would cause (especially if having to act upon those), and on the extra expenses required to compensate those involved. Later on, the correspondence around the costing for an advisory group (3-4 months) indicated the resource constraints

of a study that was not planned to involve the public, as the study PI writes there is “no specific study budget for this” and thus, to mobilise the necessary resources “I need to ask the permission of the Dean, and to provide justification” (4 months). This meant that some of the items, not essential but part of good PPI practice (such as respite care for relatives of those involved) could not be granted. Later on, at 5 months, the PI showed concern over the “expected time commitment” and the number of staff that would have to dedicate time to be involvement.

Researchers’ focus on this model was prompted not only from the cultural context, but also by fear of failing to comply to all the regulations and to complete the study successfully, which may have severe implications for participants and for the researchers themselves. This fear was more prevalent when discussing the compliance of PPI activities with the ethical and legal requirements for research locally and related to a lack of guidelines and experience in working in partnership with non-experts, that could otherwise have given them some confidence. The study PI stated at one month that it “make[s] me anxious about calling this [the Community Advisory Group] a ‘study’ group” and preferred not to associate new methods like PPI directly to his study. This feeling had been preceded in August by the study Liaison for PPI, who argued that they would “definitely need to put an IRB application for your focused group research activity” in order to protect themselves from possible suspicion of using research participants. Also, at 7-8 months, during the planning for the PPI Hawker, the main concern was deciding whether a consent form and other formal documents would be required for people to join the conversations.

For some, especially for the study PI, part of this fear of failing to comply to all the regulations and to successfully complete the study related to being held accountable. As previously discussed, he suggested asking for the “permission of the Dean” at four months, and later at 10 months, the worries resurfaced over the publication of a blog post

on the lessons from the PPI Hawker. They wanted to make sure to “reduce the risk” by seeking school approval and preferred to be “conservative about things”, wary of the impact this experience could have on the “perception of the School and the Programme”. Ultimately, this would “protect [us] in the event that there is a problem”.

Sub-Theme: Lack of Confidence in the Potential Contribution of Lay Knowledge

Linked to the first sub-theme was the consideration that increased reliance on public insights may result in researchers becoming less proficient and sacrificing research quality, in particular due to the fact that members of the public might have their own “private agenda” (study PI 6) which could potentially hinder the goals of the study. In fact, at times, even the idea of seeking public insights was questioned. At 15 months, the study PI contested the value of “in-depth opinions” from the public, the PI Liaison linked this debate to wider debates on research methods, and on the prejudices around the value of “quantitative versus qualitative research”, arguing that researchers would appreciate the opportunities offered by PPI only “if one considers that in-depth understanding matters” to complete what “surveys” can offer.

The public shared an understanding of scientific pursuit from a biomedical lens. Members of the public noted the importance of efficiency and the expert-driven nature of research and their inability to comment on certain matters. Members of the public commonly argued that the PPI Hawker that researchers’ opinions and decisions were the most effective and reliable route to impactful research. Some participants of the PPI Hawker highlighted researchers’ role as expert decision-makers, so that, as experts, they should be the one making decisions for them. It may, therefore, be the case that public expectations on professionals and research entrenches researchers’ concerns and validates their position with the conventional biomedical expert-driven model of research.

Various theoretical domains were useful to explain these observations. Researchers comments and concerns suggested that that the biomedical model shapes not only the *environmental context* of research and but also defines *professional role and identity*, granting them the role of decision-makers. Together with a lack of confidence, which can be mapped to the domains of researchers' *beliefs about capabilities* and *emotions*, these observations imply that researchers' insights are at the core of the expected *goals* of the study, thereby challenging the adoption of public involvement. Figure 40 illustrates the relationship between these TDF domains:

Figure 40: Factors influencing researchers' preference for the traditional biomedical approach

This schematic representation shows how 'environmental context and resources' unidirectionally affect 'professional role and identity'. This domain, as well as 'beliefs about capabilities' and 'emotions: fear', were in turn shown to relates unidirectionally to the domain of 'goals'. Moreover, both 'beliefs about capabilities' and 'emotions: fear' influence each other. The preference for a biomedical approach emerges from a combination of factors.

Nevertheless, some researchers gave less significance to their own knowledge and perspectives, making a distinction between the more technical decisions, and those

elements having direct resonance and impact on the experience of members of the public and participants. Therefore, these members of the team acknowledged the advantages of PPI, namely the possibility of having first-hand knowledge of public perspectives on particularly challenging aspects of the research that experts had been hesitant to resolve since early phases of the study, such as the format and content of the report and recruitment strategies to “attract” the diversity of the local population (study PI Liaison, 12 months).

8.5.4. Principal Finding 4: Practical Concerns with PPI

Sub-Theme: Time Pressure

Relating to the first sub-theme, researchers were concerned about the time it would take to establish a partnership with the public, as well as the time taken during the conversations with them. The team stressed that involvement could be a waste of time and would only be sustainable if it was efficient to pursue. Researchers emphasized the need to educate and “train” members of the public before they can make constructive comments (March 8, 2018, study PI 2), concerned about the time this would take and highlighting that it would be my task rather than the study team’s. In a later stage, the PI Liaison showed unease over the “commitment” of those involved (Feb 21, 2019), and considered whether creating “some sort of tenure track for them” would encourage members of the public to make time for PPI.

Sub-Theme: Resource Limitations

Regarding the use of involving the public in routine aspects of research, some researchers expressed concerns that addressing minor concerns from the public could detract from more urgent matters, and disrupt study flow and quality, resulting in poorer research output and waste of resources. During my first meeting with the study team (one

month), the study PI stressed that there was “no rush” in getting people's inputs on elements of the study because they already worked “well” for two years with their own way of designing and conducting research, arguing also that “people can come and give their opinion any time”. Immediately after, the meeting was over because the session was late, and they were in a “rush”.

Linked to this, researchers later emphasised that for them to embed PPI, they would have to be convinced that the recommendations made by the public must be feasible within current regulations and existing study procedures that were already established. It would then be up to the researchers to evaluate how reasonable the public insights are and decide whether to act on them. The PI Liaison, in February 2019, described the community advisory group as a strategy for “quality improvement [based on] honest feedback” that could then only strengthen their work, rather than challenge it.

From a theoretical standpoint, the domain of *environmental context and resources* is once more especially relevant to understand this finding, together with *goals* and *pessimism*. Researchers’ focus on the pressures stemming from context of research and of their own lives (time and resource limitations) could be a challenge to accept involvement. Similarly, the concern of public perspectives undermining their priorities for the study and slowing down research led to pessimistic and avoidant attitudes regarding the implementation of PPI. Another barrier stressed within the domain of environmental context and resources was the “sustainability” (PI Liaison) of involvement, since the current wider research culture does not favour PPI with extra support and resources. At 12 months, the PI liaison wondered how the links with the community could be sustained and expanded once my case study was over, since the local researchers and the study team are not familiar with the theoretical and practical aspects of public involvement.

Nonetheless, a few members of the team had a different perspective, recalling personal experiences when collaborating with members of the public yielded positive results (for example, in the case of the recruitment manager, asking past participants to become “study ambassadors” and tasking them with recruiting members of their community) and presented themselves as favourable and as enablers of involvement. It was thus considered that if the value of PPI was demonstrated for other researchers, the team would become more accepting of embedding it within current research practices. The study Liaison, after being part of the pilot PPI Hawker, had become a strong advocate for involvement: “The public’s opinions are very diverse and I learned that if you spend the time listening to the public, there are many things that you can learn from. People are generally willing to help, and their feedback will only make our research stronger!”.

In this context, involvement was not identified as an inherent negative influence on research *environmental context*, but was rather *optimistically* recognised as a likely positive approach, provided it could be situated within current research design and practices. Figure 41 illustrates how these domains relate to each other to illuminate findings around the practical concerns with PPI.

8.6. Discussion

8.6.1. Summary of Key Findings within Existing Literature

This case study presents empirical evidence on the process of introducing PPI to a new and expanding research study in Singapore. I focussed on its acceptability, and provided examples of challenges and facilitators for collaborating with the public from the

perspective of the study team. Disparate views and experiences were highlighted for each finding and were linked to the domains of the TDF.

Figure 41: Researchers’ perceived impact of public involvement on current research methods

Schematic representation of the concepts discussed mapped into the TDF domains: ‘environmental context and resources’ directly shape the ‘goals’, which subsequently have a unidirectional impact on ‘optimism’ and ‘pessimism’

There are four principal findings (schematised in Figure 42): acceptability of research study shaped by PPI, impact on the research quality and outputs, implementing a participatory approach within traditional research, and practical concerns with PPI.

Figure 42: Relationship between the key findings of the case study

The first principal finding appeared to be central and affected by the three others.

This case study suggested that researchers’ acceptability of research shaped by PPI is influenced by how PPI is perceived to relate to the theoretical domains of *skills*, *knowledge* and *professional role and identity*. Indeed, all these influence researchers’ decision-making. Here, a number of researchers were concerned that PPI might threaten their *professional identity* and could limit their autonomy. Other studies have highlighted similar attitudes from researchers who, as experts, wish to preserve control and are concerned about outsiders’ imposed pressure on their research work (207,629–632). Retaining autonomy and personal control over their work has been highlighted by Powell and Davies as key elements of clinician’s professional identity (633). In this case study, whilst PPI was intended to enhance the quality and relevance of research, it was clear that some researchers rejected interference of the public, assuming a degree of unfavourable influence of lay “opinions” on their own work and thus on their status. This constrained the potential role for the public. On the other hand, during the PPI Hawker, members of the public themselves supported the argument that enduring respect for the expert judgment prevails within the ‘Asian mindset’ of Singaporeans, demonstrating that participatory research methods are in their infancy in Asia. In the literature, this is expressed by what McClean and Shaw called the “lay-expert divide” (634) – that is, a

fundamental epistemic distinction between lay and expert knowledge, according to which only the latter is valid in the context of research as the impartiality of expert knowledge makes it trustworthy.(635,636)

This study also showed how study team members can manifest contrasting positions. Not all of them recognised that the contributions of members of the public could complement and strengthen their *knowledge* and *skills* for better design and conduct of the study. Similarly, for a given researcher, the perspectives on the value and need of PPI fluctuated. These findings can be situated within other reports of varied and conflicted perceptions and attitudes on PPI (498,632,637), including my findings from interviews to local researchers (516). These could signify researchers' evolving views on PPI, as their awareness of theoretical and practical aspects increases, and the recognition of the value of public perspectives in research and healthcare becomes the norm. I found that these contrasting positions were also expressed on the impact of PPI on professional-lay relationships. Indeed, while some researchers stressed the potential for PPI to promote consensus and strengthen relationships between researchers and the public, others considered that collaboration could place these groups in antagonistic positions, leading to conflict and straining professional-lay relationships. Central to this was *professional role and identity* and the possibility to forge a new type of relationship, whereby both researchers and the public would stand at a more equal footing. Researchers conceived several ways to involve the public in research, with different degrees of active contributions that allow researchers and the public to reach shared decisions. The degree of compromise between professional autonomy and empowerment of the public to shape future research will be a key part in the conversation to encourage researchers and the public to partner through PPI in research. Linked to this, PPI was perceived as an extension of the patient and community-centred approaches are currently being encouraged in healthcare by policymakers. Indeed, those also rely on information and education, respect for individual preferences, shared goals and mutual decision-making (638). From this

perspective, PPI was understood as a natural extension of a wider shift in healthcare and thus was perceived as a natural and welcome evolution for research. In any case, both possibilities were interpreted as radically different from the typical way to relate to the public and their role of experts.

This case study illuminated the challenges for genuine involvement within the dominant biomedical model for health and research. Researchers' *goals* and the priorities of research institutions are oriented towards a particular understanding of science, prioritising the value of scientific expertise over lived experiences. Research endeavours in Singapore have always prioritised biomedical thinking – reflecting that researchers' set of values are still aligned with Mode 1 of knowledge production (636), as highlighted in other reports (147,297). As expert knowledge is still held in higher regard than lay knowledge (639), researchers' control and authority has remained unquestioned. This position emerged from my data as researchers described their role as experts and rightful decision-makers. This hierarchy was also emphasised by members of the public, and their apparent desire for the researchers telling them what to do.

Importantly, I highlighted how this challenge relates to an underlying fear of refraining from existing guidelines for research practice amongst some researchers. This anxiety might emerge partly from the rapid transformation of Singapore's research, whereby experts are exposed and held accountable, and carry great responsibility. Rosenblum et al. linked these attitudes to the emphasis given on the "value of, and need to adhere to, established standards of professional practice, reinforced through the application of detailed national and international competency frameworks" (640) on clinician-researcher's training, and Glaser links them to a type of "red tape" imposed by bureaucracy in academic spheres (641). In this study, researchers' comments also indicated a concern with potentially corrupting their professional image and career by mishandling a new research approach. PPI could be perceived against current guidelines,

as no institutional support on how to involve the public in research exists to date. Such multilevel anxiety and concern could prevent researchers in Singapore from trying to bring the public onboard and thus negatively affect their own level of understanding and skills around PPI. This finding is reflected in Blackburn's Cost and Consequences Framework for PPI, which features both monetary and non-monetary costs, gains and losses caused by PPI. This framework highlighted how time is the main cost of PPI for professionals, and that other negative effects such as increased pressure/stress and criticism are linked to worse PPI practices (642). These concerns also relate to previous literature noting that negative researchers' attitudes result from lack of awareness and understanding of PPI, leading to tokenistic and less sustainable practices (297).

Finally, researchers' concerns revolved around practical issues in PPI. How to facilitate researchers' work within the (time and resource) limitations of research was a common consideration. Even though views were often disparate on other issues, the totality of the study team members agree that PPI should not be time-consuming, a view also shared by members of the public. This priority reflects once more the time-pressure on researchers who are expected to produce results as quickly as possible. Nevertheless, researchers also implied that the cornerstone for embedding PPI would be its recognition as an effective and fruitful addition; in this context, researchers would mobilise the resources necessary to facilitate PPI within the challenging context of research. These concerns, relating to *environmental context and resources* and *goals*, are frequently cited in the literature (64,206,643), that demonstrates polarised, although shifting, views on involvement within the scientific community (297,644).

Last but not least, this case study revealed some insights into the usefulness of the TDF in the context of research in Singapore. Although the domain "professional role and identity" in the TDF is an individual concept, in the Singaporean context, this item often applies to a collective, whether this is the whole study team or a specific professional

group in an institution. This reinterpretation of the TDF is situated in an Asian context, where the collective is still emphasised over the individual (106,114,493), and hierarchies and professional deference dominate relationships both in the professional and the social spheres.

8.6.2. Recommendations for Research Institutions and Policy Makers to Implement and Promote Good PPI Practice in Research in Singapore

My findings showed a relationship between the theoretical domains of *environmental context and resources*, *professional role and identity*, *beliefs about capabilities*, and *emotions* (fear). These domains can be used to illuminate the effect of expert-driven priorities on researchers' goals for the study. Although PPI is a complement to professionals' perspectives on study design and conduct, the bias towards a biomedical understanding of health and science – due to elements of the *environmental context* or to researchers' own personal values – represents a challenge that will need to be overcome for researchers are to be susceptible to collaborating with the public and considering their experiences.

Although the findings often portray researchers as experts decision-makers, members of the team acknowledged that things would have to be adapted over time. This would particularly be the case for their study, which aims to reach a hugely diverse demographic, both in terms of age and ethnic background, and so, likely will have very diverse expectations and preferences. For some researchers, this realisation was seen as encouragement to consider the public perspectives: if these were diverse and representative of the local populations, sustainable decisions would be made based on the experiences of their target, and thus designing the study in a way that is relevant and convenient for prospective participants. For researchers to perceive PPI as an acceptable addition to the usual methods of research design and conduct, it is necessary for them to

acknowledge the limitations of the biomedical expert-driven model as well as the useful additions that PPI can make to fill those gaps. Emphasising the possible contributions of PPI to researchers' skills and confidence, by training and supporting them with relevant knowledge and resources, will also facilitate their work with the hugely diverse public.

To face some of these challenges and encourage discussion around these, I recommend four areas for action with specific recommendations derived from the TDF domains. These are broad and varied concerns that research institutions and policy makers need to prioritise, consider and implement if they wish to promote good PPI in research in Singapore.

1. To promote PPI at all stages of research cycle (goals and emotions: fear)

- i. Conceptualising PPI as a central element of research, displaying both the rationale for it and its potential contribution to research

By seeing PPI as a core element of any health research project, PPI practice will increase and be consistent across research areas and designs.

- ii. Identifying and sharing role models and best examples of PPI practice in different research areas and at different stages of the research cycle to enhance PPI understanding and practice of stakeholders in all domains

By showcasing role models and good examples, other researchers will realise the benefits that they could harness if they did PPI as well and feel motivated to try, knowing they could be supported. By showcasing PPI in different stages of the research PPI will not be limited to a few activities, and best practice and maximum impact from PPI will be achieved. Having inspiration and support from colleagues will give researchers the confidence needed to try PPI.

- iii. Making PPI a mandatory consideration and requiring appropriate justification for not doing it

Due to the top-down organisation of Singaporean society, it was reiterated that policies are the most efficient way of encouraging people to change practice. However, by making it mandatory there is the risk of making PPI a 'tick-box' exercise and encouraging tokenism, so the regulations will have to be flexible.

2. To consistently carry out PPI following best practice (knowledge and skills)

- iv. Establishing and implementing recommendations and suggesting domain-specific frameworks to support good practice

Researchers in Singapore are apprehensive to transgress current regulations and are used to follow guidelines and best research practice. It will be necessary to provide them with this type of reassurance if they are to take the lead of PPI in their own projects.

- v. Encouraging collaboration across research institutes to share best examples and resources

Collaboration is a pillar of PPI and can ensure efficient and consistent implementation of best PPI practice in Singapore.

- vi. Improving researchers' and the public's skills – provision of tailored training and support

Due to the current lack of awareness and PPI, it will be imperative to train all stakeholders to provide them with the confidence, knowledge and skills needed to contribute as a group

with a shared aim. Training for all partners can also support their meaningful engagement by increasing their ability to fully engage in decision-making with other members of the research team.

- vii. Establishing ground rules for valuing contributions of the public by:
 - a. Ensuring fair compensation routinely
 - b. Educating researchers in thorough PPI costing following best practice guidelines

Feeling valued is essential for positive team interactions and an inclusive research environment. Two conditions are essential: (i) acknowledgement of the value of contributions made by all stakeholders and (ii) sufficient compensation for their contributions. Researchers need to be made aware of this and be provided with guidelines to create equal opportunities.

- viii. Encouraging transparent reporting of PPI ensuring that guidelines for best practice provide sufficient resources to guide researchers

There is growing evidence that PPI carries a number of benefits in a research context. Nonetheless, evidence specific to the Asian context is very scarce. It is important to showcase what has been done to build the evidence base for PPI and to improve its practice. To justify the value of PPI and sustain its support from funders and other stakeholders, researchers will have to aim for best practice and openness.

- 3. To manage the time constraints introduced by PPI (environmental context and resources)

- ix. Raising awareness of the resources necessary for good involvement practice

The resources and skills available for PPI are likely to be limited. Therefore, it is important to develop involvement plans with a realistic understanding of what is available. Understanding the resources available may also help determine the level of participation appropriate for the project.

- x. Encouraging researchers to plan for PPI at the conception stage of the study

Time is the biggest cost for researchers doing PPI. By taking it into account at the early planning stages of the project, PPI will be perceived less as a burden and the time as a challenge. PPI that is rushed and unsubstantial will lead to frustration and disengagement. PPI well-planned as a central element of the process will allow researchers to realise and maximise the positive impact brought by it.

- 4. To change researchers' attitudes: PPI is good for research and researchers (professional role and identity)

- xi. Showcasing and celebrating the contributions of the public to research

Due to the current lack of awareness and experience of PPI, it is important that all stakeholders can be reminded that PPI is good for research and researchers. Seeing real life examples from their peers and other valuing their success after trying will serve as positive reinforcement.

8.6.3. Strengths and Limitations of this Case Study

A limitation of this study is that PPI implementation was suggested after the pilot phase (finished in March 2018), when over a year of preparatory work had already been

finalised. Observations and discussions were therefore limited to some aspects of the research design that were still being discussed and to improve ideas (e.g. on the format of the results report, on the handling of incidental findings, the recruitment in the community or participants' ergonomics during the study), rather than centred around study goals and design and overall relevance from the perspectives of the public. Evidence has shown that the impact of PPI on research is greater when collaboration with the public occurs from the early stages of a project, and that their sense of ownership and contributions are limited for ongoing studies. However, PPI when finalising the pilot phase could have permitted to incorporate the public voice for the improvement of the research study, and so this case study took place at a convenient time.

Although I pursued conversations with as many team members as possible to have insights on their own perspectives of PPI, I could only get snapshots of the continuous process led by the research team. Because I only stepped for very specific reasons into the study rather than spending full working days with them, I will have missed things. For example, how the opinions of the PIs might have influenced the discussions with other researchers, since PIs' views were often simply agreed by the others. When considering the personal views of other team members, it is important to acknowledge the pressure experienced by those to align themselves with the bigger vision established by those in control of the study. This is particularly the case in Singapore, a highly hierarchical Asian context (106,511). Moreover, in this case, the PIs firmly manage and oversee daily research activities and follow-up on all the team members' work, which affected how other researchers' perspectives were sought (e.g. informal corridor conversations rather than formal discussions or email). Nevertheless, the account of subjective views could be considered as a part in itself of these observations, rather than as a limitation of this case study, exposing the wider mindset shift for research to include PPI in Singapore. In any case, the variation in views observed (across the team and for specific individuals across

time) suggests that team members could adopt evolving individual stances that did not necessarily align with others’.

A central strength of this study is its generalisability to other research studies in Singapore, since the biobank followed typical research processes in Singapore. As announced in the methods, this population-based study was chosen as an example of research in Singapore. It was organised in the traditional hierarchical way within a wider research institution and employed researchers with diverse backgrounds. The processes and behaviours observed and conceptualised within the TDF are thus typical, and the findings and recommendations can be extended to the wider health research processes.

An additional strength of this case study is that it explores team members’ actual experiences compared to researchers’ views on PPI in the same context, to provide a multidimensional understanding about needs, expectations, challenges and facilitators to PPI. Observing how PPI was implemented whilst the study was already taking place generated further insights onto how PPI could be actually implemented and experienced in a real research project.

Another strength of the case study is the use of the TDF to reflect on the process of implementation of PPI in a research project. There are no previous reports exploring the operationalisation of PPI using this theoretical framework, validating and strengthening the conclusions presented here. A further strength of the study is the use of a theoretical framework with a critical lens. By relating the TDF domains to the overarching topics emerging from earlier thematic analysis of that data. Finally, the longitudinal observation of the process of implementation of PPI in a research study over two years also adds a temporal dimension to this case study, further enhancing the robustness of my findings.

8.7. Conclusions

The TDF domains of *knowledge, skills, professional role and identity*, *environmental context and resources*, and *goals* could best describe the study team members' perceptions of the acceptability of PPI. Views across the data diverged and evolved over time; researchers at times signalled some resistance to PPI due to the impression that it would hinder their professional independence and status; while at times, the team perceived it as a valuable complement to current research methods. Therefore, whilst a recurrent topic in the literature identifies researchers' need of control through the resistance to the recognition of lay knowledge and public perspectives, my theoretical interpretation indicates that the situation is convoluted. For local researchers, the desire for independence and control did not imply exclusion of the public voices but rather a will to maintain the authority to decide when to consider lay insights and include public propositions to the experts decisions. Researchers' and some members of the public's consideration of public choice and engagement emerged from the data, with shifting intentions that indicated acceptability (or lack of thereof) of PPI. PPI was either conceptualised as a fruitful addition to the study or as a burden that would delay and negatively affect the quality and image of the study, with a middle stand of seeing it as a "nice to have" element that nonetheless could not be considered before other priorities were resolved. Furthermore, researchers underlined barriers for PPI, most often stemming from limited time and resources, such as the pressure on research to produce results and be efficient and accountable while using public monies. Nonetheless, researchers' past experiences of collaborating with the public were described as a motivation for PPI implementation.

This case study suggests that for researchers and other stakeholders, including (prospective) participants, research funders and universities, to accept PPI as a valuable part of any research study, public perspectives should be seen as complementary and supportive of current expert *knowledge* and *skills*, rather than replacing or subverting researchers' identities and roles. Moreover, these should be conforming to be smoothly consolidated within the *environmental context* research studies. My conclusions could be applied to refine recommendations for PPI practice in Singapore and informing the design and conduct of future studies from early stages.

Conclusions from these data can also be framed within wider theoretical debates on how to raise awareness and improve researchers' skills on PPI, and the possibilities of using TDF and behavioural change as mechanisms to sustain change. Using the complex relationships between theoretical domains applied to my observations allowed in the investigation of researchers' evolving attitudes and experiences. The application of a validated theoretical framework based on evidence allowed to inform crucial elements that will need to be targeted through behaviour change programs to support researchers implementing PPI.

9 DISCUSSION

9.1. Aims of this Thesis

The aims of this thesis were i) to understand the perspective of different stakeholders in Singapore about public involvement in health research, and ii) to examine how public involvement could be implemented in health-research studies conducted in the local context. These research aims were exploratory and broad, given the scarcity of existing research and the need to begin developing our current understanding.

To achieve these aims, I was guided by the following questions:

1. What are the existing uses, policy, and drivers for public involvement in health research globally and in Singapore (if any)?
2. What are the current models of patient involvement in healthcare-related research in Singapore?
3. What are the views, preferences, and experiences of local key stakeholders on public involvement in research?
4. What are the recommendations for research policy and practice in Singapore to move the public agenda forward?

9.2. Summary of Main Findings

Chapter 1: Background: Public in Research and Lay Knowledge explored the first research question, as it provided an overview of the rationale and development of public involvement in health research globally. I also explored the nature of lay knowledge. This chapter described how the promotion of involvement in health research began in Western countries over two decades ago. In the UK, PPI is now required for publicly funded health research studies, while in North America, Australia and some European countries (such as Denmark and Spain) public engagement is strongly encouraged by research commissioners and national organisations.(14,32,33,37,39,257–259) An international network advocating for “a world where the patient and public involvement is an integral part of health research” was launched in late 2017 and has been joined by 240 organisations and individuals worldwide.(41) Chapter 1 also showed that involvement can inform all aspects of research, from identifying and prioritising questions through to design, data collection, analysis, and dissemination, being useful in all fields of medical

research. Its benefits increase when the public is involved at all stages of the research cycle, and there are both ethical and utilitarian arguments in favour of PPI.

Chapter 2: Review of Research Practice, Policies and Anecdotal Evidence on Public Involvement in Singapore contributed answers to research questions 1 and 2 as it examined the current models of patient involvement in healthcare-related research in Singapore. A collection of evidence highlighted a shift towards patient-centeredness both in clinical curriculum and practices, and a desire to continue the road of patient activation and engagement. I noted that this shift in the mindset for the clinical aspect could facilitate a shift in research-oriented tasks; some researchers were already considering introducing active roles for members of the public in their studies. Moreover, I discussed how new complex health challenges have pushed the Ministry of Health to look for innovative solutions. These included higher levels of collaboration with the public and a wish to empower all individuals. Overall, I concluded that public involvement is not to be a dormant field in Singapore but an increasingly popular one that, although still in its infancy, could inevitably reach the wider health research domain as well.

Chapters 4-6 included results from the qualitative study carried out to answer the third research question, outlining a national perspective on the potential for public involvement in health research in Singapore. This section highlighted that while most interviewees expressed a lack of experience of PPI, the interview process provided an opportunity for reflection on PPI concepts. Involvement was perceived as a beneficial strategy, both by researchers and by lay members. Interviewees highlighted both utilitarian and ethical reasons for implementing PPI, particularly around increasing the relevance and efficiency of research. Involvement was also expected to provide opportunities for public empowerment, strengthening relationships and understanding between the public, academics, and health professionals. The major challenge highlighted, specific to the Singapore-Asia context, included the hierarchical power

relationships between professionals and the public, making involvement at an individual level less likely to be successful. Interviewees identified formal (e.g., policies requiring involvement) and informal (e.g., community-based awareness campaigns) strategies to overcome barriers, favouring an asset-based, more community-oriented approach. Finally, these Chapters introduce a new pathway for public involvement in the Singapore context: the group model of involvement. This politically sensitive model takes into account the local context and provides a flexible and fluid framework from which to adopt public involvement in a context where participatory methods are not the norm.

Chapter 6: Can the 2018 NIHR Standards for public involvement be used in a Singaporean context? Understanding the perspectives of Singaporean researchers and public demonstrated that there was a close agreement between Singaporeans' aspirations for public involvement and the 2018 NIHR Standards for public involvement in the UK. This examination, relating to the fourth research question, showed the concepts behind the British Standards seemed to have varying levels of complexity and urgency in a context where PPI is novel like in the Singaporean one. Overall, I concluded that although our interviewees came from different backgrounds, their perspectives indicate that the NIHR Standards could provide a broad framework for an efficient implementation of involvement in Singapore. However, supplemental resources specific to the local context as well as education and training will be required.

Chapters 7 and 8 provided a commentary on a case study to illustrate perspectives of the implementation of public involvement in research in Singapore; this contributed to research questions 3 and 4. The review in Chapter 7: A Scoping Review of the Impact of Public Involvement in Biobanks, which also related to the first research question, highlighted that involvement (in biobanks) and its impact are often reported in a very descriptive manner, centred in the process rather than the outcome. Moreover, I found that involvement is often bounded by the researchers' agenda, defined prior to the

partnership. This might be due to researchers' limited understanding of involvement and its value; involvement is seen as a technical process rather than as a radical transformation of the nature of knowledge and research. This narrow understanding limits the impact of involvement and its reporting, as the evidence and lessons learnt from the experience cannot be incorporated by future biobanks planning to involve.

In Chapter 8: Case Study of the Introduction of PPI to a Population-based Study in Singapore, the theoretical domains of knowledge, skills, professional role, professional identity, environmental context and resources, and goals could best describe study team members' perceptions of the acceptability and observed challenges and facilitators of PPI. This chapter provided some answers, based on practical experience in Singapore, to the final research question: what are the recommendations for research policy and practice in Singapore to move the public agenda forward? Views across the data diverged and evolved over time. Occasionally researchers signalled some resistance to PPI, fearing it would hinder their professional independence and status, while at times, the team perceived it as a valuable complement to current research methods. A recurrent topic in the literature identifies researchers' need for control, for example resisting to acknowledge the value of lay knowledge and public perspectives. In my study, the situation is convoluted: for local researchers, the desire for independence and control did not imply the exclusion of the public voices, but rather a will to maintain the authority to decide when to consider lay insights and include public propositions to the experts' decisions. Researchers' and the public's consideration of public choice and engagement emerged from the data, with shifting intentions that indicated acceptability (or lack of thereof) of PPI. PPI was conceptualised sometimes as a fruitful addition to the study or as a burden that would delay and negatively affect its quality and image. Other times, PPI was simply seen as a middle "nice to have" element, but not one to be considered before other priorities were resolved. Furthermore, researchers underlined barriers for PPI, most often stemming from resources (time and budgetary), including the pressure to produce results and the efficient

use of public monies. Nonetheless, researchers' past experiences of collaborating with the public were described as a motivation for PPI implementation. Finally, this chapter introduced the PPI Hawker, a culturally-specific method for public involvement that was piloted in the context of the case study with potential to be widely adopted in other Asian contexts. The feasibility, acceptability and utility of the PPI Hawkers was demonstrated, and the practicalities and impact of the PPI Hawker are expanded on in Appendix 13: The "PPI Hawker": An innovative method for Patient and Public Involvement (PPI) in health research.

9.3. Interpretation of the Results

Both researchers and the public agreed that introducing PPI must be a coordinated effort, with leadership from an established and respected body, such as the National Medical Research Council and other research institutions. I believe the greatest responsibility and most critical task for these institutions is including the theory and practice of involvement in the training of early-career researchers,⁽⁷⁶⁾ who will be the future leaders of scientific research. Their awareness, skills, and expertise in public involvement will be essential for championing meaningful and sustainable involvement in Singapore. The up-and-coming generation of principal investigators needs to provide personal examples that can be used in PPI training of researchers and health care professionals' training. The involvement of public contributors must become a natural way of working, rather than just a 'tick box' exercise.

There are other things that research institutions have to consider if they wish to promote awareness and encourage PPI. Making space for discussion of PPI in events frequented by researchers, such as conferences and continuing education workshops, will help increase awareness amongst already established researchers. Moreover, to shift power relationships and gain public trust, research institutions must create opportunities to open their doors to members of the public. Research institutions could host training programmes for lay collaborators, who on completion of the training, could be included in a registry of lay PPI experts who could be contacted when opportunities arise. This would motivate both researchers, who are concerned about the difficulty of finding the right people to involve, and the trained public, who are anxious to be given practical opportunities to share their expertise, akin to the emergent concept of living laboratories in which users and researchers come together to identify and implement innovative solutions, including in the field of health.(645)

Interviewees noted that making small steps towards PPI would be the most sustainable approach, allowing involvement to be “nurtured”. This would give a wide array of stakeholders, including publishers, funders, and ethics boards, the time and space to play a vital role in supporting a progressive transformation of research. Interviewees acknowledged that support from the funding bodies would be fundamental in the implementation of sustainable PPI practices, rather than merely leaving PPI as “something good to have”. Funders need to support active forms of involvement and to acknowledge their critical role in achieving a paradigm shift in research, creating new ways of working that share the power of decision-making. Indeed, the introduction of funding and resources for those willing to get involved was recognised as the best motivation for researchers, as well as receiving other benefits in recognition to their efforts to involve. Additional support and resources were often seen as a better solution than enforcing PPI, embedding it as a customary rather than a compulsory feature of the research process. Indeed, interviews noted that involvement could exist as an add-on to most research

projects and at some stages, but not always be relevant. Consequently, they reflected on some of the risks of making PPI a requirement. For example, researchers not very aware of it could be prevented from seeing it as an evidence-informed activity that often requires an evaluation of mechanisms and outcomes. Involvement could become tokenistic, rather than achieving its transformational potential, with teams of researchers and patients co-producing new knowledge that has a positive impact on peoples' lives. On the other hand, for funding bodies to support involvement (e.g., identifying and valuing good practices in grant applications), its lay and professional panel members should also be educated about PPI.

These findings also have implications for other organisations in Singapore, as both researchers and the public emphasised the role of community organisations to support involvement. The significance of the potential role of these organisations was emphasised in the supported model of involvement introduced in Chapter 5. Community organisations need to consider becoming a “host” agency, an intermediary between the public and the researchers and research organisations. Simple ways to start this partnership could be regularly hosting events for researchers and the public to meet and exchange ideas, similar to the PPI Hawkers. Training sessions for the public could also be hosted and facilitated by these organisations, as it is the case for other lifelong learning opportunities at the moment in Singapore.

For the government, my work highlights the need for a national strategy for public involvement in health research, following its very successful interventions in other areas of health that have been intensively researched (e.g., tobacco, diabetes). Most interviewees agreed that government-led campaigns would be the most effective in raising awareness and in prompting trust and engagement from all stakeholders. Forming a Citizens' Panel similar to the one created to tackle the war on diabetes could be a way to start discussions about a locally appropriate framework. This panel could also

contemplate important questions such as the advantages of mandating rather than strongly encouraging PPI.

My findings have major implications for the Singaporean public, as they introduce a novel role for them. Patients and the public could seize upon this chance to bring about patient-centered healthcare systems by adding their knowledge, skills, attitudes, values, and beliefs to researchers'. Their involvement in health research could have transformational effects, expanding beyond the research domain. While the ideological basis for PPI is widely recognised in Western countries, where public involvement in research has grown over the last decades, this rationale may be less acceptable in Asian societies like Singapore's. Indeed, many countries in this region have high Hofstede Power Distance, which defines the extent to which less powerful members of institutions and organizations within a country expect and accept that power is distributed unequally. With a score of 74, Singapore more than doubles the UK's score of 35, and nearly doubles Australia's 38 and Canada's 39.(646) This index is another example of inequalities among individuals in Singaporean society and of the attitudes towards it. This was also illustrated in Chapter 5, in the discussion of the government's defined five "Shared Values", namely in the first "Nation before community and society above self".(114) A shift in Singaporean society, which is already on the way in aspects of power relationships, will be needed for PPI to be justified from an ideological perspective. As some interviewees noted, Singaporeans could also seek active roles in other areas of their life, such as health services organisation and city planning. The evolution will be slow, as even in contexts where PPI was introduced two decades ago, such as the UK, the roles of the public in research are still expanding.

For me, as a researcher, this thesis changed my understanding and approach to research. In my previous research, in the fields of materials engineering and neuroscience, I did not consider what the public might think about my work; instead, I just hoped that

whatever I discovered would be useful for someone, someday. Like all researchers, I wanted to do something meaningful, but I did not acknowledge the public's perspectives at critical steps of the process. On the other hand, as I had always had a passion for science dissemination, I was well aware of the need to bring information to lay people's level. Nonetheless, I had never realised that I could work with them in that endeavour. From the first day I started reading literature on PPI, I recognised the shortcomings of the traditional research paradigm I had been part of and knew. My research endeavour has been radically transformed by what I have learnt during my doctoral studies.

For my future career, I would like to gain more experience on the practical aspects of public involvement, bring what I have learnt about the role of the public in a fields previously reserved for experts to areas that are gaining in popularity and will eventually transform how our societies are organised (e.g., Artificial Intelligence, applications of quantum technologies in health).

9.4. Implications of these Results

9.4.1. Impact of my Work

During the conduct of my thesis, I already saw my work have an impact on various levels.

Firstly, the principles of public involvement have had local infiltration within my own research group of Family Medicine and Primary Care. For example, in August 2019,

we started a pilot study of health literacy, in which we aimed to evaluate both the feasibility of assessing health literacy at a household level and of working with eight lay members co-researchers. Lay members of all three major ethnic groups in Singapore were trained and supported, with discussion sessions mid-way and another one planned for the studies close. Lay co-researchers have shared their perspectives on the recruitment and research materials, been recruiting households, and assisting with data collection (including the conduct of the interviews and questionnaire delivery). They are expected to inform the interpretation of findings and to contribute to the identification of the implications for future research. Three researchers from my department and two from NHGP (one of the three national healthcare providers) have been actively involved at all stages, learning about the practice of public involvement locally.

Local infiltration has also expanded within my medical school as, with my main supervisor, we submitted a proposal for an LKC PPI initiative. After preliminary discussions, the medical school will be considering how to promote public involvement forward at the school level, with a shared resource. This would mean creating a lived experience panel, composed of past research participants or patients with various conditions who could be involved: i) at some point in any of the research studies being conducted in the school, and/or ii) in the design and delivery of the medical curriculum.

The impact of my work has benefited from dissemination opportunities. Locally, I delivered a workshop centred around the basics and practicalities of public involvement, which included healthcare professionals from different organisations in Singapore. During this workshop, discussions around the various rationales for involvement, who to involve, and the differences between patients and the public demonstrated the interest that local researchers have for learning about PPI. Conversations around ethics, time, resources, and other barriers showed, in most cases, professionals' willingness to give PPI a try. They

were particularly attracted by the concept of the PPI Hawkers, as those imply less administrative and logistic burden than other methods of involvement.

I have also had the opportunity to disseminate my work to a wider Asian audience. In June 2019, I had the privilege to attend the Asia-Pacific Primary Care Research Conference, where I delivered an introductory workshop to public involvement based on my research findings. It was rewarding to contribute to the experience and discuss researchers' efforts to give the public a voice and an active role in research in countries as diverse as Malaysia and Australia. These conversations unveiled commonalities in terms of the motivations behind involvement, as well as in facilitators (flexibility, being upfront, planning) and challenges (time, funding, and resources). It was also very constructive to listen to the positive impact that public involvement had had on Australian projects. Two research abstracts (one presenting the findings from qualitative interviews, one discussing the PPI Hawker and its adaptation to other cultural contexts) were accepted for an oral presentation at the 2020 WONCA Asia-Pacific, showing the increasing interest around public involvement in research in this region. Unfortunately, this conference has been postponed due to the Covid-19 pandemic.

Finally, regarding my publications,(516,628,647,648) the early impact can be seen on Twitter. My tweet disseminating my first paper(516) (which focused on researchers' perspectives on public involvement) had a very positive response, with over 3,000 impressions and 107 engagements (many more than usual). Other tweets related to pieces I have written based on my work have gathered similarly positive responses, with over 2500 impressions and around 70 engagements from researchers and members of the public from around the world, although mainly based in the UK. This same publication, has an altmetric attention score of 22 as of July 2020.

9.4.2. PPI Expansion in Singapore and Asia since I started

The topic of my thesis is unique and working in the field began as a rather solitary task. There were rare opportunities to discuss the goals, facilitators, and challenges of involvement outside my own research group. An exception to this was the 11th Singapore AIDS Conference, discussed in Chapter 2. Also, the lack of evidence limited the types of questions I could consider.

At the start of this project, I mapped the existing policies on the role of the public in health care research in Singapore. While the local drive to innovation and excellence in health care and research includes an emphasis on the advancement of patient care through translational research and patient-centered care, the results of the local literature search suggested that the role of the patient remains limited with respect to participation in research. The literature also suggested that while in recent years the doctor-patient relationship has shifted and the expectations of the public changed, the organization of health is still geared in a top-down fashion. Alongside, the rhetoric has also evolved from the paternalistic discourse as leaders have voiced the need to work in partnership with members of the public in research. But for the moment, these intentions have not been translated into policies that encourage an active role for the public in research. Consequently, studies are still conducted ‘for’ the members of the public rather than ‘with’ them and public involvement does not happen in research practice locally.

Due to the scarce evidence on public involvement in the literature, both through bibliographic and hand search, I decided to help fill these gaps with evidence collected from observation and discussion. This body of ‘anecdotal evidence’ was collected opportunistically and recorded in daily memos. These provide good examples of the shift towards patient-centeredness both in clinical curriculum and practices, and a desire to continue the road of patient activation and engagement. This shift in the mindset for the clinical aspect can facilitate a shift in research-oriented tasks, and some researchers are

already considering introducing active roles for members of the public in their studies. Similar transformations are occurring at a broader scale in parallel to the ones in the clinical arena; people in Singapore, like the students, seem to be increasingly encouraged to have an individual voice.

Moreover, anecdotal evidence also demonstrated how new complex health challenges have pushed the Ministry of Health to look for innovative solutions that have included greater levels of collaboration with the public. Particularly, community engagement methods have been used by policymakers in the health domain since 2016 to find innovative ideas to tackle the 'war on diabetes'. These events have reinforced the trust of the citizens on the government and have demonstrated the power of public involvement to the policymakers.

A shift within the researchers' community, for researchers working with vulnerable and marginalized groups, was also noted. These have already started to establish relationships of equals with the communities they are working with and are slowly figuring out how to adapt Western participatory research methods to the local research culture and socio-political context.

The collection of anecdotal evidence captures a shift in health services, the government, and learning institutes towards a greater appreciation of the voices, perspectives, needs, and values of citizens. Public involvement is not a dormant field, but one in its infancy and with increasing popularity.

Also, since the start of this project, key organisations worldwide came together to create the International Network for Public Involvement and Engagement in Health and Social Care Research, as it has become a new priority to elevate involvement and engagement internationally. In an attempt to create the paradigm change required in

academic research, stakeholders worldwide have recognised the strength gained from joining forces, creating new opportunities for linking together, identifying common challenges and creating solutions.(47) So far, however, no Singaporean organisations are part of the network. PPI aspires to be a global endeavour, but it has barely taken off in East Asian countries, despite global organisations making efforts.

9.4.3. What I learnt

This thesis started with ideas I have been wondering about for a decade, since *Decide Madrid* came to life. I remembered Madrid's example and wondered whether the same eagerness to open up reserved spaces could also apply to health research and in Singapore, a new context for me. There were many things I wanted to explore, including public participation in research, qualitative research, and the Singaporean culture. In my two and half years' journey through doctoral studies, I learnt about qualitative research methods and their theoretical underpinnings, and I acquired and consolidated practical skills around it. While researching the origins and arguments for involvement, the most captivating area I could learn and reflect on was the different modes of knowledge and theories of lay knowledge.

I have also learnt extensively about the local context in different domains, from local research and healthcare organisation to the welfare system and the challenges it presents for retirement. In particular, I could understand the reluctance and fears that many members of the public experience towards research, listening to their perspectives on being a research participant. Learning about some of the complexities of Singapore's education system, and its effect in later life, in particular the work culture, was very telling. Singaporeans work long hours, which has dramatic implications for involvement in research. Indeed, the most common forms of involvement require people attending group events such as focus groups at specific times, which most likely represents a real

challenge for the public in Singapore. Through the interviews, I also learnt that retired people still have a lot of commitments and activities to attend to. These areas served as an introduction to Singapore's history and Asian cultures, particularly values rooted in Confucianism.

Finally, through this thesis, I learnt about the critical factors behind successful involvement, and how some of those might be a challenge in Singapore, not only in research but in any domain. For example, experts need to be open to check their power and acknowledge that involvement in research will occur in a current (and historical) context of imbalanced power relationships between experts and the public. Stakeholders will need clearly defined objectives while maintaining the flexibility to find common ground and move forwards. Also, all stakeholders need to see involvement as a dialogue and collaboration, where active listening is a fundamental feature. This would also allow them to be ready to start conversations and maybe discuss uncomfortable points that might not have been initially considered. Linked to this, researchers must invest time in getting to know who they are working with, including who they are, their hopes and fears, their expectations around involvement and their passions and talents that could be incorporated into the research. Finally, it is necessary to continue building the evidence-base, evaluate and reflect.

9.5. Limitations

9.5.1. What I might have done differently if starting again

If I were to start this program of work again, I would introduce and prioritise the voice of the Singaporean public in the design and conduct of the study. This work focused

on PPI, but little PPI was used in the design of this study. The reason for this was a lack of a framework for involvement in Singapore in January 2018. Since I already had a limited time to complete this work, I had no experience of involving the public and no one knew what the challenges and facilitators here would be, I considered it would be too complicated and risky to involve the public in this study. In retrospect, I can propose ways I could have involved the public all along: in defining the research question in a way that made the most sense for Singaporeans, in refining the methods (e.g., who to recruit? when? how? where?) and the interview guide, in the dissemination of the results in community events or in drafting a plan for future action.

Another challenge was the linguistic diversity in Singapore, and only being able to converse in English. I would have teamed with medical students able to speak Mandarin, Hokkien, Malay or Tamil for them to interview in those languages and have access to an even wider population. Indeed, even though English is the *lingua franca*, Singapore is a multi-ethnic country with four official languages, and accessing those populations would have made my research richer. Moreover, by collaborating with medical students, it would have also contributed to raising awareness of PPI amongst future professionals.

In terms of research content, I would have liked to have completed two case studies. One would be the population-health study, a very ambitious project with researchers not necessarily onboard and not seeing PPI as a priority (as seen in Chapter 8: Case Study of the Introduction of PPI to a Population-based Study in Singapore). A second one would focus on a smaller scale project for which researchers are very keen to involve the public. These two cases would have allowed me to reflect on the differences between the two scenarios, and on the impact of close relationships as well as that of researchers' willingness to involve the public in their work.

I would have liked to give interview participants the possibility to check my interpretation of the results, as a way of quality assurance through of members checking. This would have strengthened my study, adding rigor and credibility.

I also would have liked to organise a series of focus groups bringing together researchers and members of the public to discuss together the findings from the interviews. This would have been useful both to further strengthen the rigour of the findings presented, as my interpretations of the interviews would have been challenged by the interviewees, as well as to reach consensus on some major conclusions. This would have been a preferable step in the development of a framework for involvement in Singapore, but unfortunately, outside the financial and time constraints of a doctoral thesis.

Further, I would have asked participants' consent for secondary data analysis conducted by other researchers in Singapore and overseas, to facilitate more research on this topic and permit analysis of the transcripts from another perspective in the future. For example, if others used this data, they could complete a cultural comparison on expectations, barriers, and challenges for involvement, or they could focus on the perspectives of particular groups of researchers or particular populations.

Finally, if I had the opportunity to expand this body of work, I would introduce cultural comparisons, for example, contrasting the ideas for PPI in Singapore versus the reality in the UK. I would reflect, for example, on what are the challenges still faced in the UK, what challenges they have overcome and what Singapore can learn from it. I would also prioritise the focus to working with multicultural groups and minorities, to learn how working in different languages and cultural differences can be integrated towards a common goal, and how to reach a diverse public.

9.6.

Recommendations: What Practical Actions or Scientific Studies Should Follow?

9.6.1. Principles for Successful and Sustainable Involvement

Despite not having a recipe for involvement, successful work with members of the public is more likely if adhering to some basic principles.

- **Adapted to the local context:** Involvement is localised within a cultural moment and is affected by context and process. Social, economic, political, and ecological particulars need to be understood and acknowledged, as well as how the various beliefs and needs of stakeholders are affected by those. Starting with the supported model of engagement, proposed in Chapter 5, would allow to anchor involvement in the local context.
- **Diverse & inclusive:** The process needs to include a wide range of perspectives, knowledge, and experiences, including consideration of gender, ethnicity, and age. Different approaches, perspectives, skills, styles, and contributions need to be valued.

- **Timely & purposeful:** Clear goals to be identified and shared to clarify the purpose of PPI. Involvement needs to be focused, planned, and included as part of the research programme, while allowing flexibility. Specific roles should be discussed and agreed together, and expectations managed; identifying a common goal allows building of open, honest, trusting, and reciprocal relationships. Sufficient preparation, training, support, supervision, and financial remuneration should be provided to enable stakeholders to contribute and undertake the roles required fully.
- **Reciprocal & respectful:** Reciprocal relationships to be established where all involved can benefit, allowing stakeholders to be able to contribute in different ways. This implies researchers are open to relinquishing and sharing control to facilitate new ways of working. Involvement is an iterative and ongoing process, allowing continuous two-way learning for all stakeholders, shared commitment, frequent support, and communication. “Feeling valued” is essential for positive team interactions and the creation of an inclusive research environment.

Moreover, the successful involvement of the public requires some antecedents, such as planning and early work. Before co-creating knowledge, teams can work building relationships and trust, identifying potential tensions and challenges, and understanding the expectations of all collaborators. These processes prepare fertile ground for collaboration.

In the Singaporean context, the timeliness of involvement implementation will heavily rely on political opportunities, as central coordination and support appear to be a decisive factor for many. The supported model of involvement offers a useful framework to develop and support PPI in the Singapore-Asia context. Following this model, a partnership between researchers, the government and community organisations would allow for a progressive and sustainable involvement of the public in research, building on

the central role that the government and the community already have in the lives of most members of the public. These three contributors are represented in the 'Supported group model' for PPI, whereby researchers hold the technical knowledge, the community represents the members of the public and the government, and other civil organisations form a mediator-partner host. On the other hand, a thinking group, bringing together diverse actors (researchers, clinicians, patients, carers, and managers), could support the development of local public involvement. Following the example of The Exchange Network technique⁽⁶⁴⁹⁾ such structured events, independent from specific research projects, could enable participants to challenge organizational norms and expectations collectively. These events could also seed capacities for learning, as well as generate new understandings around involvement in Singapore. This model could be brought to the attention of the ministries by writing a short report for each of the relevant ministers (education, health), inviting them for further discussion.

Finally, both interviewees, researchers in the case study and the literature highlight the importance of impact evaluation, and here I suggest some strategies based on the principles for successful involvement previously mentioned:

- **Adapted to the local context:** reflect and capture the degree to which involvement processes are situated within a particular location and tailored to individual relationships and challenges. Some questions that the team can use as a guide are: Was involvement initiated by an actor already immersed in the problem at hand? Is the intention behind involvement related to the current priorities and activities of stakeholders collaborating in the process? Involvement evaluation frameworks and methods can be used to assess these.
- **Diverse & inclusive:** document various elements that contribute to the diversity of involvement process, e.g., inclusive opportunities, diverse systems of knowledge. Encourage the use of qualitative methods to record and reflect on those, such as memos, personal narratives, and continuous surveys. These can also provide

insight into whether the knowledge and perspectives of those involved are sufficiently mobilised and incorporated into the process.

- **Timely & purposeful:** assess the degree to which the involvement process facilitates the generation, revision, and attainment of desired goals, outcomes, and impact. For example, how does the knowledge generated directly inform study governance? Building new understandings, relationships, and networks are examples of such outcomes that could be captured along the process using evaluation frameworks.
- **Reciprocal & respectful:** record the nature, frequency, and quality of interactions between collaborators, using simple qualitative tools (e.g., meeting minutes, memos) or richer qualitative methods (e.g., interviews, focus groups). Evaluation of this principle must also attempt to capture learning, how the perspectives of collaborators evolve throughout the process, and the degree to which shared perspectives and understanding of the problem at hand emerge.

Critically, with these steps, it is hoped that all stakeholders will see involvement, not as a technical process, but emerging from a values system, relating to interpersonal relationships, organisational issues, and societal values. These values will have to be made explicit, while all parties involved acknowledge various motivations to undertake involvement.

9.6.2. Future Perspectives for Singapore

Linked to the strategies mentioned above, researchers and other players expected to provide support will need substantive evidence-generating studies from Singapore for involvement to take-off in the local context. Such studies have the potential to create new knowledge about involvement, alongside the more routinely supported ‘doing’ activities, which although valuable, do not always generate research-based evidence to push

knowledge forward. Like in other contexts, a foreseeable challenge will be to promote high-quality reporting, which researchers often feel like an additional element to their main focus. Building the evidence-base for involvement in Singapore and Asia would avoid research waste, as key information collected in a study is reported in its final paper. For these reasons, reporting guidelines, such as PiiAF(650) and GRIPP2,(96,205) which were created to change the inconsistent nature of involvement, to encourage careful reflection and to support the researcher and patient in making the most of reporting their study, should be introduced in researchers' training as early as possible.

I have noted that one of the major culturally-specific challenges is the hierarchical power relationships within a culture of "consensus not conflict". The cultural reluctance of individuals to question perceived authority figures, such as health professionals, clinical scientists, and researchers may be overcome by adopting an approach to PPI that is closer to local community values, and which facilitates patients and the public collectively engaging in research.

Careful consideration also needs to be given to issues of resource and support to enable members of the public to engage in meaningful ways that will deliver research best placed to improve patient outcomes. While all interviewees acknowledged the need to provide funding to accommodate involvement, it was less clear what other forms of support would be needed, or who should be coordinating those. Similar considerations will have to be made for the design of lay and researchers' training.

Our case study suggests that for researchers and other stakeholders, including (prospective) participants and research funders and universities, to accept PPI as a valuable part of any research study, public perspectives should be seen as complementary and supporting current expert knowledge and skills, rather than replacing or subverting

researchers' identities and roles. Moreover, these should be conforming to be smoothly consolidated within the environmental context research studies.

Conclusions from our data can also be framed within wider theoretical debates on how to raise awareness and improve researchers' PPI skills, and how the Theoretical Domains Framework and behavioural change could be used as mechanisms to sustain change. Using the complex relationships between theoretical domains applied to our observations allowed us to investigate researchers' evolving attitudes and experiences. The application of a validated theoretical framework based on evidence allowed us to inform crucial elements that will need to be targeted through behaviour change programs to support researchers implementing PPI.

Our interviewees emphasised how busy Singaporeans are, noting that lack of time for everyone (researchers and the public) challenge involvement. To facilitate PPI in such a busy context, I propose the development of novel methods of participation, tapping on technology. As Singapore continues to develop its 'Smart Nation' (651) profile, there are increasing opportunities to explore the role of e-learning, e-meetings, and the use social media to engage the public, as well as facilitation of involvement, including providing support for those involved and funding for those involved in their work. In light of COVID-19 and policies encouraging social isolation and lockdown, innovative strategies relying on remote opportunities to collaborate have gained momentum. (652,653)

Some participants suggested starting small and taking little steps. This could be done in different ways, for example, slowly introducing involvement to selected research topics or through a few 'pioneer' researchers. Indeed, some lay interviewees acknowledged that not all areas of health research are as appealing to the general public. For example, people expressed that a health topic that has a lot of media attention, such as nutrition or cancer, would attract more members of the public to be involved more

easily. On the other hand, some researchers expressed the need to learn from their colleagues in Singapore. It would be beneficial to start exploring the practical aspects of involvement at a reduced scale, as feasibility studies, in particular areas of health that receive more public attention. During such studies, all involved should document and reflect on the process and at the completion, researchers and members of the public having experienced PPI could share their experiences. Documentation, evaluation and dissemination of evidence from local studies would have significant impact on Singaporean researchers' willingness to try involvement by themselves.

Interviewees also emphasised a generational shift; with younger generations, educated in English and very much part of a globalised world, being very different from the pioneer generations that contributed to the founding of Singapore. Exploring together with the youth what they think their role in medical research is, what might attract them to get involved, and what they would expect to get out of it, will be necessary to pave the future of sustainable involvement in Singapore.

Although the role of qualitative research is gaining momentum in Singapore, quantitative research is still the dominant research method. Globally most work with PPI concerns qualitative research, although recent studies explore its potential and impact in clinical trials,(50,424) calling for more quality research into involvement practices in quantitative studies. The literature, like researchers interviewed, highlights specific challenges for involvement in this approach to research, which is characterised by formal and often rigid methodologies. However, some studies provide advice on how to overcome some of these barriers, such as being upfront on how methodological and practical questions can be resolved together, establishing whose perspective can be considered and how.(424) Other solutions cited include an emphasis on sustained dialogue and reflection, whilst also noting the need for the research culture to shift from the current positivistic paradigm.(654) Attention to further progress on how involvement can be best

incorporated into quantitative studies will be necessary for PPI to be widely adopted in Singapore.

Finally, all stakeholders will need to make flexibility in PPI a priority. This would benefit everyone; only then will involvement have the potential to respond to the needs, abilities and expectations of most, and only then will researchers and those involved have the chance to learn to work with each other. Flexibility in timing of involvement and on mechanisms for contributing could demonstrate to busy Singaporeans researchers' willingness to have the public on board. Flexibility could appease researchers' anxiety, providing adaptability to different research processes and allowing the exploration of novel avenues of involvement. Linked to this, the willingness to take risks by starting a new learning journey and leadership's support to integrate patient partners into the project will also be paramount.

APPENDIX

1

THE IMPACTS OF PUBLIC INVOLVEMENT

In the next paragraphs, the different forms of impacts of public involvement are presented, with some illustrative examples. These were retrieved from a narrative synthesis of articles and systematic reviews on various issues around involvement in research I have come across during this study. The taxonomy of impacts proposed by Staley (Figure 43) is used to structure the following paragraphs.

1.1. Impact on Research

PPI can be understood as a technical process to improve research, as the current evidence suggests that produces better quality research.(13–28,201,299,655–658) For example, involvement improves the design, conduct and dissemination of research studies.(25,94,658) Public involvement has been shown to make research more efficient and more implementable.(19,65) It is argued that PPI improves cost-

effectiveness,(48,49,78,281,659) particularly as it optimises the research process in terms of recruitment and retention and representativeness.(22,660)

Importantly, as involvement can occur at different points of the research cycle, its impacts exist for all stages of the research.

1.1.1. Involvement can Influence the Research Agenda

PPI plays a central role in the first stage of the research cycle. Members of the public can identify new topics for research, widening the scope of questions and areas considered by academics and health professionals working alone.(180,185,194,661,662) Indeed, members of the public contribute to the identification and clarification of research objectives and questions by grounding them in ‘real’ experiences that better suit the needs, values and preferences of the public,(19,94,663–668) shifting the focus of research. Involvement results in research more appropriate to patients’ health-care services’ needs,(18,25,94,286–288,669) promoting more reliable, relevant research.(180,194,201,289,656) This is the case since priorities of researchers and members of the public differ.(291,670) For example, young people can identify topics overlooked by researchers (671) and a woman detecting an unusual smell in her husband, who was to be diagnosed with Parkinson’s disease 10 years later, opened new avenues for research on the detection of the disease based on odour signals.(672)

New research projects can arise from the motivation and momentum brought by the public, accelerating the research process.(194,658,669) In the case of PXE International,(585) this patient organisation around a rare condition worked to incentivise research and established the PXE International Blood and Tissue Bank to address patient’s needs, to which all patients eagerly donated their samples and that gave researchers enough samples to discover the PXE gene. Involvement widens the scope of

research to include the subjective, experiential knowledge of the patient as well as the objective knowledge of the experts (663) and thus considering a wider range of perspectives.(94) When the focus is on seldom-heard voices and communities, involvement also might determine the success of research.(158,159,673,674) Researchers working with Gypsies and members of traveller communities reported that by having the public studied side by side, they could “learn much more about” those populations and by having public involved since the very beginning made them confident as they “were going to be in a win-win situation”.(673)

Finally, as PPI becomes an imperative to receive public funding, the inclusion of members of the public as advisers early on can influence funding, by enhancing the likelihood of successful funding applications.(174) For example, the European Union expects ‘citizen involvement’ to be part of research proposals,(675) and many UK funding panels challenge application that do not include PPI, or present PPI practices that appear to be tokenistic. Researchers have reported how involving the public can make research more fundable, as proposals become more credibility and feasibility and overall design are strengthened.(180) Since an increasing number of committees include members of the public as part of the funding process alongside clinicians and academics, there could be extra value in including PPI to shape proposals and in the proposal.(176–178)

1.1.2. Involvement Influences Research Design and Delivery

Involvement has the potential to influence research design and delivery when members of the public are involved at early stages of the research cycle.

Firstly, when the public is involved from the identification and prioritisation stage, they have refined research question and shaped the design.(185,194,662,669,672,676–680) For example, Dickson and Green reported how the preferences of researchers and

the public differed on topics to focus within a same study: while professionals placed greater focus on issues around ‘problems’ and ‘health needs’, the public focussed on ‘community strengths’, forcing experts to reshape the research.(681) The public can also contribute to the definition of study outcomes, and influence the approach to measure them.(194,196,673,682) Consequently, study findings become more grounded and relevant and thus useful to other members of the public.(683) In a mental health clinical trial, the public involved raised the fact that the outcomes measured (such as attention, memory and concentration using neuropsychological tests) would not be relevant to users of services in their daily lives, and instead suggested a new more practical measure to assess attention and memory, asking people to recall items from a shopping list.(662)

Secondly, when involved at the design stage, the public positively impact research tools, methods and materials. Members the public can have an impact on the research tools used. In some cases, the public provided background information on potential participants,(185,684,685) helping researchers to adjust their tools to the communities concerned.(676,684) They can improve questionnaires, interview and focus groups schedules, by making them more user-focused, and can test them to improve reliability.(19,683,685,686) For example, younger people advised researchers not to use language used by the adults in the materials.(671) Research methods are also affected by PPI: they can be refined to work better in practical situations, by making it easier for participants to take part.(18,687) For example, service users involved in mental health research noted that it would be difficult for participants to take part in focus groups and their ability to remain active during discussion would be limited by the side-effects of medications.(181) PPI can also improve the research materials’ usefulness (167,686,688,689) as it improves patient information, resulting in more appropriate and accessible participant information for potential participants, both in terms of language making sure the right language is used (18,170,689–691) and content.(18,684,692) For example, members of the public gave ideas on how to make the tools more informal,(689)

avoiding questions around sensitive issues (18,684) and more culturally relevant.(693–695)

Thirdly, PPI has an impact on the recruitment, as it is often reported to lead to increased participation rates,(22,50,94,170,174,194,695,696) and thus to study completion.(162,664,666,668,697,698) This effect was greater when people with lived experience of the condition under study were involved.(50) This could be because the research topic chosen by members of the public is more attractive to potential participants.(699). Members of the public can increase access to potential participants from their communities,(185,655,684,687,700,701) improve the information provided to them,(702,703) advice on the sensitivity of recruitment procedures and make them suitable to the needs of people.(661,693,704) For example, by working with voluntary organisations researchers can make direct contact with large groups of patients.(199,693,703) Members of the public can also help engage seldom heard groups,(142,185,699,701,705,706) as they often enhance the credibility of the study and of researchers,(170,185,695,700,706) and can encourage people to take part, motivating potential participants who witness their commitment, energy and enthusiasm.(142,684,685,701,707,708) For example, a poll of 1295 British adults commissioned by the Health Research Authority (HRA) found that 44% of respondents thought that trials using PPI in research would increase their confidence and trust in a trial.(52,53) An additional 49% of respondents stated they were not sure either way, although very few thought PPI would reduce their confidence. The authors issued a press release widely advertising that “if health researchers communicate the fact that patients and the public have been involved in the design of their research when approaching potential study participants, it might help to boost recruitment”.(52,53)

At the conduct of research stage, involvement has diverse impacts on the data collection and data quality. Members of the public contribute to the collection of richer

data and have new ideas and perspectives for data analysis.(162,665–667,698,709) Participants' response rates to questionnaires has been found to be higher due to a higher sense of ownership of research when other members of the public are active collaborators in the study,(199,695) thus enhancing quality (710) and the representativeness (684) of the data. Peer interviewers or the presence focus groups co-facilitators also enhance data collection, and qualitative data can become more relevant and reliable.(170,690,711–713) Broad and Saunders acknowledged that peer interviewers can “reach parts which other research does not meet”,(714) and others have noted that peer-interviewers are better able to probe and ask the right questions.(142,706) Children give different answers when being interviewed by peers rather than adults (714–716) and drug users can disclose sensitive information with other drug users, perceived as ‘insiders’.(696) Nonetheless, the ‘shared experience’ between participants and peer interviewers has also been found to negatively impact data collection in some cases,(661,665,666,698,706,709) for example because peer interviewers did not think some issues were interesting enough to be recorded or because they did not want to intrude on some difficult topics.

PPI also adds value to data analysis and interpretations,(19,25,717,718) particularly when analysing qualitative data.(685) For example, on Health Technology Appraisal (i.e. the assessment of research evidence to produce guidance and recommendations), the perspective and experience of members of the public ‘provides meaning to the data, bringing the numbers to life’.(719) Researchers can check the validity of their conclusions with members of the public.(185) The latter can provide other perspectives,(293,658,676,686,705,712) allowing new themes to be identified,(720) highlighting findings most relevant to the public (658,705) and correcting possible data misinterpretations.(721) In an ethnographic study of the culture of pregnancy and childcare among African American women, an interviewee referred to “black bars” in her neighbourhood. While the interviewee thought this referred to African American bars

offering alcohol, a community partner knew that the participant was talking about some newly built, black, wrought iron fences built to discourage criminal activity and not accepted by local residents. Finally, the public can also advice on how to describe results in reports.(170) Importantly, being involved at this stage increases co-researchers' commitment to the study, as it provides greater sense of ownership.(658) This in turn encourages to take action in response to study findings.

During the writing of results, involvement helps researchers to present the study in a more accessible way for the target audience,(671,722,723) giving them a chance to use the findings. When writing 'lay summaries', members of the public help to make those more relevant, readable and understandable.(724,725) Public involvement has also been shown to improve readability of complex documents such as clinical guidelines.(123) Indeed, members of the public involved start from the same place where the reader is and can explain it in their terms, generating shared understanding (while losing some of the scientific nuances).

Involvement encourages wider dissemination of findings, as members of the public help engage the audiences,(676,692) in particular other members of the public.(94) More accessible findings become more powerful messages.(18,688) The public can also ideate novel ways of discussing and giving feedback.(711,726) For example, people with schizophrenia led a study and performed a theatre piece to present the results and recommendations that emerged from the study.(726) Nonetheless, involvement has also been suggested to decrease research impact at the dissemination stage, due to some audiences' dismissive attitudes when hearing presentations by co-researchers.(664,668)

Finally, members of the public bring positive impact to the last stages of the research cycle, such as in the implementation of research findings. Members of the public increase the credibility of the findings, encouraging all stakeholders to make more direct

(i.e. changes in policy and practice) and conceptual (i.e. awareness, knowledge and attitudes) use of research. Johns et al. report a commissioner's comments emphasizing the greater impact that members of the public have presenting the study findings and recommendations: "Hearing it directly from service users improves the validity and the weight of the findings from the perspective of councillors and service managers".(712)

1.1.3. Involvement Enhances Implementation of Findings and Promotes Change

Involvement has an impact on how research outcomes bring about change and increases the impact of studies.(18,22,23,25,50,195) Research produced with the public results in research outcomes that may be better translatable into patient benefit,(94) with results that are genuinely useful to patients and carers,(727) and are more often implemented, resulting in changes of policies and care.(25)

Firstly, PPI in health services research leads to development of new and improved services that respond to the real needs identified and understood by those involved.(168) For example outreach services were developed after the need was identified in a study with intravenous drug users.(696) Involvement can also impact practice and how services are delivered.(726) Aboriginal young people involved on a study on their health and well-being suggested a separated clinic for their peers that was open and that introduced a new model of informal consultation that proved to be highly successful.(704)

Secondly, by forging relationships with key actors, such as local agencies and policy makers, those involved develop capacity to bring about change.(181,658,681,693,704) Their new skills and increased self-confidence may lead them to take greater community action, and people who have been involved in research can become local experts in PPI. For example, Ross reports older people members of

advisory panels that move on to developing PPI strategies in local health and social care services.(658)

New partnerships created from PPI are often sustainable in the long term (684,685,721) and potentially offer long-term possibilities to transform communities.(673,693,701) The sense of shared ownership between citizens, researchers and other stakeholders increases their willingness to act on the findings.(684,693,707) All along the research study, PPI ensures openness, transparency and public accountability of researchers and other key stakeholders involved in the research process.(94) Involvement also contributes by enhancing learning from experience and good practice.(94)

1.1.4. Impact on Research Ethics

PPI improves the consent process,(702,704,728,729) as the information is clearer and more accessible in patient information sheets and other recruitment materials developed with the public.(13,691,703,705,730) Moreover, when involved early, members of the public can pinpoint potential ethical concerns arising from the study design and solutions for them.(18,197,687,731) For example, researchers designing a clinical trial for a new treatment of stroke had to overcome the fact that most potential participants would be incapacitated to communicate and give consent. Patients were involved at the design and ran focus groups to confirm acceptability of the trial and to find solutions to some of their ethical dilemmas, such as how much detail to provide on the potential risks and benefits, and the roles of relatives and healthcare providers in conversations around consent.(197)

1.1.5. Cost-Effectiveness of Involvement

Last but not least, PPI has been shown to be cost-effective in some cases. A paper focussing on the return of involvement in pharmaceutical research estimated that PPI could produce an over 500-fold return in investment, due to a reduction of protocol amendment and increased recruitment and retention in trials.(48) This study also found that involvement accelerated the process of completing a trial to launch a new drug by *2½ years*. Also, Chlebowski et al.(732) reported that recruiting trial participants using traditional a non-PPI strategy (commercial mailing lists to send postal invitations) costed four times more than via existing research participants a PPI, implying the cost-effectiveness of partnership with members of the public.

Although the GRIPP-2 guidelines (reporting guidelines for PPI widely promoted)(205) include an item referring to an economic assessment of PPI, studies often fail to reflect on the cost-effectiveness of PPI and to perform an economic evaluation.(50,257,642,733) Indeed, it is difficult to reduce the range of PPI outcomes to a single quantifiable measure, as it is an interplay between numerous aspects of the context and process. The outcomes of PPI can hardly be translated into a single monetary value as needed for traditional methods of economic evaluation.(734) For this reason, the evidence is very scarce on the cost of PPI and on its cost-effectiveness.

1.2. Impact on People

In a systematic review of 89 articles focussing on the impacts of public involvement,(25) Staley found that positive impact on people involved as well as on the research participants was most frequently reported. On this basis, researchers' accounts

of their experience potentially provide a source of insight and learning to influence others, in the same way that the patient experience helps to shape research.(68)

Figure 43: Taxonomy of impacts of involvement. Based on Staley (25)

1.2.1. On Members of the Public Involved

Members of the public involved gain new skills and knowledge,(25,204) and challenge their assumptions and prejudices.(162,664,666–668,697,709) Some authors have described PPI as a “job training”,(170,293,661,693,696,735,736) as the public acquired skills necessary to do research, for example how to do a systematic review, looking for new information, analysing and critiquing studies.(737,738) Patients involved become more aware and knowledgeable about their condition.(204) This is important, as 81% of respondents to a survey on the motivations to be involved cited putting knowledge gained from being ill or caring to good use.(53) After PPI, members of the public have a better appreciation of research scope and processes, insights into the issues of their community, in-depth understanding of topics surrounding the study they were involved in and new practical skills that might be related to research are transferrable to other contexts. For example McCormick detailed how members of the public involved in the development of a breast cancer research program developed a new understanding of the potential benefits and of the timescale of research studies (669) and Rowe reported co-researchers exploring new assumptions about family life different from their own by studying ways of living within their own community.(692) Some studies report that involvement improves the professional prospects of those involved, providing educational opportunities for younger people involved and opportunities for career progression more generally.(162,664,666,668,709)

Involvement is an opportunity for personal development, as the public often reports feeling more self-confidence and greater self-esteem,(170,194,533,671,681,692,696,701,705,712,716,735,736,739,740) so that involvement is described as an empowering experience.(25,194,204) Involvement provides psychological benefits, such as intellectual stimulation, enjoyment and sense of achieving by being valued and giving something back for older people.(162,664–668,697,698,709) These forms of impact are central to the altruistic motivations of most members of the public deciding to become involved in research.(53,741,742) This could

also be particularly the case from marginalised groups, such as Aboriginal woman able to have their own voice to advocate for themselves and their communities (681) or users of mental health services that appreciate “being normal”.(168,735) Other members of the public feel more confident when speaking up in groups (185) and delivering presentations,(168) in line with the public desire to improve their own communication abilities through involvement.(742) For patients, involvement can be a milestone in their recovery. Allen et al. described how a listening to recovery stories during a study on alcohol abuse encouraged those involved to understand their own sobriety process while also giving active listening and support to participants.(700)

Involvement also brings social benefits, for example in later life.(162,664–668,697) The experience of working as part of a team provides support and friendship for those involved, in particular for patients and carers who receive peer-support.(168,661,681,726) For example, a carer considered that PPI “had filled a void left by my husband dying and I am now able to help in any way I can... I have met and become friends with some lovely people who are also members of the team. We chat and share day-to-day events and problems and we also have some laughs”.(729) New relationships based on trust develop between people with diverse experiences and backgrounds.(194,714,743) It is surprising that those who have been involved in research do not always cite building relationships as a motivation to become involved,(53) although other studies note the importance for the public to exchange with peers and professionals when becoming involved.(741)

Those involved value feeling useful and being part of a team,(26,168,661) as they would with regular employment.(661) Authors have highlighted that for the public involved it is important to be part of something meaningful,(533) where the possibility to forge bonds with different kinds of people (710) and to think about something else than their conditions.(714,744)

Lastly, financial rewards also play an important role as they are part of valuing members of the public,(293,671,735) who receive regular and fair payment for their contributions.(705) Nonetheless, Ashcroft et al.(53) noted that the lowest reported motivation was gaining financial income (9%) for the 143 patients and carers having been involved in research in the UK who filled in a questionnaire exploring their motivations to be involved and the impact of PPI. Also, some authors have highlighted that payment is a controversial issue, as some might interpret it as devaluing their altruistic reasons to be involved.(26) Indeed, Lowes et al.(26) found that although time and money were cited as constraints to be involved, the satisfaction of having made a difference and enjoyment were a greater motivation.

Finally, negative impacts of PPI on those involved are also cited in the literature. In particular, members of the public might feel emotionally burdened, for example when interviewing a peer relating difficult (and close) experiences that remind them of their own.(688,714,744) For example, a researcher wrote: “Some of the things the interviewers were told affected them, brought certain things up for them, and they found it hard just to swallow their feelings and carry on”.(714) Also, peer interviewers might feel burdened by participants’ stories,(714,745) for example when hearing experiences of abuse. Support and training for them are necessary to provide them with coping mechanisms.(714) Members of the public might also feel overloaded with work,(664,668,681,697,709) as co-researchers might lack sufficient skills (public feeling underprepared and thus unable to contribute), the tasks assigned might be burdensome and co-researchers are limited by a working “contract”. This occurs particularly if lacking support for those involved.(293) Linked to this, feelings of frustration, especially at the limitations of PPI are sometimes cited, as members of the public might feel powerless to make a real change on the study.(692,703,743) Frustration and feeling of abandonment can also arise once the study finishes and their role as co-researchers is not needed anymore.(170) Those

involved can be unsatisfied or unclear about the level of involvement defined by the rest of the team for them.(162,667,668,698,709) The public might experience challenging relationships with the experts,(162,664,667,668,697) particularly if coming from a seldom-heard communities.(681) Finally, in some cases members of the public can be harmed by improper media coverage of the research, exposing personal matters of those involved.(688)

1.2.2. On Research Participants

Research participants benefit from a better research process when the public perspectives are taken into account. PPI informed material improves participants' knowledge (203) and participants find it easier to take part in those studies. Similarly, participants might gain wider access to information and services about issues relevant to them identified by those involved.(185,696,745)

The presence of members of the public conducting the research helps participants to feel more comfortable and relaxed,(162,661,664,666,668) as there is a greater shared experience and understanding between them.(730) Encounters become less threatening as hierarchies are less prevalent,(671) which might encourage participants to talk and voice new issues, as well as to be more honest in sharing their experiences and views.(671,704,712,713,726) For participants with mental health conditions, being interviewed by a peer “offer[s] a talking space to explore their mental health without some of the fears, barriers and constraints that characterised many of their other experiences of talking about mental health”(711) and older woman interviewing other older woman express greater sensitivity around emotional topics of discussion.(710)

Participants also have greater emotional support if difficult experiences arise during the study, as close members of the public conducting research can help them relief

the burden. For example, being interview by local parents who shared their experiences reduced participants' feelings of isolation.(692)

Finally, those involved can be seen as a source of hope and inspiration by the research participants, serving as role models (712) and encouraging them to be involved in the future.(713) Faulkner reports how PPI “gave some people who lived without much hope, the opportunity to see that someone had moved on and was able to live and work in the community.”(170)

1.2.3. On Research

Researchers working with the public have greater knowledge and understanding of the community,(688) of living with particular health conditions (194,658) and of local culture.(185,187,204,671,746) For example, a researcher described how disability impacts people's daily lives.(142) Involvement is not about researching the patients' experience but about building insights out of it,(167,664,665,686,698,709,747,748) and its main impact on researchers is learning what they do not know they do not know. Through involvement researchers also increase their skills and change their priorities, so as if PPI changed what they 'think'.(56,746) Researchers develop different way of understanding research, as the experience of involvement is opposite to the mechanics of 'analysing data' or 'making sense of evidence'. For example, a systematic review found that involvement had challenged researchers' attitudes and beliefs towards mental health.(194) This in turn informs future research and practice, PPI also having the potential to change what they 'do' (56,746) and what they report in their studies, including the processes of involvement.(56,746)

Researchers also report enjoyment and satisfaction,(170) and PPI is described as a rewarding process.(194) Researchers build new relationships, based on respect and

understanding,(187,204,746) and appreciate the energy and enthusiasm they notice in those involved. Researchers enjoy the experience of working alongside members of the public, and become more empathetic towards the public.(124,194) Researchers have declared enjoying “seeing the world with different eyes, being trusted, cared for, valued.”(714)

Also, researchers might benefit from sharing workloads, as some tasks can be undertaken by members of the public involved.(664–666,698,709)

Finally, PPI might present career benefits, as they receive wider recognition for their work, and validation from their employers where PPI is encouraged.(749)

Nonetheless, involvement might also have negative impacts on researchers. Researchers might feel threatened to have their beliefs and attitudes challenged, which might impact their attitude towards PPI.(297) Involvement can also directly negatively impact their work, as it requires more resources (including energy and money) and often slows down the research.(167,184,185,671,691,704,714,750) Researchers are accountable to their funders and institutions, and tensions between the rigid traditional format of research and the flexibility required for public involvement might be difficult to cope with.(658,686) PPI often requires changes in working practices,(661,671,692) as researchers need to learn new skills and face new challenges (184,671) and see their values and assumptions challenged,(661) which might lead organisations to question researchers’ work. Researchers have to cope with the tension between participatory approaches and traditional forms of research, while providing extra efforts to meet the demands added by involving the public.(668,697,698) Finally, researchers will have to give up some power to establish genuine collaborations with the public,(170,180,668,698,705,709,722,750) and might struggle with this new type of relationship.

1.2.4. On the wider community

Involvement also has an impact on the wider community as it has been shown to increase public confidence in health research.(94,681,693) Involvement creates trust and acceptance of research, particularly where communities have experienced discrimination as a result of past bad research practices.(685) PPI can re-establish mutual trust (677) and systematic reviews have shown that PPI is an effective way to build important links with communities.(201–204,208) Involvement gives voice to marginalised groups.(158,162,664,666,668,681,751) PPI can help overcome barriers to community participation in research, as it was the case for Aboriginal young people who took an active role in a study focussing on young people's health (704) or for Black American forming a Community Advisory Board for research on diabetes in their community.(684) In particular, PPI encourages seldom-heard communities to take action and ownership of research. Improved relationships between communities and professionals, can also lead to improvements in services and increase service use.(684,694)

PPI keeps projects grounded to truly benefit the community,(700,722) increasing credibility and legitimacy, forcing stakeholders to defined tangible benefits to deliver.(185,700) Involvement gives the community to have a greater understanding of research.(695) PPI can then assist with accessing participants; improving response and recruitment rates; with development of greater empathy with research participants; and better-informed consent based on more informed participants.(201–204,693,700)

APPENDIX

2 LAY KNOWLEDGE

Public involvement in health research must be understood in the context of wider theoretical debates, related to political, philosophical and social shifts of last century.(752–754) PPI lies at the interface between science and citizenship and invites to consider what being a citizen means and how the varied attributes of citizenship can find expression in societal engagements with science and technology.(755)

Of particular relevance are the topics of knowledge and expertise. The utilitarian rationale for PPI arises from the belief that by including lay perspectives, research can be ‘better’. Those would serve as a form of ‘counter expertise’ pushing the limits of ‘traditional’ ones.(756) To evaluate the validity of this argument, it is necessary to understand what the differences are between the contributions that members of the public and professionals can make to research. How does the public construct knowledge and what is the value of the public’s contributions to otherwise reserved professional’s activities?(61,757)

This section will explore these matters, starting with the work of Habermas and his critical theory of society and continuing with the concept of ‘lay knowledge’ advanced by Williams and Popay.(758)

2.1. Habermas’ critique of scientism

Habermas’ theories illuminate the topics of science and society and can be used to interpret the origins of public involvement in research.

Habermas suggested two distinct forms of knowledge, lay forms, and certified forms, (759) that reflect the division of social life in modern societies into two spheres: the system and the life-world (760–763). Each of these spheres supports a set of ‘knowledge-guiding interests’ (759) or rationality (764): instrumental rationality (aimed towards successful actions and outputs (761,762)) for the system world, and communicative rationality (aimed towards reasoning and mutual understanding) for the life-world. This vision is represented in Figure 44.

The life-world encompasses culturally produced knowledge and understandings,(759,761) materialized in the elements of ‘informal’ (762) social life such as traditions.(765) The ‘experiential expertise’ (760) of patients is the expression of the life-world in the context of health. On the contrary, the ‘formal knowledge’ (i.e., expert professional knowledge) from the system sphere (764) is carried by the ‘voice of medicine’ in the area of health.(766) Researchers and other professionals are the actors of the system.

Figure 44: Representation of Habermas's theories

Habermas criticized 'scientist' attitudes claiming that science is the only enterprise giving access to an objective knowledge of the world and despised the 'colonization of the life-world' (767) by the system.(765) This is expressed in the systematization of different areas of the life-world by the scientific endeavor. For example, in the domain of health, this is reflected in the 'medicalization' (768,769) of the life-world, as medical knowledge guides human behaviors that are explained within a medical or biological lens,(770) professional expertise further replacing culturally produced knowledge.

Habermas' postulate of the 'colonization of the life-world' occurs in the context of care. Mishler (766) studied the interplay between doctors (the voice of the 'system') and patients (voice of the 'life-world') in 25 consultations. He concluded that experts always had a tight control of the situation, and that the system's technico-scientific discourse nullified the life-worlds.(760) More recently, Britten (761) drew on Habermas' model of two spheres to explore medicine prescription and use. In this case, the patient's concerns were again overruled by professional's decisions. Nonetheless, Britten also noted that patients ignored professional advice and self-administered prescribed medications according to their own judgment. Practices of non-compliance and adherence are today a

growing concern for medical professionals.(771,772) This was interpreted by Britten as a re-appropriation of the life-world by patients who confront professionals' expertise.

To summarize, Haberman's theories on the split between the 'system' and the 'life-world' of professionals and the public can be used as a theoretical rationalization of public involvement in health research. By inviting the public from the 'life-world' into the sphere of professionals, the 'system', both their perspectives can be accommodated to repair the trust and confidence of patients wishing to preserve their autonomy.

2.2. Evolutions in the relationship between lay and formal knowledge

2.2.1. The Construction of Two Types of Knowledge

Since the Enlightenment, a positivist view of science has given a preferential role to certified expertise (755) or 'formal knowledge'.(764) Experts become so through formal education. For centuries, only a reduced elite group having access to education earned certificates validating their expertise, in a way that could not be accessed nor understood by the majority. This was exacerbated by the fact that it was the same class who set the definition of what knowledge was and judged expertise.(61)

In contrast, lay knowledge arises from common sense and is inherited by subsequent generations. This form of latent knowledge, contained within society,(773,774) is shared by all members of the community.(760) Lay knowledge is presented in a narrative form and has an ontological purpose, as it guides individuals' actions and relationships in the life-world.(61) Lay understandings of health and illness evolve through lived experiences, intuitions, perceptions and awareness on themselves and of people like themselves.(775,776)

In health, scientific medicine focuses on the etiology and course of diseases while lay practices prioritize patients' own subjective lived experience of them.(777) While the first is 'universalistic', the latter is temporal, situated, and embodied.(778,779) For these reasons, lay knowledge has long been reduced to, at best, 'flawed scientific knowledge', or simply to 'something else than knowledge altogether'.(780,781) In the research context, the subjectivity of lay knowledge has long been claimed to be irrational and of questionable validity, and against the principles of a positivist paradigm equated with reason and moderation.(149,498,776)

The case of knowledge translation

The boundaries established between the two types of knowledge are materialised through the concept of knowledge translation, which encompasses the need to 'translate research into practice'. The language used to refer to this illustrates Habermas' postulate of 'colonisation of the life-world'. The notion of 'translation' stems from the assumption that knowledge is created by scientists in academic institutions (or the industry) and is then transformed to make it accessible to non-scientists. This mainstream positivist understanding of knowledge is 'hegemonic' (782) in research.

In 1994, *The New Production of Knowledge* presented a taxonomy that distinguished two pathways for knowledge creation: 'Mode 1: scientific discovery' and

‘Mode 2: knowledge production’.(636) The first mode represents the traditional understanding of the scientific endeavour, whereby scientists and their institutions sit at the top of the hierarchy, and non-scientists have no or little say. On the contrary, Mode 2 knowledge is ‘socially distributed, application-oriented, trans-disciplinary, and subject to multiple accountabilities’.(782) This knowledge is created outside academic institutions. In this mode, multiple stakeholders come together to shape and undertake the study and to implement the knowledge emerging from it. Stakeholders possess a range of expertise and skills and collaborate to work towards a shared goal. Despite their different perspectives, practical steps are put in place to achieve results of immediate relevance to local communities and all stakeholders who participated in the design of the study. In this case, relationships evolve to be horizontal, and academics and research users (including policymakers and members of the public) co-produce research rather than occupying roles of “producer-consumer or contractor-commissioner”.(147)

2.2.2. Lay and Professional Expertise are Complementary Forms of Knowledge

Mode 2 of knowledge production reflects a recent transformation in the understanding of knowledge. Similarly, the way past scholars have referred to experiential forms of knowledge illuminates a shift in how its value is perceived by society: from ‘lay beliefs’ and ‘lay accounts’, the idea of ‘lay knowledge’ was introduced, and later evolved to ‘lay expertise’.(783) While the first implies doubtful and superfluous perceptions of lay ideas of health and science (referred to as the ‘deficit model’ (55) whereby lay beliefs should be mitigated), the most recent form endorses the value of non-certified knowledge, considered to be a different form of expertise.(780)

During the 20th century, the public contested the positivist paradigm.(634,784,785) Broader cultural and political shifts (755) led to a

democratization of knowledge.(783) In what has been described as a ‘meeting between experts’,(786) lay perspectives have been strengthened, and today the two types of expertise defined by Habermas interact in health research through public involvement.

To understand the implications of this transformation, it is useful to borrow concepts of early feminist theory, namely those of standpoint theory (778,787,788) and of strong objectivity.(789,790) These suggest that lay knowledge is a ‘privileged’ form of expertise for two reasons. Firstly, because marginalized groups excluded from the system, such as patients, have access to both mainstream discourses and their own, their knowledge is more complete. Secondly, due to their marginalised position, these individuals can notice patterns of behaviour that may be invisible to those immersed in more powerful groups.(157) Consequently, lay knowledge would add value to a professional one.

Currently, a growing number of professionals acknowledge that both types of knowledge can in fact, complement each other and that a ‘more robust and more holistic’ (61) depiction of health and illness necessitates non-expert knowledge. Professional knowledge, rather than a ‘mirror of nature’, is a ‘version of reality’ (791) that needs to be combined with lay interpretations to reveal complex realities, and none of these accounts is sufficient individually.(792) Within a purely biomedical model, which builds on measurable objective factors, other variables impacting on health are ignored, and only the ‘surface’ (752–754) of ill-health can be dealt with. As diseases become more complex, and the prevalence of chronic illness and disability increases, multidimensional understandings are necessary, which need to build on both objective and subjective knowledge. For example, more than 20 years ago, Brown et al. highlighted the role of lay knowledge in understanding health concerns in relation to environmental problems in the US (777) and Williams and Popay reported similar cases on the issues of toxic waste in the UK.(793) In both cases, lay people experiences could be used to contextualised ill-health

of their communities in relation to the local environment when using other traditional scientific methods.

In research, the knowledge brought by those involved, particularly patients, is bounded to the problems investigated by research and provides new perspectives onto the same topics of interest for researchers. In his 'theory of distance', Beresford argued that the closer the researchers are to experiences related to the researched topic, the better the knowledge they create.(287,794) The public offers a viewpoint complementary to that of the researchers since *"they know what it feels like to undergo treatments and their various side effects [...] they will have a good idea about what research questions should be asked [...] and how questions might be asked differently"*.(52) In research, bringing the public perspectives widens the scope, transforming the problems research is concerned with (although not necessarily the solutions to those).(787) Public accounts are necessary but not sufficient to maximise objectivity.(157) By suggesting an alternative mode of knowledge production, PPI has the potential to transform knowledge.(55)

2.2.3. Shift in Power Relationships

Underlying traditional imbalances in the status of knowledge are inequalities in power. And, despite the fact that lay and expert knowledge complement each other, the encounter of both entails 'clash of cultures between the experts and the lay'.(795) Indeed, Murphy and Fafard argued that: *"Knowledge.... can be used to...exercise discursive power in ways that privilege some definitions of health and social problems and marginalize others"*.(796)

Lay knowledge has been conceptualized as a form of "oppositional discourse", (797) highlighting its political nature.(798) Mishler suggested that the system and life-world are bound to clash due to the divergence of their rationalities.(760) This

proposition has been materialized, as some academics have stated that “attempts to broaden evidence to include experiential knowledge are misguided”.(799)

Inclusion of lay expertise has long been seen as a threat not only to the impartiality of science (and thus as an epistemic challenge), but to the expert knowledge in general, which now occupies a power position in institutions. Professionals working within the biomedical paradigm have tended not to question their epistemological assumptions or positions as they simply exercise their role through the “normal science”.(800) This hegemony of formal knowledge has implications beyond the science itself: not only lay forms of knowledge are dismissed, but the whole public is disempowered, incapacitated to make any contribution and to debate over the implications of research findings, in policies and clinical care.(775,801) On the other hand, the acknowledgment of “lay knowledge” creates opportunities to challenge the status of formal experts and of the way they characterize problems,(61,802) and is thus a source of tension.

Nonetheless, Britten proposed that public involvement in decision making could help to close the gap between professional and lay perspectives: both spheres could be reconciled by redressing the power balance and inviting the ‘life-world’ into the ‘system’.(761) For example, the idea of shared-decision making implies a new relationship based on equality between patient and doctor.(775)

These tensions become relevant today, as some limitations of a biomedical approach to health and illness have been identified. One of the major concerns is the occurrence of a ‘legitimation crisis’,(784) that is, a potential loss of public confidence in medical expertise. This occurs if the prevalent position of professionals determines the care provided, ignoring the needs and preferences of the patients, who might feel ignored as moral, competent and knowledgeable individuals.(775,803,804) For example, when the foundations of clinical care rely on the idea that diseases can be treated ‘objectively’,

independently of individuals' experiences and the ability to understand the origins and implications of ill-health for individuals and societies is limited.(61)

Moreover, as information has become widely available and easily accessible, the value of formal expertise is being further questioned. Today the public does not always require professionals to access information and knowledge. Research is widely disseminated to millions of citizens,(805–808) with popular writing of scientific topics formerly exclusive on the rise.(809,810) For example, the book *The Emperor of All Maladies: A Biography of Cancer* is a mix of the authors' experiences as a hematology/oncology fellow and of the history of cancer treatment and research was awarded 2011 Pulitzer Prize for General Non-Fiction and has topped best-seller lists. Also, lay summaries have been encouraged to enhance science communication and increase impact and visibility of scientific results.(724,811,812) In parallel, a growing number of groups of researchers and citizens have called for free access to publicly funded scientific work for everyone and governments are giving the public access to research of community value (813–815) and the concept of 'citizen science' is widely recognized.(816–818)

To avoid this 'legitimation crisis',(784) lay accounts need to be acknowledged as valid interpretations of health and illness, and thus culturally-produced knowledge has to be considered for the organization and developments of the health care and research. The inclusion of public perspectives has the potential to rebalance the power dynamics and thus to reshape the relationship between citizens and researchers. While paternalistic practices have so far prevailed, new models must emerge with informed patients and the public at large at the center.(216,819,820)

Public involvement in research: an empowering experience?

As I have discussed, PPI alters both the outcomes of research and the relationship between knowledge producers, leading to more equal rapports between different types of

experts. PPI is understood as a social movement, an embodied health movement,(821) with an emancipatory goal.(822) Williamson distinguished eight aspects that patient movements have shared with emancipation movements: the radicalization of activists; the creation of new knowledge; the identification of guiding principles; the sense of direction; the unmasking of new issues; schisms within the movement and allies outside it; and the gradual social acceptance of some of the ideas (here standards of health care) that activists work to promote.(775)

However, some authors have disputed the real threat that lay knowledge could represent to traditional forms of expertise. Firstly, much of the work of the experts benefit patients, who would want to maintain this *status quo*.(775) Secondly, professionals' dominance might simply be accepted as it is 'normal'.(823) Thirdly, since the discourse of the experts occurs outside everyday public life, members of the public willing to enter the system sphere need to become aware of the technical aspects and jargon of health-care professionals' work to make their case,(795,824,825) as professionals dominating the conversation have to be challenged in their own terms.(775) Finally, due to professional deference, members of the public can be 'muted' in their interactions with certified experts, who are held in high regard by the public unaware of their own expertise.(826,827) In light of those barriers, researchers and other experts should be responsible for facilitating public involvement in their work.

Barnes and Walkers (828) distinguished eight foundations of empowerment (shown in Figure 45). Since involvement requires an active and continued participation of members of the public and their role broadens beyond being informed and consulted through collaboration, research carried out with members of the public generally achieves the first three foundations established by Barnes and Walkers.

PPI transforms professional-lay relationships, closing the gap between both through collaboration. Nonetheless, tokenistic practices and inflated rhetoric are insufficient to fulfill a commitment towards public empowerment. In these cases, existing boundaries between the researchers and the public remain, and attempts to rebalance power relations and give a voice to marginalised groups are unsuccessful; hierarchies endure.

Researchers must adapt their methodologies to facilitate real collaboration in doing research ‘with’ the public, and other stakeholders (such as research commissioners) must provide the necessary resources. Only then true mutual learning and respect and two-way communication can occur, leading to a genuinely empowering experience for the public. Only in this case, the inclusion of experiential expertise to health research fulfills all of the eight foundations, and PPI becomes a mechanism for public empowerment.

Figure 45: Eight foundations of empowerment. Source: Barnes and Walkers (828)

Previous sections (2.2.1. and 2.2.2.) have shown that at the heart of public involvement lies the fact that knowledge extends beyond ‘expert knowledge’. Partly, this

is important from a practical perspective, as including the expertise that patients have from living with an illness and receiving treatment results in better research.(65–67)

On the other hand, the rise of lay knowledge also feeds into the ethical argument for public involvement, concerned the concepts around civic participation and democratisation of science, and with rebalancing power and giving a voice to those that do not concur with the dominant form of expert knowledge.(55) Through PPI, members of the public, who are ‘marginal knowers’ and yet ‘agents of knowledge’,(72) can find an avenue to express their ‘new’(55) expertise.(533,829) Rose argued that fundamentally, the ethical argument was intrinsically related to lay knowledge and based on the fact that changing who produces the knowledge transforms the knowledge itself.(55)

Beyond the evidence showing the benefits of involvement for research, PPI is first and foremost a matter of doing ethical research: it is researchers' duty to tailor the development of interventions to the experiences of the community and individuals that will benefit from the findings. Since individuals and communities experience the issues research attempts to solve, it is important to work with people to enhance research. Using their experiential knowledge is invaluable not only as a source of data but also to inform how research is conducted. The wider public possesses a range of perspectives, needs, values, and priorities different from those of researchers that are also needed to make research relevant to the society. The best research questions and designs will emerge from productive dialogue between the two types of experts.

Researchers have a responsibility towards society, and their work concerns not only the creation of new knowledge but also issues power and ethics. Researchers are trained in the latter, and have it especially in mind when conducting qualitative research or working with vulnerable groups. However, researchers are often less aware of the unequal power relations establish between them and their participants. This is reflected in their language where often individuals become no more than "subjects," and diseased participants are

referred to as "burdens" in academic papers. Simply acknowledging the value of lay knowledge is not sufficient to correct power imbalances between the system and life-world spheres.

Academics must become facilitators of research rather than leaders, by educating and empowering the intended beneficiaries of the research to contribute with their experiential knowledge, since '*...extensive personal communication and health education efforts by the health official or scientist should lessen the conceptual distance*'.(830)

Only then can research sustainably involve the public with lived experience at all stages of the research, from prioritization of research topics to dissemination of research findings, producing a positive impact not only on the research but also on its beneficiaries.

APPENDIX

3

SEARCH STRATEGIES FOR THE MAPPING REVIEW

Database: Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) <1946 to Present>

Search Strategy:

1 ((user* or service user* or lay or consumer* or patient* or client* or public or carer* or citizen*) adj (involvement or engagement)).ab,ti,tw.

2 (health or health care or healthcare or social care or public health).ab,ti,tw.

3 exp Health/ or exp "Delivery of Health Care"/ or exp Public Health/

4 2 or 3

5 (research or participative research or participatory research or participatory action research or evaluation).ab,ti,tw.

6 exp Research/ or exp Evaluation Studies as Topic/

7 5 or 6

8 1 and 4 and 7

9 limit 8 to (english language and humans and yr="2001 - Week 2 of 2018")

Database: Embase <1974 to 2018 January 10>

Search Strategy:

1 ((user* or service user* or lay or consumer* or patient* or client* or public or carer* or citizen*) adj (involvement or engagement)).ab,ti,tw.

2 (health or health care or healthcare or social care or public health).ab,ti,tw.

3 exp health/ or exp health care/ or exp social care/ or public health/

4 2 or 3

5 (research or participative research or participatory research or participatory action research or evaluation).ab,ti,tw.

6 exp research/ or participatory research/ or action research/ or exp evaluation study/

7 5 or 6

8 1 and 4 and 7

9 limit 8 to (human and english language and yr="2001 - Week 2 of 2018")

Database: PsycInfo and PsycArticles

Search Strategy:

TI (((user* OR service user* OR lay OR consumer* OR patient* OR client* OR public OR client* OR carer* OR citizen*) N (involvement OR engagement))) OR AB (((user* OR service user* OR lay OR consumer* OR patient* OR client* OR public OR client* OR carer* OR citizen*) N (involvement OR engagement))) OR KW (((user* OR service user* OR lay OR consumer* OR patient* OR client* OR public OR client* OR carer* OR citizen*) N (involvement OR engagement))))

AND

(TI ((health OR health care OR healthcare OR social care OR public health)) OR AB ((health OR health care OR healthcare OR social care OR public health)) OR KW ((health OR health care OR healthcare OR social care OR public health))) OR (DE "Health" OR DE "Global Health" OR DE "Holistic Health" OR DE "Mental Health" OR DE "Occupational Health" OR DE "Oral Health" OR DE "Physical Health" OR DE "Public Health" OR DE "Reproductive Health") OR (DE "Public Health" OR DE "Epidemics")

AND

(TI ((research OR participative research OR participatory research OR participatory action research OR evaluation)) OR AB ((research OR participative research OR participatory research OR participatory action research OR evaluation)) OR KW ((research OR participative research OR participatory research OR participatory action research OR evaluation))) OR (DE "Experimentation" OR DE "Action Research" OR DE "Animal Research" OR DE "Consumer Research" OR DE "Interdisciplinary Research" OR DE "Online Experiments" OR DE "Qualitative Research" OR DE "Quantitative Methods" OR DE "Research Setting") OR (DE "Evaluation" OR DE "Clinical Audits" OR DE "Course Evaluation" OR DE "Forensic Evaluation" OR DE "Geriatric Assessment" OR DE "Needs Assessment" OR DE "Peer Evaluation" OR DE "Personnel Evaluation" OR DE "Program Evaluation" OR DE "Psychiatric Evaluation" OR DE "Risk Assessment" OR DE "Self-Evaluation" OR DE "Treatment Effectiveness Evaluation" OR DE "Vocational Evaluation")

Limiters - Publication Year: 2001-2018

Search modes - Find all my search terms + ENGLISH + humans

Database: CINAHL

Search strategy:

TI (((user* OR service user* OR lay OR consumer* OR patient* OR client* OR public OR client* OR carer* OR citizen*) N (involvement OR engagement)))) OR AB (((user* OR service user* OR lay OR consumer* OR patient* OR client* OR public OR client* OR carer* OR citizen*) N (involvement OR engagement))))

AND

(TI ((health OR health care OR healthcare OR social care OR public health)) OR AB ((health OR health care OR healthcare OR social care OR public health))) OR ((MH "Health+" OR MH "Public Health+"))

AND

(TI ((research OR participative research OR participatory research OR participatory action research OR evaluation)) OR AB ((research OR participative research OR participatory research OR participatory action research OR evaluation))) OR ((MH "Research+" OR MH "Evaluation+"))

Limiters - Published Date: 20010101-20181231

Search modes - Find all my search terms + ENGLISH + humans

Database: ERIC

Search strategy:

TI (((user* or service user* or lay or consumer* or communit* or patient* or client* or public or carer* or citizen*) N (involvement or engagement)))) OR AB (((user* or service user* or lay or consumer* or communit* or patient* or client* or public or carer* or citizen*) N (involvement or engagement)))) OR KW (((user* or service user* or lay or consumer* or

communit* or patient* or client* or public or carer* or citizen*) N (involvement or engagement)))

AND

(TI (health OR health care OR healthcare OR social care OR public health) OR AB (healthcare OR social care OR public health) OR KW (healthcare OR social care OR public health)) OR (DE "Health" OR DE "Child Health" OR DE "Mental Health" OR DE "Occupational Safety and Health" OR DE "Physical Health" OR DE "Public Health" OR DE "Wellness") OR (DE "Health Services" OR DE "Community Health Services" OR DE "Hospices (Terminal Care)" OR DE "Medical Services" OR DE "Prenatal Care" OR DE "School Health Services") OR (DE "Public Health")

AND

(TI ((research OR participative research OR participatory research OR participatory action research OR evaluation))) OR AB ((research OR participative research OR participatory research OR participatory action research OR evaluation))) OR KW ((research OR participative research OR participatory research OR participatory action research OR evaluation))) OR (DE "Research" OR DE "Action Research" OR DE "Architectural Research" OR DE "Behavioral Science Research" OR DE "Case Studies" OR DE "Cohort Analysis" OR DE "Communication Research" OR DE "Community Study" OR DE "Cross Cultural Studies" OR DE "Dropout Research" OR DE "Educational Research" OR DE "Environmental Research" OR DE "Exceptional Child Research" OR DE "Feasibility Studies" OR DE "Field Studies" OR DE "Institutional Research" OR DE "Investigations" OR DE "Language Research" OR DE "Library...") OR (DE "Evaluation" OR DE "Alternative Assessment" OR DE "Computer Software Evaluation" OR DE "Course Evaluation" OR DE "Curriculum Evaluation" OR DE "Educational Assessment" OR DE "Equipment Evaluation" OR DE "Formative Evaluation" OR DE "Holistic Evaluation" OR DE "Informal Assessment" OR DE "Institutional Evaluation" OR DE "Instructional Material Evaluation" OR DE "Medical

Care Evaluation" OR DE "Medical Evaluation" OR DE "Needs Assessment" OR DE "Peer Evaluation" OR DE "Personnel Evaluation" OR ...)

limit to (yr="Jan 2001 –Jan 2018")

APPENDIX

4

OTHER EXAMPLES OF ANECDOTAL EVIDENCE

4.1. Youth Conversations Panel

Youth Conversations was a platform organised in 2018 that allowed young Singaporeans (aged 16-40) to speak up and deliberate with peers about their beliefs values and aspirations while partnering with policy-makers to create solutions on issues relevant to them. This initiative was led by the Ministry for Culture, Community and Youth and the National Youth Council A report, written from the perspective of the youth can be found online.(831,832)

Firstly, more than 5000 young Singaporeans participated in online polls, contributing some 3,000 statements casting close to 140,000 votes on topics of discussion that mattered to them—aspirations for young people, doing more for the environment, building an inclusive society, mental health, and geopolitics. “Active Citizenry” was ranked amongst their top-three concerns. Secondly, close to 3000 joined

30 Youth Conversations on these topics, diving into issues and listening to new and diverse voices and perspectives.

Figure 46: Cover page of the Youth Conversations report, "We are more". Source: (831)

Finally, over 100 of them joined a 3-hour dialogue session and shared their aspirations and concerns to articulate their vision for Singapore in 2025 and to create an action plan. This event, and its report (cover is shown in Figure 46), was premised by inviting messages such as *"Your Voice Matters"* and was structured around calls to remain engaged such as *"Turn Conversation Into Action"*. The youth summarised their beliefs as a new mindset, *"WE ARE REWIRING MINDSETS"* they claim in the report, that is expressed through a wish to discuss topics like mental health and racism, stigmatised or taboo for previous generations, a focus on equality and environmental sustainability and a wish to occupy a central place in South East Asia. Young Singaporeans envisioned for 2025 a Singapore that is kind, inclusive, fair, and that treats each and every person, citizen or not, with dignity.

Overall, *Youth Conversations* gave participants opportunities to hear and appreciate new perspectives, and to become more aware, they had a better understanding of the issues faced by Singapore, as 79% of the participants indicated. According to the

Executive Summary of the *Youth Conversations*, 9 in 10 young Singaporeans consider helping the less fortunate and contributing to society as important life goals, two in five have volunteered in the past year, and more than three in five have participated in at least one civic activity in the past year.

This initiative and these numbers demonstrated that youth in Singapore has a strong sense of purpose and play an active role in society. In fact, three-key points are highlighted as lessons from the *Youth Conversations*:

Youth are not Apathetic

The initiative highlighted the interest of young Singaporeans for issues relevant to them. They expressed a desire to hear from policy-makers, and particularly about the complexities of their decisions, highlighted the imperative for accountability and transparency in today's world.

Youth want to make a Difference

Young Singaporeans are determined to take action across various issues and causes, and a minority of them are already doing so. Nonetheless, most of them, although sharing these aspirations, may lack the awareness, opportunities, resources and networks.

Youth want to be engaged through different modes, reflecting their Diversity and Versatility

Youth are under chronic stress, and time is precious for them. Consequently, they may lack the time to engage face-to-face, and they prefer to be involved digitally through social media and online polls.

These three lessons have enormous implications for public involvement in Singapore, as they demonstrate the potential interest of opportunities to be active and involved amongst young Singaporeans. As evident from the second lesson, it will be important to reach to them and let them be aware of the possibility of involvement and to provide them with support to sustain their involvement. Finally, the third lesson stresses the importance of using creative and innovative ways, particularly digital ones, to reach them, making possible their involvement and maintaining it over time.

4.2. Transform MedEd 2018

During a conference held at NTU on the topic of medical education, one of the conversations after a talk shifted from the topic of medical humanities to the medical curriculum and how to encourage more humanistic thinking and highlight the importance of soft skills in for medical students. A foreign member of the audience mentioned ideas of co-design of medical curriculums and the impact of bringing patients and their perspective into the classroom. This intrigued local attendees that nonetheless acknowledged the immense value that the patient's feelings and views treatment and care could have for the medical students. It was a recognition of their lived experience and the knowledge that they possess too.

4.3. Public calls for a new paradigm from citizens and healthcare professionals

With the heading “The days of ‘doctor knows best’ are over”, a post from the National Cancer Centre (18 Mar 2019) discusses the new paradigm of engaged and empowered patients who are seen as partners, improving their health outcomes.⁽⁸³³⁾ The article cites the SingHealth Patient Advocacy Network (SPAN), an initiative based on the recognition of the value of patient voices, which aims to invite deep conversations between patients, caregivers, and healthcare professionals to shape future healthcare based on what matters to those meant to benefit from it. Nonetheless, a patient advocate, Ms. Ai Ling Sim-Devadas, noted in April 2019 that some health professionals are resistant to engagement and that “a mindset change” is needed from them. While she acknowledges their workload and time-constraints, resulting from a process-oriented organization of care, as well as the lack of awareness and coordination at the organizational level, she claims the need to engage patients in healthcare.

Out of the bounds of healthcare, a citizen wrote to the *Straits Times*, the major newspaper, urging fellow citizens to “make decisions as a community instead of relying on a central government decision” and asking the policy-makers to teach and empower citizens to come up with innovative solutions to their problems, besides asking the

Residents' Committee from each community to consider the voices of individuals to come up with their recommendations.(834)

4.4. Changes within my university

Since NTU is increasing its efforts to engage the public in research, I finally decided to look for clues of student involvement in research and wider participatory initiatives for students.

I used the weekly newsletter sent to students, Campus Buzz, where events, new initiatives, and programs and even opportunities to be a research participant are collated weekly. This is the only email that is sent to all students registered in the university across courses and ages. I chose an example from February in three consecutive years (2017, 2018, and 2019) and compared the content of the newsletter.

While only one relevant entry could be found in 2017, encouraging students to participate in a yearly survey of the student experience, two could be found in 2018 (the same annual survey and a second survey for the university magazine). In 2019, there were four relevant newsletter entries: the NTU Student experience survey, another one on the library services, and two invitations for students to bring their ideas for the design of the city and another one to “speak up on issues that matter to them”. All the entries are gathered in Figure 47.

The way the messages are phrased has also evolved. In 2017 the NTU Student experience survey was introduced as “What’s on your Wishlist?”, that could be seen

almost a rhetorical question: a “wish” does not necessarily need to be translated into action. The determination to have the student perspective was firmer in 2018, using the expression “We want to hear from you”, and in 2019 the confirmation that the students’ perspective was needed and would have an impact arrived, as “Your voice counts”.

Also, for the second survey in 2018, the emphasis was on the prizes that could be won from participating rather than on the opportunity to have an opinion: the students needed incentives, maybe because they did not feel their voice could make a difference.

Moreover, there is an intent to promote a culture of volunteerism and active citizenship on campus. The title “Plan your part in Sharing our city” evokes both to the shared experience of living in Singapore and to the individual responsibility of its citizens to be actively involved in it, echoing the motivations behind the *Youth Conversations* panel mentioned earlier. Similarly, the last entry in 2019 also illustrates the emerging duty of all Singaporeans to define their common identity, so as not to be a “stranger”.

Figure 47: Excerpts of NTU Student Newsletter (2017-2019)

In conclusion, there is a growing emphasis on the voice of the students and growing opportunities for them to rise it. The perspectives, values, and needs of the students are increasingly being sought beyond simple feedback and consultation. People's opinion is wanted, feedback is always sought in Singapore, but now their own ideas are also valued. In these three examples, one notices an evolution of the language that now resembles to that used in the UK in PPI campaigns in the UK (e.g., "we want to hear from you", "your voice counts").

APPENDIX

5

ETHICAL FRAMEWORKS TO CONSIDER IN QUALITATIVE RESEARCH

'Learning ethical principles is not sufficient to become an ethically responsible researcher'
(835)

Ethically found research is a necessary condition for good research.(836,837) However, the literature on ethics for qualitative research has been less studied in medical literature.(838) Qualitative research has particular implications for participants, research requires to establish a relationship with participants following methods that require in-depth insights and anticipated events. Those risks can be minimised by the researcher,(483) for example by being clear about the boundaries of the research and following four basic moral principles: respect for autonomy (protection of human rights, specifically the choice to participate or not), non-maleficence (avoidance of harm), beneficence (provide benefits), and justice (observing fairness through avoiding exploitation and benefit-risk balance).(839,840)

Since conducting ethically sound research heavily relies on researchers' skills, in the next sub-sections I will describe the ethical framework I established for my research and describe my approach to it. I also provide personal reflections on some ethical challenges I faced since taking a reflexive stance to the research is fundamental in understanding the possible ethical risks arising from a study.(836,838)

5.1. Procedural Ethics

I first sought ethical approval for my research project from the LKC Institutional Review Board (IRB). I developed a flyer, a participant information sheet and an interview guide that all went through the ethical review process before I could use it.

The application form for ethical review included a detailed protocol with information on aims of the study, recruitment, informed consent, anonymity and confidentiality, and health and safety.

The files were grouped under the application “IRB-2018-02-028 Patient and Public Involvement (PPI) in research in Singapore” and the application was approved on April 4th 2018.

These documents prepared for the Ethics Applications constituted the basis of communication with participants during the study.

All documents were gathered in a digital folder with copies of the tracked files produced by me, a Research Associate and the PI of this project. This permitted to follow a quality assurance process that helped in the application for ethical review.

Informed consent

Consent is a prerequisite for all research involving subjects and a minimum requirement for conducting interviews.(838)

A set of materials was prepared to inform research participants about the nature of the study before agreeing to take part. The materials included: a study information sheet, a consent form for further contact, and a copy of the flyer with my contact information. Those provided them with information about the purpose, the research team, what would be required from them if they agreed to participate and how the data would be used. The flyer insisted in the fact that their participation was voluntary. The materials were distributed through people contacted by email (for researchers) or direct casual encounter. This gave prospective participants the opportunity to take information away with them, to read it in the privacy of their own homes and to discuss with friends and relatives if they considered necessary. Once prospective participants had contacted me to agree to participate, I gave them a phone call. During this conversation I checked that individuals had read through the information and invited questions; after this I agreed an appointment for the stage one one-to-one interview. The phone call was also a chance to gauge participants' communication and understanding of the conversation in English (see eligibility criteria).

Consent was recorded on the form approved by NTU ethics and two copies were completed. I kept one of them and the participant kept the second copy. Consent forms were filled prior to the start of the interview and reviewed once the interview had finished to verify that participants maintained their consent.

Filling the consent forms together was often an opportunity to build rapport and trust with participants and also to have an idea of the familiarity of participants with research and the topic of the interview. At the beginning of interviews completion of the consent forms provided opportunities to reassure participants about what they could expect and to remind them that should they feel uncomfortable during an interview they retain the right to stop at any time and that not all questions had to be answered if they did not feel at ease with any of them. The post-interview review of the consent form

continued the process of informed consent as the timing meant participants were aware of what they had said during interviews and were in a position of knowing the content of that which they were consenting to be used.

Avoiding harm to participants

The study did not carry an intervention and the questions asked did not focus on sensitive topic and narratives, so the risk of harm was minimal and only stemmed from emotional responses and consequences and consequences of disclosing personal information.

The research methods, did not presented a risk in terms of conducting research in an uncontrolled environment (i.e. public space) since I invited them to choose the time and location so that they could be in familiar spaces. I gave participants enough information about the study so that they could know what would be required and what topics would be covered. Also, I made it clear that they could ask for the recording to be stopped and that answering to all questions was not necessary should they feel unable to continue. In the case of participants becoming distressed during interviews I was prepared to stop an interview and explore with participant's possible avenues of support (e.g. to contact a friend, relative, their GP).

Avoiding harm also includes harm to the researcher. Arrangements for getting to interview site were not necessary, since Singapore has a confined geography with excellent public transportation that I could use to go to participant's preferred space for interview. I observed NTU Office of Health, Safety and Emergency directives and I always had opportunities to debrief with colleagues from the office following data collection with should support after data gathering be needed.

Maintaining confidentiality

NTU's Research Data Policy and procedures therein, have been incorporated into the process of data management within this research study. In terms of data storage, the paper-based field notes, interview transcripts and consent forms were stored in a locked filing cabinet and all electronic data stored in a password protected computer that stayed in my office in LKC at all times. Fieldnotes, audio recordings from data gathering activities were transported securely to the office as soon as possible after collection, where possible using electronic encryption, and stored in a locked filing cabinet. When the data were transferred to the qualitative analysis software package NVivo (Version 10) for analysis purposes, project and personal details were removed. The NVivo files were also saved in a password protected computer.

Snowball sampling presented risks to maintaining confidentiality where individuals (community members or participants) identified prospective participants whom they knew from their social network. Participants always decided to ask their relatives and friends voluntarily.

All research data obtained during the course of this study is strictly confidential and, will be kept by the study team at the end of the study for at least 10 years.

Anonymity

In order to indemnify participants' anonymity, all identifying information was irretrievably removed prior to any data analysis. Participants were assigned a code in replacement of their identities, which consists of a letter corresponding to the group (R for researchers, P for members of the public) followed by a two-digit number in order of sequential recruitment to the study (i.e. R01, R02, etc. for researchers and P01, P02, etc. for lay participants), and this code was applied to all their data, before transcription.

Codes have been replaced with pseudonyms after analysis for this report, to facilitate reading. Pseudonyms maintained the culture of the person interviewed to achieve cultural credibility and were selected through discussions with academic supervisors and partners. The chronological order was maintained, i.e. participant 01 has a name starting with P/R 01, participant 02 has a name starting with P/ R 02.

5.2. Situational Ethics

Situational ethics have been described as ‘the unpredictable, often subtle, yet ethically important moments that come up in the field’.(841) The self-reflective skill of the researcher to react to events that present ethical challenges as they occur are thus the main safeguard of situational ethics. I sometimes had to turn recording equipment off, mainly during interviews to clinician-researchers, as to preserve the confidentiality of their own work or to let them respond to urgent matters that required their immediate attention. described above situations in which participants either experienced distress or requested that the interview recording equipment be turned off.

Letting participants choose the environment where they thought they would feel more at ease (such as their homes or even a coffee shop, twice) helped in making them feel comfortable and allowed me not to risk seeming paternalistic by deciding on all aspects of their participation.

5.3. Relational Ethics

In a review of the ethical challenges faced by researchers conducting qualitative research, Sanjari et al.(842) cited the researcher-participant as the principal ethical concern, as the researcher faces “multiple dilemmas”.

This challenges, including anonymity, confidentiality and informed consent,(838) are grouped in what has been coined as relational ethics, i.e. the ethics that:

‘...recognizes and values mutual respect, dignity, and connectedness between researcher and researched, and between researchers and the communities in which they live and work’.(841)

Indeed, in qualitative research it is the relationship between the researcher and the participant that is at the centre and thus relational ethics are the central aspect too. Participants were met face to face and often in intimate circumstances, as I entered their homes or workspaces and ask them to tell me their opinions and stories.

For research to be ethical participants must be treated with consideration and the line between caring and not exploiting of participants must be made clear at all times. Participants right were protected through consent procedures, confidentiality and anonymity, as discussed before.

The conversational style of the interviews provided scope for them to feel at ease and ask any question they might have about the research and even my personal views. I believe this could help to engage in a reciprocal two-way discussion where trust and rapport could be at the forefront.

Often at the end of the interview the rapport was inverted, and participants would give words of appreciation for my work and my interest in Singapore and were eager to keep talking about research or other non-related topics informally.

5.4. Exiting Ethics

The process of ending the research relationship and of the use of research data is referred to as exiting ethics.

Participants were informed of the expected length of the contact and knew when our relationship would come to an end.

The reporting of findings can carry its own ethical challenges with regards to participants as they will probably have access to them and will be able to recognise their own voices. Thus when reporting I also kept in mind the ‘do no harm’ principle and made sure I considered the possible effect that the outcomes of my research could have on participants.⁽⁸³⁶⁾ As Brewer put it: ‘informed consent does not prevent informants from feeling angry once results are published’.⁽⁸⁴³⁾ Asking for consent again at the end of the interview allowed to verify that they were keen in sharing their views, but that consent could not include my interpretation of their voices.

Finally, for research to be ethical results presented as an outcome must followed principled conventions. In this sense, an honest reflection of the study’s strengths and limitations, as I presented in Chapter 9: Discussion, builds the integrity of the research.

5.5. Ethical Reflections

From the beginning of the data collection, and during the research, I have faced a number of ethical considerations:

Firstly, recruitment of lay participants was challenging. Some colleagues aware of those challenges suggested going through doctors to recruit participants. However, I was aware of the level of trust that local citizens have for their doctors and how they simply abide to their requests without questioning or seeking to clarify information. I thought that using the relationship of power and trust to recruit them would introduce a hierarchical rapport between my participants and myself, while I wanted them to understand my research and to think about it and ask all the questions they needed before agreeing in being interviewed.

Similarly, I found that some participants were keen on being interviewed on the spot, right after I asked them, and they were surprised I insisted in giving them time to consider their participation and in finding a quiet private space for the interview. Some even wanted to be interviewed with other people, which I refused insisting on the fact that the interviews were one-to-one. This made me lose many of the participants, but I considered it was ethical to give them time to reflect on my research and to find a location where they could speak with autonomy and privacy.

Another concern was that despite going with them through the participant information sheet and the consent form, frequently participants (including both researchers and lay participants) asked to skip it because they were “fine” with it and I was never sure they had actually listened to my explanations, and no one really asked any question about those forms.

Finally, as my research sometimes touched on sensitive topics such as political, I had to make sure I was trying to understand their views and it was challenging for me at times to bracket my ideas and experiences of growing up in Europe. Thinking and writing in a neutral way could be achieved by doing memos and reading them out loud so that I could hear whether I was doing any judgement based on my own values and opinions. Besides, in the reporting, I had to make sure that the vision of Singapore I was giving was true and not over-critical or praising, which was difficult (and often daunting) as a foreigner living in Singapore.

APPENDIX

6

USING NVIVO AS A COMPUTER ASSISTED QUALITATIVE DATA ANALYSIS

6.1. Rationale for using NVIVO

Qualitative methodologies are rich, diverse and complex spheres of knowledge and practice. NVIVO, like other Computer Assisted Qualitative Data Analysis (CAQDAS) software, allows to work in a 'method-free' way, which was critical to a novice qualitative researcher like me. Indeed, I could start gathering data and coding it without being forced to choose an approach to it (for e.g. ethnography or phenomenology) from the beginning, risking to wrongly choose the first option I encountered.

An advantage of choosing NVIVO to collect, classify and examine the meaning of data was thus the possibility to explore qualitative concepts as I worked, selecting different tools and using different approaches in for a variety of methodological purposes until I could figure which was best suited to my data.

Although 'tools extend and qualitatively change human capabilities', (805, p.222) the use of tools such as NVIVO also presents issues that have been discussed in the literature. (487)

6.2. Precautions when using CAQDAS

Bazeley and Jackson (487) listed four types 'concerns' that using computerized software for qualitative analysis raise: (i) researchers distance to the data; (ii) excessive code-and-retrieve methods at the expense of analytic tasks (iii) concerns with mechanisation of the qualitative method, losing its essence (iv) homogenization of qualitative approaches to analysis.

(i) When analysing and interpreting the data, a qualitative researcher needs to find the right balance between distance and closeness, (845) to secure a rounded perspective. After working through a document, I could be surprised or frustrated by the nuances in the text, while I also had to stand back and think of the whole and its implications for the larger set of documents.

The first reading of the interviews - and all of the data - while purposeful, was not bound on my research questions, as to get a sense of the general context. After this first broad but directed reading I could begin to identify specific points and issues that emerged, while seeing it the wider picture of things and escaping from the 'coding trap'. (844,846)

(ii) Making efforts to see the larger picture also encouraged not to lose sight of the need to play with emerging thoughts and ideas, instead of simply coding and organising into folders lines of data. I acknowledged the possible challenge that working with computerized files would be for me, and I did a first read and coding of all the interview transcripts in paper files. This was a way to prevent excessive coding and find a more comfortable way of familiarising myself with the content, as I wrote emerging ideas in memos. Besides this was also the best strategy for having conversations with my coding partner, as we discussed sharing a printed copy of the transcripts. Other analytic and interpretive activities were necessary to produce not simply 'themes from the data' but also drawing connections from those themes and reflecting.

(iii) I did not automate repetitive processes like coding or any other step in the analysis nor did I use keyword searchers within the qualitative analysis. I always favoured interpretive coding, done first on paper to find the essence of each passage and then done interactively in NVIVO. When I used NVIVO functions I had previously read about the logic of each function and trained to see how data was being manipulated. Thus, at all times I remained in control of the methods I was using to get the results I was looking for.

(iv) There is not a unique way of 'doing' qualitative research. Different approaches are using in qualitative analysis and NVIVO was a tool that allowed me to complete the analysis strategies defined beforehand, and never ways a method of analysis. I read about foundational qualitative methodologies and philosophies for understanding social realities and questioning, that I integrated into a conceptual framework that was always mine, independent from the use of NVIVO.

Lastly, I was aware of the risks of novice researchers, like myself, 'messing up' with a refined tool like NVIVO without even realising it.(844) Indeed, 'the appropriate use of

software depends on appreciation of the kind of data being analysed and of the analytic purchase the researcher wants to obtain from the data'.(808, p.166) For this reason, literature was examined to avoid a simplistic understanding of the role that NVIVO would play in my interaction with the data. I have been well aware the final solidity and trustworthiness of my findings would depend on my skills as a researcher, first choosing the theories driving my analysis, but also executing the methods and using the software.

APPENDIX

7

INTRODUCTION TO THEMATIC ANALYSIS AND THE CODING PROCESS

7.1. Thematic Analysis

What is thematic analysis?

The method chosen for this thesis is thematic analysis, as it is a flexible and useful approach to data analysis, and importantly, is accessible, providing a fundamental understanding of qualitative research for a novice qualitative researcher like me. Thematic analysis is a method for summary and analysis of the data through the use of extended phrases and/ or sentences rather than shorter codes.(848) By describing the process and practice of thematic analysis, in this section I give the reader enough insight into how I analysed my data and what assumptions informed my analysis.

Thematic analysis has been qualified as a ‘foundational method’ for qualitative analysis (455) amongst a rich, complex and nuanced range of qualitative approaches.(391) Despite the fact that at the core of thematic analysis is the search for ‘thematizing meanings’(391) like in all other approaches of qualitative analysis, thematic analysis stands as a method by itself. It is not simply a tool to be used in other approaches

by ‘*themeing* the data’ as some have argued,(456,457,848) and thus should not be used as an umbrella for different (and often unclear) approaches to research.

Since thematic analysis is based on the unifying principle of qualitative research, thematic analysis is a flexible method that can be employed under the umbrella of most methodological approaches and is the most commonly used form of analysis in qualitative research.(488) Thematic analysis is indeed popular amongst essentialist, realist and in constructionist approaches. Importantly, thematic analysis has been used within a critical realism framework.

Because of this unique ability to be used across a range of epistemologies and research questions, only by following a series of clear guidelines can thematic analysis be ‘trustworthy’,(849) provide insightful findings and respond to the ‘anything goes’ critique (458) that any qualitative researcher must face.(455)

Despite its universality, there is an apparent lack of agreement in the how-to of thematic analysis,(456,459,460) I have used the 6-phase approach to thematic analysis suggested by Braun and Clarke:(455) familiarisation with data, generating initial codes, searching for themes among codes, reviewing themes, defining and naming themes, and producing the final report. I will now discuss each of these steps.

What is a theme?

Since thematic analysis is based on the search for themes across the data set, a proper definition of what constitutes a theme is needed before explaining how data is analysed. There is no definitive definition of what a theme is. When defined as ‘repeating patterns of meaning’,(455) one expects to have an indication of minimal prevalence across and within cases. However, no guideline regarding minimal prevalence for relevance exists, accounting for the flexibility and variability of thematic analysis.

Ultimately, “themes are abstract (and often fuzzy) constructs the investigators identify [sic] before, during, and after analysis”,(457) and again, it is by providing a clear explanation of how themes were established that the analysis becomes trustworthy.

7.2. Intercoder Analysis Plan

Analytic Approach

An exploratory framework was adopted using applied thematic analysis.(488) Because there are a wide variety of approaches to qualitative data analysis and we were a multi-disciplinary team, it was important that there is a shared understanding around the commonly used terms. This analysis uses the following definitions:(485)

1. Data: the interview transcripts.
2. Case: the data arising from each participant/focus group where applicable.
3. Coding: linking specific codes to specific data segments – occurs in a staged approach resulting in five levels of coding (see below). Coding is thus an heuristic process of paramount importance in qualitative research, has been described as the “critical link” between data collection and the explanation of meaning in the data.(488)
4. Codes: are ‘...a researcher-generated word or short phrase that symbolically assigns a summative, salient, essence-capturing, and/or evocative attribute for a portion of language-based or visual data.’(850) Codes are labels of meaning which can be applied to:

- a. Words, phrases, sentences, whole paragraphs;
 - b. Can be straightforward or metaphors.
5. Types of codes: these may be descriptive (usually at preliminary stage) or interpretive (usually at higher levels of coding).(455,488)
6. Levels of coding: coding occurs in distinct stages beginning with each case before moving to a cross case comparison/analysis. An overview of the stages, from Braun and Clarke,(455) is given in Figure 48.
7. Analytic memos: Memos that are kept as the coding proceeds, and which provide an audit trail to explain how codes developed and changed.(851)
8. Codebook: a structured compendium of codes that includes a description of how the codes are related to each other.(455,461) The codebook provides findings "at glance"(852) and is organised in three columns providing:
 - I. the name of the code or theme,(column 1)
 - II. the datum supporting the code or theme (column 2) and
 - III. the researcher's interpretive summary.(column 3)

Figure 48: The six stages of coding, adapted from Braun and Clarke (455)

Coding process in interviews on PPI in research

Importantly, the analysis process was iterative to encourage reflexivity in a process where analysis and data collection were concurrent.(489) By familiarizing myself with the data from one interview I could use new insight to inform the next data collection, and this reflexive process has been recognized as key to sparking insight and developing meaning by repeatedly moving from the concrete reality of data to abstract constructions.(490)

Adopting the principles outlined above, the process of coding adopted the following operational framework:

1. Analysis team met to agree plan.
2. Preliminary analysis was concurrent with data collection to incorporate emerging themes and questions into subsequent interviews, using the interview schedule as an initial framework.
3. Random selection of transcripts (6 in first instance) for detailed independent coding taking interview questions as starting point: within and across cases, looking for confirmation, disconfirming evidence and inconsistencies.
4. Coders meet: emerging codes and categories were discussed and consensus was reached – further transcripts could then be analysed independently and scanned codes and/or categories that require further checking.
5. Coding frame developed from above.
6. Codes and categories were checked through remaining transcripts for confirmation, disconfirming evidence and inconsistencies. Amendments to coding frame were done.
7. Coders met to review/confirm final themes and codes, checking for gaps and inconsistencies and to confirm theoretical constructs.

Importantly, constant comparison is a common analytical strategy employed in qualitative research. Comparisons can be internal to a particular case or across

cases.(443) Contrasting segments of data were compared to one another to assess existing codes, to compare codes and then to build conceptual categories around common properties of groups of codes. In the process of comparing codes internal validity against researcher’s conceptual categories was achieved, both within and across cases.

Example of codebook development – Researchers’ interviews

In the first stage of coding (Table 14) transcripts were read, considering researchers’ perspectives in each line, phrase or paragraph. This initial process was completed using hardcopies of the transcripts, to allow highlighting of key parts and to comment and write preliminary thoughts on the margins. Participants’ own words (in-vivo codes) were retained, as a means to stay ‘true’ to the data at this early stage.(853) Initially, each in-vivo code and initial idea formed a potential category, and there was a great amount of them. These codes were then arranged and combined with other initial ideas to form the Level 1 codes, gathered in a coding index. The initial categories and 5 transcripts from which they were derived were examined by two experienced researchers to ensure the rigour of my study. The changes suggested were tracked in Memos and through notes added to the margins of the matrix.

The index (reproduced in Table 14) organised the whole dataset, facilitated tracking changes and recording progress, such as ideas for initial themes and sub-themes. Indeed, the index would be constantly polished throughout the process of data analysis and interpretation, as my understanding of the topic and of participants’ perspectives evolved.

Table 14: Level 1 of Coding: Coding Index. Adapted from (461)

Initial themes	Initial sub-themes	Initial categories (Level 1 codes)
Singapore		Education & Health literacy
		Cultural diversity
		Age differences
		Community
		Asian Mindset

		Young Nation
Healthcare in Singapore		High quality
		High standards
		Well-functioning
		Boundaries
		Collaboration and partnership in health
Singaporeans		Pragmatic
		Busy
		Self-interest
		Conservative
		Complaining
		'One Singapore'
		Educated
		'kiasu'
		Inequalities
Research	General	Stigma
		Reasons to do research
		What makes good research
	Roles and responsibilities	What makes a good researcher
		'User' and 'Consumer'
	Researcher	'Subjects'
		Education
		Connect
Research in Singapore	Pillars	'Works for' & patronising attitudes
		Innovation
	'Top-down'	'hub'
		Government role
		Paternalistic
		'Missing half'
		Funding
		Ownership
		Collaboration
		Position
		Qualitative research
		Lay attitudes towards research
		Superstitions
		'Lab animals'
		New
		Ethics
		Anonymity and confidentiality
	Feedback	Feedback benefits
		Lack of feedback
Recruitment	Participants	Explain
		'Subjects'
		'Samples'
	Motivations	Money
		Helping out others
		OK to professionals
		Boredom – fill waiting time
		'close to heart' topic
	Barriers	Time
		Incentive

		Interest
		Blood and needles
	Quadruple Jeopardy	Age (older people & ageism)
		Education
		Ethnicity
	Migration	
Attitudes towards PPI		Researchers’ attitudes towards PPI
		Researchers’ beliefs on public attitudes towards PPI
Knowledge and power positions		Hierarchies
		Doctor-patient relationship
		Lay knowledge
		‘Consensus not conflict’
		Trust
Shift		‘think out of the box’
		Numbers vs. stories
		Public outreach
		Different expertise
	‘Bottom-up’	Participation
		Healthcare 2020
		Patient-centred care
		Advocacy
		Voices
		Life-long education
Tensions	Passive-aggressive relationships	
	Patient’s voice vs physician’s opinion	
Understanding of PPI		‘Good to have thing’
		Learning experience
		Belief
		‘progressive idea’
	How – modalities of PPI	Levels of participation
		Participatory Action Research
		Co-Design
	Wrong understanding	Not taking consent
		Not feedback
		Not simply consultation
		Reasons to do PPI
		Examples of PPI
	Role of PPI	Understanding
		Study Design
		Recruitment
Prioritization		
Consultation		
Wrong ideas		
Doing PPI	Fundamentals	Flexibility
		Two-way communication
		Learning experience
		Try
	Who	Representatives
		Patients & caregivers
		Skills and knowledge required

	When	Suspensions of personal agenda
		As early as possible
		All along
	How	Milestones
		Job description
		Gatekeepers
	Implementation	Communication
		Education
		Support and Training
		Awareness
		Pilots
	Barriers	Government role
		Tokenism
		Time
		Recruitment challenges
		Money
		Language
		Resources
		Lack of guidelines
		Education
		Conflict
	Challenges	Bad outcomes
		Out of comfort zone
		Anxiety/fear (researchers)
		Compromise
		Representativeness
		Complex fast-changing landscape
		Public feeling incapacitated
	Implementation	Research inaccessible
		'baby steps'
		Government
		Public outreach
		Examples of good practice
PPI Impact	Positive	Researchers and universities
		Recruitment
		Understanding of research
		Relevance of research ('grounded')
		Normalization of research
		Better materials
		Holistic research
		Ethical research
		Translation and implementation of research
		Sustainable research
	Negative	Feeling of ownership and empowerment
		Social change
		Interference in researchers' work
		Slow things down
		Cost
		Misunderstandings

The qualitative software package NVIVO[®] (for Mac, version 11.4.3) was used to aid data retrieval when searching for patterns within the data. Although initial data management required handling hardcopies of written notes and contact summary forms, those were subsequently transferred into an NVIVO project. Memos were created and archived using this software, which was also used to complete the coding process more intuitively, by applying tags or “codes” to the data and organising those into relevant categories. Easy retrieval and gathering of codes facilitated in-depth analysis necessary for the second level of coding: preliminary thoughts were linked to initial categories and themes, while also being able to see directly how those were expressed in the original data source.

At this level, the wide and diverse range of Level 1 codes were summarised and synthesized, refining the initial categories. Consequently, level 2 codes (shown in Table 15) were less descriptive and more interpretative; this analysis required critical thinking involved in finding links and patterns between categories.(853)

Table 15: Level 2 of coding. Data was synthesized by refining the initial themes and categories using NVIVO

	Source Codes (Level 1 or Initial categories)	Code Definition Elements
Background on Singapore	Community Cultural diversity Education & Health literacy Inequalities Stigma	Introduces the ethos, history, culture, social realities and values of Singapore
The Singaporean identity	'kiasu' 'One Singapore' Asian Mindset Busy Collectivist Complaining Conservative Educated Pragmatic Self-interest	Describes the personality and mindset of Singaporeans

Healthcare in Singapore	Best practice Boundaries Collaboration and partnership in health High quality & standards Well-functioning	Describes the background and organization of healthcare system in Singapore Introduces opinions on the healthcare system
Research landscape and expectations in Singapore	Good research Good researcher Reasons to do research	Describes researchers understanding of the role, aims, organization and impact of medical research
Research in Singapore	Ethics New 'Top-down' 'Hub' 'Lab animals' Anonymity and confidentiality Collaboration Funding Government Innovation Lay attitudes towards research Missing ½ Ownership Paternalistic Position Qualitative research Superstition <u>Feedback</u> Feedback benefits Lack of feedback	Describes the role, aims, topics, actors, operationalization and impact of medical research in Singapore
Expectations of research in Singapore	Good research Good researcher Reasons to do research	Describes researchers understanding of the role, aims, organization and impact of medical research
Lay understanding of research	Understanding	Researchers ideas of lay expectations, attitudes and ideas about research
Lack of understanding of PPI	<u>Attitudes & assumptions</u> Beliefs on public attitudes towards PPI Researcher attitudes towards PPI <u>Levels of participation</u> Co-design Participatory Action Research <u>Positive impressions</u> 'Good to have thing' 'progressive idea' Belief Learning experience <u>Wrong understanding</u> Not feedback Not simply consultation Not taking consent	Researcher describes or gives first impressions of his/her assumptions on PPI

An ever-changing country	Lifelong education Young Nation	Describes the evolution and changes that Singapore has experienced in its short history
Generational gaps	Age differences	Describes the contrasting views, habits or mindsets of different age groups
Emerging roles and responsibilities in research	'User' vs 'consumer' vs 'subject' <u>Researcher</u> Education Connect <u>Work 'for'</u> Patronizing	Describes the researcher's expectations of patient's and the public's role in research and their idea of their own role
Knowledge and power positions	Consensus not conflict Doctor-patient relationship Hierarchies Trust	Describes the hierarchical structures and the gaps existing between the sphere of the researcher and that of the lay
Types of knowledge	Lay knowledge	Researcher states or alludes to a belief that researchers construct meanings on the basis of their certified training that may be quite different from those of the experiential knowledge of the lay and realizes complementary forms of knowledge
Transition in healthcare and research	'think out of the box' Different expertise Numbers vs. stories Public outreach <u>'Bottom-up'</u> Advocacy Healthcare 2020 Participation Patient-centered care Voices	Describes the transformation of practices, guidelines, objectives and mission that healthcare services aim to achieve, and healthcare professionals aspire to, and reflections on practices being encouraged abroad and not dominant in Singapore
Tensions	Passive-aggressive relationships Patient's voice vs physician's opinion	Describes some of the conflicts arising from the previously mentioned transformations at different levels Identifies contradictions within and amongst cases
Examples of PPI	Examples of PPI	Researchers telling their own experiences of PPI
Reasons to do PPI	Reasons to do PPI	Describes the different justifications that researchers have for PPI
A belief in PPI	Belief Researcher attitudes towards PPI	Includes researchers' attitudes and the impact on the motivation to include PPI in their work
Role of PPI	Consultation Prioritization Recruitment Study Design Understanding	Researchers expectations and ideas on PPI, focusing the role PPI should have

	Wrong ideas	
How to do PPI	Communication Flexibility Flexibility Gatekeepers Job description Learning experience Trust Try Two-way communication	Describes the way researchers consider that PPI should be done and the strategies that can facilitate the process
Who to involve	Patients & caregivers Representatives Skills and knowledge required Suspensions	Researcher makes direct/indirect reference to specific elements of lay involved' culture/ background (e.g., race, socioeconomic status, language, educational level, etc.) that may impact the involvement process and individual motivations to be involved
When to involve	All along As early as possible Milestones	Describes the steps of research cycle in which researchers consider that PPI would be useful and the reasons for it
Implementation	'baby steps' Awareness Education Examples of good practice Government role Pilots Public outreach Researchers and universities role Support and Training	Researchers advice on how to encourage the implementation of PPI in a culturally relevant manner
Barriers & Challenges	Anxiety/fear Bad outcomes Complex fast-changing landscape Compromise Conflict Education Lack of guidelines Language Money Out of comfort zone Public feeling incapacitated Recruitment challenges Representativeness Research inaccessible Resources Time Tokenism	Researcher expresses uncertainty, lack of clarity, and/or concern, about some aspect of the "how, what, or when" of involvement
Expected impact of PPI	<u>Positive impact</u> Better materials Ethical research Feeling of ownership and empowerment	Describes the expected outcomes of PPI practice on research, the society and individuals

	Holistic research Normalization of research Recruitment Relevance of research ('grounded') Social change Sustainable research Translation and implementation of research Understanding of research <u>Negative impact</u> Anxiety Cost Interferences Misunderstandings Slow things down	
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As a new researcher using qualitative methods, special attention was paid to remain close to the original transcripts, in particular when incorporating more abstract concepts drawn from the literature. Iterations from in-vivo codes and initial categories to broader overarching themes and more abstract concepts kept the data interpretation grounded on participants' descriptions. Firstly, level 1 codes were synthesized while remaining close to the transcripts, by going back to those and checking the meanings contained in participants' descriptions, until a 'whole picture' of all accounts was obtained (level 2). Secondly, a higher level of interpretation of the synthesised codes permitted the incorporation of abstract and theoretical concepts encapsulating key aspects of the original data, associating themes and concepts (level 3). An example of how level 1 initial themes and categories in the coding matrix (Table 14) were linked to firm refined categories and themes from which core concepts were developed is shown in Table 16.

Table 16: Level 3 of coding: Developing the core concept, labelled X, and the final themes within the concept, using NVIVO. Adapted from (461)

Initial themes	Initial categories	Refined categories	Final themes	Core Concept
Implementation Lay understanding of research The Singaporean identity Transition in healthcare and research Types of knowledge	'One Singapore' Advocacy Asian mindset Bottom-up Collectivist Community Patient-centred care Public outreach Public outreach Support and Training Understanding Voices	Bridge the gap between research and the public Lay knowledge Outreach activities PPI at an intergenerational-household level and within community groups	Community-based PPI	Opportunities for implementation
Implementation Lay understanding of research The Singaporean identity Who to involve	Collectivist Conservative Patients & caregivers Representatives Skills and knowledge required Support and Training Understanding	Ground community ambassadors PPI Pioneers Role of respectable people in the community	Role models and advocates	
Generational gaps Healthcare in Singapore Knowledge and power positions Lack of understanding of PPI Lay understanding of research Who to involve	Attitudes & assumptions Boundaries Collaboration and partnership in health Consensus not conflict Passive-aggressive relationships	Availability of information: what the research is about, what can people contribute Bridge the gap between research and the public Clarity in the boundaries between PPI and research	Building trust	

	Patient's voice vs physician's opinion Suspicions Trust Understanding	Recognise the value of each individual Refine community ideas to implement PPI Transparency		
Background on Singapore Expectations of research in Singapore Healthcare in Singapore Knowledge and power positions The Singaporean identity Transition in healthcare and research	Age differences Asian mindset Best practice Bottom-up Community Education & Health literacy Lifelong education Patient-centred care Reasons to do research Self-interest Young Nation	Consensus not conflict Develop the idea as part of the culture Doctor-patient relationship Emphasize PPI as an opportunity to contribute to the wider community good Hierarchies Introduce active roles in research from early ages Trust	Integrate PPI principles into Singaporean culture	
Background on Singapore Emerging roles and responsibilities in research Expectations of research in Singapore Generational gaps Implementation Lack of understanding of PPI Lay understanding of research The Singaporean identity	'kiasu' Age differences Attitudes & assumptions Awareness Cultural diversity Education & Health literacy Examples of good practice Inequalities Levels of participation Lifelong education Stigma Understanding	Culturally appropriate methods (e.g. consideration of language) Educate all ethnic groups and amongst all ages in research Educate emerging researchers and health professionals in PPI principles Raise awareness of research from early age Updating and engaging existing researchers through continuous professional education	Raise awareness (amongst diverse groups including professionals)	
Background on Singapore Implementation Knowledge and power positions Lack of understanding of PPI	'baby steps' 'top-down' Asian mindset Collectivist	Education and raising awareness amongst professionals at all levels (e.g. ethics boards)	Strategic leadership	

Research in Singapore The Singaporean identity	Consensus not conflict Conservative Government role Hierarchies Researchers and universities role Trust Young Nation	Government setting standards for PPI Policy makers rewarding PPI		
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APPENDIX

8

STYLE OF THE THESIS

‘Voice echoes the researcher’s involvement with the studies phenomena; it does not reproduce the phenomena. Yet through struggling with representing our research participants’ experience we may find the collective in the subjective.’ (854)

Most often, scientific literature is written in a formal third person style, as academic language is expected to be generally objective rather than personal, so that the identity of the author has no place to be, and only the arguments made matter.(855) Positivism, detachment, passivity are all widely accepted elements of scientific reporting, as science communication becomes an exercise of report writing. However, this view has been challenged, so that ‘academic writing need not be totally devoid of the writer’s presence.’(856) Freshwater argued against the objectivity of the third person writing style, alleging the plainness of the language and how that form of expression limits the coexistence of the concurrent interpretations.(857)

As Charmaz explains in the quote above, the voice reflects the presence of the researcher in the study and his involvement with the phenomenon studied. If writing in a detached and objective style, the analyses, the findings and the conclusions would appear as emerging organically by themselves. However, it is the researcher that is responsible for thus interpretations, and thus is bonded to all elements of the research. Using the first

person, the creative and active role of the researcher is recognised.(858) Thus, if separated from it, the researcher would be unable give an accurate idea of the process of construction of his work and of the decisions he took in the process. For reporting my thesis, I have tried to reach a compromise between first and third person, with the aim of transparently presenting my scientific endeavour whilst being part of the research.

APPENDIX

9

THE IMPORTANCE OF MEMO WRITING IN THIS STUDY

For a qualitative researcher, memos provide an ‘interactive space’ in which to gather thoughts, ideas, questions, assumptions, and to be reflexive.(851) Memos allow to take some distance from the first level meaning of the data and unleash the thoughts of the researcher as to encourage interpretative work, and thus opening the possibilities to producing high quality research, following Stake’s statement. Including raw data in researcher’s memo writing maintains the participant’s voice and their meaning through to the theoretical outcome.(859) Memos are a way to state problems and imagine solutions as abstraction derives from the original data.

The need for reflexivity when working within critical realism,(413,448) and memos provide a way to materialise the researcher’s thought processes. Birks, Chapman and Francis summarized the main purposes of analytic memos in qualitative research following a simple mnemotechnic trick:(860)

With all its complementary functions, memos are an essential element of the research process(452) and belong to many qualitative research epistemology and methodology. Memos can contribute to the application of critical realism principles,(861) for example facilitating reflection on observations, suggesting different mechanisms explaining them and the underlying mechanisms behind these hypothesis to finally conclude on the most simple and likely explanation of the initial observation.

10

INTERVIEW TOPIC GUIDES

10.1. For Researchers' Interviews

Interview Guide (Researchers), version 1 dated 12 Feb 2018

1. Biographical Questions about the interviewee
 - Could you please describe your position and work?
 - How long have you been in this position?
 - Please describe your research process.
 - How do you recruit people?
2. Questions about the concept of patient and public involvement in research
 - What do you think Patient and Public Involvement in Research refers to?
 - What do you think is interesting about the use of PPI in research?
 - What should be the role of the public in your research?
 - If you were to introduce lay views in your research,
 - What would change?

- Where and when would it be better to have them?
 - What would be difficult?
 - Could your research be hindered?
 - How should the role of the public be negotiated?
 - In your opinion, how does the public see your research?
 - How do you think the public benefits from your research?
 - Would there be particular challenges of working with X group?
 - Why you think your research is meaningful and useful to the public?
 - How do you communicate your research to the public?
 - Do you think PPI should be encouraged in government policy?
 - Some people think that increasing the role of the public in research reduces the role of the professional. What are your views on this?
3. Questions about the nature of research
- What do you think successful research is?
 - How could you maximize the impact of research?
 - How would you like to make your research better?
 - What is specific to research in Singapore?

Interview Guide (Researchers), version 5 dated 24 May 2018

Note: To give the reader an understanding of how the changes and additions to the guide were done, some of them have been written in orange in the guide below, and footnotes provide a brief justification for them.

1. Introduction

Thank participant for agreeing to be interviewed.

Check has read/understood study, confidentiality and anonymity, that is free to answer/not answer any questions/stop the interview at any point, etc.

Answer any questions participant has.

Sign consent form.

2. Personal background

These are some questions about you.

- In terms of your background more generally, where do you come from?

Probe: tell me a little more...

- Please tell me about your current role and work?

Probes: how long, main role, etc.

- What sort of training and education have you had?

Probes: how useful, anything missing etc.

3. Views on research generally

I would now like to ask you some questions about research generally.

- In your view, what sorts of factors make a research study 'successful' or not?
- What sorts of factors influence research in a Singaporean context, compared to other countries, in your view?

Probes: funding policies, cultural issues, availability of training etc.

- Are there particular characteristics of a 'good' researcher? Tell me more...
- In what ways might these characteristics be different in Singapore to elsewhere?
- In your view, what are the main reasons for research?
- *Probes: beneficiaries etc.*

4. Own research experience

These next questions are around your own research.

- Please tell me something about your experience in research and how you came to be involved. *Probes: what sort of research (methods, collaborators, funding etc.)*
- Thinking about the public, how do you think your research is viewed? Say more about that, does it have meaning, is valued?
- In what sorts of ways do you feel your research has public benefit? Say more....
- Are there particular participant recruitment strategies that you have used?
Probes: challenges, what went well, particular populations more difficult (reasons) etc.
- In terms of disseminating your research findings and maximizing impact, please tell me how you usually do this.
Probes: audiences (academic, practitioners, patients/public, research participants, others); anything that works well, could be better?
- How can you maximize the impact of your research?⁶

5. Patient and public involvement

These are some questions about involving patients and the public in research

- For you, what does the notion of Patient and Public Involvement in Research mean?
- Do you have any views/experience of involving patients/the public in research?
- If yes, probes: say more about that, what went well, what were the challenges?
- If no, would you see a role for it in your work? Probes: say more about that, in what ways might it impact?
- Some of my previous participants have talked about Patient Advocacy⁷. When thinking about PPI, do you think there is any distinction between them?

⁶ Added after C. Mallen workshop and my discussion with Prof Lim. Evidence and PPI do not necessarily bring impact

⁷ Advocacy is more politicised

- What sorts of knowledge might patients/public have compared to academic knowledge? Say more...
- What are your thoughts on how patients/public could be involved/what sorts of stages in research? *Probes: say more about that, main challenges, practical issues, etc.*
- In what ways, if any, might involving patients/public be different for different sorts of research? Say more about that...
- *Probes: positive effects, negative effects, what strategies to address these etc.*
- Are there particular patients you feel would be more open to involvement than others? Say more about that.
- *Probes: which groups, reasons, implications, strategies that could be employed etc.*
- Thinking about ethics in a research context, would you see any particular challenges or opportunities in relation to patient/public involvement? Say more... different for different populations etc.

6. Singapore

Some questions particularly about Singapore and PPI⁸.

- Are you familiar with the Ministry of Health's Healthcare Manpower Plan 2020 to improve health services? (Explain if not).
- Are there any particular implications of patient/public involvement in research?
- *Probes: challenges, opportunities, benefits, research priorities, maximizing benefit etc....*
- The term 'public good' is often used, can you tell me what that means to you?
- *Probes: who defines it, etc.*
- In what ways, if any, is it different in Singapore to other parts of the world?
- *Probes: say more about that...*

⁸ So that I do not need to remind after every question

- Thinking about the local context, and the different communities and cultures, are there any particular opportunities around getting involved in research? And similarly, what are the challenges?⁹
- *Probes: Say more, what strategies to address etc.*
- What, if any, would you as the role of government policy in strengthening patient/public involvement in research?
- *Prompts: say more...*

7. Finally...

Any other final remarks/additional views that you would like to add?

Check that consent is still in place.

Thanks and reminder of how the participant can get in touch if they have any queries etc.

10.2. For Interviews with Members of the Public

Interview Guide (Public), version 1 dated 12 Feb 2018

⁹ Clarified this question that previous participants struggled to understand

1. Biographical Questions about the interviewee

- Could you please describe your position and work?
 - How long have you been in this position?
 - Have you ever have research experience?
- Have you participated in research before?
 - How did you benefit from it?
 - Why did you decide to participate?
 - How were you recruited?
- Have you volunteered in any health related activity (in patients organization, hospitals, nursing homes...)?
 - How did you benefit from it?
 - Why did you decide to participate?

2. Questions about the concept of patient and public involvement in research

- What do you think Patient and Public Involvement in Research refers to?
- What do you think there interesting about the use of PPI in research?
- How could you contribute to science?
- Which challenges of you being involved in research should be taken into account? (paperwork, distractions, advance notice, training, access, meeting times, remuneration).
- Do you think the public should...
 - Decide which research is publicly funded?
 - Have an active role in publicly funded research?
 - Why?
- How do you think the research being done?
- Is relevant to you?
- Helps to solve problems that matter to society?

- Do you think your opinion could make a difference in research?
- How do you think your involvement could benefit/ dis-benefit the patient group you could represent?
- Do you think PPI should be encouraged in government policy?

3. Questions about the nature of research

- What do you think are the skills a good researcher needs?
- How do you learn about research being done in Singapore?

Interview Guide (Public), version 4 dated 10 Aug 2018

1. Introduction

Thank participant for agreeing to be interviewed.

Check has read/understood study, confidentiality and anonymity, that is free to answer/not answer any questions/stop the interview at any point, etc.

Answer any questions participant has.

Sign consent form.

Remind participant there are no right or wrong answers, and anything they can share will be very helpful.

2. Personal background

These are some questions about you so that I can describe the sorts of people who helped with the research.

- Please tell me about your work and a little about yourself?
- *Probes: how long, main role, background etc.*
- What sort of education have you had?
- *Probes: how useful, anything missing etc.*

3. Views on research generally

I would now like to ask you some questions about research generally.

- In your view, what sorts of factors make a research study 'useful' or not?
 - Rate relevance and impact of research in Singapore (1 to 5)
- What do you think makes a 'good' researcher?

Probes: Tell me more...

- How do you learn about research being done in your local area?
 - Do you find it is relevant to you?
 - Does it help to solve problems that matter to society?
- In your view, what are the main reasons for research?

Probes: beneficiaries etc.

4. Own research experience

These next questions are around your own experiences.

- Do you have any experience of taking part in research?
- *Probes: any particular reasons etc...*
- Please tell me something about how you came to be involved.
- Probes: what sort of research (methods, collaborators, funding etc.)
- Do you understand the meaning and the value of the research you are involved with?
- In what sorts of ways do you feel the research you are involved in has benefit?
- Probes: Say more.... To the public, who else?
- How do you think we can maximize the impact of research?

5. Patient and public involvement and engagement

These are some questions about involving patients and the public in research.

- For you, what does the notion of Patient and Public Involvement and Engagement in Research mean?

Probe: different to volunteering more generally?

- In what ways do you think the public should be involved, for example deciding which research is funded, how it is carried out etc...

Probes: Why?

- (If appropriate) From your experience as a member of a Research User Group:
 - How were you recruited?
 - What were your reasons for deciding to participate?
 - What went well?
 - How did/do you benefit from your involvement in research?
 - Friendships/ Confidence/ Skills/ Making a difference
 - What were the challenges?
 - How do you think your involvement benefits patients?
 - What have you found most helpful in terms of being able to take part?
 - What sorts of training did you have?
 - What was useful/less useful?
- Some people see PPI as a form of advocacy - is that how you see it?

Probe: Say more...

- What sorts of knowledge might patients/public have compared to academic knowledge or researchers?

Probe: Say more...

- What are your thoughts on how patients/public could be involved/what sorts of stages in research? *Probes: say more about that, main challenges, practical issues, etc.*
- In what ways, if any, might involving patients/public be different for different sorts of research?

Probes: Say more about that... positive effects, negative effects, what strategies to address these etc.

- How would you describe Singaporeans?

- Are there particular groups you feel would be more open to involvement than others? Say more about that.

Probes: which groups, reasons, implications, strategies that could be employed etc.

- Are there ways that researchers could help more people to be involved?

Probes: What are these? Are they different for different groups (I.e. older people etc)

- Thinking about ethics in a research context, would you see any particular challenges or opportunities in relation to patient/public involvement?

Probes: Say more... different for different populations etc.

- Rate relevance and impact of research with PPI in Singapore (1 to 5)
- Rate likelihood of PPI to happen in Singapore (1 to 5)

6. **Your local area**

Some questions particularly about your local area and PPI.

- The term 'for public good' is often used, can you tell me what that means to you?

Probes: who defines it, etc.

- In what ways, if any, is it different in your local area to other places?

Probes: say more about that...

- Thinking about the local context, are there any particular opportunities around getting involved in research? And similarly, what are the challenges?

Probes: Say more, what strategies to address etc.

- What, if any, would you as the role of government policy in strengthening patient/public involvement in research?

Prompts: say more...

7. **Finally...**

And finally:

- What would you suggest to anyone thinking of getting involved?
- Any advice to researchers thinking of starting to bring PPI into their research?
- Any other final remarks/additional views that you would like to add?

Check that consent is still in place.

Thanks and reminder of how the participant can get in touch if they have any queries etc.

APPENDIX

11 CONTACT SUMMARY FORMS

11.1. Template

Contact summary form

Written by:

Date:

Contact type: Interview

Site:

Contact date:

What were the main issues or themes that strike you in this contact?

(In CAPITALS indicate the existing themes or create new themes)

Summarize the information you got:

Missing:

Anything else that struck you as salient, interesting, illumination or important in this contact?

What follow-up questions in conducting the next contact?

11.2. Example of Contact Summary Form

Contact Summary Form – R05

Written by Lidia

Date: 27/04/2018

Site: his own private clinic in a Medical Centre

Summarize the information you got:

- People with interest in the research topic are very welcomed to the research team
- Imagines the idea of having members of the public at the same level
- Diplomas would not be a must
- Would like workshops on how to involve the patients
- Wants more support to do more and better research
- Thinks public benefits from research
- Thinks researchers would benefit most from involvement
- Clear that must pay those involved: max. 5% of research budget
- Involvement most useful to know if topic is relevant and to design questionnaires and information materials
- Talks about levels of involvement without being aware of it
- Clinicians in Singapore not aware of the value of research
- Singapore population not educated in research

- Institutions running research never take the time to give feedback and explain research results to participants
- Some might not be interested in involvement, but all should because it totally makes sense
- Involvement is very new: never thought about it but now thinks it is very helpful
- Recruitment of people to be involved might be challenging
- If it is hard to recruit it might mean that the topic is not relevant to the public, so it shows that the research topic is not good
- For researchers the barriers for involvement would be money
- Also, could be worried that it slows down the research (but not the main worry)
- Each involvement experience should be adapted to those involved

Missing: Ethics implications of PPI

What struck you as salient, interesting, illumination or important in this contact?

- Feels very isolated as a researcher
- No knowledge of the Healthcare 2020 Masterplan
- Enthusiastic with the idea of consulting and getting help from patients
- I am not sure he really understood what involvement is...
- Talked with mask on → makes understanding difficult → dissonance in our conversation – we were never at the same level
- Seemed to feel the interview was an exam

What follow-up questions do you have in conducting the next contact?

- Know more about GPs research training → purposively sample more GPs
- More information on the cultural background of the researcher
- What are their motivations to do research?
- Do older generations of researchers and clinicians have different views?

Notes to self

Need for sensitivity. When I mentioned the 2020 Masterplan seemed embarrassed that he did not know. → Reflexivity – Sensitive Research

Interviewee kept cutting on my questions when I tried to ask longer questions → frustrating.

He needed to speak out, had things to voice that no one else would be listening to. This interview was a chance to talk about something he cares about, research. Was this the reason why he accepted the interview?

He really wanted to get out his message, a call for support for GPs wanting to do research
Asking him about PPI when his research is not figured out is like trying to put the icing on a cake when you are still deciding on the recipe!

12

SELECTING AN IMPLEMENTATION THEORY

12.1. Introduction to Implementation Theories

Implementation strategies “constitute the ‘how to’ component of changing healthcare practice”(862) and have been used to inform the implementation of specific evidence and behaviours within complex programs,(613) and to enhance their sustainability.(863) Interventions, at any phase of implementation, can be strengthened by these theoretical approaches.(864) Before, theories can assist in planning an intervention strategy, anticipating barriers and ensuring that all relevant stakeholders are engaged. During the intervention these can serve to identify how to introduce and embed new ways of working, to make explicit the mechanisms of action and to track and explore process of change. Finally, after the intervention, implementation theories can be used to

identify data that should be collected to evaluate success, framework for reporting evaluation outcomes, understanding what happened and why.

Moreover, different theories can serve to fulfil specific aims around successful implementation. Indeed, three aims have been distinguished: 1) describing and/or guiding the process of translating research into practice, 2) understanding and/or explaining what influences implementation outcomes and 3) evaluating implementation. Within the second aim, determinant frameworks, classic theories and implementation theories can be used to understand and/ or explain influences on implementation outcomes (see Figure 49).(613)

Figure 49: Taxonomy of theoretical approaches used in implementation science. These can fulfil three different goals, and five categories of theories, models and frameworks can be distinguished. Source: Nilsen (613)

In my study, the use of implementation theories was adopted to facilitate reflection on the process of introducing public involvement to the research study; implementation theory was not used to guide the implementation. This approach was consistent with my role advising and observing how the plan unfolded within the study, in an exploratory manner, rather than evaluating the implementation. This aligned with the second aim of implementation theory displayed in Figure 49.(613)

Understanding and explaining barriers and facilitators of implementation

Nilsen (613) described the three categories of theories, models and frameworks to be used to achieve this goal: determinant frameworks, classic theories and implementation theories, and gave a list of examples of each. This information is summarized in Table 17.

Since at the start of this project I was acquiring new skills in the social sciences, and this doctoral study is my first experience of qualitative work, I decided to not resort to classic theories drawing on fields I was previously not familiar with. I was left with determinant frameworks and implementation theories.

The first describe groups of determinants that could influence implementation outcomes, using barriers and enablers (independent variables) having an impact on the outcome (i.e. the dependent variable). Moreover, these do not focus on the process of change, nor the causal drivers of change (and thus are referred to as frameworks rather than theories). Importantly, the types of determinants are multilevel, so as to include individual, organization and other determinants at the macro level. Implementation is acknowledged to be a multidimensional complex phenomenon, where multiple factors interact to affect the outcome and where the context needs to be taken into account. Context, which has been referred to as “an important but poorly understood mediator of change and innovation in health care organizations”,(613,865) is nonetheless an indispensable part in the process of understanding and explaining of barriers and enablers, as it refers to the “conditions or surroundings in which something exists or occurs, typically referring to an analytical unit that is higher than the phenomena directly under investigation”.(613) Determinant frameworks thus provide a system approach to implementation science, encouraging to retrospective interpretation of outcomes, reflecting on the multiple related levels of influence and determinants.

Secondly, implementation theories have been generally developed by implementation researchers seeking enhanced understanding and explanation of certain aspects of implementation. These draw on existing theories and concepts from other disciplines (e.g. psychology, organizational sciences) by modifying specific aspects, for example increasing the focus on organizational climate and culture.(625)

Since both of these approaches were suitable to fulfil my objectives, I decided to examine the examples provided by Nilsen,(613) using existing published studies, to select the most suitable theory or framework for me.

Table 17: Three categories of theories and frameworks used in implementation science to understand and/or explain what influences implementation outcomes. Source: Nilsen (613)

CATEGORY	DESCRIPTION	EXAMPLES
DETERMINANT FRAMEWORKS	<ul style="list-style-type: none"> Specify types (also known as classes or domains) of determinants and individual determinants, which act as barriers and enablers (independent variables) that influence implementation outcomes (dependent variables). Some also specify relationships between some types of determinants. Overarching aim is to understand and/or explain influences on implementation outcomes, e.g. predicting outcomes or interpreting outcomes retrospectively 	PARIHS (666,673), Active Implementation Frameworks, Understanding-User-Context Framework, Conceptual Model, framework by Grol et al., framework by Cochrane et al., framework by Nutley et al., Ecological Framework by Durlak and DuPre, CFIR (672), framework by Gurses et al., framework by Ferlie and Shortell, Theoretical Domains Framework (840)
CLASSIC THEORIES	<ul style="list-style-type: none"> Originate from fields external to implementation science, (e.g. psychology, sociology and organizational theory) Can be applied to provide understanding and/or explanation of aspects of implementation 	Theory of Diffusion, social cognitive theories, theories concerning cognitive processes and decision making, social networks theories, social capital theories, communities of practice, professional theories, organizational theories
IMPLEMENTATION THEORIES	<ul style="list-style-type: none"> Developed by implementation researchers (from scratch or by adapting existing theories and concepts) To provide understanding and/or explanation of aspects of implementation 	Implementation Climate (675), Absorptive Capacity, Organizational Readiness, COM-B (841), Normalization Process Theory (671)

12.2. Selecting a Theory

The most popular implementation research frameworks in academic publications (866) and theories used by implementation experts (615) were reviewed in two publications in 2017. In 2018, Lynch et al.(864) collated those and summarized the 10 theoretical approaches that occupied the most highly cited and commonly used ranks from both publications. I then cross-referenced those with the list of examples of determinant frameworks and implementation theories in Nilsen.(613) Five theories and frameworks (shown in Table 18) were included for further evaluation.

Lynch et al.(864) provide practical guidance to choosing a theory. To support the selection of a theoretical approach, they suggested some prompts and issues for reflexion:(864)

1. Who are you working with?

Theories are concerned with different organizational levels, from autonomous individuals (micro-level), through teams (meso-level) to wider settings such as entire health services (macro-level implementation). For example, the TDF is majorly concerned with experiences and behaviours of individuals, while PARIHS comprises broader contextual factors situated in a wider setting. At times, implementations spanning through different levels might require more than approach. In this case study, a few key individuals (study PIs particularly) are driving the strategy for public involvement within the research study team. A strategy to understand decisions and behaviours of individuals who have complete autonomy (micro-level) within their team (meso-level) is most relevant.

2. When in the process are you going to use the theory?

As previously stated, implementation theories can be used at all stages of implementation with different purposes. As this case study aims to explain what influences the success of PPI implementation in a local research process, approaches lending themselves to focus on the aspects after implementation, understanding what happened and why, are needed in this case study.

3. Why are you applying a theory?

Specific aims for the use of implementation theories, linked to what aspects need to be understood, lend themselves to different theories. In this sense, TDF is more suited to assess achievement of a specific change while PARIHS and CFIR can be used to achieve better understandings of barrier and facilitators to inform and evaluate implementation approaches.

4. How will you collect data?

The type and volume of data available for analysis can also be a factor when choosing a theory. NPT requires in-depth data that provides sufficient insight to illuminate mechanisms of action, for example in the case of professional or patient experiences.

5. What resources are available?

The resources and support available, and the familiarity and experience of the researcher using the theories need also to be considered when choosing a theory. Structured tools, such as TDF, NPT, CFIR and PARIHS, are more accessible to less experienced researchers. Moreover, facilitation, a core component of PARIHS, might be required, and variable amounts of time and staff are needed for optimal use.

Table 18: Summary of five commonly applied theoretical approaches to understand and/ or explain what influences implementation outcomes.
Source: (864)

	Theoretical Domains Framework (TDF) (619,620)	Normalization Process Theory (NPT) (621)	Consolidated Framework for Implementation Research (CFIR) (622)	Promoting Action on Research Implementation in Health Services (PARIHS) (623,624)	Implementation Climate = Implementation Effectiveness Model (625)
Purpose (as described by authors)	An integrative theoretical framework, developed for cross-disciplinary implementation and other behaviour change research to assess implementation and other behavioral problems and to inform intervention design.	Provides a conceptual framework for understanding and evaluating the processes by which new health technologies and other complex interventions are routinely operationalized in everyday work, and sustained in practice.	Framework to promote implementation theory development and verification about what works, where and why.	Organisational or conceptual framework to help explain and predict successful implementation of evidence into practice and to understand the complexities involved.	An integrative model to capture and clarify the multidetermined, multilevel phenomenon of innovation implementation
Brief description	Provides a holistic list of factors that influence behaviour – application of TDF can give researcher confidence that factors influencing an individual's behaviour will be identified, which in turn can identify factors that need to be addressed in order for behaviour change to occur (i.e. can be used to inform behaviour change	NPT is an Action Theory, which means that it is concerned with explaining what people do rather than their attitudes or beliefs. Proposes that for successful sustained use: individuals & groups must work collectively to implement intervention; work of implementation occurs via four particular processes; continuous	List of factors (5 domains and 37 constructs) that can influence an implementation project, can be used in planning or in evaluation stages (does not guide how to implement). Research focus in contrast to doing/practitioner focus.	Conceptualises how evidence can be successfully implemented in health care settings using the process of facilitation. Underlying premise is that facilitation will enable people to apply evidence in their local setting, which is situated within a broader organisational and societal context.	A list of constructs that can influence implementation effectiveness, based on the premise that implementation effectiveness is a function of an organisation's climate for implementing a given innovation and the targeted organisational members' perceptions of the fit of the innovation

	strategy development/selection). Can be used in conjunction with Behaviour Change Wheel to develop and deliver behaviour change strategy.	investment carrying forward in space and time required. Can be helpful to understand and evaluate how new health technologies/ complex interventions are routinely operationalized and sustained in practice. Not designed to guide implementation.		Framework strives to capture the complexities involved in implementation, so most useful in more complex projects.	to their values. Does not provide specific guidance for how to implement, was not designed specifically for the context of health care. Likely to be most useful for projects with a clear organisational approach.
Background for development	Through an expert consensus process and synthesis of 33 theories and 128 key theoretical constructs related to behaviour change.	In iterations, based on experiences of authors. Initially, developers mapped the elements of embedding processes and developed the concept of normalization. Next a robust applied theoretical model of Collective Action was produced, and applied to trials, government processes and healthcare systems. The final stage focused on building a middle-range theory that explains how material practices become routinely embedded in their social contexts.	Published theories which sought to facilitate translation of research findings into practice in the healthcare sector were reviewed. Team identified constructs that had evidence that they influenced implementation and could be measured. Some constructs were streamlined and combined, whereas other constructs were separated and delineated.	From authors' experience working as facilitators and researchers on quality improvement activities and health service research projects.	From authors' personal experience with reference to literature

Changes/ development over time	Validity was investigated by behavioral experts sorting theoretical constructs using closed and open sort tasks. Validation study demonstrated good support for the basic structure of the TDF and led to refinements, leading to publication of new iteration of framework in 2012.	Through its focus on being a theory, the authors continually refine and test NPT to ensure its validity. More recently, NPT has been extended towards a more general theory of implementation (867).	None	Has had several iterations since first publication in 1998 in response to findings from empirical testing. Revised to integrated or i-PARIHS framework in 2015. (624)	None
Ease of use	Quite straightforward to apply, can be time consuming to use for analysis – potential to overwhelm novice researcher given the 14 domains and 84 component constructs. COM-B and Behaviour Change Wheel work together with TDF.	Easy to apply with use of specifically developed resources.	Clear, but may be difficult to digest language if new to area of implementation science.	Does not operationalize its constructs, so may be difficult for novice to understand and apply, particularly when not being supported by expert facilitator. Facilitator's toolkit easy to apply to conduct pre- and post-implementation evaluation. For people experienced in implementation, framework provides guidance on all of the things to consider when implementation is complex.	Main manuscript very wordy (text-based). Concepts are clear.

12.2.1. Implementation Effectiveness Model

Although this framework could be useful in that it considers the impact of organization's climate on the effectiveness of implementation, I did not seem the best fit for my goals for a number of reasons:

- since it was first published in 1996, this model has not been updated nor validated. This work was based on author's experience and, although it contains references to literature, it does not synthesize previous frameworks to build its constructs;
- the model targets member's perceptions of the suitability of the strategy to be implemented for their values. In my case, I did not interview the research study team, and thus I would not know their perceptions beyond my own observations;
- this model is not particularly targeted for the field of health, and maybe some aspects of my observations would not be considered by the model.

12.2.2. Normalization Process Model, Normalization Process Theory (NPT)

Normalisation Process Theory presented some clear advantages:

- using NPT would give me a visual representation of the process of implementation, with direct understanding of the most challenging areas. By responding to the propositions at different points in time, I would be able to assess the changes in practice of PPI;
- I was familiar in the use of this theory, since I had attended a workshop on its use;
- this theory has been constantly refined and updated, and numerous resources created by the authors are easily available.

Nonetheless, there was a major drawback in using this theory which was deciding from whose standpoint to consider its propositions. While ideally it should have been from the research study team members', since they were the ones trying out PPI in their work, I did not have the resources to interview them at different stages of the process to get

their own perspectives. I could not think on the propositions considering what they would think and thus I did not have the data necessary to utilize this theory.

12.2.3. Promoting Action on Research Implementation in Health Services (PARIHS)

PARIHS would be useful for me:

- in that it captures complexities of implementation process, at different levels, from individual people to the broader societal context, through the organisational one;
- has been updated since its creation and refined for the quickly evolving healthcare field.

However, this framework also presented some disadvantages that made it not fit for purpose:

- uses successful implementation as an outcome, as it aims to explain and predict successful implementation. In my case, I would not aim to evaluate the implementation per se, but rather to understand the process and infer recommendations for other research studies aiming to practice PPI;
- difficult for researchers not experienced in implementation theories to understand and apply (864). This was particularly problematic in my case as I did not have anyone familiar to guide me nor a facilitator for using it, as the framework recommends.

12.2.4. Consolidated Framework for Implementation Research (CFIR)

This framework builds on PARIHS, to also consider barriers and enablers of the whole process of doing research. As in the previous case, successful implementation is defined as an outcome and particular attention is given to what works, where and why. In

this case, the focus changes from on the experience and skills of those doing research to the research itself.

However, this framework has not been validated nor evolved over time since it was proposed in 2009, and thus would not suit the level of rigour desired for the analysis this case study.

12.2.5. Theoretical Domains Framework (TDF)

The Theoretical Domains Framework is a holistic framework used to analyse behaviour and motivations for change. It is a very comprehensive framework since it was built by synthesizing 33 theories and 128 key theoretical constructs through expert consensus. The current 14 domains of behavioural determinants thoroughly scope current scientific accounts for human behaviour (i.e., 'Knowledge', 'Skills', 'Social/professional role and identity', 'Beliefs about capabilities', 'Optimism', 'Beliefs about consequences', 'Reinforcement', 'Intentions', 'Goals', 'Memory, attention and decision processes', 'Environmental context and resources', 'Social influences', 'Emotion' and 'Behavioural regulation'). Consequently, this integrative framework can replace individual behaviour change theories.

TDF states a list of factors that could determine a behaviour rather than an explanation of how change occurs,(868) that is, it “provides a theoretical lens through which to view the cognitive, affective, social and environmental influences on behaviour”.(869)

The framework includes personal values and also organizational dynamics as factors of implementation that are considered in a pragmatic and straight forward manner. The initial publication (619) included sets of questions based on each domain in the

framework that can be used in identifying and understanding each aspect of the process, that I could consider when going through my notes to associate my observations to each domain.

This framework has been used commonly to code interview data to analyse barriers and enablers for interventions. This would give me the chance to reflect back on the findings from the first part of my work and see similarities and discrepancies between the constructs emerging from the case study and those in the interviews.

The TDF is not only coherent and comprehensive but can also be linked to a model of behaviour, as it can be mapped to the Wheel of Behaviour Change. This would be useful to map the domains to concepts around capacity, opportunity and motivation linked to specific functions and related policies. This could be useful at later stages to suggest ways to move forward and drafting recommendations for future research studies willing to introduce PPI.

Last but not least, my choice was further strengthened because a senior research fellow in my department is familiar with this framework and has previously used it in her work.⁽⁸⁷⁰⁾ The possibility of having her support when using it made me finally decide on using TDF for reflecting on this case study.

13

THE “PPI HAWKER”: AN INNOVATIVE METHOD FOR PATIENT AND PUBLIC INVOLVEMENT (PPI) IN HEALTH RESEARCH

13.1. Plain English Summary

Public involvement in research is defined as research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them. The aim of this paper is to describe and evaluate a new public involvement initiative, the “PPI Hawker”. This event creates a space in an Asian context for the public to comment on health-related research.

“PPI Hawkers” are a modification for Singapore of the PPI Café where the public are invited by baristas” (researchers, public facilitators and PPI facilitators) to enjoy a drink in exchange for commenting on research issues about which the public’s perceptions and comments were needed. The PPI Café’s ‘guests’, write down their comments and these are collected for later analysis. In Singapore, hawker centres, also known as food courts, are used more than cafés, and are frequented by a wide range of people. In “PPI Hawkers”, a team of facilitators joined people at their table to discuss questions of relevance to a local research study. During the encounters one facilitator introduced and guided the conversation in the appropriate local language while a second made notes about the discussion.

During three “PPI Hawkers”, we engaged 72 members of the public in discussions about a population-based research study. The people sharing their views came from three different ethnic groups and were from a broad range of ages. Both researchers and the public recognised the usefulness of this method to facilitate informative conversations which highlighted perspectives not previously heard by the researchers.

We were able to demonstrate that “PPI Hawkers” are effective in Singapore for involving lay people in discussions about research. This method facilitates co-informed conduct of research studies with diverse members of the public and requires few resources or preparatory time. We think this method of PPI may work well in other Asian countries too.

13.2. Background

Patient and public involvement (PPI) in research is defined as research that is carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them. Although PPI is a common component of health research in Western countries, such as the UK, Australia and Canada (33,34,37,98,257), PPI is still in an early stage of development in Asian countries, including Singapore (516). It is recognised that PPI enhances the quality and relevance of the research, and its impacts are greater when implemented early in the research cycle (25,85,642). If Singapore wishes to remain at the forefront of Asian health research, public involvement in health research must be cultivated, with public perspectives being heard and their concerns addressed.

Often when PPI is in its infancy, a few selected public collaborators are invited by the researchers to engage in a two-way conversation (871). These same individuals may contribute repeatedly during the research process and also return for future studies led by the same team. Whilst this model of involvement is strong on continuity, it generates concerns about tokenism. There is a risk that the public contributor remains as a “thinker

at the edges” (297,498). Other PPI initiatives strive for greater diversity in involvement, whilst some focus on greater levels of public impact (88,872). Public involvement is a complex and diverse endeavour; each PPI approach has its merits and their appropriateness varies according to the characteristics of the study (for example, research question, study design, resources available and skills of lay-researchers (147,225,873,874).

Recent PPI developments have focussed on ways to include disadvantaged communities in these “privileged” spaces, recognising it is often vulnerable people who have the greatest health needs (159,871,875). PPI Cafés are an example of such developments, whereby the characteristics of a “science café” and a PPI workshop were blended. A “science café” is where scientists and science professionals are invited to speak in a casual non-academic setting where everyone can learn and discuss the scientific issues of the day in science and technology, generally for the price of a cup of coffee or a glass of wine (876). In contrast, PPI workshops a formal, organised training sessions for researchers wanting to learn how to involve lay people in their research activities and for members of the public wishing to familiarise themselves with research and PPI ²². The PPI Cafés borrow from the science café the casual setting and conversational style and from the PPI workshops learning objective to create an opportunity for the public to have learn about PPI as they contribute to the development and refinement of a real-life research project.

The first PPI Café was piloted at the 2018 Imperial Festival(647), a science festival for the public organised by researchers at Imperial College London. The public were invited to join the “baristas” (researchers, public facilitators and PPI facilitators) for a drink in a space customised to look like a café (647). Tables were dedicated to different research studies, and at each table a facilitator introduced the research study before the researcher asked about their ‘guests’ perceptions and comments on specific issues. Guests were encouraged to write down their comments and leave them in a container in the centre of each table.

In Singapore cafés are not as common as in Western countries, but hawker centres, also known as food courts, (shown in Figure 50 Figure 50 Photograph of Serangoon Gardens Market & Food Centre. Photo Credit: Cynthia Chew (882)) are used frequently for eating and socialising. In hawker centres, seating facilities are shared and a complete meal can be enjoyed at one table with each course taken from different vendors. This differs from the Western context, where only food and drink purchased from that vendor can be consumed on the premises exclusive to the vendor. Hawker centres are also more accessible, both physically and financially, to a wider sector of society than cafés. Described as “Singapore in a nutshell” (877), they provide a one-stop destination for everyone, offering a wide choice of high-quality food at inexpensive prices (meals are priced at S\$3-4 and a local drink costs about S\$1.5 (878)). Open from 7 AM to 10 PM and managed by the National Environment Agency, hawker centres are typically found near public housing estates or transport hubs. The 15,000 food stalls (879) serve the majority of the 5.64 M people living across the country (880). Hawker centres are so integral to Singaporean life that in March 2019, the Singaporean government nominated hawker culture for UNESCO listing of the Intangible Cultural Heritage of Humanity (881).

Figure 50 Photograph of Serangoon Gardens Market & Food Centre. Photo Credit: Cynthia Chew (882)

To date there has been little attention to the inclusion of PPI in research conducted in Asian countries. Currently in Singapore the role of the public is almost exclusively

limited to taking part in research. While the benefits of public involvement and co-production are well established in the literature (14–23,25–27,84), methods for an Asian context have yet to be explored. Here we describe the “PPI Hawker”, an adaptation of the PPI Cafés used in Western cultures. The “PPI Hawker” was designed to enable the Singaporean public to share their personal perspectives relevant to a local population-based study (described in Box 1) in an informal environment throughout the country. This article shares our experiences of developing and conducting “PPI Hawkers”.

Box 1: Overview of the population-based study

This population-based study, coordinated by Lee Kong Chian School of Medicine in collaboration with the National Healthcare Group (Singapore) and Imperial College London, was established to identify the genetic and environmental factors that underpin the development of chronic conditions, such as obesity, diabetes, and cardiovascular disease, in Singapore. Ultimately, the goal is to use this knowledge to develop novel ways of predicting, preventing, detecting early and treating chronic diseases in Singapore.

The genetic and medical predispositions differ between population, and to date similar studies have been conducted in the US, UK and Germany. However, 60 per cent of the world’s population do not have European heritage and this biobank will improve the understanding of disease predispositions in South East Asians. The phenotypic, physiological and biological

13.3. Methods: “PPI Hawker” as a PPI Method In Health Research

13.3.1. Towards an Asian friendly PPI Café

Conceptually, the “PPI Hawker” was designed to be similar to the PPI Café. We envisioned the “PPI Hawker” would reduce the hierarchies between researchers and the public, enabling a two-way conversation, which could facilitate the sharing of knowledge and improved relevance of research studies. Through short and informal conversations, the “PPI Hawker” was created to bring together members of the community (past, current, and future patients and their caregivers) with researchers, reducing the boundaries between non-experts and experts. The design of “PPI Hawkers” would encourage recognition of complementary expertise by positioning lived experiences and personal perspectives at the same level as expert knowledge. Like for the PPI Café, organising the discussion in a setting familiar to the public would facilitate discussion, encouraging ideas to be explored in spontaneous conversation, building trust between lay people and researchers.

13.3.2. Designing and testing the feasibility of the “PPI Hawker”

To progress the design of the “PPI Hawker”, we formed a development team with a coordinator, two PPI Leads with experience of conducting PPI Cafés in the UK, a researcher from the population-based study (Box 1) and a Singaporean resident. The coordinator was a Spanish doctoral student, exploring the potential for PPI in Singapore

(LLP) and the two PPI Leads were from Imperial College London's Patient Experience Research Centre (PERC), UK with extensive experience of PPI. Other members of the team were an Asian post-doctoral researchers from the study population-based study and a Singaporean resident, an engineer who was interested in PPI.

Adaptation of the PPI Café to the Singapore context required more than just change in location: the multi-ethnic community required us to consider how we would facilitate, and record discussions conducted in several languages. We decided to work organised in such a way as to maximise the local languages available for discussion (Mandarin Chinese, Cantonese, Malay and Tamil). Note taking was always in English as this is the *lingua franca*, that is the language adopted as a common language between speakers whose native languages are different. By documenting in English, the one common language between the speakers of many different languages in Singapore, our documentation was accessible to all facilitators and researchers.

In taking the PPI Café (Figure 51) into the Singaporean context we wished to retain the informal atmosphere but to use the more open, non-institutional and public space of a Hawker Centre. We transferred the idea of using members of the public as facilitators, involving researcher from project, offering participants refreshments (but not making them ourselves), and facilitating in pairs. We dispensed with displaying research materials, but we added the use of cue cards to aid round table discussion (Figure 52). Participants were also able to refer to a card briefly summarising the study's aims and methods, to reinforce the initial oral explanation. One facilitator introduced and guided each conversation, using their local language skills whilst the second facilitator documented the discussion.

Figure 51 Design of the “PPI Hawker”, building on the PPI Café

Figure 52 Example of cue card containing a question and prompts for the “PPI Hawkers”

Having piloted the first “PPI Hawker” as a team of five, we subsequently worked as four (“PPI Hawker” coordinator, researcher from the study, and two public facilitators). The first public facilitator was the same one as in the development team; the second one was an early career scientist who wanted to develop her communication skills with the public and who studied in the same university where LLP is conducting her doctoral studies. None of them had been previously involved in research and they facilitated the

“PPI Hawker” on a volunteer non-paid basis. The public facilitators were selected for their language skills (speaking English, and one or more local official languages: Mandarin, Malay and Tamil), their comfort engaging with the public and an interest in research. They were briefed on the research study objectives and the issues the researchers wanted the public to consider. Before going to the Hawker Centres the team used role play to familiarise themselves with the cue cards and how to focus discussion on those topics.

Although LLP coordinated the event, all four facilitators had equal roles and voice during the whole event.

A step-by-step guide to the “PPI Hawker”

The ten stages in organisation of the “PPI Hawker” are summarised in Figure 53. Such an event starts with a group of researchers willing to seek the lay perspectives in a “PPI Hawker” and to collaborate with a group of facilitators for it. A facilitator familiar with PPI would then work with the study team to come up with topics and questions about which a public perspectives would be valued (Step 1). The facilitation team is then formed, including a representative from the research study and at least two members of the public able to converse in local dialects and comfortable talking to new people (Step 2). Deciding on a suitable venue for the event attention must be paid to the ambience, a relaxed atmosphere in a place frequented by a diverse population and the time envisaged for the “PPI Hawker” (Step 3). As a team the facilitators need to refine the phrasing of the questions (Step 4) and then practice using role play how best to approach people in the hawker (Step 5).

When the “PPI Hawker” event takes place it is advisable for the facilitators to work in pairs (Step 6) to approach people already sitting at a table, either alone or in a group, to introduce them to the study and the aim of the “PPI Hawker”. In our case, the coordinator paired with a lay facilitator, whilst the researcher paired with the second lay facilitator. Once verbal consent is obtained, the discussion of the PPI questions begins with one facilitator managing the discussion and the other documenting the conversation (Step 7).

As hawker centres are generally frequented by large crowds, not everyone will be approached, instead the facilitators select based on whether people are already engaged in conversation, appear to be leaving soon or are from the demographic group targeted.

Figure 53 The ten stages in organisation of the "PPI Hawker"¹⁰

To document the conversations, one of the researchers listed down the main points discussed for each of the questions. After each "PPI Hawker", the main issues brought up by participants were summarised each facilitator reflected on their interactions with the public, documenting difficulties encountered, for example engaging the public in conversation around a particular aspect of the research (Step 8).

¹⁰ In preparing for this series of 10 stages, attention has been paid to the UK Standards for Public Involvement in Research(883)

The findings were presented to the research team orally and in a report for them to discuss and agree what adjustments should or could be made to the study (Step 9).

When conducting “PPI Hawkers” the note taking is not routinely verbatim. However in this development and feasibility phase we captured exactly what members of the public offered as feedback on their experience of taking part in the “PPI Hawker”. Facilitators also noted of the number of people sitting at each participating table, together with their observations on demographic characteristics (gender, age and ethnicity) and the attitudes of everyone taking part; this data was used for assessing feasibility but not shared with the population-based study’s researchers.

Ethical considerations

In the UK, application for apply for ethical approval to involve the public in the planning or the design stage of research is not necessary(884). Since Singapore does not yet have guidelines for PPI in research, we followed INVOLVE guidelines from the UK. We did not record any identifying information from “PPI Hawker” participants (885).

Criteria for evaluation

Before piloting the “PPI Hawker”, we agreed on the desirable characteristics against which we could evaluate the initiative:

- Feasibility was defined by the capacity to engage members of the public in discussion. Our goals were:
 - at least 50% people approached agreeing to participate,
 - to engage a minimum of 20 participants in each session, at least 10 individuals responding to each of the questions posed by the researchers (the questions from each session are listed in Appendices 1 and 2). This criteria was based on sample sizes commonly used in qualitative research (443,886).

- Acceptability of the “PPI Hawker” was judged by our success engaging with a cross section of the general adult population of Singapore, the target audience for the population based study. We sought representation from diverse ages (20-80) and all major ethnic groups (Chinese, Malay and Indian). To monitor this facilitators made notes about the perceived age of “PPI Hawker” participants and their ethnic group. Acceptability was also assessed by the informal feedback and comments made by participants.
- Utility was the extent to which the public generated ideas were incorporated into the study design by the population-based study’s researchers. Utility was assessed by the researchers’ responses to presentations and written reports about the views elicited by the “PPI Hawkers”.

13.4. Results

13.4.1. The conduct of three “PPI Hawkers”

The “PPI Hawker” Pilot

We conducted three “PPI Hawkers”, the first as a pilot to see if we needed to improve on the design. This “PPI Hawker” was held in November 2018, in Serangoon Gardens Market and Food Centre (Figure 50) and it soon became apparent that inviting participants to join our table as they queued to buy themselves refreshments from the hawker stalls was not going to work (Figure 51). Everyone approached refused to join our table, but instead invited us to join theirs. After a quick discussion, we decided to approach people already sitting and asking if we could join their table. With this amendment, 28 members of the public participated, but all declined the offer of a free drink.

Our preliminary “PPI Hawker” highlighted the need to be clearer when introducing the concept of PPI and describing the overall aims of the research study to be discussed. The need for this additional information became apparent when some members of the public thought we were trying to recruit them to the study rather than ask for their ideas

and opinions. The pilot reinforced the need to work in pairs, with one person documenting the insights shared by members of the public whilst the other facilitated the discussion. To increase the clarity and utility of the documentation we developed a coding system that we could use in subsequent events.

The conduct of two further “PPI Hawkers”

Our first “PPI Hawker” engaged mostly Chinese, so to achieve greater ethnic diversity the two subsequent events were conducted in locations frequented by more Malay and Indian residents (Malay and Indian represent 13 and 9% of Singapore’s population respectively, 74% being Chinese (880)). With our revised method (Figure 51), we were able to approach a further fifty-nine members of the public of whom we engaged forty-four (24 Indian, 13 Malay and 7 Chinese), in short conversations (around 15 minutes per table) sitting at 33 tables (16 in Admiralty and 17 in Tekka Centre).

13.4.2. Achieving our goals

The “PPI Hawkers” exceeded our predefined goals for feasibility, acceptability and utility.

Feasibility: Capacity to engage members of the public

At each “PPI Hawker” more than twenty members of the public were engaged, and within each session most individuals (85%) responded to each of the questions posed (these are listed in Appendices 1 and 2). The “PPI Hawker” concept was well received by the public; 96 members of the public were approached, whilst 72 took part in one of the three sessions. In other words, 75% of those approached at their tables agreed to engage in a conversation with us.

Acceptability: The public's perspective of the "PPI Hawker"

We involved members of all three ethnic groups in Singapore and spoke to adults who appeared to be from a wide age range, confirming accessibility of the "PPI Hawker".

From the public's feedback the opportunity to take part in the "PPI Hawker" conversations was appreciated, supporting "PPI Hawker"'s acceptability. Most members of the public we spoke to were *"happy to give [us their] opinion"* and to informally share with us their thoughts on the "PPI Hawker". Participants enjoyed *"feeling helpful"* contributing to something that would benefit their community. They felt that by meeting in the familiar space of the hawker centres, researchers lost *"their authoritarian attitude"*. Moreover, they recognised that *"researchers don't know [our needs and wants], we have to tell them"*. The format of the "PPI Hawker" as an involvement method for Singaporeans was widely supported; participants valued its concise and one-off nature, because of the pressures on their time and no wish to talk about research on a regular basis. One member of the public finished their conversation with us by thanking us for meeting the public: *"You are doing a very good thing for people [coming to ask for people's perspectives at the hawker centre]. I have to appreciate"*.

Utility: Population-based study's researchers' feedback

Results of the "PPI Hawker" were presented to the study's Steering Group, composed of the 6 Study Principal Investigators, the Operations Manager, the Recruitment Manager and occasionally other researchers from the team. The Steering Group's response to the feedback from the public about their population-based study was encouraging, and they expressed the need to continue with the "PPI Hawkers" to also understand the views of populations from different neighbourhoods. The researcher involved as a facilitator commented on how *"The public's opinion are very diverse, and I learnt that if you spend the time to listen to public, there are many things that you can learn."*

People are generally willing to help, and their feedback will only make our research stronger!" With subsequent "PPI Hawkers" her appreciation of their value was strengthened by observing the hidden knowledge within different communities. She commented: *"An eye opener, certainly I could see the totally different perspective from those of lower socio-economic classes about research health screening"*.

The discussion of the feedback from participants prompted refinements to the "PPI Hawker" including more consistency in the terminology used. For example, while some facilitators had used the word "confidentiality" others had used "anonymity" when discussing data sharing issues. This inconsistency made the PPI feedback less useful as it was not always possible to know which term the public were responding to. As a result, we agreed facilitator's should only use the terminology on the cue cards and would always explain any technical terms before engaging in discussion.

Examples of how PPI impacted on the design of the population-based study can be found in the box 2 below. Researchers considered the feedback provided by "PPI Hawker" participants for all questions and intend to incorporate some aspects for each of the issues discussed. Some of those have already been operationalised, as discussed in box 2.

Box 2: Impact of the “PPI Hawkers” on the population-based study design

After the “PPI Hawker” Pilot, members of the Steering Group were receptive to the public’s suggestions to allay concerns about data security by sharing more information on how participant data is stored and by requesting additional consent for data sharing with commercial collaborators (Question 1), to consider how the research data could be incorporated into the individual’s health records (Question 2) and to regularly update participants on the study’s progress (Question 3).

After the two subsequent “PPI Hawkers” the researchers on the population-based study introduced a number of changes to the research process in response to the public’s comments and support. Researchers began establishing new recruitment strategies, by formalising agreements with various employers (Question 1) and setting up a community Advisory Group to provide regular and more detailed advice on matters arising as the project progresses. (Question 3). Further changes included amendments to the informed consent form:

- i) An improved explanation of the term 'incidental findings', using simpler terms and detailing the pros and cons of being informed of these abnormal results.
- ii) Giving study participants the option to decide whether they would like to have their incidental findings communicated to them or not (Question 4).
- iii) Including a question relating to data sharing. It was decided to offer research participants at initial recruitment the opportunity to choose who in the future their data could be shared, thus negating the need to recontact them (Question 2). The four options to select from are (i) Universities/ academic institutions, (ii) Health institutions, (iii) Government institutions and/or (iv) Commercial bodies.

13.5. Discussion

13.5.1. Summary

In three “PPI Hawkers” we were able to engage 72 members of the public in discussions about issues the researchers of a population-based study wanted the public’s perspective. This novel approach of involving lay people on research-related matters achieved an engagement rate of 75%. Participants came from the three main ethnic groups in Singapore and appeared to be broad in age. Since the hawker centres are spaces visited by almost all Singaporeans, this PPI method facilitates engagement with a broad sector of society in different neighbourhoods. Using short one-off conversations in their

mother tongue in a familiar environment the majority of participants were willing to discuss all of the questions posed by the researchers. Researchers recognised the utility of the “PPI Hawker”, reflecting on people’s willingness to consider research issues, engaging in informative conversations and ask relevant questions. During these conversations, facilitators observed the traditional barriers between experts and non-experts being broken down, leading to mutual respect and sharing of ideas.

PPI facilitator’s experience

Facilitators observed how the informal setting allowed members of the public to talk openly and freely share personal experiences. This relaxed environment allowed us to approach audiences unfamiliar with research, where they felt able to contribute and also to ask questions about other topics beyond those suggested by the researchers. Facilitators were encouraged by their experiences of the “PPI Hawkers”, and highlighted the feasibility and accessibility of this method of involvement in the Singaporean context.

The reflexive notes of the “PPI Hawker” team were universally encouraging, sometimes describing characteristics that exceeded expectations:

“I was surprised by how most people were receptive and keen to discuss the project with us. Singaporeans are often zealous in the protection of their privacy and are reluctant to share their opinions. However, those we interacted with were willing to talk at length about the issues, curious about the research, and seemed to enjoy the experience” (“PPI Hawker” co-ordinator).

One facilitators recorded how the public’s initial hesitancy to be involved was quickly transformed into engagement:

“People were apprehensive when we first approached them (like we were going to sell something/ask them for something/like we were disturbing quiet, family time) but once it was clear we just wanted their OPINIONS, the conversation flowed quite effortlessly. I was surprised to see them have so much to say, so much to contribute to each of the questions asked. The public are not as oblivious or ill-informed as some may think, they may not be

researchers but everything that was said made perfect sense and was of great value. We could not have predicted those responses or gotten a more honest feel for their perception of research in general or the barriers and facilitators to research if we did not sit down and talk to them in person, in a natural setting as we did today.” (Public facilitator, reflecting on sessions #2 and #3)

13.5.2. Advantages of the “PPI Hawker”

The “PPI Hawkers” have the potential to be used more widely for PPI in Singapore, and potentially in other Asian contexts. This approach to PPI has identified two major attributes:

Firstly, the “PPI Hawker” reduces communication barriers, making it easier for researchers to interact with the public and vice versa. The process of the public inviting researchers to join them at their own tables appeared to enable the public more control over the encounter, and guide the amount and direction of the discussion. These conversations become opportunities to share knowledge and work together to improve the research design. We observed within the “PPI Hawker” dialogue, reciprocity, openness and respect, enabling thoughtful communication between the facilitators and the public.

Secondly the “PPI Hawker” reduces the barriers between experts and the public, flattening or reversing the pyramid of hierarchy (887). Conventionally lay people are reluctant to challenge perceived expertise (106,481), but the round table discussions appeared to generate mutual trust, and a willingness for the non-expert to comment, critique and challenge the research. Such exchange is often difficult to achieve in very hierarchical societies, like Singapore (106,511) but the “PPI Hawker” appears to achieve this by the development of a collective consciousness.

13.5.3. Effective and efficient use of resources

PPI is often characterised as a time and energy intensive activity, and it can be this that deters researchers' enthusiasm and engagement for PPI (516). The "PPI Hawker" addresses some of these concerns as it does not require the administrative burden or the expenses of sending out invitations, hiring a venue or transport for participants. However, it does require time for the initial planning (a one-off activity), and then the conduct of each "PPI Hawker" and the collating of ideas. In our experience the time spent planning preparing and training for the project-specific PPI was 10 person hours in total. Each "PPI Hawker" required 2 hours of facilitators time (including a 30-minutes briefing in advance). The final collation of comments and summarising them for the research team required a further 8 hours of the coordinator's time and 1 hour for each of the other facilitators' time.

13.5.4. Limitations and strengths of the "PPI Hawker"

A challenge for PPI globally is the need to hear a wide diversity of perspectives. Increasingly more groups have been empowered and are being heard, but some groups still remain at the margins. Reluctance to participate in PPI (516) is known to be more challenging to those with poor research knowledge, lower literacy and limited oral skills, characteristics often seen within those sub-populations who have the greatest health needs. We found the presence of the public facilitators was particularly helpful with developing trust, for example with the Indian population an introduction in Tamil defused feelings of being caught in an unfamiliar situation to inclusion in a conversation in which they were central.

"PPI Hawkers" offer a helpful solution to this challenge, but they are not without their limitations. For example, it is recognised that long-term involvement throughout the different stages of a research project increases the impact of PPI (25) but the "PPI Hawker" is a one-off encounter. Not collecting personal and demographic data from participants makes it difficult to characterise them exactly. For example, we wanted an

ethnic mix and used appearance to identify the ethnic group of participants. Using appearance may not always be adequate, for example if one wishes to target people of a specific age, sexuality, marital status or income group. Lastly, the “PPI Hawker” may not be appropriate for all types of research, including studies about sensitive topics or complex studies where substantial background and explanation are needed before the public are able to comment.

Finally, alongside positive aspects of the “PPI Hawker”, some negative views were also noted. Around a quarter of members of the public approached wanted to be “left alone”, others wished to discuss topics not related to the research study (for example, digressing to complain about the government). However, only one individual responded with some aggression, sharing their dogmatic beliefs about medicine. None of our offers of a drink were accepted, and occasionally a participant expressed mild offense when offered a free drink, they considered it as too small a token of appreciation, because it was something that they could easily afford for themselves.

We have demonstrated the feasibility of the “PPI Hawkers”, a novel approach suitable in a non-western culture, complementing widely used PPI Cafes and User Groups. Although our experience is currently confined to Singapore we anticipate that this model of involvement would be applicable to other Asian countries where the traditional concept of public food markets are also commonplace.

As a potential refinement of the “PPI Hawkers” may be the use of some advanced publicity of the event, rather than descending unannounced on diners. This may have reduced the suspicion some people expressed and confirm our legitimacy. We are also keen to explore in the future whether the “PPI Hawker” could be an avenue for dissemination of research findings, an under-developed aspect of PPI (205). Research findings continue to be shared conventionally, disseminated in academic environments (for example, conference presentations, journal papers and academic books) and far less through channels easily accessible for the public (for example, public exhibitions, podcasts and blogs). “PPI Hawkers” may be an effective way to increase the public’s

awareness of the findings of health-related research that could impact on their lives. The feasibility of this needs further exploration and piloting.

13.6. Conclusion

This study has demonstrated how the “PPI Hawker” aligns with the ethos of public involvement in research. It has the potential to be the major model for PPI initiatives in Singapore, facilitating knowledge exchange in community spaces accessible to a wider number of people. Further feasibility studies are needed to confirm the “PPI Hawkers” utility when used to discuss studies in different topic areas and with different methods, but preliminary findings are encouraging.

Appendix A: Questions for the public in the “PPI Hawker” Pilot

1. If you were a participant in the study...
 - What would be needed for you to be reassured that your personal data is being protected?
 - What types of information are acceptable to collect from people participating?
 - Would it be acceptable for anonymized data to be shared with:
 - Other health care professionals in Singapore?
 - Industries in Singapore?
 - Overseas organisations?
2. Increasingly health records are being digitalized: in theory personal health records and the research study could be linked, and data shared...
 - What do you think the benefits could be of such data linkage?
 - What concerns might you have of researchers from this study accessing (*taking data*) your electronic health data or contributing (*providing data*) to your electronic health data?

3. If in the future this study asked its participants to return for further data collection...

- What concerns might people have about continuing involvement?
- How could these concerns be reduced?

Appendix B: Questions for the public in “PPI Hawker” Sessions 2 and 3

1. If you were to be recruited for this study...

- What would be attractive in this study?
- How would you like to be recruited?
- What concerns would you have about it?
- How could these concerns be addressed?

2. Research records are anonymised, so the researchers don't know participants' names and personal information. The information researchers work with is called anonymised research data.

- How would you feel if your anonymised research data was shared with:
- Other healthcare professionals in Singapore?
- Other researchers in Singapore?
- Public institutions in Singapore?
- Commercial partners in Singapore?

Then ask the same for overseas.

3. The study has a commitment with the communities it serves and would like to engage its participants further, even after their visit. Previous participants are part of the study “family”, and we want them to feel included. By building long-term partnerships with them they can advise on how to develop the study and share their expectations.

- Would you like to be engaged with the study after your visit?
- If so, how often? For how long? With whom?

4. 10 years after the study has finished, researchers find a gene in a research participant which might indicate increased risk of cancer later on in life (this is known as an incidental finding). However, treatment for this cancer still does not exist.

- Do you think the study should track back the participant and inform them of this finding?
- Would you think differently if there was some form of treatment available?
- Do you have any concern/ anxiety knowing that this could happen?
- What sort of incidental finding do you think should be reported back to participants?

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