



**Facilitators and barriers to implementing Patient  
Reported Outcome Measures (PROMs) in wellbeing  
activities delivered by third sector organisations**

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## List of abbreviations used

AOC- Alicia O’Cathain- primary PhD supervisor

ASCOT- Adult Social Care Outcomes Toolkit

CFIR- Consolidated Framework for Implementation Research

CBPR- Community-Based Participatory Research

ePROM- Patient Reported Outcome Measures which are collected electronically e.g. via a tablet

HRA- Health Research Authority



IPA- Interpretative Phenomenological Analysis

JH- Janet Harris- PhD supervisor

LC- Liz Croot- a fellow researcher who supported the systematic review of reviews

MYMOP- Measure Yourself Medical Outcomes Project

NEF- New Economics Foundation

NHS- National Health Service (United Kingdom's healthcare system)

NIHR- National Institute for Health Research (funders of the PhD)

ONS-4- Office for National Statistics 4 Wellbeing Questions

PhD- Doctor of Philosophy (the qualification being undertaken)

PPI- Patient and Public Involvement

PREMs- Patient Reported Experience Measures

PRISMA- Preferred Reporting Items for Systematic Reviews and Meta-Analyses

PROMs- Patient Reported Outcome Measures

PROSPERO- International prospective register of systematic reviews

QI phase- Qualitative Interview phase

REM- Ripple Effects Mapping

ReQoL- Recovering Quality of Life- A mental health outcome measure

ROBIS- Risk of Bias in Systematic Reviews

SchARR- School of Health and Related Research

SWB- Subjective Wellbeing

SWEMWBS- Short Warwick Edinburgh Mental Wellbeing Scale

TSO- Third Sector Organisation

UK- United Kingdom

USA- United States of America

WEMWBS- Warwick Edinburgh Mental Wellbeing Scale

## Abstract

### **Background**

Third Sector Organisations (TSOs), also known as charities and community groups, deliver health and wellbeing improvement activities including social prescribing. TSOs use Patient Reported Outcome Measures (PROMs) to demonstrate whether service-users' wellbeing improves when attending activities.

### **Aim**

To identify the facilitators and barriers to implementing PROMs in TSOs delivering wellbeing activities.

### **Methods**

A sequential mixed methods design including: (1) A systematic review of reviews identifying the facilitators and barriers to implementing PROMs within healthcare services. (2) A Qualitative Interview phase involving 30 interviews with TSO managers, front-line workers, service-users, and commissioners to explore their perceptions of implementing PROMs. (3) A Community-Based Participatory Research phase, which involved supporting two TSOs to implement PROMs and learn from their experiences. This included four group participatory events, five key informant interviews, analysis of a reflective diary, and statistical analysis of 324 collected PROMs. A triangulation protocol approach was used to integrate the findings and to inform guidance for TSOs.

### **Findings**

TSOs were primarily using PROMs to secure funding. Despite this motivation, organisations struggled with implementation. Facilitators included having a proactive Implementation Lead, accessing support from external advisors, involving front-line workers in choosing a PROM, investing resources and time into implementation, providing front-line workers and volunteers with sufficient training, and having an 'embedding' period to provide time to reflect on and develop the PROMs process. TSOs faced significant barriers including difficulties identifying suitable measures, a lack of infrastructure and staff capacity to support the collection and analysis of PROMs, and perceptions that their wellbeing activities were not amenable to measurement.

### **Conclusions**

The need for funding incentivises TSOs to implement PROMs. However, TSOs face considerable barriers, many of which are related to the characteristics of the third sector.

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I have been fortunate to have undertaken my PhD in the supportive environment of ScHARR. My colleagues have provided me considerable practical and emotional support. This includes fellow researchers and the central resources team/administrators especially Veronica Fibisan who was always willing to help despite having her own thesis to deal with!

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Alexis Foster, April 2020

## Chapter 1- Introduction

### (1.1) Outline of the chapter

The focus of the thesis is on the implementation of Patient Reported Outcome Measures (PROMs) within third sector organisations (TSOs) delivering health and wellbeing activities. Specifically the steps an organisation needs to undergo between deciding to use PROMs and using them within routine practice (Nilsen, 2015). In this chapter, I provide a summary of the topic before giving an overview of the research design and my role within it.

### (1.2) The focus of the research

#### (1.2.1) Third Sector Organisations

Third Sector Organisations (TSOs) are viewed as an important component in the delivery of health and social care within the United Kingdom (UK) (Hardwick et al., 2015). The UK's statutory sector including the National Health Service (NHS) and local authorities spend over £2.1 billion annually on health and wellbeing related services delivered by TSOs (NCVO, 2019a). Furthermore, the third sector is viewed as integral to elements of current UK health policy such as delivering social prescribing through the NHS Link Worker programme (NHS, 2019).

Generally TSOs are defined as organisations which are formally organised, non-profit making and value driven and that operate in a unique space outside of both the state and profit-making organisations, hence the term 'third sector' (Curry, 2010). Globally, different terms have been used to describe these types of organisations including TSOs, charities, voluntary organisations, community organisations, non-governmental organisations and not-for-profit organisations (Bach-Mortensen and Montgomery, 2018). The term TSOs is used within the thesis because it is commonly used within academic literature in the UK.

I specifically focused on UK based TSOs that deliver health and wellbeing activities, subsequently known as wellbeing activities. Whilst diverse in their nature, the focus of wellbeing activities is on preventing ill health and addressing the social determinants of health (Bull et al., 2014). For example, if a person is experiencing depression exacerbated by financial issues, a TSO may provide the individual with debt advice and support them to attend the organisation's community allotment and craft group. Examples of TSO delivered wellbeing activities include advocacy services, lifestyle coaching, social prescribing, healthy eating classes, confidence-building courses, social cafés, community allotments and knitting groups.

TSOs often fund their wellbeing activities through gaining short-term contracts from statutory services or grant making organisations. Consequently, organisations are continually having to demonstrate their impact to current and future commissioners to justify their funding (Harlock, 2013). One method used to evidence impact is Patient Reported Outcome Measures (PROMs), but there is little guidance available to support TSOs with implementing PROMs.

#### (1.2.2) Patient Reported Outcome Measures (PROMs)

PROMs are defined '*as questionnaires that measure patients' perceptions of the impact of a condition and its treatment on their health*' (Greenhalgh et al., 2014, p1). PROMs consist of a number of questions concerning a person's health, wellbeing or symptoms of a condition and usually an overall score is produced (Kyte et al., 2015). If a person completes a PROM at two or more different time points then it can be ascertained whether their health, symptoms or wellbeing has improved e.g. before and after they have received a specific healthcare intervention (Devlin and Appleby, 2010). Examples of measures include the EQ-5D-5L (Herdman et al., 2011), the Warwick Edinburgh Mental Wellbeing Scale (WEMWBS) (Maheswaran et al., 2012) and Recovering Quality in Life (ReQoL) (Keetharuth et al., 2018).

TSOs are increasingly trying to use PROMs (Nathoo, 2017). For example, as part of the national Health Trainer programme, organisations had to collect specific PROMs (Mathers et al., 2016). However, organisations can struggle with using measures within wellbeing activities, illustrated by low completion rates (School of Health and Related Research, 2019).

### (1.2.3) Implementation

Research on PROMs has primarily focused on developing new measures or the impact of using PROMs on service delivery but there has been relatively less research on implementing measures within services. The studies which have been conducted were primarily focused on healthcare services such as palliative care (Antunes et al., 2014) and oncology (Howell et al., 2015) and it is not known how transferable their findings are to the unique context of TSOs. Consequently, there is a need for specific research on implementing PROMs within the third sector. Alongside the lack of research, TSO stakeholders want further support with implementing PROMs. When I was developing the idea for a Doctorate in Philosophy (PhD), TSO managers, front-line workers, commissioners and service-users identified a number of challenges with using PROMs in practice and wanted more guidance. Given this, I decided to undertake research focusing on implementing PROMs within TSOs.

## (1.3) Research aims and objectives

### (1.3.1) Aim

The aim of the research was to identify the facilitators and barriers to implementing PROMs in wellbeing activities delivered by TSOs.

### (1.3.2) Objectives

- (1) Undertake a systematic review of reviews to identify the existing knowledge base on the facilitators and barriers to implementing PROMs within organisations delivering health and/or wellbeing related services, irrespective of the type of provider.
- (2) Identify the facilitators and barriers to implementing PROMs within TSOs delivering wellbeing activities through interviewing stakeholders about their perspectives and experiences of using PROMs.
- (3) Understand the issues arising in practice when implementing PROMs in wellbeing activities through using Community-Based Participatory Research (CBPR) to support two TSOs to implement PROMs.
- (4) Integrate the findings from the different phases to develop guidance suitable for TSOs and commissioners on implementing PROMs within wellbeing activities.

#### (1.4) Design of the PhD

A sequential, qualitative-dominant mixed methods study was undertaken to fulfil the objectives (Creswell and Plano Clark, 2011). This firstly entailed conducting a systematic review of reviews exploring the literature on implementing PROMs. Secondly a Qualitative Interview (QI) phase was undertaken which involved interviewing people from different interest groups. Thirdly, a Community-Based Participatory Research (CBPR) phase took place to support two TSOs to implement PROMs and learn from their experiences. The CBPR phase combined both qualitative methods such as key informant interviews and quantitative analysis of collected PROMs data. Finally, integration was undertaken to synthesise the findings of the different phases of the research through using a triangulation protocol approach and holding an integration event with stakeholders. Undertaking integration enabled me to identify the pertinent issues to include in guidance aimed at supporting TSOs and commissioners with implementing PROMs.

#### (1.5) Terminology and voice used in the PhD

Language is important within the PhD both in terms of the words used to describe concepts but also whether I wrote in the first or third person. Different terminology is used within the third sector compared to health services. For example, the descriptor of ‘patients’ is often used within health services whereas within the third sector, terms such as ‘service-user’ or ‘clients’ are used to describe the person attending wellbeing activities. Thus the term ‘Patient Reported Outcome Measure’ does not fit with the language of the third sector. However, I use the term PROM because within academia there is a shared understanding of what PROMs are and how they may differ from other types of outcome measures. I do this with the awareness that ‘Patient’ could be substituted with ‘Person’, as in Person Reported Outcome Measures. I mainly use TSO-centered terminology within the PhD. The exception is in Chapter 3, because I wanted to be authentic to the language used by the authors of the reviews included in the systematic review of reviews. Furthermore I use the term ‘healthcare services’ throughout the PhD to describe organisations and services which are not based within the third sector that deliver services seeking to improve people’s health e.g. primary care and cardiovascular services based in the NHS. Whilst at times there could be overlap between the third sector and healthcare services, such as when third sector

hospices deliver palliative care, the distinction helps to understand how the implementation of PROMs in TSO delivered wellbeing activities compares to the implementation of PROMs within other contexts.

Throughout this thesis, the language moves between the more traditional academic style of writing in the third person and using the first person. I generally write in the third person because this is common within my sub-discipline of applied health research. However, as I developed as a researcher during the PhD I revisited my writing style. I considered the importance of writing in the first person to demonstrate my influence on the study, particularly during the CBPR phase where I was an active part of the research. Moving between the first and third person reflects the wider challenges of language when undertaking mixed methods research within an academic healthcare services research discipline (Johnstone, 2004).

### (1.6) My experience of the third sector and academia

The idea for the PhD arose from my previous experience of TSOs and my desire to have an impact on the third sector through research.

Since being a teenager, I have volunteered and worked in a range of TSOs. These roles have included front-line delivery in wellbeing activities and managerial roles. In the latter roles, I was responsible for supervising front-line workers, collecting and reporting monitoring data to commissioners and applying for funding bids. I have also been a trustee of one TSO. I have been involved in a diverse range of organisations. They differed in terms of the type of service-users they focused on, their size and structure, along with geographical reach. For example, I worked in a small TSO based in one city which supported people living with eating disorders. In contrast, I also managed a carers' support service based in one region which was part of a national TSO.

In 2009, I moved from the third sector to an NHS public health team. My role involved working with TSOs to develop their services and commission wellbeing activities. During this period, I worked with several neighbourhood-based organisations to help develop their wellbeing activities such as social prescribing, exercise classes for women of Somali origin and wellbeing support for Slovak-Roma migrants. Alongside this, I was responsible for commissioning TSOs to



undertake wellbeing activities within specific localities. As part of my NHS role I was funded to study for a Masters in Public Health at the University of Sheffield. This was a wonderful opportunity to develop my research skills and inspired me to move into academia.

Following the decision to work in academia, I gained a research assistant role at the University of Sheffield in 2011. I was involved in studies using a range of methods including qualitative interviews, literature reviews and a Delphi study. The projects entailed partnership working between service-users, clinicians and researchers which developed my interest in co-designing research. Following a promotion, I managed a number of randomised controlled trials focusing on supporting people with longer-term conditions.

Alongside my main roles, I continued developing my interest in undertaking research in the third sector. I undertook a scoping review on social prescribing, which I published in 2015 and presented at conferences. Through the review and additional insights, I identified that some TSOs were trying to use PROMs to demonstrate their impact but struggled with response rates. During the preparatory work for the PhD, it became apparent that commissioners were regularly requiring organisations to use PROMs but gave little support to TSOs to help them implement the measures. I also found that there appeared to have been little research on implementing PROMs within the third sector and that people within the sector together with commissioners wanted some guidance on using measures.

Locally, one of my supervisors: Dr Janet Harris had been developing partnerships with a number of TSOs on strengthening the evidence base about their impact. Part of this work entailed developing CBPR projects on improving evaluation in the sector (Harris, 2015). I worked with Dr Harris to support organisations in the local area with implementing PROMs (explained further in Chapter 8).

Concurrent to this work, I applied and was awarded a National Institute of Health Research (NIHR) Doctoral Research Fellowship in 2016 to undertake a PhD on implementing PROMs within TSOs. As part of the application process, I developed a full research proposal which underwent academic review. When preparing my application, I gained a small grant which enabled me to conduct a range of stakeholder consultation (equivalent to Patient and Public Involvement). This ensured my research ideas were influenced by service-users and other third sector stakeholders such as front-line workers.

## (1.7) Reflexivity

I explain what reflexivity is and why it is important in the methods related chapters and address reflexivity in Chapters 7, 9 and 10 of the thesis. In summary, my demographics and experience influenced how I conducted the research and interpreted the findings. I am in my thirties, white, female and have been university educated. Consequently I would probably be perceived by people involved with TSOs as ‘middle class’ and this may have had a detrimental impact on the rapport developed with some stakeholders. For example, front-line workers may have thought that I was someone who did not understand the challenges facing their communities.

Having worked as both a front-line worker and manager within TSOs, alongside having some commissioning experience enabled me to consider issues from different perspectives. It also helped me to develop rapport with participants because I could demonstrate that I was not an outsider but understood and was passionate about the third sector. However, I was aware that I had not worked in the third sector for a number of years, albeit I have stayed engaged with the sector through attending conferences and working with TSOs.

My personal viewpoint about PROMs is also relevant. I was aware throughout the research that stakeholders may think that I was promoting the use of PROMs in the third sector because of choosing to conduct research on their implementation. However, my position has always been one of pragmatism, in that PROMs are used within the third sector and there is a need for greater knowledge about their use. I have always questioned how valid or useful the data generated from the routine use of PROMs within TSOs is. But I am also aware that quantitative data is wanted by policy makers on wellbeing activities and the use of PROMs is one way of generating this evidence. Furthermore, there is a trend for outcomes-based commissioning within UK statutory services, so the use of PROMs is likely to continue. Given my views, I have tried to maintain a balance between skepticism and passion by emphasising to participants and TSO stakeholders that my reasoning for undertaking the research was to support them with using PROMs.

## (1.8) Timelines of the PhD

I undertook the PhD full time over a three and half year period between 2017 and 2020.

Beforehand, I conducted some preparatory work to inform the development of my application to the NIHR for a doctoral fellowship. Between 2014 and 2016, I developed the idea for the PhD through conducting stakeholder consultation events including running a discussion group with front-line workers and having meetings with service-users. I formally commenced the PhD in January 2017. I undertook the systematic review of reviews during 2017, culminating in a stakeholder event in November 2017. The QI phase took place between September 2017 and December 2018. Finally, the CBPR phase occurred between July 2018 and Spring 2020. The majority of the thesis was written during the final year of the PhD.

## (1.9) Presentation of chapters

The thesis is organised by the following chapters:

- (2) Background to the study
- (3) Systematic review of reviews exploring the implementation of PROMs within healthcare services
- (4) The relevance of the systematic review of reviews to the third sector
- (5) Design of the primary research
- (6) The methods used in the Qualitative Interview phase
- (7) The findings of the Qualitative Interview phase
- (8) The methods used in the Community-based Participatory Research phase
- (9) The findings of the Community-based Participatory Research phase
- (10) Discussion- Integration of the findings of the study, discussion and link to the guidance on implementing PROMs.

## Chapter 2- Background to the research

### (2.1) Outline of the chapter

The purpose of this chapter is to explore the key constructs relevant to the PhD and to justify the need for the research. The chapter provides a detailed overview of TSOs, wellbeing activities and PROMs along with discussion of how relevant terms such as wellbeing and implementation have been conceptualised within the thesis.

### (2.2) Third Sector Organisations (TSOs)

TSOs are a global phenomenon, contributing to supporting the health and social care infrastructure in many countries, particularly helping the most vulnerable in society e.g. people experiencing socio-economic deprivation (Bach-Mortensen and Montgomery, 2018). The research focused on UK based TSOs because logistically that was feasible within the parameters of a PhD.

Within the UK there are over 166,000 registered TSOs (NCVO, 2017), equivalent to more than one TSO per 380 people (NCVO, 2012). TSOs operate in a range of disciplines including health, social care, training, law and advocacy, culture, housing and research (NCVO, 2016). However, these are not mutually exclusive and increasingly organisations deliver a mixed portfolio of services e.g. housing associations providing wellbeing activities alongside housing provision (Buckingham, 2012). This PhD focuses on TSOs which deliver wellbeing related activities, irrespective of what other services an organisation may provide.

TSOs have a number of shared characteristics which make them both structurally and ideologically distinct from other types of organisations (Macmillan, 2010). Firstly, TSOs are organised, so have an institutional reality (Salamon and Anheier, 1997; Alcock, 2010). Secondly, TSOs are self-governing, so are in control of their own affairs and are institutionally separate from the state (Cody, 1993). Thirdly, TSOs are non-profit distributing so any profits are used for social good rather than being returned to owners or directors (Salamon and Anheier, 1997; Crampton et al., 2001). Fourthly, TSOs have a meaningful degree of voluntarism, in that organisations will be reliant on people doing some unpaid work, e.g. unpaid trustees or

volunteers delivering wellbeing activities (Crampton et al., 2001). Finally, ideologically TSOs are considered to be value-driven, want to achieve social good (Crampton et al., 2001) are innovative, and responsive to their users’ needs (Macmillan, 2010; Dickinson et al., 2012; Wilson et al., 2012).

Despite these similarities, the sector has been described as a ‘loose and baggy monster’ (Kendall and Knapp, 1995) because of the diversity of TSOs. Differences between organisations include size, geographical spread, income profile, degree of voluntarism and purpose (Buckingham, 2012). For example in terms of annual income, TSOs range from micro or small organisations with an annual income of less than £100,000 to being large TSOs, with an annual income of over £1,000,000 (NCVO, 2012). Within the UK, the majority of TSOs are classed as micro or small organisations (84.7%), with less than 5% considered to be large or major organisations (NCVO, 2012).

TSOs also vary considerably in terms of their geographical reach. Some organisations deliver services within a specific neighbourhood, whereas others may deliver support throughout the UK. Further detail is provided in Table 1. However, there is some crossover in reach, e.g. a locality-based TSO may be affiliated to a national charity or a neighbourhood-based organisation may be contracted to deliver a specific service throughout the city.

**Table 1- Geographical scope of TSOs**

Type of TSO	Example
Neighbourhood-based	Darnall Wellbeing (based in a specific neighbourhood in Sheffield)
Locality-based- typically serving a whole town/city	St Luke’s Hospice (a palliative care hospice in Sheffield)
Regional	South Yorkshire Housing Association (runs services throughout South Yorkshire)
National	Rethink (a mental health charity which runs services across the UK)
International	Oxfam (delivers services in multiple countries).

TSOs have to generate an income in order to deliver wellbeing activities. The sector relies on different sources of funding including philanthropy (where people donate money to an organisation), trading (e.g. charity shops), grants and contracts with statutory services, including the NHS (NCVO, 2018). The latter two are common funding sources of wellbeing activities. In the case of grants, a TSO will design a wellbeing activity and apply for funding to deliver it. Grants may be provided by statutory services or funding bodies such as the National Lottery Community Fund (National Lottery Community Fund, 2019). In contrast, contracts are instigated by the funding organisation (commissioners). They will prescribe what activity they want delivered for a specific price, and TSOs will apply to deliver the activity. Contracts are usually provided by statutory organisations e.g. local authorities (NCVO, 2018). Alongside grant-giving organisations and statutory services, TSOs may also provide funding to other TSOs (usually smaller organisations) either through their own grant-giving programmes or by subcontracting out some of their service delivery (SOAR, 2018). The term commissioners is used within the thesis to describe anyone responsible for funding TSOs, be it through grants or contracts.

Over time there has been a shift in funding models, with statutory services increasingly funding TSOs through commissioned contracts rather than grants (Clark et al., 2010). The use of contracts has led to organisations being subject to a greater amount of performance management including outcomes-based commissioning (Ellis and Gregory, 2008), fuelling the use of PROMs. Individual TSOs will usually receive funding from a number of different sources to deliver their wellbeing activities e.g. having contracts with both a local authority and the NHS. Grants and contracts are usually for a time-limited period such as an organisation receiving a year's worth of funding to deliver a new wellbeing activity. The time-limited nature of funding requires organisations to seek further funding to be able to continue delivering activities. To help strengthen the case for further funding, TSOs need to be able to demonstrate an activity's impact (Kilgarriff-Foster and O'Cathain, 2015).

### (2.3) The context in which TSOs operate

The importance of wellbeing activities is increasingly recognised within UK health policy, with TSOs commissioned by the NHS and local authorities to deliver activities. This is partly because of concerns about people accessing NHS services with non-medical needs, with one in five GP appointments being for non-medical reasons (Citizens Advice, 2015). Consequently, TSOs are viewed as playing a role in easing demand on statutory services because they are considered better placed to support people with non-medical needs (Dayson and Bashir, 2014).

The current UK context has implications for both how TSOs operate and the implementation of PROMs. A number of recent government policies have contributed to the increasing role of TSOs within health and social care provision in the UK (Dickinson et al., 2012; Wilson et al., 2012; Hardwick et al., 2015). Firstly, there have been several UK Government White Papers which have emphasised the pivotal role of TSOs in improving people's health such as through the latest NHS Long-term Plan (NHS, 2019). Significant within the plan was the development of social prescribing through the NHS Link Worker initiative. Social prescribing has typically been delivered by TSOs and entails supporting service-users to access non-medical sources of support often in the form of third sector based wellbeing activities (Bickerdike et al., 2017). Secondly, increasingly health and social care is being integrated through initiatives such as the Better Care Fund (NHS England, 2017). Such initiatives seek to join up health and social care services to help people manage their own health and wellbeing. Thirdly, there has generally been an increase in non-statutory providers because of policies e.g. Any Willing Provider, which enable any type of organisation including TSOs to bid for contracts to deliver health and social care provision (Department of Health, 2010).

Alongside specific health and social care policies, the UK Government between 2010 and 2019 undertook the fiscal policy of Austerity. This entailed the Government reducing expenditure such as decreasing budgets to local authorities. The approach had significant implications for statutory services and the communities TSOs often serve. Statutory services faced financial difficulties and had to reduce expenditure and justify any projects they did fund (Curry et al., 2011). Furthermore, austerity had a significant impact on individuals, with changes to welfare benefits and reduction in statutory services linked to increased levels of poverty and ill health (Marmot et al., 2020). TSOs have been credited with supporting people experiencing the consequences of

austerity including providing food banks and debt advice (Jones, 2016). So the impact of austerity on TSOs has been twofold, they face greater demand on their services but this increased need is within a challenging funding context.

Outcomes-based commissioning has been another development in funding practice over time (Bovaird et al., 2012). This shift in practice involves commissioners wanting to understand the impact of funded services on the health and wellbeing of service-users (outcomes) whereas previously the focus was on outputs e.g. how many people attended an activity. The shift to outcomes-based commissioning is viewed as compatible with austerity because as resources become scarcer, commissioners need to justify their expenditure on wellbeing activities.

#### (2.4) Wellbeing activities

As discussed previously, TSOs deliver a range of services but the focus of the PhD is on wellbeing activities. The focus of wellbeing activities is to support individual service-users to experience an improvement in their lives. This differs to services which primarily focus on improving community wellbeing or addressing the structural causes of poor wellbeing such as the welfare system (Attree et al., 2012). Whilst there have been criticisms of focusing on individual rather than structural aspects of wellbeing (Trayers and Lawlor, 2007), nevertheless this is the current focus of many public health interventions (Hunter et al., 2010), such as social prescribing. Thus the PhD focuses on wellbeing activities aimed at the individual. Although it is acknowledged that through their work, many TSOs are seeking to bring about changes to community wellbeing and campaign for improvement to the structural causes of poor wellbeing.

Wellbeing in this study is defined as how an individual perceives their life (Layard, 2016) (see Section 2.5 for more detail). There is no agreed definition of what constitutes a wellbeing activity delivered by a TSO, rather it is an umbrella term used to describe a diverse range of activities. I developed a definition for the PhD through drawing upon existing literature e.g. Dailly and Barr (2008) and on criterion used by funding programmes such as the People Keeping Well scheme in Sheffield (NHS Sheffield and Sheffield City Council, 2016). So in this PhD the focus is on wellbeing activities which:



- seek to improve an individual’s wellbeing
- are delivered by a TSO
- take a holistic approach based on the psychosocial rather than medical model of health- e.g. the activity considers the social determinants of health rather than treating the biological symptoms of a specific condition.
- may be aimed at a certain type of service-user but the defining characteristics will not usually be someone needing to have a specific clinically diagnosed health condition. For example, wellbeing activities may be aimed at people self-identifying as experiencing low mood rather than people with a clinical diagnosis of depression.

Examples of wellbeing activities are provided in Table 2. These are drawn from my own experience, input from stakeholders and a range of academic sources including Attree et al. (2012); Wilson and Cordier (2013); Pescheny et al. (2018) and Siette et al. (2017).

**Table 2- Types of wellbeing activities**

Type of activity	Description	Example
<b>Social prescribing</b>	Social prescribing entails signposting to support service-users to access non-NHS activities and services.	Rotherham Social Prescribing service
<b>Community allotments</b>	Community allotments are allotments run by TSOs where service-users can spend time gardening and having social contact.	Firth Park Community Allotments
<b>Health trainers</b>	A national project delivered within local TSOs to help service-users make healthy lifestyle changes.	Darnall Wellbeing Health Trainer service
<b>Befriending</b>	Service-users are matched with a volunteer and they meet on a regular basis for social support.	B-friend
<b>Men’s Sheds</b>	Community spaces which resemble workshops/sheds for men to connect, converse and create.	Horsham Men’s Sheds
<b>Personal Development courses</b>	Fixed term group courses where facilitators help service-users to support each other with personal development such as increasing confidence.	STEPs to Excellence Course delivered by Manor and Castle Development Trust

Wellbeing activities are based upon the psychosocial model of health. This involves not purely focusing on the biological aspect of a person's illness, but taking into account the person as a whole by considering the wider determinants that impact on their health including social, economic and societal factors (Dailly and Barr, 2008). This is particularly relevant because wellbeing activities are often targeted at people experiencing poorer health outcomes (Cameron, 2010; Centre for Mental Health, 2012). An example being the Sheffield Healthier Communities programme, which funded health and wellbeing improvement activities in deprived geographical areas and with vulnerable communities of interest e.g. gypsy and travellers (NHS Sheffield, 2011).

Within this PhD, the term 'front-line workers' is used to describe people delivering wellbeing activities. A generic term is used because within the third sector there are plethora of different job titles depending on the TSO and precise job role. Front-line workers are often viewed as community workers (Woodall et al., 2010), lay health workers, peer-support workers or advisors (Lewin et al., 2010). Front-line workers differ from health professionals because they do not necessarily have a formal professional tertiary education nor are they required to hold a specific professional qualification (Lewin et al., 2010; Woodall et al., 2010). Furthermore front-line workers are often peers of the service-users, so share similar characteristics to the people they are supporting such as living in the same neighbourhood or being former service-users (Harris et al., 2014). Whilst wellbeing activities may be delivered by paid front-line workers, some are run or supported by volunteers. These are people not paid for the work they are undertaking within the TSO (Southby and South, 2016). For example, the British Red Cross delivered a social prescribing service where support was delivered by both paid front-line workers and volunteers (Holding et al., 2020).

Whilst wellbeing activities have a number of shared characteristics, their specific focus, service user group and delivery model vary considerably (as illustrated in Table 2). Firstly, activities may be delivered on an individual basis, such as befriending or in a group setting e.g. community allotments. Secondly, service-users will receive support for different lengths of time. Some activities will be time limited e.g. 6 week long confidence building courses, whereas others will be based on an ongoing support model. An example is service-users attending craft groups for several years. Thirdly, wellbeing activities may consist of specific appointments, where the

expectation is that the service-user will attend, whilst other activities will be more informal and people can attend as and when they wish e.g. social cafes (South et al., 2017).

In terms of service-user groups, wellbeing activities are aimed at different types of people depending on the nature of the TSO, remit of the activity and perceived needs. For example, activities may be aimed at people living in a certain geographical area or people who are experiencing a specific life circumstance e.g. individuals experiencing bereavement. Generally, TSOs will seek to be inclusive and support people who feel they are suited to the wellbeing activities rather than service-users having to meet a specific clinical threshold. For example, a national social prescribing service supported people who perceived themselves as feeling lonely rather than only supporting individuals who were classed as lonely against a standardised set of criteria (School of Health and Related Research, 2018). Although some wellbeing activities may be aimed at people with a specific clinical diagnosis such as a health trainer service for people with chronic pain (Harris et al., 2013). Examples of TSOs aimed at different service-user groups include:

- Age UK- support people aged over 50
- Manor and Castle Development Trust- support people living in a specific neighbourhood
- Sheffield Young Carers- support people under the age of 24 who have caring responsibilities.

There are no statistics available on the number of people engaged in TSO delivered wellbeing activities nationally. However, the numbers are likely to be substantial. For example, in one Sheffield based programme there were 21,528 service-users (3.9% of the Sheffield population) in 2014/2015 (Horsley, 2015). If this figure was extrapolated to the UK population, this would equate to over 2.5 million service-users annually. However, the number is likely to be much larger because the calculation was based on a single statutory funding stream.

The PhD focuses on TSO delivered wellbeing activities for a number of reasons. Firstly, there appear to be specific challenges to using PROMs within wellbeing activities compared to using them in healthcare services such as cancer services (discussed later in the chapter). Secondly, TSOs are increasing their use of PROMs to demonstrate their impact as a condition of funding (Nathoo, 2017). However, there has been a lack of guidance on implementing PROMs within the

third sector. Thirdly, increasing wellbeing has been a priority within UK policy for a number of years (Cameron, 2010). For example, the health policy: ‘No Health Without Mental Health’ (Centre for Mental Health, 2012) and Public Health England (2015a) included wellbeing alongside health in their framework for young people. Given these issues, greater knowledge is needed on how to evidence the impact of TSO delivered activities seeking to improve wellbeing.

## (2.5) What is ‘wellbeing’?

Despite wellbeing increasing in prominence within UK public policy (Stiglitz, et al., 2010; Hicks et al., 2013), it is a heavily contested concept, with no agreed definition (Huppert, 2017). The first issue relates to whether one is considering community or individual wellbeing. Community wellbeing focuses on what is it about a community which makes it a good place to live and thrive, e.g. how safe people perceive the area to be (South et al., 2017). Whilst a case has been made about considering the impact of wellbeing activities on community wellbeing e.g. measuring social capital (Public Health England, 2015b), the focus of the PhD is the implementation of PROMs which measure individual wellbeing. The justification is that stakeholders identified this as a priority during discussions when I was developing the research idea.

In relation to individual wellbeing, definitions differ for objective and subjective wellbeing. Objective wellbeing is defined as a list of criteria developed by a third party that a person should meet in order to be classed as having good wellbeing e.g. having an income greater than a specific amount (Western and Tomaszewski, 2016). However, the objective approach does not consider a person’s lived experience, someone may feel they have poor wellbeing despite meeting the objective criteria (Stiglitz et al., 2010; Naci and Ioannidis, 2015). Consequently, there is a growing focus on Subjective Wellbeing (SWB), that is, how an individual experiences their life (Layard, 2016). There are different theoretical stances regarding how SWB is defined, measured and the approaches needed to improve wellbeing (Huppert, 2017; Testoni et al., 2018). These include hedonist, eudemonic and evaluative approaches (Peasgood et al., 2014). The hedonist perspective defines SWB as the positive emotions a person experiences, so their sense of happiness (Kahneman et al., 1999). The eudemonic perspective defines SWB as a person having a sense of meaning, functional ability and positive relationships (Ryff, 1989). The

evaluative perspective perceives SWB as how a person evaluates their life e.g. their life satisfaction (Diener et al., 2010). Whilst these distinct perspectives still exist, increasing in popularity is the viewpoint that SWB is multidimensional consisting of concepts drawn from a number of wellbeing theoretical approach (Layard, 2016). So, having a higher SWB is a combination of feeling good and functioning well, with a person also having inner resources to help manage difficult experiences e.g. resilience (Layard, 2016; Huppert, 2017; Testoni et al., 2018). The multidimensional definition is utilised within the PhD, with the perspective that wellbeing activities aim to support people to improve how they feel and function as well as helping them to develop their inner resources. Given this, the term 'wellbeing' is used throughout the thesis, with the appreciation that it relates to SWB.

A further source of debate is the relationship between wellbeing and other concepts. For example, the term wellbeing is often used interchangeably with concepts such as 'self-esteem' and 'life satisfaction' within the third sector (Nathoo, 2017). There is also disagreement regarding how wellbeing relates to mental illness, particularly the distinction between the two (Testoni et al., 2018). The absence of mental illness does not necessarily mean a person has high levels of SWB (Huppert, 2017) but there may be correlation between wellbeing and some dimensions of mental ill health (Huppert and So, 2013). This raises questions about whether PROMs designed to measure symptoms of mental illness are also capturing wellbeing (Layard, 2016).

Improving wellbeing is considered a valid objective in its own right, in that society should want people to have higher levels of wellbeing (Layard, 2016). In addition, higher levels of wellbeing appear to have a positive impact on health outcomes, people with higher levels of wellbeing have an increase of life expectancy of 4-10 years (Diener and Chan, 2011) and reduced morbidity (Chida and Steptoe, 2008). This may be partly because as an individual's wellbeing increases, they may feel more empowered to address unhealthy behaviours and live healthier lifestyles (Woodall et al., 2010).

## (2.6) The evidence base on TSO delivered wellbeing activities

Whilst there is emerging evidence on the impact of wellbeing activities, undertaking research in the field has faced challenges (Bach-Mortensen and Montgomery, 2018). Firstly, wellbeing activities have generally been on the fringes of healthcare compared to the dominance of health professional led/statutory services (South et al., 2013). Secondly, wellbeing activities are diverse and often are tailored to the local context e.g. social prescribing services are configured differently (Kilgarriff-Foster and O'Cathain, 2015). So even if research is undertaken, it is difficult to know how transferable the findings are to other TSOs. Thirdly, TSOs and the wellbeing activities they deliver are often small scale and thus the organisations do not have the capacity or funding to undertake research or they conduct small-scale evaluations (Bach-Mortensen and Montgomery, 2018). Fourthly, there is a tension between the traditional hierarchy of evidence within applied health research and what TSOs may regard as evidence/knowledge, where a greater priority is given to experiential knowledge (Ramanadhan et al., 2012). Given these four reasons, often the research which has been conducted on wellbeing activities consists of attendance statistics, case studies or small scale qualitative evaluations (Year of Care, 2011) and TSOs have been criticised for the lack of quantitative research considering the impact of activities on the wellbeing of service-users (Dailly and Barr, 2008; Mullins, 2013). This perceived gap has contributed to TSOs being encouraged to use PROMs in routine practice as a method of generating quantitative data on their impact (Nathoo, 2017).

Demonstrating impact means seeking to show the consequences of the wellbeing activity (Harlock and Mcalf, 2016). In this case, TSOs collecting PROMs to understand whether service-users appear to be experiencing an improvement in their wellbeing from attending an activity. This may be viewed under the umbrella of performance management, also known as performance monitoring (Bauer, 2015). In the case of PROMs, this entails an organisation collecting PROMs on an ongoing basis to enable commissioners or the TSO themselves to analyse whether the wellbeing activity is having an impact e.g. TSOs reporting collected PROMs data on a quarterly basis to commissioners. PROMs may also be used within the context of evaluation, in terms of researchers analysing routinely collected data (Bach-Mortensen and Montgomery, 2018).

## (2.7) What are PROMs?

The use of PROMs within TSOs stems from the context of the increasing use of PROMs within the NHS, such as the National PROMS programme (Black, 2013). As explained in Chapter 1, PROMs are validated questionnaires which consist of a number of questions, often referred to as 'items'. Each item is scored using a prescribed formula and the scores usually combined across items to give an overall score which is considered to relate to the person's perception of their health, symptoms or wellbeing (Kyte et al., 2015). Usually PROMs are administered at two or more time points to explore how a person's responses to the items have changed over time to establish if their perceptions of their health, symptoms or wellbeing has improved after receiving a specific healthcare intervention (Devlin and Appleby, 2010). There are thousands of PROMs available and they are diverse in terms of what they measure, their length, the structure of scoring, the recall period and how they are administered (Kyte et al., 2015). Key differences include generic PROMs which can be used across the general population, such as the SF-12 (Weenink et al., 2014) and condition-specific measures which ask about symptoms associated with a specific disease, e.g. the Beck Depression Inventory (Beck et al., 1988). There are also PROMs which measure people's health related quality of life, for example the EQ-5D-5L (Herdman et al., 2011). The next section focuses on wellbeing related PROMs.

Whilst PROMs have been used within healthcare research such as randomised controlled trials for many years, it is only in the last twenty years that there has been considerable interest in using PROMs within routine healthcare (Devlin and Appleby, 2010). Their use has increased because firstly, PROMs are seen as a way of capturing the service-users perspective, so fits with the idea of patient-centered care (Greenhalgh et al., 2018). Secondly, PROMs capture the impact of an activity on service-users, whereas other types of measures such as Patient Reported Experience Measures capture information on delivery of an activity (Devlin and Appleby, 2010). Thirdly, the PROMs scores from a number of service-users can be collated in order to evaluate the performance of a particular worker, activity or organisation (Kyte et al., 2015). For example within the UK, PROMs are collated for knee replacement operations in different hospitals to compare whether there is variance in patient outcomes between hospitals (NHS England, 2017). Fourthly, PROMs usually undergo significant development and psychometric testing, meaning that their supporters feel they are both valid and reliable for measuring change in a service-user's health. For example, the National Institute of Health and Care Excellence (NICE) (2013) use the

data collected from PROMs as a source of evidence when making decisions on which interventions they recommend the NHS should fund.

Despite the interest in using PROMs, there have been challenges with implementing them in healthcare services (Gibbons and Fitzpatrick, 2018). Barriers include:

- Attitudinal- not all stakeholders believe PROMs are an appropriate tool to use
- Structural- organisations not having sufficient resources to use PROMs
- Lack of knowledge- clinicians not receiving training on how to administer PROMs.

The challenges of implementation is discussed further in Section 2.9.

### (2.8) Which PROMs are relevant for measuring the impact of wellbeing activities?

As discussed previously, this PhD focuses on PROMs used to measure wellbeing. A recent review identified 99 potential wellbeing measures (Linton et al., 2016), and new measures are continually being developed (Diener et al., 2010; Bann et al., 2012; Joseph and Maltby, 2014). Examples of wellbeing PROMs include the WEMWBS (Tennant et al., 2007), the Flourishing scale (Diener et al., 2010) and the Office for National Statistics 4 Wellbeing Questions (ONS-4) (Office for National Statistics, 2018a). The array of measures indicates there is no universally agreed PROM for measuring wellbeing, this is highlighted by different departments within the UK Government using different measures (Peasgood et al., 2014).

Some of the uncertainty around choice of wellbeing PROMs arises because of disagreement about which domains a measure should contain (Deci and Ryan, 2008; Dodge et al., 2012), although in reality there is overlap in many of the questions on the different measures (Peasgood et al., 2014; Linton et al., 2016). Furthermore, questions have been raised about whether having a single score generated from a PROM is acceptable or whether this means the multiple components of SWB are not demonstrated (Layard, 2016). There is also a trade-off between having a shorter, more user-friendly PROM versus longer measures which enable a more comprehensive assessment of a person's wellbeing (Linton et al., 2016). Finally, there is debate about whether it is desirable for items to be worded positively (Layard, 2016) or whether this creates floor and ceiling effects (Mukuria et al., 2016).



At present there is little knowledge of which PROMs have been used within TSO delivered wellbeing activities. There has been some research identifying which measures have been used to evaluate specific wellbeing activities such as in social prescribing (Polley and Richards, 2019). However, there appears to have been no research about which PROMs are used within the third sector generally. Nonetheless to provide context, some examples of measures used within wellbeing activities are detailed in Table 3. These have been identified from the literature and through discussions with third sector stakeholders.

Alongside wellbeing PROMs, other types of measures have also been used within wellbeing activities. For example, the EQ-5D-EL has been used in some activities to capture changes in health related quality of life (Herdman et al., 2011) and ReQoL has been used to consider mental health issues (Keetharuth, 2018). As well as validated PROMs, individualised instruments have also been utilised including the Measure Yourself Medical Outcomes Profile (MYMOPs) (Paterson, 1996) and the Outcome Star (MacKeith, 2011). Individualised PROMs enable service-users to choose what goals or outcomes matter to them, and impact is judged in relation to whether someone achieves their goals (Kyte et al., 2015).

**Table 3- Examples of PROMs used within wellbeing activities**

<b>Name of PROM</b>	<b>Acronym</b>	<b>Type of PROM</b>	<b>Summary</b>	<b>Reference</b>
Warwick Edinburgh Mental Wellbeing Scale	WEMWBS	Specific wellbeing PROM	A 14 item PROM, with positively worded questions focusing on constructs of wellbeing	(Tennant et al., 2007)
Short Warwick Edinburgh Mental Wellbeing Scale	SWEMWBS	Specific wellbeing PROM	A 7 item version of the WEMWBS.	(Stewart-Brown et al., 2009)
Office for National Statistics- 4 items	ONS-4	Specific wellbeing PROM	Wellbeing specific tool with 3 questions focusing on wellbeing & a question on anxiety. The 4 items are scored separately rather than producing a single score.	(Office for National Statistics, 2018a)
Adult Social Care Outcomes Toolkit	ASCOT	Social care related quality of life	Measures quality of life most affected by social care. It includes 8 items.	(Malley et al., 2012 )
EQ 5D-5L	EQ-5D-5L	Health related quality of life	Generic measure exploring health related quality of life. Consists of 5 items.	(Herdman et al., 2011)
Measure Yourself Medical Outcome Profile	MYMOP	Individualised PROM	Service-users identify areas of concern they want to address and MYMOP measures how much it is a concern along with a general question on wellbeing. It has 4 items.	(Paterson, 1996)
Outcome star	Outcome Star	Individualised PROM	Tracks progress for service-users in specific areas of their life. Different versions exist for specific types of service-users/ interventions. Usually based on a 10 point star.	(MacKeith, 2011)
New Economics Foundation tool	NEF tool	Combines a number of different measures	Includes a number of PROMs e.g. the SWEMWBS, ONS-4 and a question on social trust. Produces a number of scores related to each specific measure. There are 12 items in total.	(New Economics Foundation, 2012)

## (2.9) Implementing PROMS in TSOs

Alongside choosing which PROMs to use, there are numerous other decisions which organisations need to make and steps they need to take to enable implementation such as deciding how and when measures will be collected, what training front-line workers need and how to sustain the use of PROMs (van Vliet, 2014; Aaronson et al, 2015). These issues are explored further in Chapter 3, where factors relevant to implementation were identified through conducting a systematic review of reviews. Understanding implementation is important because healthcare services and TSOs have reported issues with using PROMs routinely. For example, within one national TSO less than 25% of service-users had completed PROMs both at the start and end of attending a wellbeing activity (School of Health and Related Research, 2019). This finding was echoed by Mathers et al. (2016), who found wellbeing PROMs were collected for less than 10% of service-users accessing a wellbeing programme. Whilst there has been research within healthcare services about improving the use of PROMs such as in oncology and palliative care, to date there has been no research specifically focusing on TSOs.

Undertaking third sector focused research would enable the development of findings which could be used to support TSOs and their commissioners with implementing PROMs. For example, there have been guidance documents published about using PROMs within palliative care services, but this does not consider TSOs (van Vliet, 2014). There have been two guides aimed at the third sector, The New Economics Foundation (NEF) developed a brief guide aimed at the third sector (New Economics Foundation, 2012) and since the start of the PhD, What Works for Wellbeing issued an updated version of that guidance (What Works for Wellbeing, 2019). However, both guides focus on the *content* of PROMs and how to analyse them rather than considering implementation in the wider sense such as the resources needed and the impact of the organisational context. This illustrates the importance of my PhD, which explores contextual and process related issues which influence implementation.

## (2.10) What is implementation?

Implementation is defined as the steps that need to be taken between an organisation considering introducing a new working practice and this becoming an established part of day-to-day practice (Damschroder et al., 2009). Different terms have been used in the literature to describe this process including implementation, knowledge mobilisation, quality improvement, translation, knowledge to action and co-production. However, there is debate about whether the constructs are interchangeable or focus on distinctly different processes (Walshe, 2009). For this PhD, the term implementation was chosen to mirror the language used in other studies of using PROMs (Snyder et al., 2011; Duncan and Murray, 2012).

There is considerable debate about the steps of implementation, their relative importance and what factors may influence these (Nilsen, 2015). This has resulted in a large number of theories, frameworks and process models on implementation (subsequently referred to as implementation theories). Examples include the Normalisation Process Theory (May, 2009), Knowledge-to-Action framework (Wilson et al., 2011), Theoretical Domains Framework (Atkins et al., 2017) and RE-AIM (Glasgow et al., 1999). I decided to use an existing implementation theory within the PhD because I felt the theory could provide information on the potential mechanisms underpinning the PROMs implementation process and would help to situate the research within the wider knowledge base (Ross et al., 2015).

Despite the multitude of implementation theories, none have been specifically developed in relation to TSOs or implementing PROMs. Furthermore, existing research on implementing PROMs has generally not drawn upon implementation theories. I considered different options and decided to use the Consolidated Framework for Implementation Research (CFIR) (Damschroder et al., 2009; Nilsen, 2015). The primary reason was because the CFIR synthesises a number of existing theories on implementation (Nilsen, 2015) and thus covers more themes/constructs than some individual theories (Kirk et al., 2016). Secondly, the CFIR consists of over 25 constructs which could be used as a coding framework to help make sense of the data arising from the PhD (Damschroder et al., 2009). I felt this was advantageous in comparison to using other implementation theories which have higher level constructs that may not have been as useful for the initial categorisation of data e.g. the Normalisation Process Theory (Nilsen,

2015). Thirdly, the CFIR was developed to assess implementation of an intervention irrespective of the specific context (Damschroder et al., 2009) so can be used in relation to the third sector. Fourthly, the CFIR is used regularly within healthcare research and thus it is a well-known and understood theory (Kirk et al., 2016).

The CFIR consists of 5 domains:

- The intervention- In this case the design of the PROMs and associated processes for administering, analysing and using the data collected.
- Outer setting- Factors external to the organisation which may impact on implementation.
- Inner setting- Factors internal to the organisation which may impact on implementation.
- Characteristics of individuals- The impact of the views and behaviours of individuals within the organisation.
- Process- Issues related to using PROMs in practice.

Within each of the CFIR domains there are a number of components and subcomponents which enables the exploration of the different aspects of that domain (Damschroder et al., 2009). Whilst the CFIR is the main theoretical framework used within the PhD, it was necessary to draw upon additional concepts from other theories to help explain some of the arising findings (Nilsen, 2015). This is discussed throughout the thesis.

### (2.11) Using the concept of ‘facilitators and barriers’ to understand implementation

The concept of ‘facilitators and barriers’ has been used to frame the research. Within the PhD, facilitators are defined as factors which enable, support or assist a TSO to implement PROMs. Barriers are defined as issues which hinder, impede or create difficulties for implementation. A ‘facilitators and barriers’ framing is used because it provides a useful way to structure the research to help stakeholders understand what factors may help them to implement PROMs and issues they need to address (Antunes et al., 2014; Ross et al., 2015). But some researchers question the concept of barriers because they tend to be presented as if they exist (Checkland et al., 2007) and it may be that they are socially constructed by individuals to try and make sense of a situation (Weick, 1995). For example, front-line workers may report that they do not have time

to administer PROMs in appointments, but extending appointment times may not solve the issue because there are other reasons why the front-line worker is not engaging. Despite these criticisms, it is appropriate to use the concepts of facilitators and barriers within the PhD because I am taking the philosophical perspective of constructivism, so I am of the opinion that these issues are socially constructed (discussed further in Chapter 5). Furthermore, I wanted to identify and potentially address factors which stakeholders define as relevant.

### (2.12) Summary of the chapter

- TSOs are a unique type of organisation which are non-profit making, value driven and not part of the state. TSOs are diverse including in their size, focus, geographical scope and service-user group they serve.
- Wellbeing activities are one type of service that TSOs deliver. Wellbeing activities vary from group-based hobbies such as community allotments to individually tailored advocacy or health coaching. Activities aim to improve service-users' wellbeing such as people feeling more satisfied with their life.
- For the last 10 years, TSOs in the UK have been operating in an external context of austerity, which has resulted in financial challenges for both statutory services and individuals. Within this context, TSOs receive short-term funding, often from statutory services to deliver wellbeing activities and are under pressure to demonstrate their impact to justify receiving funding.
- PROMs, which are questionnaire measuring changes in an individual service-users' wellbeing are used by TSOs to demonstrate impact. However, organisations can face challenges with implementing outcome measures and there has been no research exploring the issues facing organisations. This is important because the third sector differs to healthcare services which have generally been the focus of studies on implementing PROMs.
- The CFIR implementation theory is used within the PhD to help frame the research.

Given the lack of research, the PhD focuses on understanding the facilitators and barriers to implementing PROMs within TSOs. To inform the primary research reported in Chapters 7 and 9, literature reviews were undertaken to identify potential issues which may be relevant to TSOs (presented in Chapter 3 and 4). The focus of the next chapter is on the systematic review of reviews, which explored the implementation of PROMs within healthcare services.

## Chapter 3- The facilitators and barriers to implementing PROMs in organisations delivering healthcare services: A systematic review of reviews.

### (3.1) Outline of the chapter

A systematic review of reviews was undertaken to learn from existing literature about which factors may influence the implementation of PROMs. The review focused on any type of organisation delivering health and/or wellbeing related services because there is an absence of literature considering implementation within the third sector. This chapter focuses on the rationale, methods and findings of the review. Much of the chapter was published as a standalone journal article in the Journal of Patient Reported Outcomes (Foster et al., 2018) (available from: <https://jpro.springeropen.com/articles/10.1186/s41687-018-0072-3>). The review was conducted in 2017, during the first year of the PhD. The terms clinician and patient rather than front-line worker and service-user are used throughout the chapter to reflect the terminology used in the included reviews.

### (3.2) Rationale for the review

When developing the idea for the PhD, initial scoping exercises identified a lack of literature on using PROMs within TSOs. Searches were undertaken through using a variety of methods. Some of this was informal, including speaking to contacts in the field, internet searches and looking at the websites of relevant organisations such as the University of Birmingham Third Sector Research Centre and NCVO. I also undertook electronic searches, using similar terms to those I then used for the formal electronic searches of the review (described subsequently). Through my searches, I identified a small number of relevant resources. For example, NEF produced a short guide on using PROMs (New Economics Foundation, 2012), but this focused on the choice of PROM. There were also a number of reports about impact measurement such as Harlock (2013) and Year of Care (2011). However, none of the resources reported research on implementing PROMs within TSOs. Through the searches, I identified systematic reviews exploring the implementation of PROMs within healthcare services such as palliative care and oncology (Antunes et al., 2014; Howell et al., 2015) Consequently, I decided to undertake a review of reviews focused on the implementation of PROMs within any type of organisation delivering



health and/or wellbeing related services. The justification being the findings would provide a useful framework of potential factors influencing implementation. This framework could inform the planned primary research and provide a source of comparison between TSOs and other contexts.

A systematic review of reviews, which integrates existing reviews, was conducted. Sometimes these are called overview of reviews or umbrella reviews (Grant and Booth, 2009; Pollock et al., 2020). The approach was chosen because there was a number of existing reviews undertaken on the implementation of PROMs (Antunes et al., 2014; Boyce et al., 2014). These reviews all focused on a particular area of healthcare, such as palliative care (Antunes et al., 2014), or on a specific stage of the PROMs process, e.g. how to report the collected data (Bantug et al., 2014). These individual reviews had not been synthesised. Increasingly, systematic review of reviews are used within health research to provide an overview of the evidence (Smith et al., 2011).

### (3.3) Aim of the review

The aim was to conduct a systematic review of reviews to identify the facilitators and barriers to implementing PROMs in organisations delivering health and/or wellbeing related services.

### (3.4) Methods used for the systematic review of reviews

Throughout the review, the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidance was followed. This is a standardised toolkit used by researchers to ensure they have sufficiently reported details of their methodology to improve the transparency and replicability of their review (Moher, 2009). The completed PRISMA checklist is presented in Appendix 1.

Before undertaking the review, a protocol was developed. Pre-specifying the methods and criteria used with the review increases transparency and also reduces the risk of bias within the review (Stewart et al., 2012). For example, stipulating the inclusion and exclusion criteria enables consistency when assessing potential studies for inclusion. The protocol was registered on the International Prospective Register of Systematic Reviews database (PROSPERO)

(CRD42017057491). Registering the protocol raised awareness of the review and improved its transparency and replicability.

#### (3.4.1) Review methodology: A systematic review of reviews

Systematic reviews of reviews involve the same processes as systematic reviews of primary research including searching, sifting, data extraction, quality appraisal and synthesis (Smith et al., 2011). However, the unit of analysis is reviews rather than individual studies. For example, the review rather than individual studies is appraised for risk of bias (Lau et al., 2014).

#### (3.4.2) Eligibility criteria

The search sought to identify published reviews of the literature which considered factors that impact on the implementation of PROMs in organisations delivering health and/or wellbeing related services. The focus was not specifically on reviews of facilitators and barriers because researchers may not use these concepts when reporting studies. The 'PICOS' criteria was used to structure the review including the aim, eligibility criteria and search strategy (O'Connor et al., 2008). The parameters used within the review are displayed in Table 4.

**Table 4- The PICOS criteria used for the review**

<b>Criteria</b>	<b>Definition</b>	<b>Rationale</b>
<b>Population</b>	Patients, clinicians, commissioners or managers of health-related services.	The population included a number of stakeholder groups because there are numerous people impacted by the use of PROMs, including patients having to complete measures and managers asking their staff to administer PROMs.
<b>Interest</b>	Issues reported as influencing the implementation of PROMs.	The focus of the research was on the implementation of PROMs because there is a need for greater knowledge on improving the use of measures within routine practice.
<b>Context</b>	Health related services irrespective of the type of provider or country.	No restrictions were put on type of provider or country to increase the number of reviews that might be identified.
<b>Study type(s)</b>	Reviews that provide a description of the methods used to conduct the review. They may classify themselves as a specific type of review e.g. a systematic review, narrative review, meta-analysis, meta-synthesis or scoping review.	There were no restrictions on the type of reviews included to maximise the number of publications which may be included. However, it was essential any included reviews described their methods to ensure transparency and enable the reviews to be assessed for risk of bias.

The PICOS informed the eligibility criteria. A publication had to meet all of the inclusion criteria and none of the exclusion criteria to be included in the review. Having these criteria meant that all potential publications were judged consistently which reduces the risk of bias and ensures they are relevant for the study (Grant and Booth, 2009). A detailed explanation of the eligibility criteria is provided below.

## Inclusion criteria

The inclusion criteria were:

**(1) Be a review of the literature and provide a description of its methods-** Included publications needed to synthesise at least two individual studies and also provide a description of their methods including search criteria and analysis technique. Providing a description of methods was considered important to provide an understanding of the nature of the research and to enable a risk of bias assessment to be conducted. This inclusion criterion is common within systematic review of reviews (Lau et al., 2014).

**(2) Include information related to implementing PROMs-** It was essential that any included reviews provided information on factors relating to implementation rather than just considering the validity or impact of PROMs.

**(3) Focus on health and/or wellbeing related services irrespective of the type of organisation-** Studies based in any type organisation delivering health and/or wellbeing related services were included to understand the breadth of literature related to implementing PROMs.

**(4) Be published before February 2017-** Any reviews had to be published before February 2017 because of when the search was conducted. The review was conducted early on within the PhD so the findings could inform the primary research.

## Exclusion criteria

Publications were excluded if they met one or more of the following exclusion criteria:

**(1) Written in a language other than English-** Reviews not written in English had to be excluded because there were no resources available to translate articles.

**(2) Focused on the measurement properties of PROMs-** Reviews which focused on the measurement properties of PROMs rather than their use were excluded. For example, reviews considering the most suitable PROMs for a specific condition.

**(3) Focused on the results of PROMs e.g. when evaluating interventions-** Reviews were excluded which focused on reporting the results of PROMs such as the effectiveness of an intervention.

**(4) Not focused on factors that impacted on the implementation of PROMs-** It was important to exclude any reviews which did not identify factors which influenced the implementation of PROMs. This was to ensure any included reviews were relevant to the aim of the study.

### (3.4.3) Search Strategy

An information specialist supported the development of a comprehensive search strategy. The search terms were refined to maximise the chances of identifying relevant publications. An important aspect was identifying phrases relevant to using PROMs as not all authors utilised the term ‘implementation’. Additionally, the search terms needed to identify reviews rather than individual studies. The search strategies of existing reviews on implementing PROMs along with systematic review of reviews more generally were consulted to help inform the search strategy. The search strategy for MEDLINE is detailed in Appendix 2

Searches were conducted in five electronic databases: MEDLINE, EMBASE, PsycINFO and CINAHL. The databases were chosen because they are commonly used within health research and have different remits, e.g. CINAHL focuses on research relating to allied health and nursing professions. Additionally, the Cochrane Database of Systematic Reviews was searched because this includes systematic reviews including ones not necessarily published in peer-reviewed journals. The searches were performed during the week of the 20<sup>th</sup> February 2017.

A number of additional search methods were used alongside the database searches. The reason was to maximise the chances of finding relevant reviews, especially ones not published in journals. The additional methods included screening the reference lists of the included reviews. To identify grey literature, the websites of UK based relevant organisations were searched including PROSPERO, the Kings Fund, NHS England, Social Care Institute for Excellence, the University of Birmingham Centre for Patient Reported Outcome Research and NCVO (this is an advisory organisation for TSOs). Five researchers who were specialists in PROMs and known to

me were asked for recommendations. The grey literature search was UK based because that is the scope of the PhD.

#### (3.4.4) Study selection

A number of steps were undertaken to select the included reviews, using established guidance from Cochrane (Sabena et al., 2017). Whilst I led the review, a second researcher based in the School of Health and Related Research (ScHARR) (Liz Croot (LC)) supported the selection process by providing a second opinion to reduce the potential bias in the review (Charrois, 2015).

The study selection process initially involved the deletion of duplicate references. I then screened all citations (titles and abstracts) for inclusion. LC independently screened 20% of the citations. We discussed our results and found they were highly consistent (inter-rater reliability of 95.6%). Therefore, full double screening of all the citations was deemed unnecessary. In cases where an abstract was not available, the full text of the publication was reviewed. Finally, we both assessed the full text of potentially eligible reviews. The results were compared and there was an inter-rater reliability of 86.2%. We discussed with the supervisory team the publications we did not agree on. Together we considered these publications' eligibility until consensus was reached on whether to include or exclude a review.

#### (3.4.5) Data extraction

A data extraction form was developed to ensure that all relevant information was consistently collected from the included reviews (Mathes et al., 2017). The initial data extraction form was tested on two of the included reviews and refinements made. Improvements included collecting more detailed information on the individual studies included in each review. The data extraction form included the following categories:

- Reference details of the review
- Aims and objectives of the review
- Eligibility criteria
- Risk of Bias in Systematic Reviews (ROBIS) criteria
- The parameters of the review
- Review method
- Details of the individual studies a review included
- Issues influencing the implementation of PROMs

Justification of the categories is provided in Appendix 3. I conducted extraction for all the included reviews. LC conducted extraction on half of these to increase the rigor of the process. As our data extraction was consistent, I decided it was unnecessary for double data extraction to be undertaken for all of the included reviews. This is common practice and reflects the ongoing tension of enhancing the rigor of reviews whilst balancing researcher capacity.

#### (3.4.6) Risk of bias assessment

A risk of bias assessment was conducted on the included reviews. The rationale was to establish whether there were problems in the design, conduct or analysis of any individual included review such as issues with the comprehensiveness of their search process (Whitling et al., 2016). The Risk of Bias in Systematic Reviews tool (ROBIS) was utilised because it was specifically designed to appraise reviews and can be used irrespective of the type of primary studies included within a review. The ROBIS was chosen over A Measurement Tool to Assess Systematic Reviews (AMSTAR). This was because the ROBIS can be used on reviews which have included any type of primary research whereas the AMSTAR specifically appraises reviews of Randomised Controlled Trials (RCTs) (Shea et al., 2009).

I assessed all of the included reviews and LC assessed half of them. We had similar results so full double appraisal was not needed. No reviews were going to be excluded based on the outcome of the ROBIS because the aim of the review was to identify factors which may influence implementation and explore these in the primary research rather than undertake a meta-analysis.

### (3.4.7) Synthesis of findings

Information extracted on the context and objectives of the reviews was used to understand the scope of each review. The findings on implementing PROMs were synthesised using the Framework Approach (Barnett-Page and Thomas, 2009). The approach entails using a framework, in this case the CFIR, as an initial basis to synthesise the findings, followed by the iterative development of the framework to ensure it is the best-fit for the findings (Carroll et al., 2013). The framework approach provided a transparent approach to analysis because all the findings could be coded against the CFIR framework and also highlighted implementation issues not identified in the reviews. Using the best-fit approach enabled development of the findings of the review beyond the initial CFIR framework.

I undertook the majority of the synthesis but was in regular discussion with my supervisors and LC. The process of framework synthesis initially involved familiarisation with the data by reading the data extraction forms multiple times. Secondly, the extracted data was categorised into the different constructs of the CFIR, which produced a summary of the issues influencing the implementation of PROMs (Oliver et al., 2008; Barnett-Page and Thomas, 2009). Whether an issue was coded as a facilitator or a barrier was determined by considering how it had been framed by a reviews' authors.

The next stage of synthesis involved developing the findings from the CFIR framework into stages of implementation. This was because it appeared that certain facilitators and barriers arose at specific stages during implementation but the CFIR does not consider when constructs may occur during the implementation process (Oliver et al., 2008). The stages were identified inductively from both the extracted data and knowledge of implementation science. The development phase involved my supervisors and I, discussing, debating and reflecting on the issues identified. During this period, it was important to regularly refer back to the extracted data and full text copies of the reviews (Noyes et al., 2015). As I read other implementation theories and frameworks, the 'Knowledge to Action Framework' was particularly relevant in terms of helping to explain aspects of the extracted data not captured by the CFIR especially in relation to considering implementation as a process entailing different stages (Field et al., 2014). Using this idea, I developed the stages of implementation inductively from the data.



To improve the rigor of the systematic review of reviews, the following actions were taken: maintaining an audit trail of decisions made and actions taken; double appraisal and extraction of a proportion of the reviews; critical discussion between the supervisory team and myself; and finally undertaking a sensitivity analysis. This included running the search without the English language restriction, comparing whether included reviews were consistent when reporting the findings from the same individual studies and comparing my reviews' findings with other publications (Noyes et al., 2015).

### (3.5) Findings of the systematic review of reviews

#### (3.5.1) Selection of reviews

The study selection process is detailed using a PRISMA flow diagram (Appendix 4). Searches of the electronic databases yielded 2040 potentially relevant publications. Of these, 284 were duplicates and removed. Four publications were identified through personal recommendations and three from reference searching. After reviewing the titles/abstracts of the 1763 potential publications, 1698 were excluded. The majority were excluded because a publication was a review of available PROMs to use for a specific health condition (n=721). Other reviews were excluded because they were not about PROMs (n=437). A further 278 reviews were excluded because they were about using PROMs in research rather than routine practice. Finally, 56 studies were excluded because they either did not provide detail about their methods or the methods did not entail reviewing the literature. For example some publications were discussion papers. These reasons are amalgamated because if a publication does not include detail on the methods used, it is not possible to know whether the authors have undertaken a review.

The next stage was to review the full text of the remaining 65 publications. These included the reviews not excluded based on title/abstract along with publications where the abstract could not be identified. Following the full text review, 59 publications were excluded, resulting in 6 reviews being included in the synthesis. At the full text review stage, the main reason for exclusion was because publications did not provide information on their methods or the methods did not entail reviewing the literature e.g. authors not including information on their search strategy (n=32). Fifteen reviews were excluded because they were not about implementation.

Twelve of these focused on the impact of PROMs, such as whether measures improved clinical outcomes or patient satisfaction. A further 11 reviews were discarded because they focused on the measurement properties of PROMs. Finally, one publication was excluded because it was about PROMs in a research context. There is some overlap of reasons for exclusion at both the title/abstract stage and the full text review. This was partly because some publications did not have an abstract so their eligibility was only assessed at the full text review stage. In other cases, only by reviewing the full text of some publications was it possible to decide whether the review should be included.

### [\(3.5.2\) Characteristics of the included reviews](#)

Six reviews were included in the synthesis (Duncan and Murray, 2012; Antunes et al., 2014; Boyce et al., 2014; Howell et al., 2015; Bantug et al., 2016; Greenhalgh et al., 2017). A description of their characteristics is provided in Table 5. The reviews provided an international perspective, including studies from South Asia, the Middle East, Europe, Australasia and the Americas and review teams based in the UK, Ireland and Canada. All of the reviews were published relatively recently, with the oldest published less than 10 years ago (Duncan and Murray published in 2012).

**Table 5- Description of the reviews**

<b>First author and year</b>	<b>Setting</b>	<b>Aims</b>	<b>Type of review</b>	<b>Synthesis methods</b>	<b>Inclusion criteria for individual studies</b>	<b>Exclusion criteria for individual studies</b>	<b>Number of individual articles included</b>
<b>Antunes, 2014</b>	Palliative care	Identify barriers and facilitators to implementing PROMs in palliative care settings and generate recommendations to inform the process.	Systematic review	Narrative synthesis	(a) Primary studies published in English, Portuguese, Spanish, Italian, German and French.  (b) Studies using a PROM alongside the clinical care of adult patients in palliative care settings.  (c) Studies reporting barriers and/or facilitators of implementing PROMs.	(a) Published literature other than primary studies.  (b) Studies reporting on the development and feasibility of specific PROMs.  (c) Studies of PROMs not completed by the patient e.g. completed by a carer.	31
<b>Bantug, 2016</b>	Any setting	Identify information on the graphical display of PROMs data in routine practice.	Integrative review	Synthesis through generating themes	(a) Reported primary studies.  (b) Addressed the communication of PROMs data to patients or clinicians.  (c) Published between 1999-2014.  (d) Published in either English or French.	No exclusion criteria specified.	9
<b>Boyce, 2014</b>	Any setting	Identify the barriers and facilitators for clinicians in using the information generated from PROMs.	Systematic review	Thematic synthesis	(a) Studies published in English.  (b) Participants were clinicians.  (c) Studies examined clinicians' views of PROMs after receiving feedback.  (d) Studies used a qualitative methodology.	No exclusion criteria specified.	16

<b>First author and year</b>	<b>Setting</b>	<b>Aims</b>	<b>Type of review</b>	<b>Synthesis methods</b>	<b>Inclusion criteria for individual studies</b>	<b>Exclusion criteria for individual studies</b>	<b>Number of individual articles included</b>
<b>Duncan, 2012</b>	Care provided by Allied Health Professionals	Identify the barriers and facilitators to using PROMs in routine practice by Allied Health Professionals.	Systematic review	Narrative analysis	(a) Studies concerned with identifying facilitators/barriers in the routine use of PROMs by Allied Health Professionals in practice.  (b) Studies published in English.	(a) If the topic in the studies was not of direct relevance.  (b) If samples were not clearly defined.  (c) If a sample was not wholly composed of Allied Health Professionals.	15
<b>Greenhalgh, 2017</b>	Any healthcare setting	Identify the processes through which, and circumstances in which, PROMs feedback improves patient care.	Realist synthesis	Realist synthesis	(a) Studies which provided a theoretical framework that describes how the process of feeding back individual PROMs intends to work.  (b) Studies which provided a critique, review or discussion of the ideas underlying how individual PROMs feedback is intended to work.  (c) Studies that provided stakeholder accounts or opinions of how individual PROMs feedback does/does not work.  (d) Studies which outlined, discussed or reviewed potential unintended consequences of individual PROMs feedback.	(a) If studies focused on PROMs as a research tool.  (b) If studies focused on evaluating or reviewing the psychometric properties of PROMs.  (c) If studies provided advice or recommendations for which PROM to use in a research context.	36

<b>First author and year</b>	<b>Setting</b>	<b>Aims</b>	<b>Type of review</b>	<b>Synthesis methods</b>	<b>Inclusion criteria for individual studies</b>	<b>Exclusion criteria for individual studies</b>	<b>Number of individual articles included</b>
<b>Howell, 2015</b>	Cancer care	Identify the PROMs used within routine cancer services, their impact and the factors influencing uptake.	Scoping review	Does not specify which method used	<ul style="list-style-type: none"> <li>(a) Studies which reported on the routine use of PROMS.</li> <li>(b) The PROM was completed by the patient.</li> <li>(c) Included cancer patients or survivors.</li> <li>(d) Evaluated outcomes at the patient, clinical practice or care process or system level or barriers/enablers to using PROMs.</li> <li>(e) Studies published from 2003.</li> <li>(f) Studies published in English.</li> <li>(g) Could be primary quantitative or qualitative studies or systematic literature reviews.</li> </ul>	No exclusion criteria specified.	30 individual studies & 4 systematic reviews.

The included reviews used different methodologies and focused on different clinical specialities or aspects of the implementation process. Half of the reviews were systematic reviews (Duncan and Murray, 2012; Antunes et al., 2014; Boyce et al., 2014). The other reviews included a realist synthesis (Greenhalgh et al., 2017), a scoping review (Howell et al., 2015) and an integrative review (Bantug et al., 2016). Methodologically, each review type differed especially in their purposes and the review process. For example, quality appraisal should be undertaken within a systematic review but is not required within other review types (Grant and Booth, 2009). The implications of the different review methodologies are considered further in the next section. All of the reviews used a form of qualitative synthesis e.g. narrative synthesis.

Three reviews focused on a specific area of healthcare: palliative care (Antunes et al., 2014), oncology services (Howell et al., 2015) and services delivered by Allied Health Professionals (Duncan and Murray, 2012). The other three reviews considered a particular aspect of the PROMs process: graphical display of data (Bantug et al., 2016) and using the information generated from PROMs (Boyce et al., 2014; Greenhalgh et al., 2017). All three reviews included studies from a range of settings. Duncan and Murray (2012) considered PROMs alongside other types of outcome measures.

Each review included a number of individual studies, ranging between 9 and 36 studies. In total, 118 individual studies were included within the reviews. Only 15 of the individual studies included in two or more of the reviews (13%), indicating that there was little repetition between the reviews. The interpretation of individual studies included in two or more reviews was broadly consistent. One review (Howell et al., 2015) included four systematic reviews, along with individual studies. This did not create a double counting issue because none of the reviews met the eligibility criteria to be included within this systematic review of reviews.

### (3.5.3) Risk of bias within the reviews

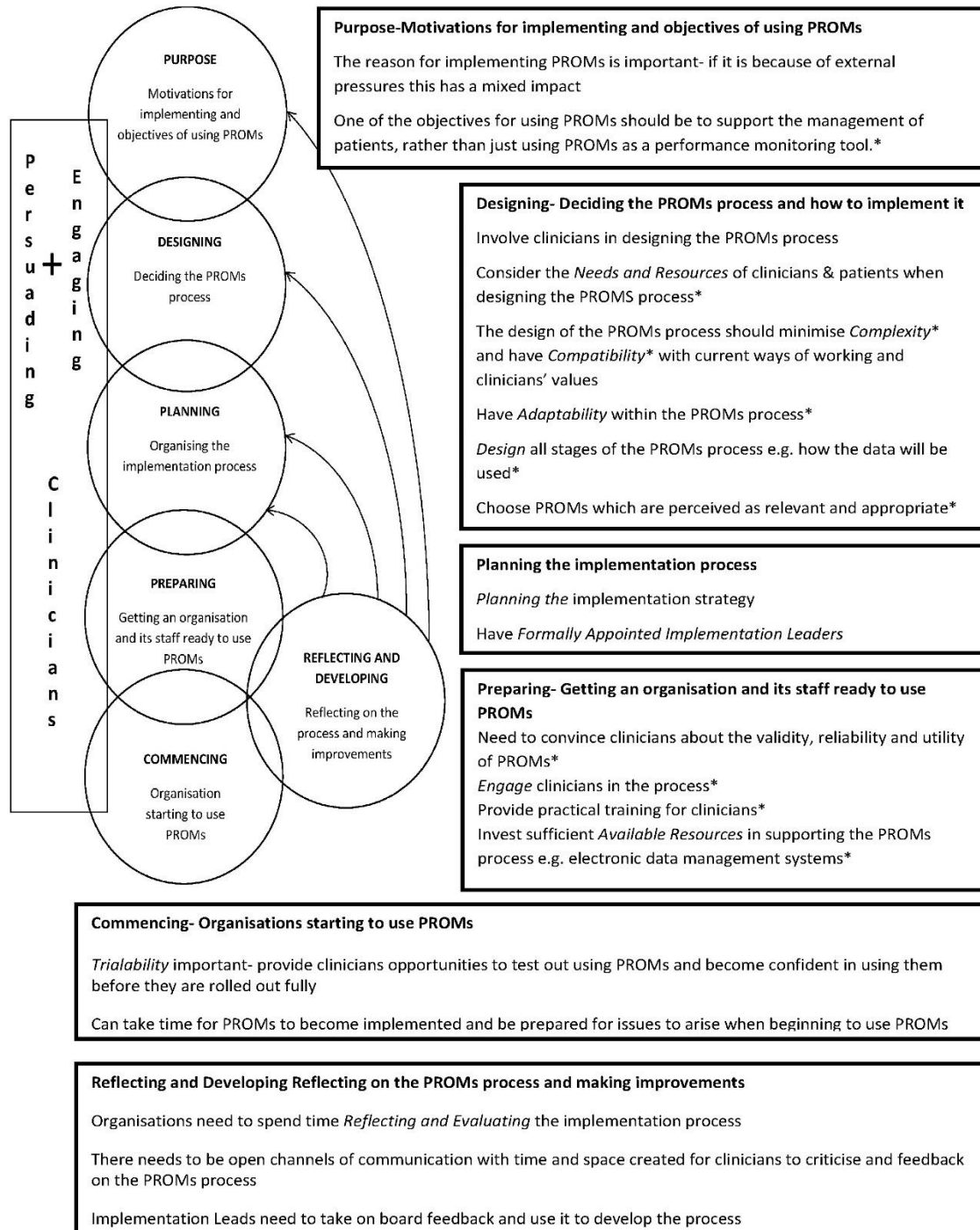
The results of the ROBIS assessments are included in Appendix 5. Whilst there were clear reasons for choosing the ROBIS, in practice the tool had little value in this review. This was because some of the assessment criteria were not applicable to the included integrative (Bantug et al., 2016), realist (Greenhalgh et al., 2017) or scoping reviews (Howell et al., 2015). The three reviews had not undertaken some criteria assessed by the ROBIS because these were not relevant

to the review methodology, for example they did not undertake quality appraisal. This meant the reviews were rated as having a high risk of bias but this was not due to quality issues with the reviews. In contrast, the three systematic reviews (Duncan and Murray, 2012; Antunes et al., 2014; Boyce et al., 2014) undertook all of the processes assessed by the ROBIS, so were categorised as having a low risk of bias. Given the issues, the findings of the ROBIS were not taken into account when interpreting the review findings.

### (3.6) Synthesis of results- Barriers and facilitators to implementing PROMs

The facilitators and barriers identified in the reviews were structured round the CFIR constructs (Appendix 6). As explained in the methods section, the data was further categorised into five stages of implementation: Purpose, Designing, Planning, Preparing, Commencing, and Reflecting and Developing. Some of the CFIR constructs were relevant to specific stages (displayed in italics e.g. *External Policies and Incentives*). Other CFIR constructs transcended several stages and were developed into new concepts. Many of the factors identified were bidirectional, so they could be a facilitator or barrier depending on their execution. For example, delivering good quality training to clinicians appeared to facilitate implementation but a lack of training was detrimental to clinicians using PROMs. Given the bidirectional nature of factors, a diagram was produced of the implementation process which focuses only on facilitators (Figure 1). In the figure, facilitators identified in four or more reviews are denoted with an ‘\*’. As these facilitators were identified in a number of reviews, and thus diverse contexts, there is a greater chance they may be relevant to TSOs than issues identified in only one specific clinical context.

**Figure 1- Issues to consider when implementing PROMs**



Issues with a "\*" arose in 4 or more reviews



### (3.6.1) Stage 1- Defining 'Purpose'- How the motivations for, and objectives of, using PROMs impact on implementation (see Figure 1)

Healthcare services had different reasons for utilising PROMs and these influenced implementation in different ways. Aligning PROMs with clinical practice guidance (*External Policies*) facilitated the use of measures because it indicated to clinicians that PROMs were part of their professional practice (Howell et al., 2015). However, *External Incentives* could be a barrier to using PROMs (Duncan and Murray, 2012; Greenhalgh et al., 2017). External incentives were when other organisations such as oversight bodies provided incentives to organisations for completing measures. External incentives could result in poor quality data because organisations were not using measures for their own benefit but rather to satisfy other people. For example, Greenhalgh et al. (2017) identified how organisations were gaming PROMs data to meet externally set performance targets.

Implementation was facilitated when PROMs were used for a therapeutic purpose to support the care of an individual patient (care management) e.g. to inform the services a patient would receive. However, if the purpose of PROMs was to collate the collected data to monitor clinical performance (performance monitoring), then this was a barrier to their use (Boyce et al., 2014; Howell et al., 2015; Greenhalgh et al., 2017). The issue of purpose appeared relevant irrespective of the specific healthcare context.

### (3.6.2) Stage 2 'Designing'- How the principles underpinning the design of the PROMs process impacts on implementation (see Figure 1)

The designing stage considers the decisions made by an organisation in relation to how they will collect, process and analyse PROMs. These decisions appeared to be influenced by underpinning principles and consideration of patients' needs.

A number of principles underpinning the design of the PROMs process were identified by the reviews. Four reviews identified the importance of *Adaptability*, so that services and clinicians had flexibility on if, when and how to administer a PROM to a patient (Duncan and Murray, 2012; Antunes et al., 2014; Boyce et al., 2014; Greenhalgh et al., 2017).

Designing a process which had *Compatibility* with clinicians' values and organisational workflows facilitated implementation, with all but one review identifying compatibility as important (Duncan and Murray, 2012; Antunes et al., 2014; Boyce et al., 2014; Howell et al., 2015; Greenhalgh et al., 2017). For example, organisations ensuring the time points for collecting PROMs data were compatible with appointment schedules so patients were not asked to complete measures outside of appointments. Clinicians' values influenced whether they engaged with PROMs and they needed measures to be compatible with their views. For example, if a clinician believed their work focused on improving patients' wellbeing, they wanted a wellbeing rather than a general health measure to be used.

Finally, all of the reviews emphasised that any PROMs process needed to be straightforward, to avoid the process being perceived as having *Complexity* (Duncan and Murray, 2012; Antunes et al., 2014; Boyce et al., 2014; Howell et al., 2015; Bantug et al., 2016; Greenhalgh et al., 2017). For example, the chosen PROMs needed to be worded simply and data management systems easy to use. One review felt involving clinicians in the designing stage helped ensure the design of the PROMs was straightforward (Antunes et al., 2014). However, it is not known whether consulting clinicians is useful outside of the palliative care context because it was only identified by the review based in that setting.

Considering *Patients' Needs and Resources* when designing the PROMs process was identified as a facilitator by all of the reviews (Duncan and Murray, 2012; Antunes et al., 2014; Boyce et al., 2014; Howell et al., 2015; Bantug et al., 2016; Greenhalgh et al., 2017). This entailed both the actual needs of patients, but also clinicians' perceptions of patients' needs. Actual needs included choosing an appropriate measure for patients, and ensuring the PROMs process was flexible, such as giving patients a choice whether to complete the measure electronically or on paper. Additionally, the reviews identified how clinicians had beliefs about their patients' needs and organisations needed to consider these. Clinicians' attitudes towards PROMs partly depended on whether they felt their patients would have their care increased or be disadvantaged because of how the patient scored on a measure (Antunes et al., 2014; Boyce et al., 2014). The reviews did not consider whether clinicians' perceptions of patients' needs aligned with their actual needs. In many ways this did not appear relevant, providing clinicians felt their concerns about patients were addressed. Two reviews discussed consulting patients about which PROMs

to use (Howell et al., 2015; Greenhalgh et al., 2017). However, they did not discuss whether consulting patients facilitated implementation.

### (3.6.3) Continuation of Stage 2- 'Designing' the PROM process- How the design of the PROMs process impacts on implementation (see Figure 1)

The designing stage encompasses decisions about the choice of PROM tool and the processes for gathering, managing, interpreting and acting on the data generated from measures. The choice of PROM appeared to have a bidirectional influence on implementation. Implementation was facilitated if the PROM was perceived by clinicians as valid and useful (Antunes et al., 2014), as did selecting a measure that clinicians perceived to be user-friendly, for both them and their patients (Duncan and Murray, 2012; Boyce et al., 2014; Greenhalgh et al., 2017). In contrast, if clinicians perceived the PROM as complex, invalid or inappropriate they would be less inclined to use the measure. 'Validity' was a term regularly used by the reviews in relation to clinicians wanting to feel the PROM captured the needs of their patients. However, licence fees associated with using a specific PROMs (*Costs*) were a barrier. This is because licence fees may prohibit an organisation from using their preferred PROM (Antunes et al., 2014). One review identified the method for administering PROMs was important. This review discussed how patients needed support from clinicians to complete measures within appointments (Greenhalgh et al., 2017).

Alongside collecting PROMs, it was important to design procedures for processing and using the PROMs data which decreased the burden on staff (Boyce et al., 2014; Greenhalgh et al., 2017). Processing related to organisations having systems in place for the data from individual PROMs to be collated for analysis. For example, reviews discussed the importance of investing in technological solutions such as web-based apps where PROMs were collected electronically (Boyce et al., 2014). These were seen as advantageous because having them in place meant that clinicians did not have the administrative burden of entering PROMs into data management systems (Boyce et al., 2014). To facilitate the use of the collected data, it appeared important for systems to be in place that enabled clinicians to utilise the PROMs data in their practice (Antunes et al., 2014; Boyce et al., 2014; Bantug et al., 2016; Greenhalgh et al., 2017). For example, organisations having reporting systems which produced easy-to-understand graphs of PROMs data which clinicians could share with patients (Bantug et al., 2016).

#### (3.6.4) Stage 3- 'Planning' the implementation process (see Figure 1)

*Planning* the implementation process (Antunes et al., 2014; Bantug et al., 2016) and having *Formally Appointed Internal Implementation Leads* (Antunes et al., 2014; Boyce et al., 2014) appeared to facilitate implementation. Planning entailed organisations deciding when and how they would start using PROMs e.g. having a timetable of when different teams would start using measures. If an organisation did not plan implementation then it was more difficult to progress the use of PROMs (Antunes et al., 2014). Two reviews identified that it was important to have someone within the organisation responsible for ensuring PROMs were implemented, referring to this role as an Implementation Lead (Antunes et al., 2014; Boyce et al., 2014). The reviews discussed how the Implementation Lead needed to support staff within the organisation to use PROMs and address any concerns people had.

#### (3.6.5) Stage 4- 'Preparing'— Investing time and resources in preparing an organisation and clinicians to implement PROMs (see Figure 1)

Investing sufficient time and resources to ensure an organisation's *Readiness for Implementation* was identified as a facilitator in all of the reviews. Furthermore, the bidirectional impact of clinicians' *Knowledge and Beliefs* was also identified by all six reviews. The reviews identified how clinicians were reluctant to engage with PROMs if they did not feel the measures were a valid way of capturing change in their patients. However, clinicians' views were not static and could be addressed through *Engaging* and persuading clinicians on the value of using PROMs. Training was identified by all of the reviews as a method for facilitating engagement. The reviews found that training needed to be both ideological and practical. The ideological element involved explaining about the validity of PROMs as well as the benefits and justification for using measures (Duncan and Murray, 2012; Antunes et al., 2014; Boyce et al., 2014; Howell et al., 2015; Bantug et al., 2016; Greenhalgh et al., 2017). The practical component needed to teach clinicians how to administer PROMs, analyse and interpret the data, and manage clinical issues arising from PROMs.

Several of the reviews identified how organisations needed to invest sufficient *Available Resources* in systems to support the PROMs process (Antunes et al., 2014; Boyce et al., 2014; Duncan and Murray, 2012; Greenhalgh et al., 2017). The main resource was organisations having electronic databases (data management systems) which could be used to record, manage and use the PROMs data. Additional facilitators included investing in administrative support to process measures and having support in place for patients who flagged up issues on the completed PROMs. The reviews highlighted how a lack of infrastructure was detrimental for clinicians using PROMs because to feel motivated to engage with measures on an ongoing basis, clinicians needed to feel the collected data was used.

The reviews generally focused on clinicians being resistant to PROMs. However, there are scenarios when managers may not be engaged, which can be problematic for implementation (Antunes et al., 2014; Boyce et al., 2014). Furthermore, the organisational culture may create barriers to implementation. However, none of the reviews gave much consideration to how an organisation's culture and structural characteristics (*Inner settings*) impacted on implementation. This is an interesting omission because the CFIR contains a number of constructs relating to the influence of the organisation on implementation.

#### (3.6.6) Stage 5- 'Commencing'- The issues that arise when starting to use PROMs (see Figure 1)

The reviews identified three barriers which arose when organisations started to use PROMs. This reflects the *Executing* CFIR construct. Firstly, it takes time and effort for PROMs to become a routine part of practice (Antunes et al., 2014). During this time, the Implementation Lead and organisation needed to be proactive in continuing to progress implementation including reminding clinicians to complete measures. Secondly, one review found only some clinicians engage in PROMs which created resentment because these staff members felt the burden was placed on them (Boyce et al., 2014). Finally, one review highlighted how organisations struggled to use measures with specific patients, such as people not understanding the measure (Greenhalgh et al., 2017). This relates back to the idea of ensuring *Adaptability* when designing the PROMs process, so that clinicians have both flexibility and discretion when utilising PROMs with specific patients. *Trialability*, which involves clinicians testing measures out with a small number of patients, was proposed by one review as facilitating implementation (Boyce et al.,

2014). However, the other five reviews did not discuss testing out the process. Generally the reviews did not consider commencing in much detail beyond reflecting on the need to address any issues which arise, this is discussed in the next section.

### (3.6.7) Stage 6- 'Reflecting and Developing'- Reflecting on the PROMs process and making improvements (see Figure 1)

Reflecting and Developing occurred when organisations gave clinicians opportunities to provide constructive feedback, and then used the feedback to develop the PROMs process. The stage incorporates the CFIR construct of *Reflecting & Evaluating*. The Reflecting and Developing stage focuses on the idea that initial problems may occur when starting to use measures in practice and organisations need to reflect on these issues and make improvements to the PROMs process. However, this facilitator was only considered in the reviews based in palliative care and with allied health professionals, raising questions about the relevance of the stage to other contexts.

## (3.7) Discussion

### (3.7.1) Summary of findings

A number of bidirectional factors were identified which arise at 6 different stages of the PROMs implementation process. It was important for PROMs to have a therapeutic purpose so that clinicians felt the PROMs could be used in the care management of their patients. Organisations investing time and resources during the 'designing' and 'preparing' stages appeared to be crucial. The 'designing' stage involved organisations planning not just which PROMs to use and how to administer the measures, but also how the data would be processed, analysed and used in the care management of patients. The 'preparing' stage involved getting an organisation and its clinicians ready to use measures. A key aspect of this stage was providing clinicians with training, including on the validity and value of PROMs. Organisations needed to invest in systems and resources to support the process such as data management systems and administrative staff. Identifying individuals to lead implementation and reflecting and developing the process based on feedback also facilitated the use of PROMs.

Organisations delivering healthcare services are diverse and it is important to consider whether they face different barriers and facilitators when implementing PROMs. This is especially relevant within the review, because if there are factors which consistently occur in different contexts, then they may be relevant to TSOs. Three of the included reviews focused on specific clinical areas, whilst the other three reviews focused on a single part of the PROMs process, but considered a range of healthcare services. There were no contradictions between the reviews, for example some reviews found that PROMs needed to support the care management of patients and none of the other reviews disputed this. However, there were some factors identified in some of the reviews but not others. This may be due to genuine differences between contexts or may have arisen because the reviews had different remits. For example, only the publications based in palliative care and with allied health professionals identified the need for there to be a reflecting and developing phase when implementing PROMs (Duncan and Murrary, 2012; Antunes et al., 2014). Therefore, there is a need for further research comparing the whole implementation pathway in different contexts.

The reviews generally considered each issue separately rather than exploring how the identified factors may interrelate and influence each other. None of the reviews considered the direct relationship of any of the identified issues on the implementation of PROMs. For example, whilst the reviews discussed the importance of training clinicians, it is unknown whether providing training correlates with an increase in the completion of PROMs. Finally, the reviews did not explore the impact on implementation if an organisation cannot or does not adopt all of the identified facilitators or address all the barriers. For example, Duncan and Murray (2012) proposed if an organisation is mandated to use a specific PROM by an external source, they can mitigate the impact of not choosing their measure through undertaking greater engagement work with clinicians. The potential impact of taking mitigating action to reduce the effect of barriers needs greater exploration.

### (3.7.2) Comparison with other literature

The review was compared with a range of existing literature including publications not included in this review (detailed throughout the subsequent sections) and published guidance on implementing PROMs. Two guidance documents were also considered: one for palliative care services (Van Vliet et al., 2014) and a generic one aimed at any type of services (Aaronson et al., 2015). A decision was made not to include the New Economics Foundation (2012) guide which considered TSOs because the included reviews did not encompass the third sector. The findings of the review are generally consistent with other literature on implementing PROMs, although this review places greater emphasis on the whole implementation pathway.

#### Purpose of using PROMs

The review found the purpose for using PROMs influenced implementation; organisations needed to find ways of making the measures useful for clinicians in respect of PROMs having a care management function. This finding is consistent with the wider literature on changing working practices, which notes that clinicians need to understand how they would benefit from any change in practice (National Institute for Health and Clinical Excellence, 2007). So, clinicians needed to believe it was beneficial for their patients and thus themselves to engage with PROMs.

#### Designing the PROMs process

Similar to other literature, this review highlighted the importance of investing time in designing the PROMs process and tailoring it to an organisation's specific context. This includes considering the needs and opinions of patients and clinicians (Meerhoff et al., 2017). Involving clinicians in the designing process was identified as useful both within the review and other studies on implementing PROMs (O'Connell et al., 2018). The need to plan all elements of the PROMs process was considered within this review. This included planning how to administer measures alongside how the collected data would be processed, analysed and used. Other studies have also discussed the need to design all elements of the PROMs process (Van Vliet et al, 2014; Porter et al., 2016).



### Training clinicians

The review found clinicians need training on both the practical aspects of using measures and the ideological reasons including the rationale for using PROMs and their validity. The ideological training can help engage and persuade clinicians to use measures. This review places greater emphasis on the ideological aspect of training compared to other literature, which generally only considers providing training on how to use PROMs (Santana et al., 2015; Porter et al., 2016; Peipert and Hays, 2017). The review identified training as a distinct phase, undertaken before an organisation starts using PROMs. Subsequent literature has identified the need for training to be ongoing, so refreshers are provided when clinicians are using PROMs (Gibbons and Fitzpatrick, 2018).

### Investing in the PROMs process

Consistent with other studies, the review identified the need for organisations to invest in data management systems (Malhotra et al., 2016). However, investment may not always be feasible, because of budget constraints or the organisation not prioritising investment in data management systems.

### Factors not identified in the review

The CFIR includes a number of inner setting constructs which focus on the structural characteristics of an organisation (Damschroder et al., 2009), such as the impact of an organisation's size. However, the publications included in the review did not consider these. It could be either that the structural characteristics of organisations are not relevant when implementing PROMs or that the included reviews did not consider organisational characteristics. None of the included reviews considered how to sustain the use of PROMs after the initial implementation activities (Moore et al., 2017). This contrasts with Gibbons and Fitzpatrick (2018), who raised questions about the ongoing use of PROMs because of organisations not investing in infrastructure to support the use of measures. Further research is

required to explore whether the use of PROMs is sustained in organisations after implementation strategies cease.

The included reviews focused on the importance of considering clinicians' perceptions of patients' needs when designing the PROMs process. It was less apparent whether consulting patients facilitated implementation. Other literature emphasises the importance of involving patients (Haywood et al., 2016), indicating this is an area which needs further consideration.

### (3.7.3) Sensitivity analysis

A sensitivity analysis was undertaken comparing the reviews' findings with other publications considering the implementation of PROMs. This included the 32 publications which had been excluded from the review because they did not include any details on their methods. The sensitivity analysis found the findings of the review were generally consistent with the other publications. However, the other publications placed greater emphasis on the advantages of using electronic methods to administer PROMs, but with the caveat of organisations needing sufficient technological support (Keertharuth et al., 2015). Some of the excluded publications also considered the external context such as the challenges of implementing PROMs in countries where there are limited resources and lower literacy rates (Bausewein et al., 2011). Whilst this PhD focuses on the UK, Bausewein et al.'s (2011) observation highlights the importance of considering the external context in relation to implementing PROMs.

#### (3.7.4) Strengths and Limitations of the systematic review of reviews

This section focuses on the strengths and limitations of the systematic review of reviews in relation to the methodology used.

##### Strengths of the systematic review of reviews

The systematic review of reviews appears to be the first review of reviews to synthesise knowledge across different clinical specialities and the whole implementation pathway. The review was enhanced through utilising the CFIR. Much of the previous research on implementing PROMs has not drawn upon existing implementation theories. The CFIR was generally a ‘good fit’ with the findings of the review (Carroll et al., 2013). Furthermore, using the CFIR enabled me to reflect on potential issues not identified within the included reviews. The review developed the findings beyond the static constructs of the CFIR through framing them within stages of implementation. Taking this approach helps to communicate the dynamic nature of implementation, and could be used as a basis for people trying to implement PROMs, including during the Community-Based Participatory Research phase of this PhD. Finally, systematic review of reviews are often criticised for including reviews which have drawn upon the same individual studies. However, this was not a problem within this review because only 13% of the individual studies were included by two or more of the reviews. Furthermore, the review encompassed 113 unique individual studies.

##### Limitations of the systematic review of reviews

The systematic review of reviews had seven limitations. Firstly, no reviews were identified which considered TSOs and it is not known how relevant the findings are to the specific third sector context of the PhD. Secondly, there may be useful individual studies that have not been included in a published review and thus were not considered. However, the impact of this limitation was reduced by comparing the findings of the review to the wider literature, including individual studies. Thirdly, the search was limited in some ways. Searches were restricted to publications written in English because there were no resources available to translate articles. The language restriction resulted in the exclusion of 3.3% of identified titles arising from the MEDLINE search. Given the relatively small number, it was unlikely that key reviews were missed. The non-electronic database search methods were UK focused because this is the setting

for the PhD. Additionally, the electronic database searches focused on health rather than social care. Whilst, additional searches did not identify any reviews based within social care, there is a need for similar reviews to ensure the search terminology and methods take into account social care.

Fourthly, 32 publications were excluded because they either did not provide detail about their methods or the methods did not encompass reviewing the literature. This is a common exclusion criterion for systematic reviews of reviews (Smith et al., 2011). A sensitivity analysis was performed which compared the reviews' findings with those of the excluded publications. The analysis highlighted that the findings of the review would have been similar even if these publications had been included.

The fifth limitation of the review was the ROBIS lacked relevance to reviews not categorised as standard systematic reviews by their authors. Therefore, there is a need for methodological work developing risk of bias tools to appraise different types of reviews. Sixthly, the synthesis of findings utilised a facilitators and barriers framework, which could mean other factors were excluded. However, the risk was minimised by not restricting the search to only studies using the terms 'facilitators and barriers' and by extracting all issues irrespective of the specific terminology used. Finally, the findings were reliant on how well the information from the primary studies had been extracted by the individual reviews. This is a limitation of all systematic review of reviews.

### **(3.8) Implications**

The systematic review of reviews was conducted to both inform the TSO focused primary research of the PhD and to increase knowledge on implementing PROMs within healthcare services. Consequently, there are different types of implications arising from the review: issues relevant to practice, areas of further research, and issues to explore within the PhD. Each type of implication is considered below.

### (3.8.1) Implications for organisations seeking to implement PROMs

The findings may be relevant to other organisations implementing measures because many of the facilitators and barriers were identified in different contexts. That is, organisations need to consider the early stages of implementation in terms of designing the PROMs process, preparing the organisation and engaging clinicians. Some issues were only identified in one review and it is unknown if they only occur in that specific context or are relevant to other organisations. This issue is salient because the reviews did not consider the influence of an organisation's characteristics. However, the CFIR contains a number of constructs related to the characteristics of organisations (inner settings), indicating their relevance to implementation.

### (3.8.2) Areas of further research

Several areas for further research were identified in the systematic review of reviews. Future research needs to consider the impact of the organisation on implementation such as potential differences between smaller and larger organisations. A key facilitator identified in the review was the need for PROMs to be useful for clinicians but research is required on how to facilitate implementation if an organisation is using measures for performance monitoring purposes. Research is needed on the implications of co-designing the PROMs process with patients. This is because whilst advice on using PROMs recommends involving patients, the reviews primarily focused on considering the needs of patients rather than consulting them directly (O'Connell et al., 2018). The review focused on the initial implementation of PROMs, however further research is needed on sustaining the use of measures. For example, how changes in organisational culture impact on outcome measures becoming part of routine practice. The systematic review of reviews identified many issues and considered them as independent components. Consequently, further research is needed on whether some factors are more important than others.

### (3.8.3) Implications for the PhD

It is questionable how relevant the findings of the review are to the third sector because none of the included publications considered TSOs or included any individual studies based within the third sector. Given this, I undertook a third sector stakeholder consultation event and considered relevant literature on evaluation within the third sector (discussed in the next chapter). The absence of published literature on implementing PROMs within TSOs highlights the need for the primary research undertaken in the PhD.

Whilst focused on a different context, the findings of the review were used to inform the primary research. The findings were used as a basis for developing the topic guides and analytical framework for the Qualitative Interview phase. Furthermore, the review provided a source of comparison to help understand whether TSOs and healthcare services had similar experiences of implementing PROMs.

### (3.9) Summary of the chapter

In summary, a systematic review of reviews was undertaken to identify factors that appear to influence the implementation of PROMs within any context. The review identified a range of factors that appear to have a bidirectional impact on the implementation of PROMs at different stages of the implementation pathway. Designing the PROMs process and preparing an organisation for implementation including training clinicians, appeared critical stages. Both stages require time and resources. The review's findings were comparable to other publications, indicating their applicability to healthcare services implementing PROMs. However, it is unknown how relevant the findings are to the third sector. Consequently, in the next chapter I compare the findings with TSO sources, including stakeholders and literature on evaluation.

## Chapter 4- The relevance of the systematic review of reviews findings to TSOs

### (4.1) Outline of the chapter

Scoping exercises between 2014 and 2017 had not identified any publications focused on the implementation of PROMs in TSOs (as explained in Chapter 3). Furthermore, none of the publications included within the systematic review of reviews considered the third sector. Therefore there was a need to consider sector specific sources of information because TSOs may differ from other types of organisations that deliver health and/or wellbeing services (Hardwick et al., 2015). This was done through undertaking a TSO literature review and a stakeholder consultation event to consider which issues identified in the systematic review of reviews may be relevant to implementing PROMs in TSOs.

The TSO review focused on exploring literature in relation to evaluation within TSOs. Within the third sector, organisations often utilise PROMs within the context of evaluation to demonstrate the impact of their wellbeing activities to current and potential funders (Carman, 2007). Given this, exploring the literature on implementing evaluation could provide some insights applicable to PROMs in TSOs. Additionally, I held a stakeholder consultation event. The event was an opportunity to explore stakeholders' perspectives on whether the findings of the systematic review of reviews reflected their experiences of using PROMs in the third sector. This chapter focuses on the literature review and stakeholder consultation event. Firstly, both methods are described. Secondly, the insights from both the literature review and stakeholder consultation event are compared simultaneously with the findings of the systematic review of reviews.

## (4.2) Literature review of a related area: Implementing evaluation within TSOs

### (4.2.1) Rationale for considering literature on evaluation within TSOs

I did not identify any literature on implementing PROMs within TSOs when conducting the systematic reviews of reviews during 2017. Consequently, I considered whether there might be a related area where there was literature on TSOs. During the preparation work for the PhD, stakeholders described how PROMs were used to demonstrate impact to external funders. Consequently, measures were often used within service evaluation or impact measurement (henceforth known as evaluation) within the third sector (Ógáin et al., 2012). The purposes of evaluation can vary. It may be utilised by an organisation to understand about service delivery and/or be used as a basis for service improvement (developmental evaluation). Evaluation may also be used by TSOs to explore the implementation of new processes or services (process evaluation). Finally evaluation may be used by TSOs or commissioners to quantify or evidence the impact, outcomes or performance of a specific wellbeing activity or the organisation as a whole (Bach-Mortensen and Montgomery, 2018). Thus within TSOs, the use of PROMs appeared to align with evaluation. Taking this perspective, I decided to search the literature on implementing evaluation within TSOs.

### (4.2.2) Methods used in the literature review

I had planned to undertake a literature review on implementing evaluation in TSOs. However, in January 2018 a comprehensive systematic review on the subject was published. The review was authored by Bach-Mortensen and Montgomery (2018). Consequently, it felt unnecessary to replicate the review and I instead drew upon its findings.

I identified the Bach-Mortensen and Montgomery (2018) review when I began undertaking the searches for my planned literature review. I undertook some initial scoping before conducting any formal electronic database searches. I began the initial scoping in January/February 2018 through undertaking a Google search and checking relevant organisational websites such as the Kings Fund, the University of Birmingham Third Sector Research Centre, NCVO and What Works for Wellbeing. Through these searches, I identified Bach-Mortensen and Montgomery's (2018) systematic review focused on the facilitators and barriers to undertaking evaluation in TSOs. The review was published on 22<sup>nd</sup> January 2018.



Data extraction was undertaken on the Bach-Mortensen and Montgomery (2018) using the data extraction form developed for the systematic review of reviews. As part of this, the review was assessed for bias using the ROBIS tool (discussed in Chapter 3) and found to have a low level of bias.

A framework approach was used to analyse the extracted data, drawing upon the implementation process developed in the systematic review of reviews (Chapter 3, Figure 1) and the constructs of the CFIR (Damschroder et al., 2009). The process is explained in the previous chapter and in short involves coding the findings from the review into pre-determined categories to identify arising issues (Booth et al., 2016).

#### (4.2.3) Description of Bach-Mortensen and Montgomery (2018)'s review

Bach-Mortensen and Montgomery's (2018) paper was a comprehensive systematic review which followed PRISMA guidelines (Moher et al., 2009). The review synthesised 24 studies which used a range of methodologies including qualitative interviews, focus groups and surveys. Twenty-five percent of these studies utilised mixed methods with an equal number of studies (37.5%) employing either quantitative or qualitative methods only. A fifth of the studies were based in the UK, with the majority of the studies based in the USA. Two-thirds of the included studies focused on TSOs delivering health or social care related support. Over 70% of the studies included organisations of varying sizes. Bach-Mortensen and Montgomery (2018) identified 30 barriers and 26 facilitators to evaluation within TSOs.

#### (4.3) TSO Stakeholder Consultation Event

A TSO stakeholder consultation event (the consultation event) was held in November 2017 to discuss how relevant the findings of the systematic review of reviews were to the third sector and to identify additional issues to explore within the primary research. Consulting TSO stakeholders was important because the systematic review of reviews did not consider the third sector. The decision to consult stakeholders reflects the general trend of increasing involvement of service-users, front-line workers and other stakeholders within systematic reviews (Pollock et al., 2015).

The approach takes a consultation type of stakeholder involvement (Cahill, 2007), where I as a researcher undertook the review and stakeholders contributed to the interpretation of findings.

The consultation event was organised by myself and two other researchers. The event arose because a number of third sector stakeholders wanted to discuss PROMs and it seemed an opportune point to update them on the research I was undertaking. More than 20 people attended the event including TSO front-line workers, managers and service-users, commissioners from statutory services and stakeholders who worked with the third sector such as community researchers.

Consultation on the systematic review of reviews lasted approximately 45 minutes. I presented the findings of my PhD review for the initial 15 minutes. For the remaining 30 minutes, attendees commented on which findings resonated with their experience of implementing PROMs, which findings they disagreed with, and any additional issues not identified in the review. Attendees wrote on different colour post-its to indicate which findings they agreed or disagreed with or whether they had additional insights. For example, an attendee would write on a green post-it if they agreed with the finding of the need to train front-line workers. Over 50 post-its were completed. Having a written exercise provided the opportunity for all attendees to express their views even if they did not feel comfortable contributing to the group discussion. Stakeholders also discussed the issues as a whole group whilst people wrote their post-its. After the event, I compared the findings of the verbal discussion and written post-its with the findings from the systematic review of reviews.

#### (4.4) Using a triangulation protocol method to compare the findings of the systematic review of reviews with the TSO sources

The findings of Bach-Mortensen and Montgomery (2018) and my reflections from the consultation event were compared with the findings of the systematic review of reviews to explore potential similarities and differences between the third sector and healthcare services in respect of implementation. A triangulation protocol method was used to support the comparison (Farmer et al., 2006). This technique was developed for bringing together multiple qualitative components of a study but has been recommended for mixed methods research (O’Cathain et al.,

2010). I felt that it would also be useful for bringing together the findings from the literature reviews and the stakeholder event. A triangulation protocol method involved developing a matrix, where the sources were in columns and the different findings in rows. The three sources of data within the columns were: (1) the Systematic review of reviews (2) Bach-Mortensen and Montgomery's systematic review on evaluation in TSOs and (3) reflections from the consultation event. Populating the matrix provided an opportunity to reflect on the findings of each source separately. In the final column, the information from the TSO sources was compared with the findings from the systematic review of reviews to identify potential similarities and differences between the third sector and healthcare services. A categorisation system, drawing upon O'Cathain et al's (2010) work was used to classify how similar or different the experiences were between the contexts. Each finding was categorised as:

- **Convergence**- whether there was similarities in the issues identified by the third sector and healthcare services.
- **Complementary**- whether there were similarities between the third sector and healthcare services but the TSO sources provided additional insights.
- **Dissonance**- whether there appeared to be differences between the third sector and healthcare services in respect of implementation.
- **Silence**- whether an issue is identified within the systematic review of reviews but has not been identified in the TSO sources or vice versa.

The populated triangulation protocol is provided in Appendix 7. The findings section within this chapter focuses on exploring the integrated findings (the final column) rather than describing the findings of Bach-Mortensen and Montgomery (2018) and reflections from the consultation event separately. Throughout the chapter and related tables, the phrase TSO stakeholders is used at times to refer to insights gained at the consultation event.

#### (4.5) Exploring how the findings from the TSO sources compared with the findings of the systematic review of reviews

The section is structured using the stages of implementation identified in the systematic review of reviews (Chapter 3, Figure 1). These are: Purpose; Designing; Planning, Preparing; Commencing; and Reflecting and Developing. A supplementary category of Additional factors was created to encompass factors identified from the TSO sources which did not fit into the stages of implementation. When CFIR concepts are identified these are denoted by *Italics*, for example *External policies*. As explained, Bach-Mortensen and Montgomery (2018) is not specifically about PROMs but their findings are considered in relation to PROMs within this chapter.

##### (4.5.1) Stage 1- 'Purpose'– How the motivations for, and objectives of undertaking PROMs, impact on implementation

It appears PROMs have a different purpose within TSOs compared to healthcare services. Within the systematic review of reviews an identified facilitator was PROMs having a therapeutic purpose, so measures supporting the care management of service-users, and a barrier was measures having a performance monitoring function (*Compatibility and Organisational Incentives and Rewards*). Stakeholders felt that within the third sector, PROMs primarily had a performance monitoring function to demonstrate impact to external commissioners. As explained earlier in the thesis, 'performance monitoring' relates to collating PROMs from a number of service-users to assess the impact of a specific wellbeing activity, front-line worker or the organisation as a whole. In TSOs, performance monitoring sometimes occurred in relation to selected wellbeing activities funded by a specific contract. At other times, performance monitoring was conducted on an organisational-wide basis to demonstrate the impact of the TSO. It was not clear whether implementation was impaired by TSOs using PROMs for performance monitoring, as experienced by healthcare services. Within the systematic review of reviews, organisations having to use PROMs because of *External Policy and Incentives* was identified as a barrier. However, Bach-Mortensen and Montgomery (2018) and TSOs stakeholders contradicted this finding. Both sources felt that TSOs were motivated to implement evaluation/PROMs to satisfy the needs of commissioners. Consequently, the CFIR construct of *External Policy and Incentives* appears to manifest itself differently in TSOs and healthcare

services. Bach-Mortensen and Montgomery (2018) did raise the issue that evaluation undertaken to meet the needs of external organisations such as funders, may be less appropriate for the specific organisation than evaluations they design themselves to meet their own needs. This observation links into an idea raised in the systematic review of reviews that imposing PROMs could result in organisations collecting poor quality data (Greenhalgh et al., 2017). Furthermore, Bach-Mortensen and Montgomery (2018) identified how TSOs faced the challenge of undertaking multiple evaluations to meet the need of different commissioners, something that may also apply to PROMs.

#### (4.5.2) Stage 2- 'Designing'- How the design of the PROMs process impacts on implementation

Designing the PROMs process (*Design Quality and Packaging*) was a prominent theme within the systematic review of reviews and was discussed in some detail by the TSO stakeholders.

Bach-Mortensen and Montgomery (2018) did not discuss design issues because their review was not about PROMs. There was convergence on the principles of design between the systematic review of reviews and TSO stakeholders. This included the need for the PROMs process to be flexible (*Adaptability*), straightforward (*Complexity*) and to take account of service-users' needs (*Patients' Needs and Resources*).

Taking a collaborative approach to design was raised in both the systematic review of review and within Bach-Mortensen and Montgomery (2018) (*Intervention Source* and *Learning Climate*). However, the nature of collaboration appeared to differ between sectors. Within the systematic review of reviews, one review suggested how the PROMs process should be designed in collaboration with front-line workers (Antunes et al., 2014). Whereas Bach-Mortenson and Montgomery (2018) emphasised collaboration in terms of TSOs and commissioners working together rather than commissioners imposing evaluation on an organisation (*Intervention Source*). Consistent with this finding, TSO stakeholders discussed how front-line workers struggled more with using PROMs chosen by commissioners.

The importance of designing how PROMs would be collected, processed, analysed and used (*Design Quality and Packaging*) was identified in the systematic review of reviews. TSO stakeholders generally agreed with the sentiment but discussed challenges with designing a process. TSO stakeholders strongly believed selected measures needed to be short and easy to understand, with front-line workers finding it difficult to use longer PROMs. Bach-Mortenson and Montgomery (2018) identified that it can be difficult for TSOs to identify appropriate evaluation tools, which may also be relevant in relation to organisations trying to choose which PROM to use. TSO stakeholders raised the challenge of identifying suitable time points to administer PROMs partly because of service-users attending wellbeing activities for varying lengths of time or on a sporadic basis. TSO stakeholders also discussed difficulties in getting PROMs data processed, analysed and used due to a lack of capacity and skills within the third sector. Bach-Mortenson and Montgomery (2018) reported a similar finding in relation to evaluation, identifying that in TSOs there was often a lack of capacity and capability to not just undertake evaluation but also to manage and analyse the arising data.

#### (4.5.3) Stage 3- 'Planning' the implementation process

Having *Formally Appointed Internal Implementation Leaders* (called Implementation Leads in this PhD) to progress the implementation process was identified as a facilitator in the systematic review of reviews. Bach-Mortensen and Montgomery (2018) did not identify the need for an individual lead but instead emphasised the importance of *Leadership Engagement*. Bach-Mortensen and Montgomery (2018) found having managers who were supportive and engaged with PROMs was relevant within TSOs in respect of evaluation. This included Board of Trustees/ Management Committees of TSOs which have overall responsibility for the organisation (NCVO, 2019b). The TSO stakeholders did not discuss the issue of having an Implementation Lead or the role of managers in facilitating PROMs. Consequently, there is some uncertainty about how relevant the role of the Implementation Lead is to TSOs implementing PROMs.

*Planning* the implementation process such as deciding beforehand when PROMs would be trialed prior to use in routine practice was considered important within the systematic review of reviews. Bach-Mortansen and Montgomery (2018) echoed this finding by discussing how a lack of planning appeared to be a barrier for undertaking evaluation. However, *Planning* was not discussed at the consultation event. This raises questions about whether TSO plan the implementation of PROMs or whether the process is more organic.

#### (4.5.4) Stage 4- 'Preparing'– Investing time and resources in preparing an organisation to implement PROMs

Getting an organisation ready to implement PROMs through investing in resources and training staff was identified as important in all three sources. In relation to *Available Resources*, Bach-Mortensen and Montgomery (2018) was consistent with the systematic review of reviews by emphasising the need for organisations to have infrastructure in place, including investing in data management systems and having sufficient staff to facilitate evaluation. However, both Bach-Mortensen and Montgomery (2018) and the TSO stakeholders questioned the feasibility of TSOs investing in infrastructure given their limited financial resources. Indeed, Bach-Mortensen and Montgomery (2018) felt a lack of financial resources was a key barrier for organisations undertaking evaluation. Some TSO stakeholders suggested commissioners could fund the infrastructure needed for PROMs given that they were mandating their use. However, Bach-Mortensen and Montgomery (2018) raised a discussion point that there was evidence indicating how, even when commissioners make money available for evaluation, TSOs did not fully utilise the budget. This indicates there may be barriers beyond financial constraints. Both TSO stakeholders and Bach-Mortensen and Montgomery (2018) discussed how having an infrastructure in place was not sufficient, TSOs also needed to have the capacity and capability to utilise the infrastructure. For example, a manager at the consultation event discussed not having time to train her front-line workers on the organisation's new data management system. Therefore whilst having sufficient infrastructure appears relevant in different contexts, TSOs may face specific barriers in relation to both investing in, and utilising, the infrastructure.

*Engagement* of staff through providing practical and ideological training (*Access to Knowledge and Information* and *Knowledge and Beliefs about the intervention*) appears relevant across contexts because it was identified as important by the systematic review of reviews and the TSO sources. TSO stakeholders felt that the training needed to be ongoing and not just part of the ‘preparing’ stage e.g. managers discussing PROMs as part of supervision with individual front-line workers. This differed from the systematic review of reviews, where training was classified as a standalone phase.

#### (4.5.5) Stage 5- ‘Commencing’- The issues that arise when starting to use PROMs

The systematic review of reviews found it takes time to implement PROMs and issues occur when measures start to be used. This includes only some front-line workers using measures and service-users experiencing difficulties with completing PROMs (*Executing*). These issues resonated with the TSO sources. For example, Bach-Mortenson and Montgomery (2018) felt that many staff within TSOs had insufficient skills to utilise evaluation. The systematic review of reviews identified how trialing PROMs in an organisation can help to identify initial issues (*Trialability*). However, the TSO sources did not consider having a testing phase.

#### (4.5.6) Stage 6- ‘Reflecting and Developing’- Reflecting on the PROMs process and making improvements

Reflecting and Developing the PROMs (*Reflecting and Evaluating*) was an implementation stage identified in the systematic review of reviews. However, Bach-Mortensen and Montgomery (2018) did not discuss the stage in relation to evaluation. There was some indication by TSO stakeholders that organisations should respond to feedback about PROMs, but this appears to be undertaken more informally than the systematic review of reviews indicated. Consequently, there is uncertainty about whether TSOs spend time reflecting and developing PROMs processes during implementation.



#### (4.5.7) Additional factors identified in the TSO literature and/or stakeholder event not raised within the systematic review of reviews

##### Structure and culture

External support and the *Structural Characteristics* and *Culture* of organisations were factors identified in the TSOs sources but not within the systematic review of reviews. These additional factors do not fit into the Stages of Implementation diagram developed in the systematic review of reviews (Figure 1, Chapter 3). TSOs appeared to benefit from having people outside of the organisations (*External Change Agents*) and/or other organisations (*Cosmopolitanism*) helping them with evaluation (Bach-Mortensen and Montgomery, 2018). Additionally, TSO stakeholders and Bach-Mortensen and Montgomery (2018) felt that *External Change Agents* was also relevant in respect of the role of individual external commissioners. Both sources felt that individual commissioners differed in their approaches towards PROMs and may be supportive or create challenges for the TSO because of the specific stance they take. For example, TSO stakeholders explained how some individual commissioners mandated a specific PROM whereas others took a more collaborative approach, working with the organisation to identify a suitable outcome measure.

Bach-Mortensen and Montgomery (2018) identified how the *Structural Characteristics* and *Culture* of an organisation were relevant to evaluation. Their findings focused on how larger TSOs had more resources available to undertake evaluation, giving them an advantage over smaller organisations. Furthermore, Bach-Mortensen and Montgomery (2018) explored how the culture of some TSOs was more amenable to utilising evaluation, such as good networks amongst staff. Nothing was discussed at the consultation event or in the systematic review of reviews about the impact of structural characteristics or culture, raising questions about their relevance to implementing PROMs in TSOs.

##### Volunteers

TSO stakeholders raised the role of volunteers in relation to PROMs. Volunteers are people who give support to organisations in an unpaid capacity (Mohan and Bennett, 2019). Stakeholders felt that volunteers could support the implementation of PROMs, although volunteers needed the same training and support as paid staff members. But stakeholders also felt that not all volunteers

would engage. The systematic review of reviews did not consider volunteers, probably because volunteers are more prominent within TSOs than in healthcare services (Buckingham, 2012).

## (4.6) Discussion

### (4.6.1) Summary of findings

There were several areas of convergence between the systematic review of reviews findings and the insights from Bach-Mortensen and Montgomery (2018) and TSO stakeholders. These included the principles underpinning design, ensuring there were sufficient resources invested in the PROMs process, and staff receiving ideological and practical training. However, there were differences. Purpose was a key area of dissonance between the systematic review of reviews and the TSO sources, especially in relation to PROMs being externally imposed and used for performance monitoring. Additional factors were identified in the TSO sources that were not present in the systematic review of reviews. Firstly, both sources discussed the facilitating influence of having organisations and people external to the TSO supporting implementation. Furthermore, Bach-Mortensen and Montgomery (2018) identified the importance of an organisation's structural characteristics and culture.

Factors being bidirectional, so having a facilitating or detrimental influence on implementation depending on their execution, was a key finding of the systematic review of reviews. However, Bach-Mortensen and Montgomery (2018) discussed how the majority of their included studies felt the identified facilitators and barriers to evaluation were not bidirectional and so were separate issues. Therefore, each issue they identified was either a facilitator or a barrier. For example, Bach-Mortensen and Montgomery (2018) identified the facilitating influence of training whereas the systematic review of reviews found that training could be a facilitator or a barrier depending on the quality of delivery. This may be a genuine difference in organisational context or it may be that the bidirectional nature of factors relates specifically to PROMs.

#### (4.6.2) Strengths and limitations

##### Strengths

Exploring the TSO sources had four key strengths. Firstly, the lack of literature on implementing PROMs within TSOs, and concerns raised in the consultation event, highlighted the necessity of undertaking primary research on the implementation of PROMs within the third sector.

Secondly, undertaking the work described in this chapter provided an opportunity to identify additional issues to explore in the primary research which were not identified in the systematic review of reviews. Thirdly, the consultation event enabled an opportunity to seek the input of TSO stakeholders. Finally, the consultation event enabled me to promote the study and to disseminate the findings of the systematic review of reviews. Some attendees approached me after the event to explain how learning about the findings of the review provided an opportunity for them to reflect on the use of PROMs within their TSO.

##### Limitations

Whilst undertaking the work in this chapter was useful, it had a number of limitations. Although, initial scoping exercises did not identify any literature relating to implementing PROMs in TSOs, I have since identified publications that include relevant information. For example, Mathers et al. (2016) considers the implementation of performance monitoring for health trainers (a national peer support behaviour change programme delivered by TSOs). The publication was not specifically about TSOs or PROMs which may explain why it was not identified during earlier searches. Its existence raises the possibility that there are further relevant publications that I did not consider. However, any relevant literature subsequently identified was considered when I compared the findings of the primary research with existing literature (Chapter 10). The consultation event was attended by people primarily from one city and stakeholders in other parts of the country may experience different issues. Consequently, in the QI phase, I sought to recruit people from other parts of the country to widen the perspectives included. Finally, the chapter is reliant on the comprehensiveness and quality of the Bach-Mortensen and Montgomery (2018) review such as whether the authors have accurately interpreted the findings from the individual studies. There will also be a time gap between when the review was published and when the searches were performed. However, when searching the literature I did not identify any recent, relevant publications.

#### (4.6.3) Implications for the primary research

Consistency between the systematic review of reviews and the TSO sources indicate there may be similarities in the experience of organisations implementing PROMs, irrespective of the specific context. However, many factors identified in the systematic review of reviews required further research to understand whether and how they may arise within TSOs. Furthermore, there were issues raised in Bach-Mortensen and Montgomery (2018) and by TSO stakeholders that differed or were not identified in the systematic review of reviews. These highlight the importance of undertaking primary research specifically focused on implementing PROMs in the third sector.

The insights arising from utilising Bach-Mortensen and Montgomery (2018) and undertaking the consultation event were used to inform the primary research. Primarily, the findings informed the ongoing iteration of the topic guides for the QI phase. For example, asking questions of TSO managers about the impact of external funders and advisors, the role of volunteers and the structural characteristics of organisations. The additional issues identified through the TSO sources were incorporated into the analysis framework used in the QI phase. Finally, the consultation event provided an opportunity to recruit participants for the primary research.

#### (4.7) Summary of the chapter

Considering the potential relevance of the findings of the systematic review of reviews to the third sector through drawing upon TSO literature and consulting stakeholders was useful. This process highlighted that there were potential differences between the experiences of TSOs and healthcare services, thus specific research focusing on the implementation of PROMs in the third sector was needed. The findings of the literature reviews were used to shape the primary research, the design of this research is explained in the next chapter.

## Chapter 5- Design of the primary research

### (5.1) Outline of the chapter

Reviewing the literature presented in Chapters 3 and 4 identified a significant research gap in relation to implementing PROMs in TSOs. Consequently, a sequential mixed methods study was undertaken specifically focusing on the third sector. The PhD included a Qualitative Interview (QI) phase encompassing interviews with 30 people who had different perspectives on PROMs in TSOs. This was followed by a Community-Based Participatory Research (CBPR) phase, which involved working with two TSOs to support them to use PROMs and learn from their experiences. The CBPR involved both qualitative and quantitative data collection. Both phases were informed by the earlier literature review work e.g. the findings of the systematic review of reviews were used as a basis for the topic guides and coding framework for the QI phase.

This chapter focuses on the following:

- Aim and objectives of the research
- The philosophical perspectives underpinning the study
- The design of the study
- Integrating the findings from the different phases of the study
- Role of the CFIR
- Stakeholder involvement
- Ethical approvals and issues
- Quality appraisal

## (5.2) Aims and objectives of the study

Exploring the facilitators and barriers to implementing PROMs within TSOs was the overall aim of the PhD. The objectives were:

- (1) Undertake a systematic review of reviews to identify the existing knowledge base on the facilitators and barriers to implementing PROMs within organisations delivering health and/or wellbeing related services, irrespective of the type of provider.
- (2) Identify the facilitators and barriers to implementing PROMs within TSOs delivering wellbeing activities through interviewing stakeholders about their perspectives and experiences of using PROMs.
- (3) Understand issues arising in practice when implementing PROMs in wellbeing activities through using CBPR to support two TSOs to implement PROMs.
- (4) Integrate the findings from the different phases, using these to develop guidance suitable for TSOs and commissioners on implementing PROMs within wellbeing activities.

This chapter focuses on the design of the primary research, so objectives 2-4.

## (5.3) Research paradigm underpinning the primary research

I utilised the stance of Dialectical Pluralism (Greene and Hall, 2010; Johnson 2015) to draw upon both Constructivist and Participatory paradigms within the PhD. Dialectical Pluralism takes the approach of drawing upon different, but compatible, worldviews to shape the research (Fetters, 2020). Ontologically, a constructivist perspective is that one believes people's sense of reality is co-constructed (Guba and Lincoln, 2005). A participatory perspective is similar, but emphasises how a person's perception of reality is ever changing and can be influenced by research. Thus research is not just about seeking to understand the world but to also influence people's perceptions of reality (van der Riet, 2008). Drawing upon these perspectives, I took the ontological perspective that reality is co-constructed and people's experiences of this reality can be influenced and negotiated (Gilbert, 1989). For example, I feel that both participants and I experience the world differently but we can influence each other's experiences. Thus, I was seeking to learn about TSOs' experiences of implementing PROMs whilst simultaneously using the learning from the PhD to influence how implementation occurred.

Epistemologically, taking a constructivist approach means viewing research as a way of co-constructing learning about a phenomena rather than identifying a truth (Coughlin, 2016). A participatory approach builds upon constructivism by valuing the knowledge of people impacted by the phenomena, in this case PROMs within TSOs (so local knowledge systems) rather than purely considering academic generated knowledge (Fletcher, 2003). Encompassing these approaches, I valued the plurality of knowledge within the PhD. Therefore, I sought to co-create the findings with relevant stakeholders, appreciating the different perspectives people brought to the research (Reason and Bradbury, 2006).

Drawing upon the constructivism and participatory paradigms, I undertook primary research consisting of two phases. The first took a constructivist approach, where I felt it was important to understand the perceived facilitators and barriers to implementing PROMs from a wide set of stakeholders. I undertook qualitative interviews where I spoke to people from different interest groups and various types of TSOs. Building upon this, I realised the possibility of identifying further facilitators and barriers through seeing how individual TSOs implement PROMs. Rather than observing organisations undertaking implementation, I wanted to take a participatory approach where I was working with TSOs to implement PROMs. Given this, I chose to undertake a CBPR phase, where I worked with two organisations to support them with implementing outcome measures and learn from their experiences.

Important to my approach was inter-subjectivity, where I was seeking shared meaning between stakeholders involved in the research (Anderson, 2012). A key product of the approach was through working together with people from TSOs, we were generating knowledge that stakeholders were using and giving feedback on during the study, and this feedback was used to refine the findings. There was a study advisory committee (explained further in Section 5.7.1) and I ran a stakeholder event at the end of the study (described in Section 5.5.2). Both of these gave opportunities for stakeholders to provide input into considering the meaning and implications of the findings. Furthermore, a member of the advisory committee was a TSO manager and incorporated the learning from the study into their implementation of PROMs. This organisation then became a partner in the CBPR phase, which provided an opportunity for their experiences to inform the PhD's findings. The sharing and refining of findings contrasts with

other types of academic research, where knowledge is generated from the study and afterwards may be used to influence practice (Morgan, 2007).

Rather than generalisability, transferability is relevant to the PhD, where readers judge whether the research is relevant to their specific context (Lincoln and Guba, 1985; Denzin and Lincoln, 1994; Tobin and Begley, 2004). A number of approaches were used to support transferability such as including thick description about the organisations involved in the CBPR phase, interviewing people from different interest groups during the QI phase and retaining varied perspectives within the analysis and write up (these issues are discussed further throughout the thesis).

#### (5.4) Design

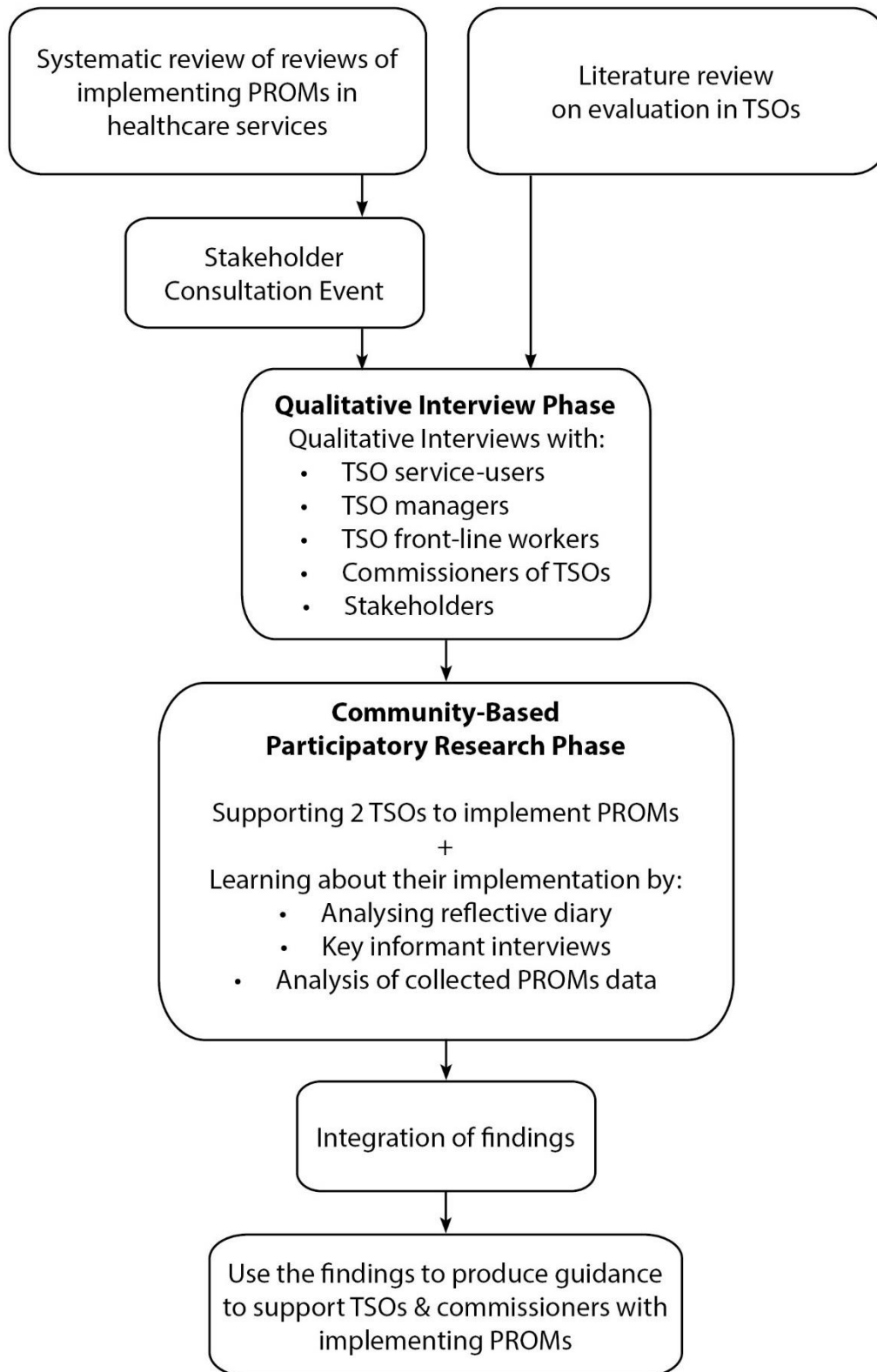
The overall research design was a sequential mixed methods study (Creswell et al., 2003) consisting of two phases:

- (1) **QI phase-** Qualitative interviews to explore people's experiences and perceptions of implementing PROMs within TSOs.
- (2) **CBPR phase-** An Action Research Spiral approach was taken with two TSOs to support them to implement PROMs and learn from their experiences. A concurrent mixed methods design was used including key informant interviews and quantitative analysis of the collected outcome measures.

The research design is summarised in Figure 2. Mixed methods entails using both quantitative and qualitative methods within a study (Tashakkori and Teddlie, 2010). The PhD consists of a qualitative research phase followed by a concurrent qualitative and quantitative research phase. Because the quantitative data in the CBPR phase was not as comprehensive as planned, the design was qualitative-dominant (Creswell and Plano Clark, 2011).



**Figure 2- Diagram of the methods used within the PhD**



The QI phase consisted of interviews with thirty people from a range of interest groups impacted by PROMs and was an opportunity to explore different experiences and perspectives.

Interviewees included service-users, front-line workers who delivered wellbeing activities, managers of TSOs, commissioners of wellbeing activities and other stakeholders. The interviews were analysed using framework analysis. The methods are reported in detail in Chapter 6 and the findings in Chapter 7.

The learning from the QI phase was used to inform the CBPR phase. The purpose of the CBPR phase was to support TSOs to implement PROMs and learn from their experiences. A concurrent triangulation design was used in the CBPR phase (Creswell et al., 2003). This involved conducting the qualitative and quantitative components separately but simultaneously and then integrating them during the analysis stage. The main reason for using a mixed methods approach at this point was that it enabled a more comprehensive understanding of implementing PROMs than if a single method was used (Feilzer, 2010; Creswell and Plano Clark, 2011). For example, front-line workers discussed the difficulty of collecting PROMs after someone received support. Analysing the quantitative data from collected PROMs enabled me to explore the scale of the issue in regard to the proportion of service-users who completed PROMs at more than one time point. The methods used in the CBPR phase are described in Chapter 8 and the findings are reported in Chapter 9.

Alongside analysing the different components of the study, it was important to undertake integration. Integration is a fundamental part of undertaking a mixed methods approach because without it there is simply a number of separate studies (O'Cathain et al., 2010; Fetters et al., 2013). Integration was built into the sequential design, with the QI phase analysed before commencing the CBPR phase. I shared the learning from the QI phase with the two TSOs involved in the CBPR phase to help them implement PROM e.g. designing training together for front-line workers. Further integration took place within the CBPR phase, where findings from different sources of data were synthesised. Finally at the end of the PhD, the findings from both the QI and CBPR phases were integrated. Different integration techniques were used because of when integration was conducted in relation to data analysis. Within the CBPR phase, a

‘following a thread technique’ was utilised (described in Chapter 8). A triangulation protocol method was used to integrate the QI and CBPR phases followed by a stakeholder event (described below).

## (5.5) Integrating the QI and CBPR phases

A triangulation protocol method was chosen for integrating the QI and CBPR phases because it enabled the findings from each phase to be compared to identify meta-themes, which are the key findings arising from the whole PhD (Farmer, 2006). For example, a finding from the QI phase was the need for TSOs to take a co-design approach to choosing a PROM but in the CBPR phase it was identified that some front-line workers still did not engage with PROMs even after being involved in choosing a measure. As part of the integration process, I held an event with a range of stakeholders to get their input into my synthesis of the findings.

### (5.5.1) Taking a triangulation protocol method

Taking a triangulation protocol method entailed populating the findings from the two phases within a matrix and comparing them (O’Cathain et al., 2010). To enhance the comparison, I also populated the matrix with the findings from the systematic review of reviews (Chapter 3) and the TSO literature review/consultation event (Chapter 4). The columns of the matrix consisted of the four different sets of findings and a column to reflect on the emerging findings from comparing the issues arising from the different parts of the PhD. Each row contained a different theme from the findings. I compared the four sources for each theme, particularly focusing on whether the experience of TSOs was similar to healthcare services (the findings of the systematic review of reviews). The themes were assessed for:

- **Convergence-** Whether the data sources corroborated. For example, the systematic review of reviews and the QI and CBPR phases identified the importance of having a committed, proactive Implementation Lead.

- **Complementary-** Whether the findings of one phase helped to explain or expand on the other phases. For example, the QI phase found taking a collaborative approach to choosing a PROM was advantageous. However, the CBPR phase expanded on this finding by identifying that taking a collaborative approach entailed considerable time and resources.
- **Dissonance-** Whether the findings contradicted or differed from each other. For example, a finding from the systematic review of reviews was healthcare services preferred PROMs to have a care management function. Whereas the QI and CBPR phases identified how TSOs were primarily using PROMs to demonstrate their impact to funders.
- **Silence-** When one phase identified a specific finding but the other phases did not. For example, the primary research identified the impact of organisational characteristics however this was not identified within the systematic review of reviews.

Initially I populated the matrix myself. This was because I was the only researcher on the study. Following the initial development, an integration event was held with third sector stakeholders to share the meta-themes arising from the triangulation protocol (event described in the next section). Stakeholders were asked to comment on whether the findings were meaningful and reflected their experiences.

#### (5.5.2) Integration event

An integration event was held to get the perspectives of third sector stakeholders on whether the overall findings of the study resonated with their experiences. The integration event was held in January 2020 at a third sector venue within Sheffield. Twenty-eight individuals attended the event. A further 10 people commented on the materials after the event. Attendees included service-users, front-line workers and managers of TSOs, commissioners, researchers and other stakeholders such as third sector advisors. Many of the people attending brought multiple

perspectives including front-line workers who were former service-users, and TSO commissioners who had previously been front-line workers. Attendees included:

- **Participants from the QI phase-** Some participants had expressed an interest in being kept informed about the study and they were sent an invite to the event. A number of participants circulated the invite to colleagues.
- **Front-line workers and managers from the CBPR phase-** Front-line workers and managers from the two organisations who participated in the CBPR phase.
- **Advisory committee members-** Members of the study advisory committee included a TSO manager, service-users, commissioners, advisors and researchers.
- **Service-users-** Additional service-users alongside members of the advisory committee were invited. They included members of the Deep End Patient and Public Involvement (PPI) group and members of a PROMs service-user group.
- **Supervisors-** JH and AOC.
- **Other individuals-** Throughout the PhD I have been in contact with researchers and people from the third sector who are interested in implementing PROMs.

The event lasted two and half hours, followed by lunch which provided an additional opportunity for discussion and networking. I presented the overall findings arising from the research.

Attendees were given an opportunity to discuss how the findings resonated with their experiences and whether I had interpreted findings appropriately or there were factors I had not identified. A visual researcher live-scribed the event. This helped to capture the discussions and provided a visual aid for people attending the event to support them with processing the findings (Papoulias, 2018). The visuals from the event are available here:

<https://www.dropbox.com/sh/r0e761hj3yjvt9/AADXFTdXAHcL1GjK-zHOQ5Vta?dl> One of the key outputs of the PhD is a guidance document to support TSOs and commissioners to utilise PROMs. The draft was presented at the stakeholder event because it encapsulated the meta-themes of the study. Attendees provided helpful feedback which was used to refine the guide (discussed further in Chapter 10).

## (5.6) Role of the Consolidated Framework for Implementation Research (CFIR)

As discussed in previous chapters, the CFIR was used throughout the PhD to provide a theoretical underpinning to the findings. The CFIR was used in three different ways within the primary research. (1) The constructs of the CFIR informed the topics guides in both the QI and CBPR phases. (2) The constructs of the CFIR formed the basis of the coding framework for the primary research. (3) The CFIR was used during the integration stage to help understand the overall findings of the study and to identify any issues had not arisen in the study that are generally relevant to implementation.

When undertaking the analysis for the primary research, the CFIR constructs helped to inform the initial coding of the data. In both phases, the second stage of analysis transcended the CFIR constructs, and entailed me generating the themes and subthemes specific to this research. Consequently, the terminology of the CFIR is not used when presenting the findings of the primary research. Instead there is further exploration of the CFIR and its relevance to the findings in the discussion chapter (Chapter 10).

## (5.7) Stakeholder involvement throughout the PhD

Involving third sector stakeholders, including service-users, in the delivery of the primary research was important to ensure the study was relevant and useful for the sector in terms of improving practice (INVOLVE, 2012; Brett, et al., 2014). The involvement builds upon the concept of Patient and Public Involvement (PPI) within health research (Elliott, 2019). A number of techniques were used to facilitate involvement including involving service-users, having an advisory committee, and conducting stakeholder consultation events. This involvement was integral to improving the design and conduct of the research. One example was the advisory committee giving suggestions when I was struggling to recruit participants to the QI phase. The involvement described in this section focuses on the contribution of stakeholders to delivering the primary research and differs from the participatory approach taken within the CBPR phase (this is explained in Chapter 8).

### (5.7.1) Advisory committee

The advisory committee was instrumental in supporting the primary research both in terms of giving suggestions about the conduct of the study and providing insights on the findings. The committee consisted of 8 people involved with the third sector including 2 service-users, 1 service manager, 1 commissioner, 2 community researchers, 1 community development worker and myself. The advisory committee met biannually throughout the study but I also had regular contact with members outside of meetings. On occasions this contact was with the whole committee including discussing the emerging findings within meetings and having email conversations about potential avenues of dissemination. At other times, I contacted individual members separately to ask their advice about specific issues. For example, speaking with one member who was a commissioner about the training her colleagues received on PROMs.

The advisory committee provided input into designing and conducting the research such as suggesting recruitment strategies for the QI phase and proposing solutions to problems. For example, it was difficult to recruit service-users in the QI phase and the committee suggested visiting service-user groups directly, which proved a valuable method of recruitment. I regularly updated the committee on the emerging findings and they provided input into interpretation and the wider implications of the study. One example was on resources, where I explained to the committee that larger TSOs appeared to have more resources to invest in the PROMs process. The committee explained that in their opinion it was not simply about size but could also be about prioritisation of resources within an organisation. So, in cases where there are two TSOs of similar sizes, only one may have prioritised investing in data management systems to enable the processing of PROMs. Finally, the committee were essential for informing the dissemination of the study such as the structure of the guidance and where it could be disseminated.

### (5.7.2) Service-user involvement

Involving service-users in the study was important to ensure the PhD was designed and delivered in a manner which was suitable for third sector service-users. I utilise the term service-user involvement to describe activities usually called PPI within health research (INVOLVE, 2012). I have not used the term PPI because the word patients is not usually used within the third sector (as discussed in Chapter 1). Involvement included running service-user consultation events during the preparation for the PhD, having service-users as full members of the advisory committee and visiting an established service-user group. Service-user involvement is integral to health research because it is imperative that any research is not ‘on’ people but ‘with’ people, so it is not just researchers who are making decisions on the conduct of a study (Blackburn et al., 2018). Furthermore, involving service-users adds value to research as it provides different perspectives which can help to identify problems and solutions (Greenhalgh et al., 2019). The value of involving service-users within health research is reflected by funders expecting researchers to incorporate service-user involvement into their studies (Blackburn et al., 2018).

During the preparatory stage of the PhD, I ran two service-user consultation events with approximately 10 people attending each. The events were an opportunity to get users’ input into the proposed methods for the study such as potential recruitment strategies and terminology to use. Attendees were given a £20 shopping voucher to thank them for attending.

Two service-users were involved in supporting the research once it commenced. The service-users were full members of the advisory committee (described in an earlier section) along with providing additional input into the study. Examples include advising on the participant recruitment materials, giving advice on PROMs in relation to service-users who have English as a second language, and helping to produce dissemination materials for participants. Service-users received payment in recognition of their contribution to the research. Payment was based on the INVOLVE guidelines (Mental Health Research Network and INVOLVE, 2013).

Additionally, I visited an established PPI group: The Deep End PPI Group. The group consists of approximately 20 people living in socio-economically deprived areas of Sheffield (Walton et al., 2017). Whilst the members were not necessarily third sector service-users, many of them lived in the geographical areas covered by the two organisation involved in the CBPR phase so were potential service-users. I visited the group in February 2019 to seek members’ perspectives on



the findings of the QI phase and to discuss the CBPR phase. In terms of the QI findings, I discussed with the group that service-users reported feeling coerced to complete measures and viewed them as an organisational tool rather than useful to their support. In respect of the CBPR phase, I discussed the service-user recruitment materials. We discussed the groups' views on PROMs such as the difficulties they faced understanding the language used on some measures.

### (5.7.3) Other stakeholder involvement

Other third sector stakeholders were consulted at specific points of the study. I held a third sector stakeholder event in November 2017 to understand how the systematic review of reviews findings might relate to the third sector (described in Chapter 4). A further consultation event was organised by JH and myself in October 2019. Ten people attended including TSO managers, front-line workers, commissioners and NHS primary care staff. As part of the event, I presented the findings of the QI phase and the emerging findings from the CBPR phase. We discussed whether the findings were salient and their implications for supporting TSOs in the locality. For example, attendees from smaller TSOs discussed how they did not have any capacity to develop data management systems for processing PROMs. Finally, stakeholders contributed to the study through the integration event (described previously).

### (5.8) Ethics committee approvals and ethical issues

Conducting the PhD in an ethical manner was important. This included ensuring the study had appropriate ethical approvals, being mindful of potential ethical issues and taking mitigating action to avoid issues occurring. In this section, there is initially an explanation of the approvals sought, followed by discussion of the potential ethical issues and how they were addressed. This ethics section has been included in the overall methods chapter because some of the issues are relevant to both the QI and CBPR phases.

#### (5.8.1) Approval from the ethics committee

It was necessary to gain separate ethical approval for each phase of the study because they were sequential. The QI and CBPR phases both received ethical approval from the School of Health and Related Research Ethics Committee. There was no need to apply to the Health Research Authority (HRA) for ethics approval because the study was not taking place within the NHS. Some commissioners recruited to the QI phase worked within the NHS and adult social care within local authorities but HRA approval was not needed. This was because participants were not recruited through NHS or local authority contexts. Before commencing both the QI and CBPR phase, the proposed research was checked against the HRA criteria and the interactive tool confirmed neither parts of the study needed HRA approval (Medical Research Council and Health Research Authority, 2017).

The QI phase gained ethical approval on the 26<sup>th</sup> June 2017 (Application reference: 013727) and the CBPR phase was approved on the 26<sup>th</sup> July 2018 (Application reference: 020700). Evidence of these approvals is included in Appendices 8 and 9. Participatory activities during the integration phase were included within the CBPR phase ethics approval.

#### (5.8.2) Potential ethical issues and how these were managed

The study had a number of potential ethical issues including:

- Participants understanding the study and giving informed consent
- People feeling coerced to participate
- Potential participants having low literacy/English as a second language
- Management of the research data
- Maintaining confidentiality of participants
- Distress arising from participating in research
- The inconvenience of taking part
- Organisational burden.

Action was taken to reduce the impact of these issues and these are discussed below.

### **Participants understanding the study and giving informed consent before participating-**

Data was collected from participants in both the QI and CBPR phases and it was important that people understood the research, what involvement entailed and what would be done with their data before they participated. In the QI phase, everyone interested in taking part was provided with a Participant Information Sheet and a copy of the consent form at least 48 hours before the interview was due to take place. There were different versions of the documents for service-users and other types of interviewees. Giving the information in advance gave people the opportunity to read and reflect about the study and ask any questions. For telephone interviews, participants had to return a completed consent form by email or post before the interview took place. In the face-to-face interviews, participants completed the consent form at the start of the interview. At the beginning of every interview, I went through the Participant Information Sheet and gave people the opportunity to ask questions, making it clear that they could stop participating at any stage.

For the CBPR phase, there was a contrast between the participatory activities, which did not require formal consent because people were active members of the research team (Pain et al., 2012) and the more traditional research activities e.g. key informant interviews, which required consent. In terms of the latter, as with the QI phase, people were provided with the relevant version of the Participant Information Sheet and consent form at least 48 hours in advance of their interviews to give individuals a chance to reflect on the study and ask any questions. At the start of each interview, I went through the Participant Information Sheets and collected written consent. It was made clear that people could stop participating at any point.

Formal written consent was not taken for the participatory activities. In participatory research, consent is negotiated because of people being co-constructors of the knowledge rather than participants in the traditional research sense (Pain et al., 2012). At the start of any participatory activities, I explained about the research, the specific activity and how the input would contribute to the project. As part of this process I would check with people if they were still willing to be involved. If someone expressed any concerns, I would discuss these with them and if necessary, arrange to meet the individual separately so they could still provide input. Outputs designed from

the sessions such as mind maps, were circulated to attendees after meetings to give them the opportunity to review them before they were incorporated into the findings. The consent process used for the participatory activities complies with guidance on undertaking CBPR and was granted approval as part of the ethics application (Pain et al., 2012).

**Coercion to participate-** Within the CBPR phase, people could have felt coerced into participating due to the involvement of their TSO in the research. It was clearly communicated that participation was voluntary and could be stopped at any time. Potential participants were also reassured that there would be no negative consequences if they chose not to take part or withdrew from the study.

**Low Literacy/English as a second language-** Some people invited to participate in the research may have had lower literacy skills or difficulty reading or speaking English. The issue was partly addressed through co-designing the study materials with service-users so they were written in plain English and a verbal description of the study was given to participants before collecting consent. People were not consented into the study in cases where it was apparent that they did not speak adequate English. This approach was necessary because there were no resources to conduct the interviews in other languages.

**Management of the research data-** As primary data was collected from participants it was essential that it was managed securely and in compliance with relevant laws including the General Data Protection Regulations (Information Commissioners Office, 2019). Throughout the study, I adhered to the University of Sheffield data management policies and national Good Clinical Practice guidelines. For example, encrypted audio recorders and password-protected computers were used. A data sharing agreement was put in place between the TSOs participating in the CBPR phase and the University of Sheffield to make arrangements for the safe transfer, storage and use of the anonymised secondary data on the collected PROMs. A data management plan was produced, which reflected on the different data management issues in the research. Developing the plan enabled me to devise how the data would be processed and stored, and consider how the study would comply with legal and university based policies. My supervisors approved the data management plan. Furthermore, I undertook regular training as part of my

employment at the University of Sheffield to refresh my skills and knowledge to ensure the data was managed in a safe and secure manner.

**Maintaining confidentiality of participants-** It was imperative to ensure the confidentiality of participants, particularly because the third sector in localities is relatively close-knit. I used a number of techniques to ensure confidentiality including anonymising transcripts and describing participants in general terms rather than using thick description. The CBPR phase provided additional challenges for confidentiality in terms of not identifying the participating organisations and ensuring the confidentiality of the content from individual interviewees within the participating TSOs. The latter was a challenge and I addressed this by analysing the interviews and generating summary findings from the different interviews as a whole to reduce the emphasis on individual participants. There were also specific issues raised in the interviews where the participant made it clear they did not want the issue shared. In these cases, I did not include the issue in the analysis. This type of information was not directly related to PROMs implementation but concerned contextual organisational issues. I undertook ongoing negotiation and agreement within the organisations about maintaining their confidentiality throughout the CBPR phase. I drew upon good practice guidance on undertaking participatory work such as Pain et al. (2012).

**Distress arising from participating in research-** Whilst it was not anticipated that the research would explore any distressing topics for participants, research always carries this risk. For example, a front-line worker could find talking about using PROMs stressful because of feeling they were under pressure to use inappropriate measures within their workplace. Topic guides were used within interviews to try and maintain focus on PROMs rather than discussing issues that may cause distress especially for the service-users. During the interviews, I had a process to support interviewees if they experienced distress. Initially, I would provide the participant with empathy and support. I would pause the audio/interview and if required terminate the interview. If necessary, interviewees would be signposted to appropriate sources of support. Before commencing the study, I undertook qualitative interview training that included content on developing skills in managing distress within interviews. This training helped to improve my practice and informed the actions I planned to take if interviewees experienced distress.

**Inconvenience of participating-** As with any research, people spent time participating in the study which could be an inconvenience to them. To manage this, I explained to people what time commitment the study entailed to enable them to make an informed decision about whether to participate. Research activities were organised at a time and place to suit participants. The research activities were also relatively short e.g. the QI phase involved a single, one hour interview. Participating in the CBPR phase required a greater time commitment. However, commitment was negotiated with each TSO and staff were told their involvement could be undertaken as part of their workload.

**Organisational burden-** TSOs are generally under immense pressure, juggling a difficult financial climate with an increasing number of service-users, many of whom have complex needs. Participating in the CBPR phase could contribute to this burden because required staff to spend time on the research activities. To minimise the burden, I designed the research in conjunction with the participating organisations so it was manageable for their stakeholders. The TSOs also benefitted directly from participating because they were given support with implementation. Organisations were given a full explanation about the study before they agreed to participate.

### (5.9) Attending to quality

As a researcher, it is essential to undertake high quality research. This was done by following methodology including using guides and advice from supervisors. It is also important to reflect on the conduct of the research e.g. the strengths and limitations, to help myself and readers of the work to understand the rigor of the research I have undertaken. There are a number of appraisal criteria available to facilitate this, however most are method specific. Consequently, the QI and CBPR phases were appraised separately (detailed in Chapters 7 and 9 respectively). However, I also used the Mixed Methods Appraisal Tool (MMAT) to ensure specific issues associated with undertaking mixed methods were considered (Hong et al., 2018) (Appendix 10). This is discussed further in Chapter 10.

### (5.10) Summary of the chapter

A sequential, qualitative dominant mixed methods study consisting of a QI phase and CBPR phase was undertaken to explore the experiences of TSOs implementing PROMs. A triangulation protocol approach was used to integrate the findings from the different phases of the study. Stakeholders were at the heart of the study. They provided input to the delivery of the research, helped interpret the findings and contributed to considering the implications of the findings on practice. Ethical approval was gained at the start of each phase and I was proactive throughout the study in ensuring potential ethical issues were addressed. In the next chapter, the QI phase is described in detail including the justification for using qualitative interviews and how the research was conducted. Later in the thesis, I include a chapter focused on the methods used within the CBPR phase (Chapter 8).

## Chapter 6- Qualitative Interview phase- Methods

### (6.1) Outline of the chapter

This chapter focuses on describing the QI phase methods. The specific objective of the QI phase was to explore people's experiences and perceptions of implementation within the third sector. I interviewed people from across England who had different roles in relation to PROMs (interest groups) including TSO service-users, front-line workers, managers, commissioners and other stakeholders. The chapter consists of the following sections:

- Justification for taking a qualitative interview approach
- Sampling strategies
- Recruitment of participants
- Undertaking the interviews
- Analysis
- Appraising the rigor of the QI phase

### (6.2) Reasons for using semi-structured qualitative interviews

The QI phase involved using semi-structured qualitative interviews to explore people's experiences and perceptions of using PROMs within TSOs. Qualitative interviews were chosen because they enable researchers to understand people's experiences and provide the scope to explore issues (Silverman, 2000). In other studies based in healthcare services, researchers have used qualitative interviews to explore the implementation of PROMs. These studies demonstrate qualitative interviews are appropriate for exploring the research question (Dainty et al., 2017).

Several reasons influenced the decision to use semi-structured interviews over other qualitative methods such as focus groups or ethnographic approaches e.g. non-participant observation. Using qualitative interviews enabled people from a number of TSOs to be interviewed about their experiences. This was important because a priority was exploring the experiences of implementation within a variety of TSOs, especially as there appears to be no research comparing how organisational characteristics may influence the process. Taking an ethnographic approach would not have been appropriate because it would have narrowed the focus to a small



number of organisations (Bryman, 2001). Qualitative interviews were selected because they enabled an in-depth exploration of the experiences of an individual. The nature of an interview gives a researcher as much time as is needed to discuss with the participant about their specific experiences and perspectives. In contrast, within a focus group there is less opportunity to explore individual experiences in-depth and instead the focus is on understanding the perceptions of participants as a collective. Using interviews is also easier logistically as the appointment can be arranged at a time and location to suit an individual and their work commitments (Coenen et al., 2012).

Semi-structured interviews were chosen over structured or unstructured interviews. The semi-structured interview format entailed using a topic guide to shape the interviews, so all participants were asked some similar questions. Having some consistency was important so people's experiences could be compared, including which measures were used or the types of training delivered. However, the semi-structured format also provided flexibility to probe issues arising within each interview (Matthews and Ross, 2010). This was important because PROMs in TSOs is a new area of research, so it was likely participants would raise issues that needed further discussion.

### (6.3) Sampling strategy for the QI phase

The sampling strategy entailed interviewing participants from across England who were from different interest groups to understand implementation from people involved with TSOs in different ways (Stake, 1994). Purposive sampling was undertaken to ensure key types of people were included. Five different interest groups who influenced or were impacted by PROMs were identified through the initial preliminary work for the PhD. The interest groups were commissioners of TSOs, TSO managers, front-line workers who delivered activities, service-users who attended activities and stakeholders. Further detail on the interest groups is provided below.

### **Commissioners of TSO delivered wellbeing activities**

Commissioners are individuals who have responsibility for funding TSOs to deliver wellbeing activities. As explained previously, the funding may be in the form of grants or procurement of specific services but the umbrella term of commissioners is used within the PhD. Different types of organisations fund wellbeing activities including:

- Local authorities
- NHS trusts e.g. Clinical Commissioning Groups
- Non-statutory funding bodies e.g. the National Lottery Community Fund
- TSOs subcontracting or providing grants to other TSOs.

Commissioners from all four types of organisations were interviewed. The commissioners interviewed held different roles, some had direct responsibility for performance managing TSOs whereas others had strategic roles, such as designing the strategy for wellbeing activities in a geographical area.

### **Managers of TSOs**

Managers are individuals who have responsibility for overseeing wellbeing activities within TSOs. Different levels of managers exist within organisations, including middle managers who have direct responsibility for overseeing wellbeing activities e.g. supervising front-line workers. There are also higher-level managers who indirectly oversee wellbeing activities, such as Chief Executives of TSOs. The size of an organisation impacts on the nature of managerial roles; smaller organisation may have one manager whereas larger TSOs could have several layers of management, each of whom has different responsibilities. Within this study, different types of managers were interviewed to capture a range of experiences.

### **TSO Front-line workers**

Front-line workers are individuals who directly deliver wellbeing activities to people. They may be paid or volunteers. Their specific role varies depending on the nature of activities they deliver, e.g. some workers may predominately work with service-users on an individual basis whilst others run group activities. Front-line workers will also work with different types of service-

users depending on the focus of the TSO. For example, some front-line workers may support people with learning difficulties, older people or users based in a specific neighbourhood.

### **Service-users of TSO wellbeing activities**

Service-users are people who access wellbeing activities. The focus was interviewing service-users who had experience of completing PROMs.

### **Researchers/ policy makers/ representatives from third sector umbrella organisations (referred to as stakeholders)**

Stakeholders was the final interest group and included people with specialist knowledge of the third sector and/or PROMs. Interviewees included researchers, representatives from third sector umbrella organisations and policy makers.

Many of the participants could have been categorised in multiple interest groups. For example, some of the commissioners had managed TSOs and a number of front-line workers were former service-users. Participants drew upon experiences from their different roles; however, the sampling frame was constructed using their role at the point of interview.

Alongside a range of interest groups, I sought to interview people from different geographical areas in England. This was to understand whether interviewees had different experiences depending on the specific external context. For example, a TSO based in a city may be funded by the city council to deliver wellbeing activities whereas in another area, a TSO may be funded by both the town and county councils which could have implications for the use of PROMs.

#### **(6.3.1) Identifying participants**

Purposive sampling was the overall sampling strategy in terms of seeking to interview people who were a rich source of data because of their experience of using PROMs (Patton, 2002).

However, there are no registers of the different interest groups so I needed to draw upon opportunistic and snowballing approaches to identify participants (Denzin and Lincoln, 1994).

Opportunistic sampling entailed me approaching people known to me such as front-line workers. Alongside, I sought to recruit people not previously known to me. To do this, I used a number of

techniques including advertising the study in the National Social Prescribing mailing list, promoting the study whilst presenting at conferences and visiting wellbeing activities. Furthermore, I also used snowballing, with interviewees recommending other people they felt could provide insight about the phenomena (Kirchherr and Charles, 2018). For example, one commissioner recommended a peer in another geographical area for me to contact. Additionally, I asked certain interviewees if they had any recommendations when I was struggling to recruit people from specific interest groups. Snowballing was fruitful because relationships and networks are an important part of the third sector and it was anticipated that people would be more willing to participate if they were informed about the study by someone they already had a relationship with.

#### (6.4) Sample size

It was anticipated that 30-40 interviews would be undertaken, with the hope of recruiting at least 5 people from each interest group. The number was determined by considering a combination of data saturation and practical issues. Data saturation is the principle of continuing to interview participants until no new information is arising (Glaser and Strauss, 1967). However, the number of interviews required to reach data saturation varies considerably between qualitative interview studies because is partly dependent on the heterogeneity of the sample and the breadth of the research question (Ritchie et al., 2003a). There were also time and resource constraints with the interviews having to be conducted within the time limited nature of a PhD. Given the need to balance achieving data saturation with the resources available, I decided upon an estimated sample size of 30-40 interviewees before commencing the research. The sample was derived from considering capacity and timescales, reviewing sample sizes of similar studies, and advice from supervisors. The sample size was a range which provided flexibility enabling less or more people to be interviewed if further data was needed. The issue of data saturation is discussed when appraising the trustworthiness of the QI phase (included in Chapter 7).

### (6.5) Recruitment of participants for the interviews

A number of recruitment methods were used, partly because it was found that specific methods were more productive in recruiting different interest groups. Information about the study was circulated amongst contacts and at professional events to ask people whether they would be interested in participating. This included approaching commissioners who used PROMs and promoting the study when I spoke at conferences. The QI phase was promoted using mailing lists such as the National Social Prescribing Network and local Healthwatch newsletter. When appropriate, interviewees were asked whether they could recommend anyone else to invite to interview (Ritchie et al., 2003). The snowballing method was particularly effective for identifying front-line workers because the TSO managers acted as gatekeepers with several managers willing to promote the study to their front-line workers after they were interviewed.

It was difficult to recruit service-users using the aforementioned methods. Consequently, the advisory committee recommended that I visited wellbeing activities and speak to service-users directly about the research. The advisory committee felt service-users would be more interested in the study if I explained the research in person and service-users had the opportunity to meet me and ask questions.

After making initial contact with people interested in participating, I explained further about the research in person, over the telephone or email depending on the nature of the contact. If the individual was still interested in participating, they were provided with a Participant Information Sheet and consent form (examples in Appendix 11 and Appendix 12) and an interview arranged.

### (6.6) The process for undertaking the interviews

Interviews were arranged with participants on a mutually convenient date, either face-to-face or via telephone depending on an interviewee's preference and logistical factors. Face-to-face interviews were encouraged because they help facilitate rapport and enable the researcher to pick up on non-verbal body language (Opdenakker, 2006). However logistically, face-to-face interviews may take longer if the researcher has to spend time travelling to the interview. This takes up time which could be spent on other research tasks (Opdenakker, 2006). Travel time was

pertinent for this study because potential interviewees were based throughout the country because I wanted to understand whether there appeared any geographical variance in experiences e.g. differences in commissioning practice. Therefore, whilst most interviews were face-to-face, some were held over the telephone. Only face-to-face interviews were held with service-users because I wanted to show them different PROMs and discuss their preferences on the content and design. Participants chose the location of their interviews, usually this was their place of work or at the TSO the service-user attended. One interview was held at a participant's home. Lone worker procedures were followed for this interview. For example, I checked in with a colleague after the interview.

Participants were usually contacted approximately two days before the interview date to confirm arrangements and if necessary, re-schedule. Telephone interviewees were reminded to provide a completed consent form before the interview could occur. At the start of each interview, I talked through the Participant Information Sheet with the interviewees, answered any questions and collected consent. This was formal written consent in the face-to-face interviews. In the telephone interviews, participants provided verbal consent because they had already provided written consent. As part of the consent process, participants gave permission for the interviews to be recorded on an encrypted digital device.

Topic guides were developed to support the interviews (Bryman, 2001). Specific versions were developed to focus on different issues with each interest group although there were several areas of overlap (an example of the topic guide is available in Appendix 13). Issues arising in the earlier literature reviews (Chapter 3 and 4) informed the content of the topic guides. The advisory committee including the service-user representatives reviewed and gave feedback on the topic guides during their development. Rather than testing the topic guides in pilot interviews, I iteratively developed them when undertaking the interviews including adding issues arising from earlier interviewees (DeJonckheere and Vaughn, 2019). The topic guides included questions on:

- Exploring which measures people had used and why they were chosen
- The support people needed to use PROMs
- The purpose of using PROMs
- People's personal views on utilising measures

- How the process was working within a specific TSO.

It was anticipated that interviews would last approximately an hour in length.

At the end of each interview, participants were thanked for their involvement and asked whether they wanted to receive a summary of the findings. After an interview, the audio file was transferred to an encrypted, secure computer drive overseen by ScHARR. The file could only be accessed by myself and the transcriber. The file was then deleted from the recording device. An administrator transcribed the interviews verbatim. I checked the accuracy of the transcripts by listening to the audio of the interview and anonymised the transcripts such as removing names of organisations. The transcripts were then uploaded to NVivo Version 11- a computer assisted coding tool, ready for analysis (QSR International Property Ltd, 2017).

#### (6.7) Justification for undertaking framework analysis

A framework approach was used to analyse the interviews (Ritchie and Spencer, 1994). There were five reasons for choosing the approach. Firstly, the study is a piece of applied health research and the framework approach has frequently been used within this context, indicating that it is an appropriate analysis method to produce usable findings (Gale et al., 2013). Secondly, the purpose of the research was to explore people's experiences and perspectives of using PROMs, and thus it was important to use a method such as framework or thematic analysis which focus on what people are saying. Alternative approaches e.g. discourse analysis would have been unsuitable because they focus on the language people use and how they discuss the phenomena (Parkinson et al., 2015). Thirdly, a priority was to undertake some deductive analysis, where the CFIR constructs and findings of the literature reviews could be used within the coding framework. This was important because the systematic review of reviews identified the need for research on implementing PROMs to draw upon established implementation theories (Foster et al., 2018). Fourthly, it was important to choose an analysis method that balances undertaking in-depth analysis with interviewing people from a range of interest groups. This would not have been feasible using interpretative phenomenological analysis (IPA) (Peat et al., 2019) because IPA entails interviewing smaller samples (Chambers et al., 2015). Finally, the framework approach was chosen because the approach consists of a number of systematic stages

e.g. charting (Gale et al., 2013). Each of these stages provides an opportunity to obtain input from other people. As I was undertaking the analysis alone, it was important that there were defined points to receive input into the analysis from my supervisors and advisory committee such as them commenting on my thematic framework.

Whilst the framework approach is considered the most appropriate analysis method for the QI phase, there are three key limitations to using this approach. Framework analysis has been criticised for ‘quantifying’ qualitative data (Polit and Beck, 2010), such as reducing the data into matrixes. I was mindful of not quantifying data when interpreting and writing up the research. For example, rather than specifying the numbers of interviewees who identified an issue, I used more descriptive language e.g. ‘many’ or ‘some’ and gave importance to issues irrespective of the number of participants who raised them. The second criticism is that framework analysis is viewed by some as a deductive approach, so there is the risk that issues may be missed from the transcripts because the researcher has a pre-determined idea of what they are looking for in the data. However, the risk of this is minimised because the framework approach does also involve an inductive element. The familiarisation stage of framework analysis enables the researcher to identify issues emerging from the data and incorporate them into the framework (Ritchie et al., 2003b). Finally, the framework approach is considered resource intensive and time-consuming. However, this criticism is relevant for qualitative analysis generally and is offset by the analysis enabling the generation of in-depth and insightful data. I was able to manage the time and resource requirements of the analysis through allocating sufficient time within the PhD and by having the support of an administrator to transcribe the interviews, which freed up time for analysis.

### (6.8) Undertaking framework analysis

A modified version of framework analysis was utilised because of the specific circumstances of the study.

**Familiarisation with the data-** Getting to know the content of the transcripts through repeatedly reading them was the first stage of analysis. Although I had undertaken all the interviews, this phase of analysis enabled me to immerse myself into what interviewees were discussing and fed into development of the thematic framework.



**Identifying a thematic framework-** One of the defining features of the framework approach compared to other qualitative analysis is having a framework which all the interviews are coded to. Within the original Ritchie and Spencer (1994) there is the sense that the framework is fixed, with any modifications requiring researchers to re-start the coding process. However, later work by the authors acknowledges that the framework will need developing during the coding process as new issues arise from the transcripts coded later in the process (Ritchie et al., 2003b).

The initial framework was developed using the findings arising from the familiarisation process along with the findings of the systematic review of reviews (Chapter 3 and 4) and the CFIR constructs (Damschroder et al., 2009). The framework was refined following discussion with supervisors and the advisory committee. I coded the first few interviews, making refinements to the framework during the process. This is where I deviated from the framework approach as I did not methodically re-code all the transcripts. Instead, I revisited parts of the transcripts that might need recoding. It was possible to take this approach because I had undertaken all the interviews and familiarised myself with the data so I was able to pinpoint the relevant parts of a transcript. Furthermore, I was undertaking analysis at the same time as conducting interviews. It took longer to recruit to the study than planned, so I needed to undertake analysis whilst interviewing participants. Consequently, it was difficult to develop a finalised framework because new insights were arising from the interviews.

Modifications to the framework mainly related to making some of the CFIR constructs more specific (Ritchie et al., 2003b). For example, the construct of “External Change Agents” was separated into two codes: “External Researchers and Advisors” and “Individual Commissioners”. The names of the codes also evolved from the terminology of the CFIR to reflect the language used within the interviews e.g. “Intervention Source” was renamed “Prescriptive or Collaborative design”.

**Indexing-** Coding the interviews through systematically applying the framework to each transcript was the third stage of the analysis process. Indexing involved going through transcripts line by line, allocating the content to the relevant codes within the framework. For example, if a front-line worker was describing attending a course to learn about PROMs this was coded under ‘training’. I undertook indexing for all of the transcripts. Additionally at the start of the process, two of my supervisors each coded a transcript, which were compared with mine to check for

consistency. Generally the coding was comparable, however it highlighted the need for me to code and reflect on not just what interviewees said but also what they did not say. An example being that several front-line workers were not aware of what their TSO does with the PROMs data that is collected. Following the supervisors' input, further refinements were made to the framework.

**Charting-** Another distinguishing feature of framework analysis is charting, where a matrix of data is produced with each code displayed on a participant-by-participant basis (Ritchie and Spencer, 1994). The purpose of charting is to explore the arising issues both within and across participants (Ward et al., 2014). Whilst I undertook some charting, such as mapping a number of variables across the interviewees, one overall chart was not generated for a number of reasons. This was because there were 72 different codes and 30 participants, which would have totalled 2160 cells. I was concerned that because I was undertaking the analysis alone, producing one overall chart would have been overwhelming and would not have helped me to identify patterns within the data. Instead, I undertook charting through producing tailored matrixes by comparing similar codes and developing overarching codes. An example of this was when I charted codes relating to collaboration, service-users' needs and front-line workers' opinions to explore whether a facilitator was engaging service-users and front-line workers in designing the PROMs process. The second reason for not producing an overall chart was because I felt immersed in the data and had been continually making links between participants and codes. It is acknowledged that not producing an overall chart meant not benefiting from the within-case aspect of framework analysis. However, the impact was somewhat mitigated because I wrote case summaries and reflective notes for each interview to maintain a 'case' perspective.

**Mapping and interpretation-** The final stage of the framework approach was interpretation of the data, where one seeks to identify patterns between codes, developing them into themes (Miles et al., 2014) so the wider meaning is captured (Hennink et al., 2011). For example within the Developing and Refining code, interviewees identified that TSOs had to make improvements to their PROMs process. However, during the interpretation stage it was apparent that there were differences in the extent to which organisations developed their PROMs process. This led to me creating a taxonomy detailing the amount of development individual organisations may undertake.

To enable mapping and interpretation I immersed myself in the data, drew diagrams to visualise the linkages between different codes, considered the processes identified in the systematic review of reviews and discussed the findings with the advisory committee and supervisors. These actions helped me to identify connections between codes and develop themes and subthemes. I continued the process iteratively during the writing up stage, getting input from the advisory committee and my supervisors. Throughout the process the raw data was continually revisited to ensure the findings were reflective of the interviews.

### (6.9) Assessing the trustworthiness of the QI Phase

Lincoln and Guba's (1985) trustworthiness criteria were used to inform the conduct of the QI phase and to appraise its quality (Nowell et al., 2017). The criteria considers credibility, transferability, dependability, and confirmability (Lincoln and Guba, 1985). Additionally, Lincoln and Guba (1985) suggested evaluating a study's authenticity. Authenticity is relevant because it explores whether a study has a wider political impact. This was important to me because a reason for undertaking the PhD was to support TSOs with implementing PROMs. The trustworthiness criteria are described in Table 6. The criteria were chosen because they are compatible epistemologically with the QI phase and are a well-respected and used set of criteria within qualitative research (Mays and Pope, 2006).

The trustworthiness criteria were used to inform the conduct of the QI phase. For example, I interviewed participants from a variety of different interest groups and undertook reflexivity. When designing and conducting the study I referred regularly to Lincoln and Guba's (1985) criteria to give me ideas about how to improve the rigor of the research. Furthermore, the criteria were used to help me appraise the rigor of the QI phase (Nowell et al., 2017). I assessed the QI phase against each of the five criteria. This is detailed in the next chapter, alongside the actions I took to enhance the study's trustworthiness.

**Table 6- Lincoln and Guba's (1985) Trustworthiness criteria**

<b>Criteria</b>	<b>Definition</b>
<b>Credibility</b>	Having confidence that the results (from the perspective of interviewees) are true, credible and believable.
<b>Dependability</b>	The findings of the qualitative inquiry are repeatable if the inquiry occurred with the same cohort of participants, researchers and context.
<b>Confirmability</b>	Whether the researcher acted in good faith.
<b>Transferability</b>	Can the information hold in some other context or at another point in time?
<b>Authenticity</b>	Wider political impact of the research.

### **(6.10) Summary of the chapter**

The QI phase consisted of 30 interviews with people involved in different ways with the implementation of PROMs within the third sector. The framework approach was used to analyse the interviews. The findings are presented in the next chapter.

## Chapter 7 - Findings from the qualitative interviews: how context, people and processes impact on the implementation of PROMS within TSOs

### (7.1) Outline of the chapter

This chapter focuses on both the findings of the qualitative interviews and considers the implications. Firstly, the sample is described. Secondly the findings of the interviews are presented. Initially, this entails considering how external policy, the structure and culture of TSOs and people both internal and external to the organisation influence the implementation of PROMs. The latter part of the findings focuses on processes undertaken in TSOs including designing the PROMs process, skilling up and engaging staff, using measures in routine practice and improving implementation. Finally, the QI phase is appraised. The chapter builds upon the implementation model developed in the systematic review of reviews (Figure 1, Chapter 3) by taking into account the specific issues relevant for TSOs implementing PROMs.

## (7.2) Description of the interviewees

**Table 7- Description of the interviewees**

<b>Participant type</b>	<b>Number interviewed</b>	<b>Mode of interview</b>	<b>Type of organisation</b>	<b>Other information</b>
Service-users	5	F-F*- 5 Phone- 0	National TSO- 0 Regional TSO- 0 City level TSO- 4 Neighbourhood TSO- 1	
Front-line workers	6	F-F- 5 Phone- 1	National TSO- 0 Regional TSO- 3 City level TSOs- 0 Neighbourhood TSO- 3	
Managers	8	F-F- 7 Phone- 1	National TSOs- 1 Regional TSOs- 1 City level TSO- 5 Neighbourhood TSO- 1	
Commissioners	6	F-F- 1 Phone- 5	Local Authority- 2 NHS- 1 Non-statutory funder- 3	
Stakeholders	5	F-F- 4 Phone- 1	N/A	Carer/volunteer- 1 Researcher/policy advisor- 2 Developer of PROMs, data management systems- 1 Statutory service implementation lead- 1

\*Face-to-face interview

Thirty people with different experiences of PROMs were interviewed, their characteristics are described in Table 7. Interviewees were categorised into specific interest groups, based on the roles people held at the point of the interview. However, several participants spoke about their previous experiences of using PROMs when in roles relating to other interest groups.

Eight interviewees were TSO managers. This was the interest group I undertook the most interviews with. The participants held different managerial roles, for example one interviewee was a director of a national wellbeing programme, one managed a team of volunteers and another was a data manager. Six front-line workers were interviewed. They worked for different types of TSOs, in various types of wellbeing activities and had a range of previous experiences including being volunteers and/or allied health professionals. Six commissioners were interviewed, some held strategic roles whereas others were responsible for performance managing TSOs. Two of the commissioners worked for local authorities, one for an NHS organisation and three for grant making organisations. In this latter group, two worked for TSOs who subcontracted services to smaller organisations. Five participants were current service-users. Alongside accessing the wellbeing activities, they all had different long-term conditions. Finally, five stakeholders were interviewed because of their diverse roles: one was a researcher, one had a combined researcher/policy advisor role, one developed data management systems and one worked for a statutory organisation implementing PROMs within primary care. Finally, one stakeholder interviewee was a carer of someone who accessed wellbeing activities and the interviewee also volunteered at two TSOs to help them collect PROMs.

Interviewees were linked to different sized organisations, one interviewee worked for a national TSO whereas the majority of interviewees worked for or with organisations with a smaller geographical scope e.g. neighbourhood or city based. Interviewees were primarily based in the North of England, with a small number based in other parts of the country. This was because I drew upon personal contacts and used snowballing recruitment strategies.

The majority of interviews (n=22) took place face-to-face, including all service-users interviews. Amongst the manager, front-line worker and stakeholder groups, all but one interview in each of these groups was conducted face-to-face. The commissioner group was the reverse, the majority of interviews were conducted by telephone. The interviews ranged considerably in their length, lasting between 15 and 90 minutes. The service-user interviews were notably shorter, with four

of the five being shorter than 20 minutes long. The reason was because service-users could only provide their perspective on completing PROMs but understandably were not able to discuss the wider implementation process such as organisational culture or staff training. Interviews were undertaken between September 2017 and July 2018.

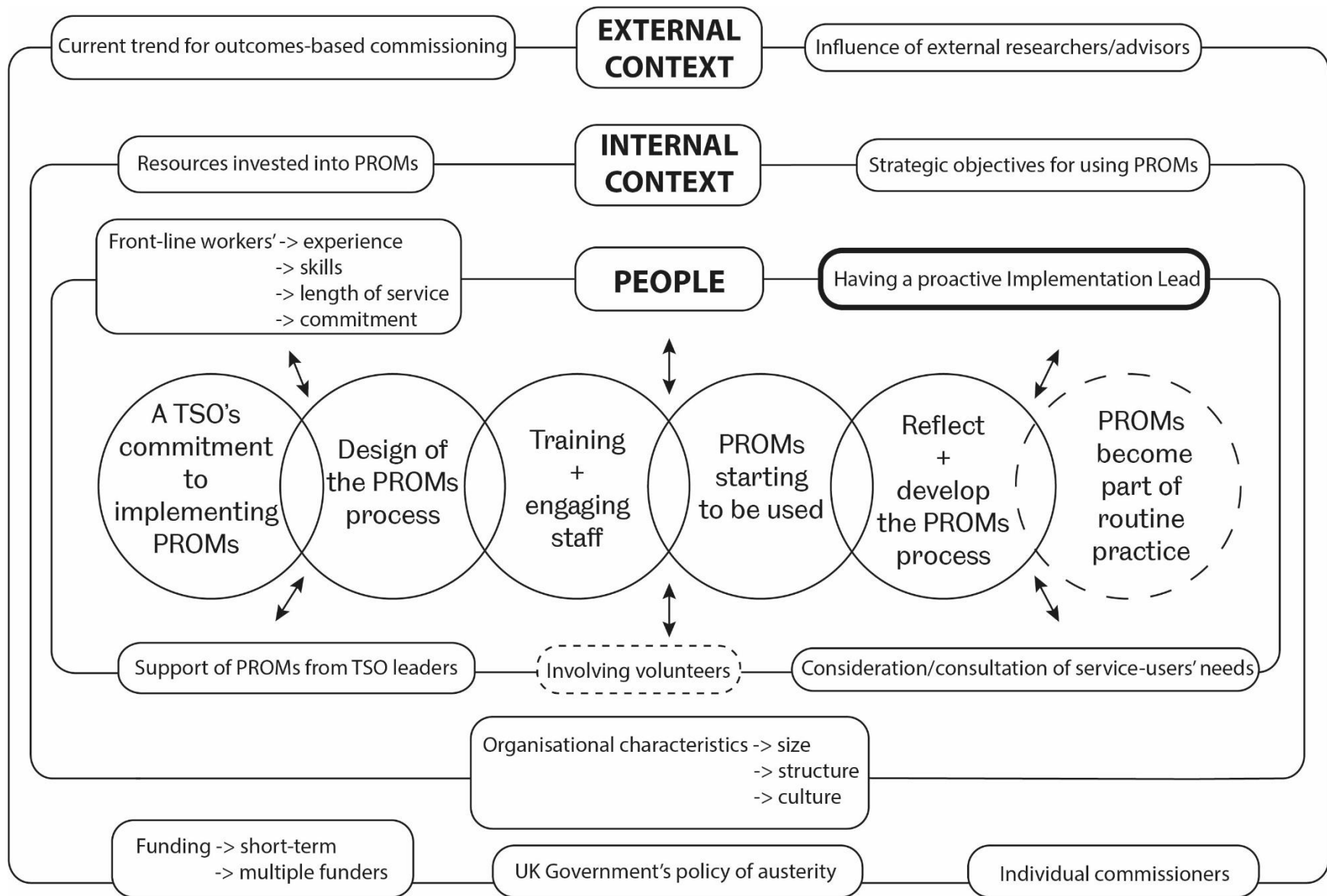
### (7.3) Overview of findings and presentation within the chapter

TSOs in this sample were trying to use PROMs but had mixed success. Interviewees felt that TSOs primarily use measures because organisations had no choice due to needing to gain or justify funding. Consequently, TSO staff and service-users engaged with PROMs to financially support their organisation, even if they did not believe measures were valid or appropriate. Despite this commitment, organisations rarely implemented PROMs successfully at their first attempt and had to develop the process iteratively. TSOs appeared to have more success if they had taken a collaborative approach to designing the PROMs process, chose an appropriate measure, trained staff, invested in systems to process and analyse collected measures, and had an individual who took responsibility for progressing implementation (an Implementation Lead).

As illustrated in Figure 3, contextual factors appeared to influence the implementation of PROMs including: the external policy and funding context (Theme 1) and the characteristics and culture of an organisation (Theme 2). Alongside, the importance of the needs, skills and opinions of people within the TSO were relevant (Theme 3). Both the context and people influenced the decisions and actions taken in respect of PROMs. These actions were grouped into a number of process related stages: designing the PROMS process (Themes 4 and 5), engaging and skilling up staff (Theme 6) and utilising and sustaining measures in routine practice (Theme 7). The way the themes are structured in this chapter means each influencing factor appears distinct, however in reality the factors all interacted and influenced each other in multiple directions. For example, the opinions of front-line workers impacted on their use of PROMs but their viewpoints were not static and were influenced by the perceived appropriateness of the measure they had to administer. Consequently, the process was rarely straightforward and required TSOs to revisit some of the issues as they progressed implementation.



**Figure 3- Implementing PROMs in TSOs- Findings arising from the QI phase**



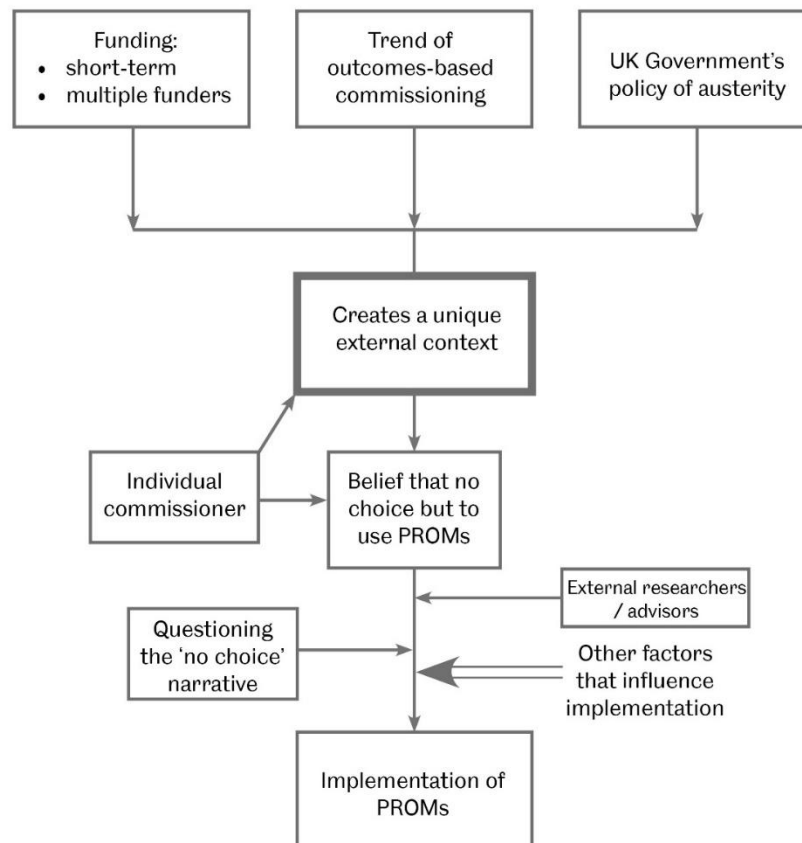
Footnote- Bold border- Appears essential; Dashed border- Not relevant to all TSOs

A summary of how the research findings link with the CFIR constructs is included in Appendix 14. *Planning* was the only CFIR construct not identified in the analysis and relates to the extent to which the implementation process is planned including timescales or which tasks need to be undertaken. This does not necessarily mean that TSOs do not plan their implementation, but given the issue did not arise within the interviews, it may indicate that organisations take a pragmatic approach to implementation. However, it may also be that the interviews were not framed in a way to capture factors related to planning.

#### (7.4) How the external context impacts on implementation

Four external influences on TSOs' approaches to PROMs were identified: external funding and policy context, individual commissioners, external advisors, and other TSOs (Figure 4).

**Figure 4- How the external policy and funding context impacts on implementation**



#### (7.4.1) 'No choice' but to use PROMs because of the external funding and policy context

The external funding arrangements of TSOs interacted with the UK Government's policy of austerity and the general trend for outcomes-based commissioning. This created an external context where organisations in this sample felt they had to use PROMs to gain funding and so engaged because they believed they had to. Everyone interviewed was mindful of the funding pressures TSOs were under and some felt measurement data helped organisations to gain or maintain funding. As discussed in earlier chapters, TSOs receive short-term funding and regularly apply for new funding in order to sustain wellbeing activities. Interviewees discussed the impact of austerity, explaining that it had created funding pressures because budget cuts were made to statutory services which had implications for funding TSOs. In this environment, interviewees felt both commissioners and TSOs needed to demonstrate the impact of wellbeing activities to justify receiving funding. Participants empathised that commissioners were working within public sector organisations that had to reduce their expenditure.

*“The reality is that you know money is getting tighter and tighter. Whether it's grants or contracts [...] the only way you'll attract funding is to be able to show that you make a difference and that you have an impact.”* [TSO Manager 4]

Commissioners also believed the shift in practice towards outcomes-based commissioning was relevant because this created an environment where PROMs were viewed as a credible way for TSOs to evidence their impact. Interviewees discussed how their TSOs were increasingly funded by contracts rather than grants, and their organisations were required to measure outcomes as a condition of funding. This context of 'no choice' permeated throughout TSOs in the sample, with service-users complying with PROMs because they did not want to create problems or harm an organisation's funding.

*“I'm scared, I really want to come to this programme and if I don't fill in the form, I might get in trouble.”* [TSO Service-user 5]

However, the 'no choice' narrative was challenged by people from all of the interviewee categories. Four reasons underpinned this scepticism. Firstly, interviewees felt it was unfair that other types of organisations' funding was not dependent on using outcome measures. This appeared to be because statutory services generally received recurring funding so did not have to

justify the investment. Secondly, participants discussed a lack of linkage between a TSO's outcome measurement data and funding decisions. For example, one commissioner felt that funding decisions were made on the basis of belief rather than evidence and some service-users and front-line workers questioned if funders even looked at the data. A lack of transparency amongst commissioners about what outcomes were expected compounded this feeling for some people.

*“It's kind of like demeaning in a way, but that's part of the government thing about wanting proof, they don't really know what the proof is that they want, so writing the questions and getting the information again like I say, it goes into a lever arch file and also a computer programme that is never ever opened again.” [TSO Service-user 1]*

Thirdly, some interviewees felt the established evidence base on wellbeing activities meant there was no need for TSOs to collect further outcomes data. Fourthly, not all commissioners requested the use of PROMs, indicating commissioners may have choice in whether they use them as a performance monitoring tool. The impact of the individual commissioner is explored further in the next subtheme. All four factors relate to participants feeling commissioners could be more transparent about why TSOs are asked to use PROMs and how the collected data influences funding decisions.

Interviewees believing there was a choice about using PROMs did result in some commissioners, managers and front-line workers not engaging with using outcome measures. However, other interviewees still engaged with PROMs, mainly out of loyalty to the TSO. The power and influence of an interviewee within their organisation had some impact on whether they did or did not engage with PROMs. For example, one front-line worker questioned the use of PROMs but still engaged because she was relatively new to the TSO. Whereas a manager and a commissioner both held strategic roles within their organisation so could choose not to engage.

#### (7.4.2) The impact of individual commissioners

The extent a TSO felt they had ‘no choice’ but to implement PROMs was influenced by individual commissioners, because they decided whether a TSO had to collect measures as a requirement of their funding contract. Interviewees discussed how individual commissioners had differing requirements in respect to PROMs, illustrated by the unique approaches of the commissioners interviewed in this study. For example, one commissioner who worked for a grant-making organisation wanted TSOs to choose the outcome measures themselves. In contrast, a NHS commissioner had introduced a system where funding was linked to the results of a specific PROM. A number of managers, commissioners and stakeholders felt a lack of standardised training for commissioners and variation in commissioning organisations’ procurement policies compounded the problem. This lack of uniformity meant individual commissioners’ personalities, experiences, relationships with TSOs and roles within their organisation influenced their approach towards PROMs. In some cases, this resulted in commissioners taking a collaborative approach to designing the PROMs process (discussed subsequently). The impact of individual commissioners was magnified because TSOs often had to meet the differing demands of a number of commissioners because organisations were funded from multiple sources. The high turnover of commissioners was also problematic, with one stakeholder discussing how a new commissioner may performance manage the contract differently to the previous individual.

*“I think I’m different because I’ve worked in the voluntary sector [...] and a lot of people who end up in my position have just either gone to medical school [...]. What you tend to find is people delivering services, commissioning services are not the people who’ve ever experienced those services.”* [Commissioner 4]

#### (7.4.3) The support of external advisors/researchers

Alongside commissioners, external advisors/researchers played a role in some organisations. External advisors/researchers were people outside of the TSO who advised the organisation on PROMs. Managers, commissioners and stakeholders had mixed experiences of external advisors/researchers. One manager discussed how the external advisor supported her to take time to reflect on PROMs and gave credibility to the process. Whereas a commissioner based in a TSO reported that an external researcher had chosen an inappropriate PROM and consequently the interviewee had to decide upon a new measure. Crucially, the message from interviewees

was that external advisors/researchers needed to adopt a collaborative approach with organisations and consider their specific needs.

*“Sometimes when you’re trying [...] and it’s not your area of expertise particularly and it’s just part of the million things that are your day job. It’s really hard to kind of keep that momentum going and to be sure, that what you’re doing is right. So I think we’d got so far down the road with it and that was the point where I felt ‘we need some help with this’. Because I haven’t got capacity to do it all and also I didn’t have the headspace and there needed to be some kind of credibility to it which having some external people who it was their area of expertise would give it that.” [TSO Manager 4]*

A small number of stakeholders and commissioners wanted external researchers to have a greater role in implementation because they felt that TSOs did not have the skills and there was a risk of bias. This raises the question of whether PROMs are used as a tool for routine monitoring or for evaluation. The interviewees felt that people within the third sector did not necessarily have the statistical skills to analyse the outcomes data. They also said that TSOs had a vested interest in showing positive results from the data. However, these were minority views and the majority of interviewees in the sample focused on developing the capacity and capability within TSOs to analyse PROMs themselves.

#### **(7.4.4) Learning from other TSOs, or competing against them**

The degree TSOs were networked with other organisations and the extent they perceived there being a competitive pressure for funding impacted on the implementation of PROMs. TSOs with good networks learnt from, and supported each other, particularly on the choice of measures. One manager commented that people also need to share what did not work. Interviewees emphasised that learning must be adapted to the context of the specific organisation (discussed further in the next theme).

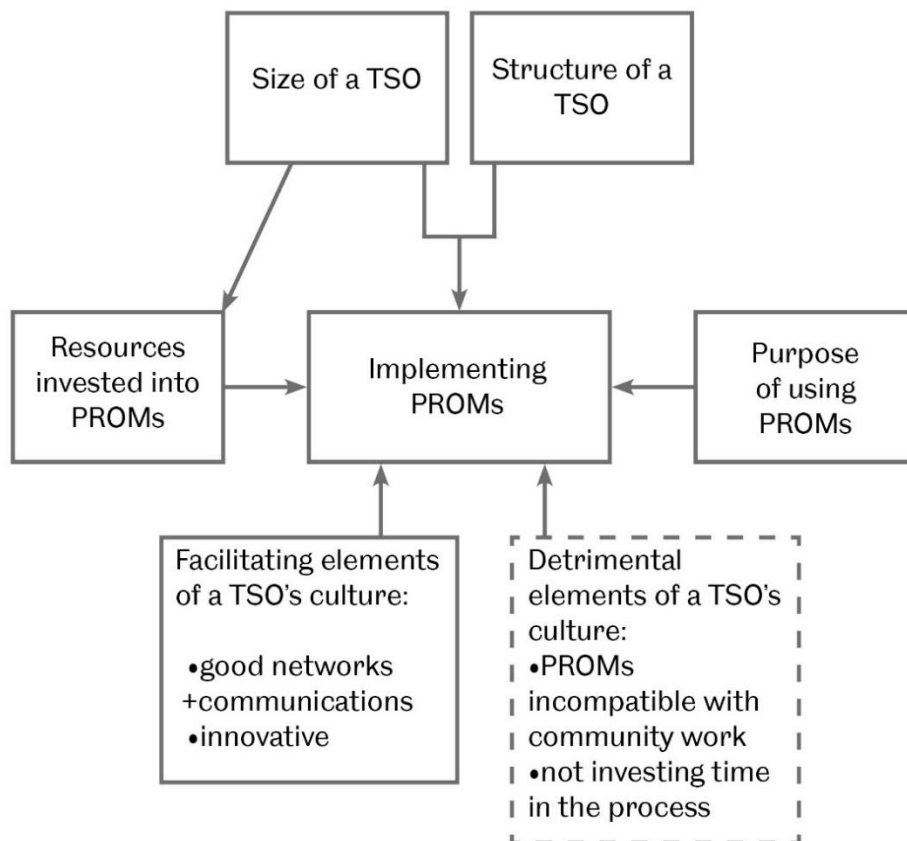
*“We’ve been seeing [name of a manager in another TSO] fairly regularly as well and we’re just kind of share information with [them] about what we’re doing and what’s working and what’s not working and [name of manager in another TSO] shared some of their stuff.” [TSO Manager 8]*

Learning from other TSOs was occasionally fuelled by competitive pressure. A couple of managers discussed using PROMs because other organisations bidding for similar work were using measures and they felt this provided a competitive edge. This stems from the external context of TSOs bidding against each other for funding. Competitiveness was raised by different interviewees to those who discussed networking earlier in this subtheme. This indicates differences in whether other TSOs are viewed as potential collaborators or competitors. Regardless, both approaches appeared to aid implementation.

### (7.5) How the internal context of a TSO impacted on implementation

Four organisational characteristics and behaviours of TSOs impacted on implementation: strategic objectives for PROMs, TSO size and structure, organisational culture, and level of resources TSOs invested in PROMs (Figure 5).

**Figure 5- How the internal context of a TSO influenced implementation**



Footnote- Dashed border- Detrimental aspects of a TSO's culture

### (7.5.1) How a TSO's strategic objectives in relation to PROMs impacted on implementation

As discussed in Theme 1, TSOs were primarily implementing PROMs because of the external funding context. However, through the interviews it became apparent that organisations took different strategic decisions on how they embraced PROMs within this context. Alongside using PROMs to justify funding, a number of managers, commissioners and stakeholders in the sample spoke about the importance of using PROMs to support the care management of service-users. The interviewees felt front-line workers would be more willing to engage if they found the PROMs useful for delivering support to service-users e.g. using the measures to inform support plans. Some front-line workers discussed how collecting outcome measures supported them with service delivery because they would share the results with service-users to help plan their support and review progress. However, many of the front-line workers did not feel that PROMs had a care management purpose, and they viewed measures primarily as having a performance monitoring function (discussed subsequently). Several of the commissioners also discussed how TSOs could use the measures to support them with service improvement, so using the data to help organisations reflect and develop their wellbeing activities. A small number of organisations in the sample did use data generated from PROMs to inform service development, but it was a less common objective than TSOs using measures to justify funding or as a care management tool. Furthermore, the service improvement function appeared more driven by the commissioners rather than a desire from TSOs to use PROMs for this purpose.

*'I think I'm more into like constant iterative improvement around this [...] how do we tweak the service to reflect that [...] than kind of batting providers over the heads saying unless you got a 2% or 10% well-being score improvement, you're losing the funding.'* [Commissioner 4]

TSOs made different strategic decisions on whether they were going to implement PROMs throughout the organisation or in selected wellbeing activities. In the latter, interviewees spoke about choosing to only use PROMs within wellbeing activities where they were required to by commissioners. So these TSOs were not choosing to use PROMs but reacting to the external context. Whereas other managers discussed taking the strategic decision to implement PROMs throughout a TSO because they wanted to develop the outcome measurement culture and perceived that using PROMs would be beneficial for the organisation. The approach a TSO took appears to impact on the narrative surrounding PROM internally within the organisation and influences the other elements of implementation such as what resources would be invested. For



example, one TSO who was implementing PROMs across the organisation had invested in a data monitoring officer and data management system. In contrast, another TSO was purely implementing PROMs in one wellbeing activity and had asked the front-line worker to process the PROMs using a spreadsheet. The implications of an organisation's strategic commitment appears to impact on decisions taken within the PROMs process and so is considered in subsequent themes.

#### (7.5.2) The impact of the size and structure of a TSO on implementation

The size and structural characteristics of TSOs appeared to influence implementation.

Interviewees discussed how larger organisations had more resources than smaller TSOs to invest in facilitating the use of PROMs. For example, larger TSOs may have data management systems and employees whose specific role is monitoring and evaluation. However, several managers of smaller organisations in the sample had overcome the barrier of size by allocating resources to the PROMs process, such as funding data support staff. So the constraints of size were not an inevitable barrier.

*“I would see lots that were struggling, I mean to be honest. Especially smaller sized organisation yeah definitely lots of people who were doing this as one small part of their job. Like, I mean, you know if you were getting medium to large sized organisations then they often have dedicated people to look at this don't they? But the smaller end, less so. So, people really trying to juggle evaluation, outcomes, measurement whatever, in amongst doing maybe delivery work or other kind of internal functions as well.” [Commissioner 2]*

A TSO's structure was also pertinent; chiefly, how much direct contact front-line workers had with an Implementation Lead (the person responsible for implementation). Within smaller organisations, front-line workers had direct contact with these Leads; interviewees cited this as a facilitator because front-line workers felt supported and involved with implementation. Not having this direct contact left front-line workers vulnerable to being influenced by people critical of PROMs. This occurred in some larger TSOs and when organisations delivered projects stemming from national programmes. One stakeholder addressed this barrier through choosing people from each team to act as locally based champions.

*“I think and it comes as well from the managers [...] that the service managers don’t have enough understanding to be able to support the [type of front-line workers]. So they all moan together and say oh its rubbish or are tempted not to use it, or are tempted to change the questions”* [TSO Manager 1]

TSOs’ structures also created practical barriers. For example, front-line workers, managers and stakeholders discussed how front-line workers were not able to access data management systems when working out in the community. These interviewees felt these structural barriers could be addressed by organisations investing in technological equipment or having regular meetings between Implementation Leads and front-line workers.

### **(7.5.3) How the culture of a TSO can both facilitate and be a barrier to implementation**

The norms and values of TSOs, especially in relation to team members feeling valued as knowledgeable partners, appeared to facilitate implementation. Firstly, several managers in the sample discussed how outcome measurement had become part of their organisation’s culture, so PROMs were consistent with the norms of behaviour. In these cases, performance monitoring was already something the TSO did and was part of their culture, so using PROMs was compatible with these norms rather than being a new way of working. Secondly, having a positive team culture with good quality social networks and informal communications within organisations were identified as a facilitator. Several managers and front-line workers described how good relationships amongst the front-line workers and the wider staff team was an asset because everyone helped each other and shared good practice.

*“There’s the coaching staff and there’s the data office staff [...]. Then we have the management tier as well. But we’re all very collaborative and everybody from all of the roles have [a] say in shaping things.”* [TSO Front-line worker 2]

Thirdly, managers and commissioners felt TSOs generally had innovative cultures, so were experienced in trying new processes.

*“I think as an organisation we are quite good at being fluid, you know and having a go at things and seeing if they work.”* [TSO Manager 4]

However, some stakeholders and commissioners felt this ‘just have a go’ approach could be a barrier, with TSOs looking for quick fixes to implementation. Sometimes this was because of external time pressures, with funders asking for PROMs data to be collected at short notice. In other cases, organisations did not want to invest time in developing the process. For example, one commissioner discussed how TSOs would ask them which measure the organisation should use rather than taking the time to choose one themselves.

In contrast to those who felt a TSO’s culture was a facilitator, a number of stakeholders, service-users and front-line workers believed that PROMs were incompatible with the organisational culture of TSOs because they under-mined the informal nature of community work. A couple of service-users felt that people were deterred from attending wellbeing activities because of being asked to complete PROMs. They explained that people were afraid that their responses may get passed onto other agencies such as the Department for Work and Pensions. One stakeholder proposed that PROMs can stifle wellbeing activities from evolving and becoming user-led because the measure pre-determines the outcomes and focus of the activity. From the interviews it appeared that there were some TSOs whose culture was more suited to implementing PROMs than others. A number of interviewees worked in organisations which delivered fairly formalised services, and these people perceived that outcome measurement was compatible with this culture. Other interviewees found it more challenging because their organisations delivered community development activities.

#### (7.5.4) The level of resources dedicated to PROMs

Managers described difficulties in allocating resources because funding from grants and contracts had to be used to deliver wellbeing activities. Consequently some of the managers and commissioners had sought external funding specifically for PROMs, using this funding for data management systems, licence fees and monitoring officers. A couple of interviewees had also used external funding to support the input of external researchers/advisors (see earlier theme).

As discussed earlier in this theme, some interviewees felt that a TSO’s size impacted on the resources available for using PROMs. However through the analysis, it appeared the issue was more nuanced and depended on whether a TSO prioritised investment into the PROMs process.

For example, managers of two similar sized organisations discussed differing levels of investment especially in regards to data management systems and staff to support the process. Several of the managers and commissioners felt that TSOs would be more likely to invest in the process if they perceived PROMs would benefit the organisation including generating additional funding. Some individuals were mindful that their decision to invest in measurement was to the detriment of using the resources to deliver wellbeing activities. This doubt, even amongst participants passionate about outcome measures, indicated that PROMs were not yet considered an essential part of routine practice within the sector.

*“It’s a tricky one because in a way, it’s a luxury for an organisation like us. I think there are no other [specific type of TSO] that have got a data analyst and funds are tight for us and it’s one of those roles that I look at and ‘is it a bit of a luxury?’ On the other hand, I do know that we’ve won funding because of the quality of the data that we’ve been able to provide to people so it’s a real balancing act.” [TSO Manager 3]*

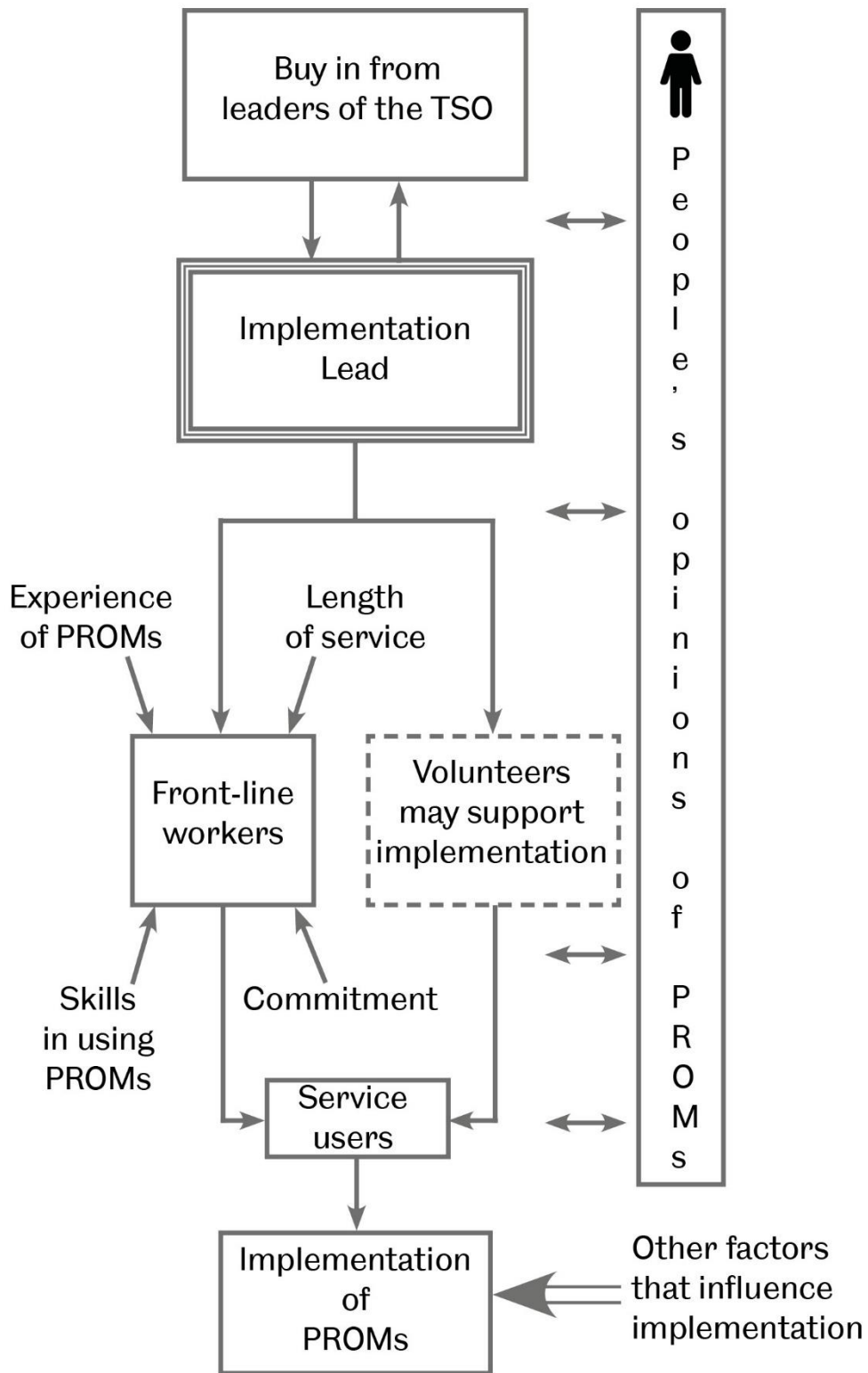
TSOs also faced challenges in sustaining the investment of resources. This appeared to be most problematic in organisations which had initially accessed external funding because the TSO had to then identify internal resources to sustain the process. For example, one TSO had accessed external funding to initially develop a data management system but was concerned about maintaining it once the grant finished.

*“The one [data management system] we’ve got is one of those that you pay a subscription every year so I [the grant] funded it for 2 years and then from this year we’ll have to find the money [...] it’s probably a couple of grand a year. For us it’s expensive. But we can’t not do it now we’re along that road.” [TSO Manager 4]*

## **(7.6) The importance of the needs, skills and opinions of people within the TSO**

There appeared to be five groups of people involved with making the implementation process work: Implementation Leads, senior managers, front-line workers, service-users and volunteers (Figure 5). Each group appeared to influence implementation, in different ways.

**Figure 5- The influence of people on implementation**



Footnote- Bold border- Crucial role; Dashed border- May support implementation

### (7.6.1) The importance of having an Implementation Lead

Having a specific individual in the TSO responsible for leading implementation appeared to be critical. Interviewees from TSOs with an Implementation Lead described how this individual motivated staff, designed the PROMs process, coordinated training, oversaw the use of measures and addressed problems. These tasks are discussed in detail in the later themes. Implementation appeared to stagnate without this Implementation Lead because no one else took responsibility for progressing the use of PROMs. Usually a senior manager was the Implementation Lead. However their status and position in the organisation was not enough, the person needed to be an advocate of PROMs. For example, one manager had not been a proactive Implementation Lead because she did not feel outcome measures were appropriate for TSOs. Alternatively there was one interviewee who had been in a relatively junior position when she took it upon herself to lead on PROMs because the TSO was struggling to use them.

*“Cos when I first came it [PROM] was just, like I said ad-hocly written into funding bids, thinking that they [The TSO] needed it. But nobody was managing it, nobody was managing the workers doing it, nobody was managing those expectations, nobody was really recording it properly and I was just like ahhhhh. How can you cope like this cos it needs to be managed?” [TSO Manager 7]*

Two problems were identified with Implementation Leads. First, relying on them could be problematic if that person went on a leave of absence or left the organisation, as identified by one manager. Second, a manager challenged the necessity of an Implementation Lead because they felt it prevented a sense of collective responsibility amongst staff towards PROMs. Interestingly, this manager had acted as the Implementation Lead but had taken a collaborative approach to implementation. This demonstrates the necessity of the Implementation Lead, but also that there may be different leadership approaches for this role (discussed in the next theme).

### (7.6.2) The commitment and involvement of senior management within a TSO

The commitment, involvement and accountability of senior management and Board of Trustees appeared important because they were the gatekeepers to both ideological and financial investment in PROMs. Senior management encompassed different roles depending on the specific TSO; in some it was a Chief Executive, in others there were a number of senior managers. In the smaller organisations the Chief Executive could sometimes be the

Implementation Lead, who then engaged the Board of Trustees in PROMs. So in all TSOs in the sample it appeared that buy-in was needed from the people with overarching responsibility for the organisation.

Interviewees reported different levels of engagement from people at senior management levels. Engagement generated a strategic commitment from an organisation towards PROMs and facilitated the investment of resources including data management systems and support staff. It appeared that senior managers were more likely to engage if they viewed PROMs as compatible with other strategic objectives, such as a desire to become outcome focused or invest in technological solutions.

*“Yeah I think it formed part of a wider strategy [...]. So we’re sort of looking at lots of different things that fall under our transform agenda [...]. So there’s a business case for this, where it actually saves time, it’s invest to save. So it was an easier ask than it would be in some other organisations.” [TSO Manager 6]*

### (7.6.3) The skills, experience and continuity of key staff

The skills and enthusiasm for PROMs of individual front-line workers appeared to influence their use of PROMs. Because of this, interviewees acknowledged that front-line workers differed in their abilities to use measures. There was a sense amongst the front-line workers and some of the managers that front-line were skilled and committed to using PROMs, even if they personally disagreed with their use. Many of the front-line workers in the sample expressed a strong sense of self-efficacy, drawing upon skills they had developed previously. For example, several front-line workers were healthcare professionals who had received training in undertaking assessments as part of their qualifications. However, a number of managers, stakeholders, commissioners and service-users felt that not all front-line workers had sufficient skills to use PROMs. They cited the poor completion of measures as evidence of this. One stakeholder proposed that the skills needed to be a good front-line worker were not necessarily compatible with being competent at paperwork. A manager expanded on this, explaining that some of her front-line workers were brilliant at working with service-users but had disabilities such as dyspraxia which made it difficult for them to use outcome measures. Several interviewees discussed how a lack of engagement was actually a symptom of issues with the PROMs process rather than a performance management issue. For example, front-line workers discussed not receiving

sufficient training in administering measures. Consequently, non-engagement motivated TSOs to deliver further training and/or to reflect and improve their PROMs process (this is explored in a later theme).

*“It depends on who was doing it, some of them [Front-line workers] were more confident than others and others were like ‘oh, here we have to do this again’.” [TSO Service-user 2]*

A number of stakeholders, commissioners and managers in the sample spoke about the skills needed within TSOs to analyse the data collected from PROMs. Not having these skills within organisations had knock-on effects on sustainability because people could not see the point of collecting PROMs if the data was not used. For example, a manager discussed how they were the only person within their organisation who could analyse outcome measures and they felt that if they left the organisation, the collected data would not be analysed. Thus there appeared to be a need for TSOs to ensure they had sufficient capabilities within their organisation to analyse as well as collect PROMs.

Staff within TSOs were perceived as being exceptionally committed to their work and dedicated to making the organisation a success. This resulted in high retention levels of staff. Managers and front-line workers discussed how this continuity could be a facilitator because people knew the PROMs process and stayed engaged. However in a few cases, continuity could be a barrier because existing staff had to learn and be willing to embrace new working practices, whereas new members of staff would engage with PROMs because they had not known anything different.

*“There’s a small minority of people that don’t like all the data that we capture, people that came to the job a long ago and [...] administration has just increased and increased and increased. So, I think we struggle with those people a little bit more than with the newer ones.” [TSO Manager 6]*



#### (7.6.4) How the needs of service-users impact on implementation

Service-users' needs, in relation to the extent these needs are known and prioritised by a TSO during PROMs implementation, appeared to be relevant. Whilst each TSO worked with different population groups, interviewees discussed similar challenges such as including having low levels of literacy, cognitive impairments, English as a second language and other complex needs. Also relevant was the reason why a service-user was accessing a wellbeing activity. Several front-line workers discussed their concerns that service-users who were accessing a wellbeing activity for practical support on a specific issue were asked to complete measures asking about their mental health or relationships, which service-users found inappropriate.

*“But people who are coming to me with the social issues such as they can't pay their rent or universal credit [...] or people come to me for bereavement, practical problem solving really. Then it really is irrelevant and some people get quite agitated at being asked to fill in such questions about their mental health, they haven't actually come to me for a mental health consultation.”* [TSO Front-line worker 1]

Participants felt that implementation was more successful if service-users' needs were considered when designing the PROMs process. Generally, interviewees believed that TSOs wanted to consider service-users' needs because this reflected the service-user driven ethos of TSOs. However, the extent to which organisations considered service-users' needs was partly influenced by how much influence the TSO had over the PROMs process. Managers and front-line workers spoke about commissioners requiring the organisation to use specific PROMs, even when they were inappropriate for their service-users. Whether a TSO considered their users' needs also appeared to be linked to how much the organisation had embraced the implementation of PROMs. A small number of managers explained about undertaking consultation with their service-users because they wanted the PROMs process to be successful. However, other interviewees spoke about considering their service-users' needs rather than consulting them directly.

If a TSO did not take into account service-users' needs when designing the PROMs process, then this could create issues when the TSO began using measures with service-users. Firstly, if the front-line worker did not perceive the measure to be suitable for their service-users, they did not administer the PROM. Secondly, if the service-user did not understand the PROM, or it was administered inappropriately, then the individual would either not complete the measure or

complete it poorly. For example, two stakeholders spoke about service-users with a low level of literacy being expected to complete measures without any support, resulting in poor completion rates. Other front-line workers spoke about their service-users with cognitive issues just giving random answers because they could not comprehend the questions.

*“It’s the sort of people that I’m using it on, it’s fundamentally flawed anyway cos some of them I have to, I deal with a lot of people who can’t read or can’t write or got dementia and that makes it irrelevant because you say the question and they say ‘ooh what number oh I think it was a three’, but they have no comprehension of what I’ve asked them” [TSO Front-line worker 1]*

#### (7.6.5) The role of volunteers in the PROMs process

Volunteers are an important component of TSO but are a less common feature of other types of organisations that use PROMs. Interviewees disagreed about the role of volunteers in administering measures. A number of managers, stakeholders and commissioners discussed how volunteers are not contractually obliged to perform tasks. They gave examples of volunteers not collecting PROMs because they did not want to undertake paperwork or felt it damaged their rapport with service-users. However, other participants felt that volunteers would engage with PROMs if organisations were transparent that collecting measures was part of their role and volunteers were provided with sufficient training. For example, one stakeholder’s specific volunteering role had been administering and processing outcome measures and they felt they had been given sufficient training to undertake the role.

*“The integration is just phenomenal; you never feel that you’re just a volunteer or that your job is not as important as them. The training, all training is given together so you’re there, you are showing that you’re just as important.” [TSO Stakeholder 5]*

#### (7.6.6) Strong positive or negative opinions about PROMs

Interviewees described how individuals’ knowledge and beliefs about PROMs impacted on implementation, although these beliefs were not static and could change during the process of implementing PROMs. A number of managers, commissioners and stakeholders in the sample viewed outcome measures as appropriate and useful for TSOs. These beliefs resulted in them being engaged and proactive in implementation. Other participants did not believe that PROMs

had utility but still engaged with them because they bought into the ‘no choice’ narrative. However, there were a number of people from across all the interest groups who were critical of PROMs and only engaged minimally with them. For example, one front-line worker only used measures when they became compulsory in her TSO. These differences in opinions were influenced by interviewees’ previous experiences and job roles. An example being a commissioner who supported PROMs because she had a background in evidence based healthcare.

The service-users in the sample felt that PROMs were not beneficial for them and only completed measures because they thought the data would help TSOs access funding. Several service-users discussed feeling ‘institutionalised’ to fill in outcome measures because they completed them when accessing NHS services. A couple of service-users found it anxiety provoking to complete PROMs because they were scared about whether it would affect the support they received.

People’s beliefs were not static and were impacted by the specific PROMs process and context, especially whether the individual felt they benefitted from using the measures. For example, one front-line worker felt that PROMs were inappropriate in the wellbeing activity she delivered, but she used them voluntarily in another project because they were useful in that context. Other interviewees spoke about feeling more supportive of PROMs once they benefitted directly from using measures. Examples include front-line worker using the measure as a care management tool or managers feeling that having the data had won them funding. Given this, TSOs could improve people’s knowledge and beliefs towards PROMs through utilising strategies identified in other themes such as taking a collaborative approach to designing the measurement process.

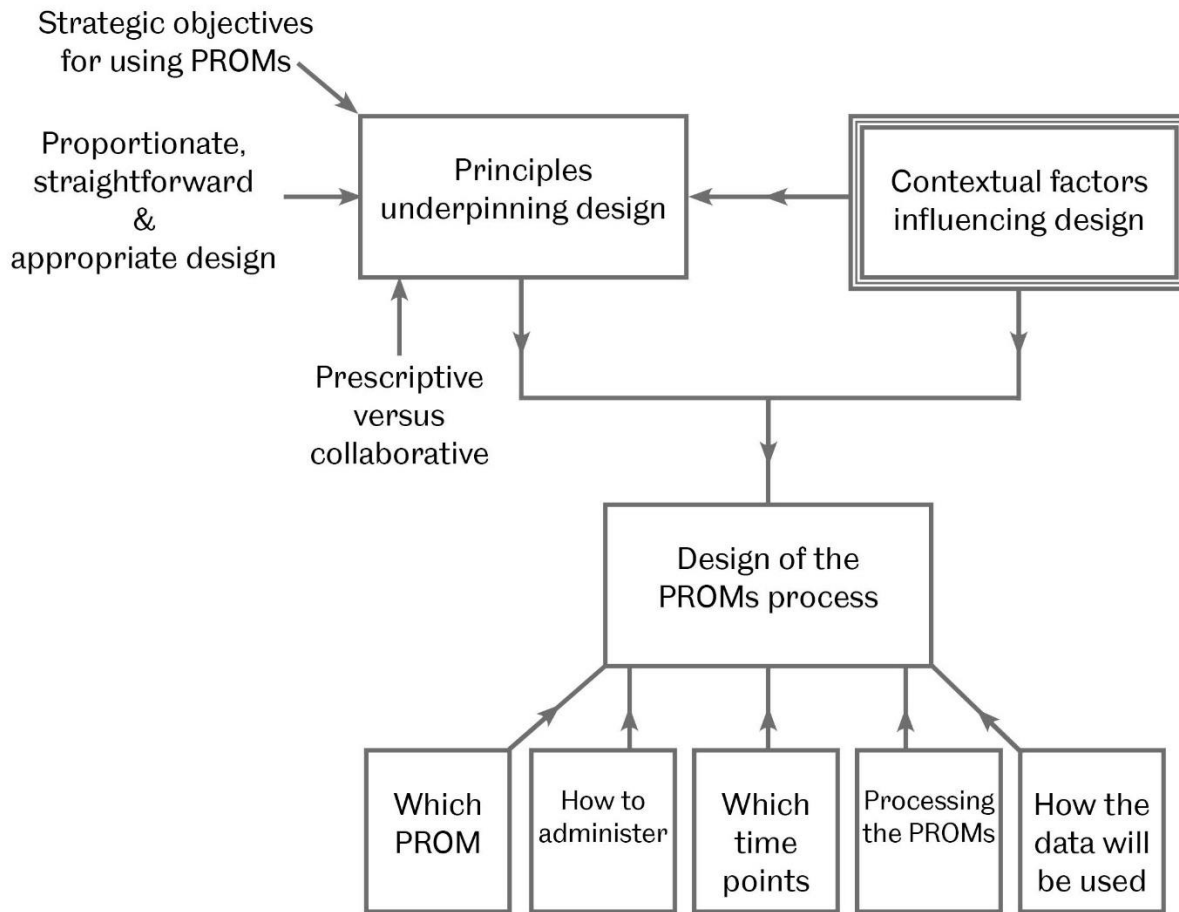
There was consensus amongst participants that PROMs were only one part of the evidence jigsaw and they were used because of an absence of alternative ways to measure impact. Several commissioners, stakeholders and managers felt that outcome measures complemented but did not replace narrative data such as case studies. Other interviewees felt that PROMs were used as a proxy because cost-effectiveness data was not available. For example, one commissioner was more interested in the impact of the wellbeing activity on NHS service utilisation than the impact captured by PROMs. This use of PROMs due to a lack of alternatives raises questions about whether they would still be used if alternative evaluation methods were identified.

*“Yeah the Outcome Measures Star is nice to have and it’s a means to attract the [name of funders] and to lock in the involvement of the voluntary and community sector. But the proof of the pudding will be the secondary care outcomes and the reduction in usage of secondary care.” [TSO Commissioner 5]*

### **(7.7) The principles underpinning the design of the PROMs process**

This theme is an extension of the ‘design stage’ identified in the systematic review of reviews (Figure 1, Chapter 3). In the interviews, three principles were identified as having a positive influence on the design and subsequent use of PROMs. The first related to the strategic principles for implementing PROMs, which was discussed in Theme 2. The other two principles are discussed within this theme and relate to whether the TSO designed their own PROMs process and whether the process was appropriate for the specific organisation. The principles underpinned the decisions taken on the design of the PROMs process (discussed in the next theme). The interaction between the two themes is illustrated in Figure 6.

**Figure 6- Designing the PROMs process**



#### (7.7.1) Prescriptive v collaborative decision-making

Who designed the PROMs process, and how they did this, was viewed by interviewees as impacting on implementation. The process could be designed by an external source, such as a commissioner, or developed by staff within the TSO. Some participants had experienced a prescriptive approach, where a small number of individuals such as a commissioner or TSO manager designed the process and imposed it on an organisation. Alternatively, some interviewees discussed being involved in a collaborative approach. This entailed commissioners and/or TSO managers consulting front-line workers and service-users on the design of the PROMs process especially which specific measure they preferred.

A number of managers and front-line workers discussed their experiences of having a PROMs process imposed on them by a commissioner or external advisor/researcher. These interviewees felt they still tried to make it work because they had no choice (as discussed in an earlier theme) but often struggled because the process was not appropriate for their specific organisation. Commissioners and stakeholders spoke about receiving poor quality data in these scenarios. For example, one stakeholder explained that they had supported an organisation which had a process imposed on them. The interviewee had anticipated receiving an analysis of outcomes data but instead received partially completed, unprocessed paper copies of PROMs.

*“[They] turned up with like a hessian bag full of questionnaires. Data doesn’t come in a bag, it comes in spreadsheets. So there is that issue to get over.”* [Stakeholder 3]

The commissioners interviewed defended imposing an approach on organisations by explaining that their design choices had originated from learning what had worked in other TSOs. There appeared to be some differences in approaches between the commissioners from statutory services and those based in the third sector or grant-giving organisations, with the latter appearing to take a more collaborative approach. This again demonstrates the influence of the individual commissioner on the implementation of PROMs.

Some interviewees discussed how staff within their TSO had taken a prescriptive approach. For example, one of the managers in the sample designed the process with his deputy but did not consult front-line workers or service-users. Four reasons for not taking a collaborative approach were identified in the interviews. Firstly, as discussed previously, some organisations had the PROMs process imposed on them by a commissioner and there was no scope to be collaborative. Secondly, some front-line workers explained their team was recruited after the process was designed. Thirdly, managers from larger TSOs identified how having multiple members of staff made it problematic to involve them all. Indeed one person who had been collaborative acknowledged this was only possible because the team they managed was small. This links to the size and structural characteristics of organisations (as discussed previously) and raises questions about which members of staff need to be consulted about designing PROMs. Finally, a couple of front-line workers in the sample were not interested in being involved in designing the process.

Many participants felt that a lack of collaboration created barriers for implementing PROMs. Whilst one manager had implemented PROMs despite taking a prescriptive approach, their case appeared to be an exception within the sample. Several managers, front-line workers and stakeholders discussed negative issues arising from TSOs not taking a collaborative approach. Examples included measures being too long, unworkable data management systems, and a lack of engagement amongst front-line workers. Interviewees explained how these problems culminated in organisations redesigning the PROMs process (discussed in a subsequent theme). Tellingly, this redesign usually included collaboration, with interviewees feeling this had enabled front-line workers to have a better understanding of the problems and potential solutions.

*“When we first started, the process had been designed for us [...]. We were given the paperwork process and it appeared to me [...] it was extremely long-winded and unlikely to be workable if I’m honest.”* [TSO Front-line worker 2]

The extent of collaboration with service-users also varied. Many of the managers in the sample did not consult service-users on PROMs, despite designing the wellbeing activity itself with users. One manager reflected on this in the interview but could not explain why they had not consulted service-users. Other managers and commissioners spoke positively of involving service-users, feeling it was essential. However, the service-users interviewed were not interested in being consulted because they felt detached from outcome measures, viewing them as an organisational tool (as discussed previously). So whilst consulting service-users could be a facilitator, the approach was not regularly undertaken in the sample.

#### **(7.7.2) Having a straightforward, appropriate, proportionate, and flexible design**

People from across all the interviewee categories felt that the processes associated with PROMs needed to be straightforward, appropriate, proportionate to the wellbeing activity, and flexible. Tailoring the PROMs process to the specific wellbeing activity was considered relevant because activities are heterogeneous and organisations may deliver a range of activities. So within this sample, even if a TSO took an organisational wide approach to PROMs, they adapted it for specific wellbeing activities. For example, several managers explained that in their TSOs, PROMs were not used in the more social activities or when support entailed one or two contacts.

Thus it appeared important that the specific context was taken into account during the design stage.

*“So long as whatever information is collected is done proportionately and appropriately, to the size of the contract then of course, it’s a good thing to do. But doing it blindly [...] doesn’t help anyone.”* [Commissioner 1]

The length of a PROM could be a barrier, with a number of participants discussing how front-line workers and service-users were less likely to engage with lengthy measures, resulting in TSOs having to change the specific measure at a later stage (discussed further in the last theme). Interviewees felt that measures should be no more than two sides of A4, ideally one side; although one interviewee caveated this by feeling that it partly depends on the amount of other paperwork that front-line workers and service-users were completing. Several stakeholders, managers and front-line workers discussed how longer length PROMs stemmed from TSOs not knowing which outcomes they wanted to prioritise, resulting in them collecting a number of outcome measures. Some TSOs managed to use longer measures, but interviewees reported engaging with them because they felt compelled to. Thus, even if the PROMs process was felt to be inappropriate, implementation could succeed because of other influencing factors such as external policy.

Having the flexibility to adapt the PROMs process to individual service-users was considered important by service-users, front-line workers and managers in the sample. For example, several front-line workers discussed administering the baseline PROM once they established rapport with a service-user, so not technically at the start of delivering support. The majority of service-users in the sample explained how their needs fluctuated so they wanted to choose at each time point whether they self-completed the PROM or had a front-line worker read them the questions. A small number of interviewees raised the issue of TSOs making a trade-off between flexibility and the validity of the data. For example, one manager spoke about using creative methods to administer measures but knew this invalidated the PROM.

*“There’s been some groups that she’s worked with where she has just literally asked the questions off the form because they’ve been able to engage with that, but there’s been others where it’s much more sensory experience and I don’t know how meaningful those answers are, really but, at least we’ve tried.”* [TSO Manager 5]



## (7.8) Variation between PROMs processes

Each TSO in the sample had a different PROMs process, which arose from a combination of contextual factors. Consequently, a PROMs process which worked in one organisation did not necessarily work in another TSO. There were different components of the PROMs process: choice of PROM, when and how the measure is administered and how the collected data is processed and used (illustrated in Figure 6). Each of these components needed to be designed.

### (7.8.1) The rationale for using specific PROMs

Interviewees had differing opinions about whether TSOs should use externally developed, validated PROMs e.g. the WEMWBS or bespoke, self-developed measures. Viewpoints were partly influenced by the reasons for using PROMs and previous experiences. A number of managers, stakeholders, front-line workers and commissioners in the sample discussed using validated measures which measured wellbeing. The WEMWBS, be it the full or short version, was the most commonly used measure in the sample. The Outcome Star, Five Ways to Wellbeing and the ONS-4 were also used. Occasionally, people spoke about using PROMs which measured quality of life or loneliness including the EQ-5D-5L and the De Jong Loneliness Scale. Rather than using validated measures, a number of interviewees were passionate about TSOs developing bespoke PROMs which met their specific needs. These measures generally drew upon conceptual frameworks of existing PROMs such as Five Ways to Wellbeing or the Outcome Star. In a small number of cases, participants had developed their own version of a validated measure to circumnavigate licence fees. Whilst I acknowledge that academics may not consider these bespoke measures appropriate because they have not undergone psychometric testing, interviewees did view them as PROMs. Therefore bespoke measures are classed as PROMs within the PhD because the purpose of the study was to understand the phenomena of PROMs within the third sector context.

Several interviewees explained that their organisations collated a number of validated measures together within a single PROM. However participants criticised this approach because made the PROM lengthy, which was considered a barrier to implementation (as discussed in a previous theme). Notably, service-users interviewed, and to an extent the front-line workers, had little awareness of which PROMs they had completed.

Seven factors arose from the interviews which appeared to influence the choice of PROM. Firstly, there was a strong sense amongst interviewees that the most appropriate measure varied depending on the specific organisation and wellbeing activity, as discussed in earlier themes. Consequently there was no appetite for a single validated PROM across the sector, with interviewees believing it was more important for a measure to be used which was appropriate for the specific TSO.

*“I would want to know that you, that an organisation had been through a process to consciously decide that yes this [the PROM] is the right thing for us rather than just defaulting [to a specific PROM] without thinking that through.” [Commissioner 2]*

Secondly, the choice of PROM was influenced by whether commissioners or TSO managers decided upon the measure, with the former more likely to opt for a validated measure. Thirdly, a number of managers chose to implement a specific PROM throughout their TSO in the hope that commissioners would be agreeable to the measure rather than imposing a different PROM on the organisation. Fourthly, it appeared from the interviews that definitions of validity differed and this impacted on the choice of PROM. Some interviewees strongly believed in using externally validated PROMs because they felt the generated data had greater credibility. However others disputed this, feeling that bespoke PROMs had greater validity within their specific context, even without undergoing rigorous psychometric testing. Often this latter view stemmed from an organisation having an unsuccessful attempt at using a validated measure.

*“Sometimes you think ooh it would be good to have a validated tool in terms of been able to compare yourself to that organisation and things like that and it’s something we definitely have thought about and considered and like I said, we first came from using validated tools but actually they just weren’t fit for what we needed them to be, even though you want to use them because you know they’re validated but it doesn’t mean they’re right and it doesn’t mean they’re going to work for you.” [TSO Manager 7]*

Fifthly, the vast majority of interviewees preferred positively worded measures such as the WEMWBS or Outcome Star which were about what people can do, not what they cannot do. These were viewed as more compatible with the asset-based culture of TSOs. Negatively worded PROMs such as the De Jong Loneliness scale were less liked and subsequently less used in this sample. A couple of service-users felt that measures should consider neutral moods including contentment rather than purely focusing on positive or negative scenarios. Sixthly, a small

number of participants discussed the time frame PROMs cover such as how people have felt over the last two weeks; the general consensus was that the time frame did not influence the choice of measure. Finally it appeared that TSOs in the sample struggled to get the choice of PROM right first time, with many interviewees discussing how their organisation had changed which specific measure was used. This is considered further in the last theme.

#### (7.8.2) How PROMs are collected

The majority of interviewees felt PROMs needed to be administered by a front-line worker or volunteer, who supported a service-user to complete the measure. Participants explained that sometimes service-users could complete measures themselves, but other service-users needed the front-line worker/volunteer to read questions aloud. A couple of interviewees spoke of service-users completing measures outside of appointments, such as receiving measures through the post. However, this process did not appear to work, with one stakeholder explaining they had low-completion rates when they asked service-users to complete measures in the waiting room before attending a wellbeing activity. The interviewee explained that this was because the service-users did not understand what they had to do or could not read and comprehend the questions. A small number of interviewees raised the issue that completing the PROM within an appointment reduced the amount of time spent on wellbeing activities within the session. Consequently, they felt service-users should receive support outside of the wellbeing activity to complete measures. Some TSOs in the sample had done this, but interviewees acknowledged that it required additional resources.

Most interviewees discussed using paper based PROMs. Several of the managers interviewed expressed an interest in developing electronic data collection methods such as digital apps (ePROMs). This was because it avoided staff having to spend time inputting collected paper PROMs into data management systems. However, financial constraints prevented managers from pursuing electronic methods. The service-users in the sample were resistant to completing measures electronically. This reflects the experience of one stakeholder who explained that ePROMs had not worked because their service-users had low levels of digital literacy. Consequently, there appears a tension between the organisational needs of TSOs and preferences

of service-users when designing the PROMs process, with organisations having to balance these perspectives.

*“We have discovered the hard way that digital doesn’t work sadly. We tried to make it work, but [...] there is a strong negative correlation between need for health services and digital literacies in the sense that people who use health services tend to be not digitally literate.”*

[Stakeholder 1]

### (7.8.3) The time points for administering PROMs

The time points PROMs were used at within TSOs appeared to depend on the duration of the wellbeing activity and the reporting requirements of commissioners. Generally, interviewees spoke about collecting measures at the beginning (sometimes referred to as baseline) and end of wellbeing activities and sometimes at middle points in the case of wellbeing activities which lasted more than a few weeks. However, people often found it a challenge knowing when to collect measures because service-users may attend wellbeing activities on an ongoing or sporadic basis. Interviewees felt using measures at every appointment, as happens in some healthcare services, would cause measurement burden. There was a sense of pragmatism about time points, with front-line workers prioritising the needs of their service-users over protocol, so they administered the PROM when it felt appropriate rather than at the specified time points. As discussed earlier, several front-line workers discussed delaying the collection of baseline measures until after they had delivered some support because they wanted to develop rapport with a service-user first.

Interviewees reported challenges in collecting follow-up measures from service-users once they finished attending a wellbeing activity. Some managers, stakeholders and front-line workers discussed how service-users would not complete follow-ups because they had no further obligation to the TSO. One manager explained that often at the follow-up point, the TSO would identify that the service-user had further support needs which took precedence over administering the PROM. This indicates concerns about the feasibility of TSOs collecting follow-up measures.

*“I’m perhaps slightly anxious about what the commissioner might say at this point because I think a year in I would have liked to have seen more follow up questionnaires. I think the issue is that people, it’s hard to get in touch with people sometimes, they just don’t always answer the phone and especially they haven’t heard from you for 12 weeks, they just think ‘oh I don’t need this service anymore’ [...]. What we’ve found is when we do get in touch with people sometimes the services that our social prescribing programme has referred them to haven’t actually been in touch with them. So then, it becomes less about doing that review and more about starting again.” [TSO Manager 8]*

#### **(7.8.4) Processing the collected PROMs data**

Throughout the interviews it was apparent that TSOs in the sample differed in terms of how they processed the collected PROMs data. Process related factors included who inputted the data, the systems used for recording and analysing this data, and whether the results were communicated with front line workers and service-users. These differences were influenced by issues raised in earlier themes, such as the resources invested in PROMs. Interviewees discussed how some TSOs were more proactive than others in planning how to process collected measures. For example, one manager spoke about having piles of completed paper measures in her office but she had not thought about how to process them. This highlights the importance of TSOs planning not just the collection of PROMs but also how the data will be processed. Front-line workers identified that it was time consuming inputting collected PROMs into data management systems and they were torn between prioritising service delivery and processing PROMs.

*“I So you were saying that the main challenges have been in terms of the paperwork it’s just kind of a repetitive and the inputting is time consuming. So would you say like a third of your job is entering the paperwork?”*

*P Oh definitely*

*I Like a day a week?*

*P Yeah” [TSO Front-Line worker 6]*

Some interviewees explained that within their TSOs, there were administrators entering the PROMs data. Many of the front-line workers viewed this as preferable because it freed up time for them to focus on delivering wellbeing activities. However several managers, especially those from smaller organisations, said having administrators process the PROMs was not an option because of financial constraints. Instead, managers spoke about developing techniques to motivate their front-line workers to process data including creating deadlines for inputting data and investing in equipment so that front-line workers could work remotely on data entry when working away from the office.

Interviewees discussed the importance of TSOs having good data management systems which were fit for purpose, reliable, straightforward and produced useful information. These systems saved front-line workers time on processing PROMs and facilitated the use of collected data. However, not all interviewees had experienced systems which were fit for purpose, which created barriers to using PROMs and resulted in people feeling resistant towards PROMs.

*“We’ve set up a management information system and part of that system is to record outcomes and it’s just a new piece of technology, it’s a new way of doing things. It’s really you know looking at it now, and thinking maybe we didn’t get the right one because it’s just so time consuming and staff are just really resistant to it.”* [TSO Manager 4]

It was apparent that not all TSOs invest in data management systems and a small number of interviewees spoke about using spreadsheets to process data. This was a not barrier per se but did indicate the extent to which investment in PROMs was a strategic priority for an organisation and demonstrates how the internal context discussed in Theme 2 has implications for the design of the PROMs process.

#### (7.8.5) Using the collected PROMs data

It was evident from the interviewees that TSOs took different approaches to using the data generated from PROMs. Some organisations pre-planned this whereas others did not have a process for sharing the data with different stakeholders. The service-users felt strongly that from their perspective there was an omission in the feedback loops because they were not informed what their PROM’s scores were or how they changed over time. This could be a consequence of PROMs being mainly used for performance monitoring purposes (as discussed previously). A few service-users accepted this because they viewed outcomes measures as an organisational

tool. However, other service-users were dissatisfied because they felt that data was taken from them without them understanding the meaning of their scores.

*“When they gave me the second form to fill in I felt happier and said ‘oh now I’ll know if I’ve improved or not’. But when I ask for the result [...], ‘no this was for the records and I can’t access them’. I felt like I’d wasted my time thinking that I will know my score.”* [Service-user 5]

In contrast, a number of managers, front-line workers, commissioners and stakeholders spoke highly of the feedback loops some TSOs had. In these organisations, systems were in place which enabled front-line workers and service-users to use the collected PROMs data. Interviewees felt that this was both the right thing to do but also important for facilitating ongoing engagement in PROMs. For example, a number of front-line workers spoke about producing graphs from the PROMs data which they used as a motivational tool with their service-users.

*“Because it all goes into a database, we say you know actually this has been the outcomes that we’ve achieved. So, where we’ve had teams which are maybe, sort of a bit disengaged [...]. It’s actually been a really effective way of saying, look you know this is the outcomes you’ve had on people so it’s been a real motivating factor, it’s been good to show customers sort of the distance travelled. So, look this is where you were then, but this is where you are now. So that’s been a good motivating factor.”* [TSO Manager 6]

Whether a TSO had developed data feedback loops appeared somewhat influenced by their reasons for using PROMs (as discussed previously). For example a manager who had used a measure purely because of pressure from commissioners had not developed any processes for sharing the data within the TSO.

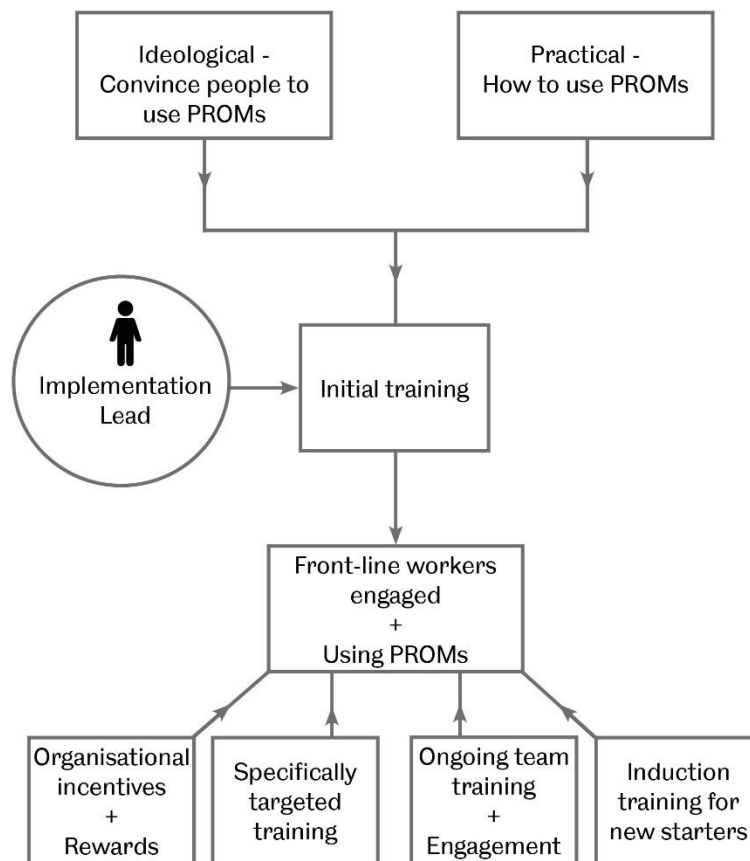
### **(7.9) Engaging and skilling up staff in using PROMs**

As discussed in an earlier theme, front-line workers varied in both their abilities to administer PROMs and their opinions of PROMs. Consequently interviewees identified that TSOs needed to deliver training to both skill-up and engage front-line workers (illustrated in Figure 7).

Participants from all of the interest groups felt that training should be both ideological (convincing front-line workers of the value of using PROMs) and practical (how to use measures). A couple of managers suggested that any training needed to be delivered by Implementation Leads or someone who was an advocate of PROMs, so that the trainer was

convincing to staff about the positive aspects of PROMs. Despite interviewees viewing training as important, several front-line workers reported receiving insufficient training. Three explanations for this paradox were identified from the interviews. Firstly, some managers saw front-line workers as sufficiently skilled because of their previous employment experience. Secondly, if front-line workers were involved in designing the process, managers felt they did not require training as they knew the process. Thirdly, newly recruited front-line workers would not have been working in the TSO when the PROMs training was delivered.

**Figure 7- Engaging and Skilling up staff in PROMs**



Interviewees felt that training should be ongoing and person-centered to maintain the engagement of front-line workers. This included discussing measures in supervision and team meetings alongside incorporating information on PROMs into induction training for new employees.



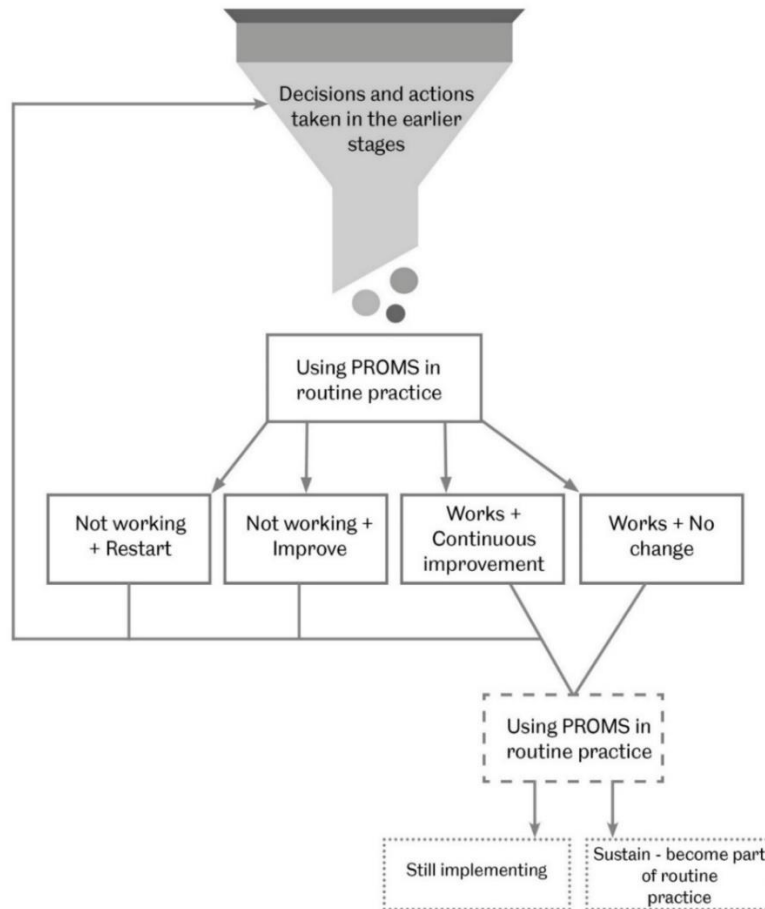
*“Me and my manager did one [team meeting] about the importance of monitoring and where it comes from and what it means and the cycle of it and why we do it, just to refresh thinking.”*  
[TSO Manager 7]

A couple of people gave examples of individual front-line workers receiving additional training when they were struggling with collecting measures and discussed how this had increased compliance. Linked to this, some managers and front-line workers discussed the usefulness of linking the collection of measures to organisational incentives and rewards. Managers primarily did this through giving front-line workers performance objectives relating to PROMs as part of annual appraisal processes. Interviewees felt that this engaged front-line workers because it emphasised that PROMs were part of their job role. This is discussed further in the next theme.

#### **(7.10) Using and sustaining PROMs in routine practice**

Challenges arose when TSOs in the sample started using measures, resulting in organisations reflecting on and redeveloping the PROMs process to enable the sustained use of PROMs (detailed in Figure 8). The issues associated with using and sustaining PROMs are explored within this theme.

**Figure 8- Using and sustaining PROMs in routine practice**



Footnote- Dashed/dotted border- Not all TSOs reach this stage of implementation

#### (7.10.1) Earlier decisions affect later stages of implementation

As alluded to in earlier themes, problems often arose when TSOs started to use PROMs within routine practice, with interviewees reporting low-completion rates, incomplete data and people having negative experiences of using measures. Three factors were identified within the interviews as exacerbating these problems. Firstly, nobody spoke about their organisation having an explicit implementation plan or a definition of what was considered a successful use of PROMs e.g. were the TSOs aspiring to have 80% of service-users complete measures? Consequently it was difficult within the interviews to identify what a TSO was seeking to achieve through implementation and whether they had reached their objectives in regards to PROMs. Secondly, none of the interviewees had experienced their TSO having an initial testing

phase and one front-line worker felt that a trial period would have enabled their organisation to identify and rectify problems with the PROMs process sooner.

*“The most useful thing I think would have been to try it with, like a trial go for customers. So to almost have a dry run because we just went straight in with referrals and almost the first six months of data was just shockingly bad.” [TSO Front-line worker 4]*

Thirdly, it did appear that if a TSO undertook the facilitators identified through this research and sought to address the potential barriers then there were fewer issues when using PROMs within routine practice. For example, one interviewee felt their organisation successfully implemented PROMs because it took a collaborative approach to design, chose measures which had a care management function, invested in data management systems, delivered ongoing training to front-line workers and had a positive team ethos. In contrast, another manager discussed how their TSO had struggled to get measures completed due to a number of the barriers identified in this research. The barriers included the interviewee not being an advocate of PROMs, a measure being imposed by a commissioner and the TSO not investing resources into implementation. However, other interviewees worked in TSOs which had not incorporated all the facilitators but had managed to implement measures. This indicates that organisations did not necessarily need to incorporate all the facilitators and that it could be possible to mitigate potential barriers through focusing on facilitators such as relationships between staff and the internal context. For example, two managers had not taken a collaborative approach to design but had successfully implemented PROMs, attributing success to having skilled and committed front-line workers who engaged in the process.

It was apparent from the interviews that the issues which arose during implementation, and how they were negotiated or addressed, depended on the unique context of each TSO. For example, having flexibility in the design of the PROMs process was viewed as a good strategy to get people to endorse the process. However in practice, one manager felt that having flexibility had become detrimental to the use of PROMs within their organisation. This was because they felt front-line workers used it as an excuse not to complete measures, regularly stating that it was not the right time for their specific service-users.

*“I struggled sometimes to get compliance because staff would say it felt really wrong to ask these questions. It was absolutely not the right place to ask these [...] I absolutely get that. But sometimes, then they get a bit naughty, don’t they? And they like ooohhh that’s not appropriate to ask. Yeah so we did get too much [...] non-compliance.” [TSO Manager 2]*

#### (7.10.2) A process under constant review

The process of implementation was described as iterative, with interviewees discussing how they had to be proactive and make changes to the PROMs process if problems arose. Participants’ experiences of reflecting on, and developing the process could be categorised into four types, each of which required different amounts of changes to be made (detailed in Table 8).

**Table 8-Taxonomy of the reflecting and developing stage**

Type	Example
<b>PROMs process not working, Stop collecting PROMs and Restart the implementation process</b>	PROM chosen by external researchers was not usable within the TSO. The organisation stopped collecting the outcome measure and were collaborating with front-line workers to redesign the whole PROMs process.
<b>PROMs process not working and Changes made to the implementation process</b>	PROM was too lengthy so the TSO were re-designing the PROM, but continuing with all other aspects of the process such as time points and data management systems.
<b>PROMs process working but TSO makes adjustments using the principle of continuous improvement</b>	PROMS were collected and used within the TSO however the Implementation Lead sought to continually improve the process such as tweaking the layout of the PROM.
<b>PROMs process working and No changes made</b>	The PROMs process was working well within a TSO and so they felt no changes were needed.

Whilst the TSOs within the sample had to make different amounts of improvement, a common factor was that organisations took a collaborative approach to making changes at this stage of the process. This was irrespective of whether a collaborative design approach had been taken initially when designing the PROMs process. For example, one front-line worker discussed how they had been involved in re-designing the PROM despite not being consulted about the initial choice of measure.

*“We thought ‘well we’ll give this a go because it’s been given to us’. But we doubt it’s gonna work and fairly quickly by the end of the first quarter we were on our knees with it saying ‘we’ve got to change it’ and what was great was our manager immediately listened. There was no defensiveness there [...]. They said you’re the [Job role], you’re front-line [...], how can we change it?” [TSO Front-line worker 2]*

However, a number of managers, front-line workers, stakeholders and commissioners explained how they were limited in the extent to which they could develop the process and had found making changes did not always produce improvements in implementation. Internal factors could constrain development, for example one manager wanted to utilise ePROMs but did not have sufficient resources to enable this approach. At other times the external context was a barrier, with an interviewee explaining that they could not make changes to the PROM because it was prescribed by a national agency. Irrespective of the reason, TSOs being constrained in the improvements they made could be detrimental for sustaining the PROMs process. A small number of interviewees found that making changes did not improve implementation in their organisation. One reason for this could be that the barriers people had identified were masking underlying issues. For example, one stakeholder discussed how front-line workers often cited a lack of training as a barrier to using PROMs despite not engaging in the available training. Given this, the interviewee felt delivering further training would not increase PROMs usage because there were other barriers to front-line workers engaging. The consequences of not identifying the relevant barriers could result in TSOs having to undergo multiple stages of reflecting and developing, as experienced by some interviewees.

### [\(7.10.3\) The role of culture change and job expectations on sustainability PROMs in routine practice](#)

Many of the managers aimed for PROMs to become routine practice (sustainability) within their TSO, but not all organisations achieved this. Some interviewees were unsure why their TSO struggled.

*“From my experience it doesn’t feel routine and I think there could be more done to embed it. But it’s a tricky one, so I don’t know how it would best work.” [TSO Front-line worker 3]*

There appeared to be differences in the key factors which facilitated sustainability compared to other parts of the implementation process. Firstly, there seemed to be a shift from the ‘no choice’ narrative to interviewees utilising PROMs because staff found them useful. Secondly, in TSOs where PROMs were part of routine practice, there appeared to have been a change in expectations so that outcome measures were considered a fundamental part of front-line workers’ roles. For example, one manager spoke about ensuring she asked potential new employees at interview about their experiences of using outcome measures because they were a key responsibility of the front-line worker role.

Interviewees expressed contradictory views on whether an Implementation Lead was still needed when PROMs became routine practice. Reasons for these differences included if other staff were also responsible for the use of PROMs, whether there was sufficient infrastructure in place supporting the use of measures and the organisational culture. One manager felt the Implementation Lead role was still needed whereas another felt outcome measures had become ingrained within their TSO, so the Lead was no longer essential.

*“It’s in the bones, we could all leave and it would still be in the bones. I think it’s sort of, we’ve been on at it long enough now that it’s just, yeah part of our DNA and people know this is just what we do.” [TSO Manager 6]*

Inevitably, it appeared to take time for PROMs to become part of routine practice. Interviewees found this problematic because funding for specific wellbeing activities was usually time limited. For example, a manager spoke about being funded for a year to deliver a specific wellbeing activity which needed measures to be collected throughout the delivery period but they struggled with data collection during the first few months. Several managers in the sample addressed this time pressure by creating organisational wide PROMs systems so that any new wellbeing activities could be embedded into the process rather than implementing measures afresh each time.

## (7.11) Discussion section

This section includes a summary of the findings from the QI phase and the conduct of the research is appraised.

### (7.11.1) Summary of the findings arising from the QI phase

Vulnerabilities arising from TSOs receiving insecure funding created an external context where some commissioners and organisations felt they had no choice but to use PROMs because they were viewed as a credible measure of impact to justify and secure funding. Internally, each TSO was unique in their approach to PROMs because the organisation's structure, culture and resources invested in PROMs varied. Consequently, some TSOs had an internal context more amenable to implementation. When the context was less facilitating, organisations relied on other facilitators to overcome internal contextual barriers. A proactive Implementation Lead appeared critical for all TSOs. The Lead drove forward implementation and engaged senior management and front-line workers such as through delivering training. Whilst it was important for TSOs to design a PROMs process appropriate for each specific wellbeing activity, in reality organisations were constrained in their design choices because of internal and external contextual factors especially because of commissioners requiring a specific PROM to be used. This resulted in TSOs trying to successfully implement a PROMs process which was not ideal. Consequently, organisations experienced problems when using measures in routine practice, struggling to sustain the use of PROMs unless the issues were adequately addressed.

### (7.11.2) Reflexivity- How I impacted on the interviews and analysis

Throughout the interviews and analysis it was apparent my personal viewpoints and experience impacted on the research process and data collected (Mays and Pope, 2006). Thus, it was important to undertake reflexivity to consider how I shaped the research process. A description of reflexivity and its importance within qualitative research is described in Chapter 6. In Chapter 1, I reflected how my demographics and opinions on PROMs may have influenced the study. In this section, I consider issues which were specifically relevant to the QI phase. Further reflexivity was undertaken in respect of the CBPR phase (detailed in Chapter 9).

**Being an early career researcher-** Whilst I had some experience of qualitative interviewing, I am an early career researcher and felt this lack of experience showed in some of the interviews. This was particularly in relation to questioning decision making as I was conscious of not wanting to appear critical. For example, one manager had not undertaken any collaboration when designing the PROMs process and I did not feel able to ask why. A more experienced researcher may have felt more confident to question the approaches people took.

**Challenge of interviews with service-users-** It was important to get the perspective of service-users in respect of PROMs but these were the most challenging interviews. As discussed in the methods chapter, I found it difficult to recruit service-users and succeeded through visiting wellbeing activities. The consequence of this was service-users were drawn from a smaller number of TSOs than other interviewees, albeit the majority of service-users had experience of accessing several organisations. Furthermore, the interviews were quite limited as I could only discuss with service-users their experience of completing PROMs and preferences for design rather than the whole implementation process e.g. staff training. In hindsight, it may have been more fruitful to have undertaken a focus group with service-users so they could interact with each other to generate further discussion. I also think that after the first service-user interview, I should have spent more time reflecting on the interview with my service-user representatives and supervisors to consider improving the subsequent interviews.

**Ensuring my findings were supported by the data-** When undertaking the analysis I was aware I could easily go off on a tangent about certain findings, such as putting too much emphasis on one interviewees' actions. There were two specific points where this felt a risk. Firstly, after conducting a small number of interviews I undertook some preliminary analysis. I was conscious that I needed to test these initial findings against the emerging data from the subsequent interviews to check whether they were regularly occurring themes or just happened to be prominent in the earlier interviews. The other risk point was when I was grouping the initial codes into higher level themes. At times, I felt I was drowning in data and was conscious of not latching onto an idea as a way of making headway through the analysis. To reduce this risk, I regularly checked out my analysis with the original interview data. Having monthly supervision helped with ensuring my findings were supported by the data because at the sessions I would propose my findings and my supervisors would ask me to justify these. Additionally, I kept a



reflective diary throughout the process and this was helpful as a way of checking out my initial insights against the analysis. Through going back and forth between the raw data and my analysis, I feel confident that the findings I developed are grounded in the data.

**Consulting with the advisory committee-** The study advisory committee was invaluable to me whilst I was progressing the analysis. At a number of meetings I presented emerging findings and the committee would critique and question them. This gave me additional perspectives on the findings and prompted me to go back to the data to develop my ideas. For example, I initially developed the idea that TSOs had different amounts of resources available to them for implementing PROMs. However, the advisory committee challenged this, explaining whether an organisation chose to prioritise investing in PROMs was also relevant. The committee's perspective prompted me to review the interview data and explore the issue of prioritisation and organisational commitment to implementing PROMs.

### (7.12) Appraising the quality of the qualitative interviews

An established set of trustworthiness criteria (Lincoln and Guba, 1985) was used to appraise the conduct of the interviews. An explanation of the criteria and the reasons for using them was detailed in Chapter 6. Within this section I consider the most salient issues, including describing some of the actions I took to increase trustworthiness.

To increase credibility, I undertook triangulation by interviewing people from a range of interest groups including managers and service-users. I utilised negative case analysis, exploring why some interviewees had a different experience or perspective to other participants and I checked out the findings with my advisory committee. I sought to increase dependability by having an audit trail, including keeping records of the decisions I made during analysis and through undertaking some stepwise-replication in terms of my supervisors each co-coding a transcript to check for consistency. Confirmability was improved by me undertaking reflexivity, discussing my work in monthly supervision meetings and through data source triangulation. This included interviewing people from different TSOs and diverse interest groups. I sought to support readers to assess transferability by being transparent about the diversity of my sample, considering data saturation and exploring how the findings compare to existing literature (the latter is presented in Chapter 10). Finally, I sought to ensure the study had fairness and educative authenticity by

seeking the viewpoints of different interest groups and I presented the findings in a way that enabled people to learn from others' perspectives; such as informing commissioners about the challenges TSOs experience.

However, there were elements of the study that were detrimental to its trustworthiness. I did not undertake respondent validation in terms of getting interviewees to read through transcripts and comment on their accuracy (member checking), which is considered by Lincoln and Guba (1985) as an important component of credibility. I chose not to undertake respondent validation because increasingly researchers question its value, saying it does not generate a 'truth' but rather provides an interviewee's interpretation of their transcript (Morse, 2015). Undertaking a greater amount of stepwise-replication would have been beneficial, such as having a greater number of transcripts coded by two researchers. However, this was not feasible because I was the sole researcher on the study. Finally, I did not undertake thick description, which is considered important for transferability (Geertz, 1973). Thick description entails providing detailed description about participants and their context to enable readers to assess how transferable the findings are to their specific scenario. However, I decided to describe the sample in general terms rather than include thick description. This was to protect the participants' identities because I was concerned that the close knit nature of the third sector would mean the anonymity of participants would be compromised by including thick description.

## (7.13) Strengths and limitations of the qualitative interviews

### (7.13.1) Strengths of the qualitative interviews

This study had four key strengths. Firstly, the study appears to be one of, if not the first and most comprehensive, piece of research on implementing PROMs within TSOs. This is important because previous research on implementing PROMs has not considered the third sector, so specific challenges have not been identified. Secondly, interviewees varied considerably in their role, the organisations they were associated with, previous experiences, geographical location and opinions of PROMs. Thirdly, the in-depth nature of the interviews meant concepts identified in previous studies were explored in greater depth. Thus provided new insights, such as how

organisations have managed to make PROMs part of routine practice. Finally, some triangulation was undertaken through comparing findings between interviewees and by utilising the CFIR.

#### (7.13.2) Limitations of the qualitative interviews

Whilst the research had many strengths, it had six main limitations. Firstly, interviewees were recruited from a range of TSOs which enabled an understanding of the approaches taken by different organisations. However, it meant that the findings could not be corroborated such as whether people within the same TSO had similar views on the training delivered. Thus, interviewing a number of individuals from the same organisation may have been useful. However, the next stage of the research takes this approach by focusing on two organisations. Secondly, the majority of interviewees worked or attended TSOs which were city-wide and neighbourhood based TSOs. Interviewing more people who worked for national TSOs could have been beneficial because there appeared distinct challenges for different sized organisations. However, TSOs delivering wellbeing activities are generally based on a more local level, so it is justifiable the sample mainly consisted of people involved with TSOs serving the local geographical area. Thirdly, interviewees were mainly from TSOs based in the North of England because I used snowballing and my contacts to identify potential interviewees. Having greater geographical variation would have been preferable to understand how differences in external context may influence implementation.

Fourthly, two aspects of implementation needed further exploration in the interviews: Planning and Defining success. In hindsight, exploring with interviewees whether their organisation had an implementation strategy or whether the process was more organic would have given greater context. Additionally, further exploration of what interviewees considered successful implementation and how they assessed success would have enhanced understanding of whether TSOs had achieved their aspirations in respect of using PROMs. Fifthly, the research relied on people retrospectively discussing implementation so it was difficult to capture processes e.g. how decisions were made if different stakeholders had opposing views. The next stage of the study will address this limitation through working with TSOs as they implement PROMs. Finally, the research relied on people reporting the barriers they felt existed. But interviewees may have

thought certain factors were detrimental to implementation as a form of sense-making (Checkland et al., 2007).

#### (7.14) Summary of the chapter

Thirty people from different interest groups were interviewed about their experiences of implementing PROMs. The findings indicated that a variety of contextual and process related issues appeared to influence implementation. The identified facilitators and barriers were shared with the two TSOs involved in the CBPR phase to help them implement PROMs. In the next chapter, I describe the CBPR phase in detail before presenting the findings in Chapter 9.

## Chapter 8- Methods for the Community-Based Participatory Research (CBPR) Phase

### (8.1) Outline of the chapter

Community-Based Participatory Research (CBPR) was undertaken in conjunction with two TSOs to support them with implementing PROMs and learn from their experiences (Israel et al., 2005). Knowledge gained from the QI phase was shared with the organisations to help them with implementation. The CBPR phase took place between June 2018 and January 2020. This chapter describes in detail the conduct of the CBPR phase and includes the following sections:

- Aims and Objectives
- The principles of and justification for using CBPR
- Explaining which TSOs were involved and in what way
- Using an Action Research Spiral approach
- The methods used to learn about the TSOs' experiences of implementation
- Appraising the conduct of the study.

### (8.2) Aims and objectives of the CBPR phase

The aim of the CBPR phase was to support TSOs with implementing PROMs and learn from their experiences. The objectives were to:

- (1) Use partnership working between TSOs and myself to support the organisations to implement PROMs within their wellbeing activities and learn from their experiences to improve their processes.
- (2) Explore people's experiences of implementing PROMs through using CBPR.
- (3) Analyse anonymised data generated from the PROMs to explore the quality of data being collected within the participating organisations.

### (8.3) The principles of, and justification for, undertaking CBPR

CBPR is a type of participatory action research (Wallerstein and Duran, 2006) encompassing the principles of partnership working between academics and community partners, capacity building, producing findings and knowledge that benefit all partners and finally, contributing in the long term to reducing inequalities (Israel et al., 2003). In relation to partnership working, CBPR involves academic researchers delivering the research in conjunction with community partners, enabling the community to influence decisions made within the project (Spears Johnson et al., 2016). The second element of CBPR involves capacity building, meaning the research supports organisations and individuals to develop their skills. In regards to the PhD, this meant I supported the participating TSOs to develop their skills in utilising PROMs. The final feature of CBPR is producing knowledge that will benefit TSOs and reduce inequalities. The latter is less likely within this research as the focus is on operational issues. However, in the widest sense it could be argued that by supporting TSOs to implement PROMs, it may help them obtain funding which can be used to continue the organisation's work on reducing inequalities in their neighbourhoods.

CBPR is an approach where the design is based on adhering to the participatory principles rather than a specific methodology (Spears Johnson et al., 2016). Therefore the design of CBPR projects differ considerably because they are developed to meet the needs of the community and the research topic. They can vary from community researchers trained to undertake qualitative interviews (Damon et al., 2017) to more creative techniques e.g. diagramming and storytelling (Coemans et al., 2015). Riffin et al. (2017) explored the diversity of methods undertaken under the umbrella of CBPR within the field of palliative care and found considerable diversity.

The nature of CBPR means some elements are findings in themselves such as which front-line workers were involved or the nature of trialing using PROMs in the participating organisations. Given this, some of the detail relating to methods is included within the CBPR findings chapter (next chapter).

Within health research, a number of participatory approaches have emerged including action research (Lewin, 1946), participatory research (Fals-Borda, 2001), Participatory Action Research (Kindon et al., 2007) and CBPR (Wallerstein, 2006). Whilst the approaches arose from different cultures and political systems, they encompass similar principles (International Collaboration for

Health Research, 2013). I decided to use a CBPR approach because the principles of CBPR felt compatible with the intentions of the PhD. This was because the CBPR approach recognizes the knowledge of the TSOs themselves and seeks to combine the accumulation of knowledge with action for change (Minkler, 2003). It was also the case that there were already CBPR projects undertaken in the locality by JH (my supervisor), so local TSOs understood and were engaged with this approach.

Rather than taking a CBPR approach, I could have decided on a measure and reporting system and then evaluated whether TSOs implemented the pre-designed PROMs process. For example, Roberts et al. (2019) are running a cluster randomised controlled trial testing the implementation of a pre-designed PROMs process within oncology services. However, evaluating a pre-designed PROMs process would have been inappropriate for the third sector for a number of reasons. Firstly, stakeholders I consulted during the preparatory work for my PhD were critical of attempts to impose a PROMs process on a TSO. Furthermore, local TSOs would have been reluctant to implement an externally developed PROM process because they had agreed with their local authority commissioners that they would be allowed to make their own decisions in respect of using outcome measures. Whilst I could have addressed this issue by recruiting TSOs from other localities, for logistical and relationship reasons I ideally wanted to recruit local organisations. Secondly, a finding of the QI phase was the need for TSOs to develop their own PROMs process. Thus it would have been inappropriate to implement an externally designed process. This is supported by Gonzalez and Trickett (2014), who emphasised the importance of taking a collaborative measurement approach because communities may find locally developed approaches more acceptable. Given the discussed reasons, there was a clear justification to undertake a CBPR approach where I supported TSOs to develop their own PROMs process rather than trying to impose a measure and evaluate whether it was successfully implemented.

## (8.4) The TSOs involved in the CBPR phase

### (8.4.1) Involving two local organisations within the CBPR phase

The nature of communities involved within CBPR varies considerably depending on the specific project (Pain et al., 2012). Examples include improving the environment within a specific neighbourhood to working with a number of people undergoing palliative care. Given this, it is difficult to provide any figures on the number of people involved in a CBPR project or the size of the community covered. For the PhD, I chose to involve two different TSOs which served different neighbourhoods (Organisation A and B). I felt there would be value in comparing the approaches they took to PROMs.

Organisations A and B were involved in the CBPR phase in different ways. Organisation A was involved from the beginning of the CBPR phase, attempting to implement PROMs again after previous difficult experiences. Organisation B officially became involved during the last six months of the CBPR phase. Organisation B had been implementing PROMs for a number of years and I had been supporting them with the process. For example, I delivered training on using the outcome measure to their front-line workers. I had initially not involved Organisation B within the CBPR phase because I wanted TSOs to be at the start of their implementation process when the CBPR phase commenced. However, when it became apparent that Organisation A would not reach the point of actively collecting PROMs by the end of the study, I felt it would be beneficial to also involve Organisation B within the CBPR phase. I felt there was value in retrospectively considering Organisation B's experiences of implementing PROMs and comparing the two organisational contexts. Further details on how the two organisations were involved are provided in the next section.

The two organisations were recruited into my study because they were participating in a CBPR project run by JH, so they already had a relationship with the university (Harris, 2015). JH's project entailed JH working with a number of TSOs in the locality to help them undertake evaluation and mobilise evidence. I was involved in the project. An outcome of JH's project was a change in attitude towards PROMs by some of the participating TSOs. Some organisations had shifted from resistance to actively trying to implement outcome measures. Through JH's project, Organisation A had expressed an interest in using PROMs but wanted support with



implementation. Given this, JH recommended they became involved in my CBPR study. In June 2018, I met with the manager in Organisation A who would be acting as the Implementation Lead. We discussed the research and they agreed Organisation A would become involved.

In respect to Organisation B, JH and I had been supporting them with implementing PROMs and their Implementation Lead sat on my study's advisory committee. During this time, I had been sharing with Organisation B the arising findings from my PhD to inform their implementation process. Given the established relationship with Organisation B, I felt it would be beneficial to involve them in the latter part of the CBPR phase. In the following section I describe the involvement of the two TSOs in greater detail and then in the next chapter, I describe the organisations' characteristics.

#### (8.4.2) The involvement of Organisation A

Organisation A was involved from the beginning of the phase (June 2018). I had not previously worked with the TSO so did not have an established relationship with them. Organisation A had previously tried to implement validated PROMs but had struggled to use them because they did not consider them appropriate. Therefore the organisation wanted support with designing a bespoke PROM. The designing of the implementation process took place over a 9-month period between July 2018 and April 2019. The TSO then trialed (piloted) their PROM in May 2019 and sought to use the measure within wellbeing activities during the remainder of 2019.

#### (8.4.3) The involvement of Organisation B

The support provided to Organisation B and how this fits into the CBPR phase is more complex than Organisation A. This is because Organisation B did not join the phase till June 2019, after I had been supporting them for a number of years with implementing PROMs. In Autumn 2016, Organisation B approached JH and myself to provide support with implementing PROMs. At that point, I had developed the idea for the PhD and secured an NIHR fellowship but not commenced the study. Initially the Implementation Lead wanted support with designing a bespoke measure because the organisation had struggled to implement validated PROMs. Consequently between January and September 2017, I supervised a Masters in Public Health

dissertation student to work with Organisation B to design them an outcome measure. With my support, the student interviewed a number of front-line workers, managers and commissioners about potential items to include in the PROM. The student then held a consensus-building workshop with front-line workers, commissioners, managers and myself to decide the content of the measure. Following this workshop, a small number of front-line workers trialed the bespoke measure during June 2017 to understand its acceptability. Through interviewing the front-line workers, the student identified that they found the PROM acceptable.

Following the trial period, Organisation B started to use the PROM. To support this period, I supervised another Masters student in 2018 to undertake further research on the measure's acceptability. Specifically this second student explored front-line workers' training needs in regards to PROMs and considered how the measure might be implemented throughout the TSO. The findings were used by the Implementation Lead and myself to progress implementation e.g. we used the findings as a basis for developing training for front-line workers. During 2019, Organisation B continued to encourage front-line workers to use PROMs.

In June 2019, I invited Organisation B to join the CBPR phase because I wanted to undertake a comparison with Organisation A. The TSO accepted the invitation in order to reflect on, and improve their implementation of PROMs. Whilst Organisation B was only involved formally within the CBPR phase for six months, I explored their experiences of the whole implementation process through the key informant interviews and group participatory events (described further in Section 8.8).

### (8.5) How the TSOs were involved in the research

Whilst collaboration is a key principle of CBPR, it is widely documented that the nature of participation varies between studies depending on the capabilities of community partners (in this case Organisations A and B), funding arrangements and the wishes of the people involved (Cahill, 2007). According to Wilcox's (1994) Ladder of Participation, the greatest level of involvement is when community partners organise their own studies of interest and researchers support the work through identifying resources and providing technical support. In these cases, TSOs own the study. This was not feasible within the confines of my PhD because I designed the

study and was responsible for the delivery of the research and use of assets, so ultimately had ownership. Instead, I sought to use an Acting and Deciding Together type of involvement (Wilcox, 1994). Whilst ‘Acting’ and ‘Deciding’ together are usually classed as two different types of participation, both approaches were used within the CBPR phase.

Acting Together involved the TSOs and myself working together to undertake the implementation of PROMs. Whilst I provided technical advice, stakeholders within the organisations made decisions regarding the implementation process and undertook the associated actions. For example in Organisation A, I provided information on potential measures but staff members decided which PROM to use and incorporated it within the TSO’s data management system. Alongside undertaking the implementation, a key part of the CBPR phase was learning about people’s experiences of implementation. For this part, a Deciding Together approach was taken. The TSOs and I decided how the research would be conducted in each organisation such as when the group participatory events would be held and who would be invited. However, the TSOs and I agreed that I would lead on the learning activities because I had the academic experience and capacity. I reflect further on these issues in the findings chapter.

The collaboration between myself and the TSO meant that together we were co-constructing the implementation process and arising learning, rather than me acting as an objective observer (Alvesson and Skolberg, 2000). In this sense, I and members of the TSOs were wearing dual hats as we were acting as both researchers and participants. This is viewed as one of the strengths of CBPR (Tronsden and Sandaunet, 2009). It was important throughout the CBPR phase that I reflected on the roles people played during the research and their implications. One way I did this was through keeping a reflective diary which I then analysed as a data source (detailed further in Section 8.8.3).

## (8.6) The individuals involved in the CBPR phase

A key part of the participatory approach was having ongoing contact with front-line workers, managers and other relevant staff such as the people responsible for the data management systems (Springett et al., 2011). The contact included meeting with individuals, having email discussions and attending events at the TSOs such as team meetings. The contact was a way to help the TSOs make decisions about the implementation process, along with progressing implementation. For example in Organisation A, I emailed front-line workers and managers the formatted PROM to get their opinions on its design.

The Implementation Lead in both TSOs was my main source of contact during the study. Earlier phases of the PhD identified the importance of having an Implementation Lead, who is a named individual within an organisation responsible for implementing PROMs (Foster et al., 2018). In both organisations there was a manager who had responsibility for PROMs. Within the PhD, I have labelled them as Implementation Leads because their actions in relation to PROMs matched both the description of the CFIR construct and the role described in the QI phase. Within the CBPR phase, the two Implementation Leads:

- Made many of the decisions in respect of the PROMs process and its implementation
- Acted as gatekeepers in terms of my access to people within their organisations
- Decided with me the specific nature of the CBPR phase within their TSO
- Were the study leads for the research within their respective organisation such as encouraging front-line workers to attend the participatory events.

I was in regular contact with each Implementation Lead including telephone calls, emails and face-to-face meetings. The contact provided opportunities to reflect on implementation and identify what actions need taking.

When designing the PhD, I had anticipated working with groups of stakeholders within each TSO (Pain et al., 2012). However most of my contact was with the individual Implementation Leads. This was acceptable within the context of implementing PROMs because a finding of the QI phase was that the process appeared to be managed by one person within a TSO.

The Implementation Leads primarily decided which front-line workers would be involved in implementing PROMs. For example, some but not all the front-line workers were involved in

designing the outcome measure. However ultimately individual front-line workers chose themselves how much they were involved in the CBPR phase e.g. whether they volunteer to trial out the PROM.

### (8.7) Using an Action Research Spiral approach

An Action Research Spiral approach was used to help structure the CBPR phase in terms of supporting TSOs with implementing PROMs and learning about their experiences (Kemmis and McTaggart, 2000). The Action Research Spiral provides a framework to follow when working with stakeholders to change practice within an organisation, in this case implementing PROMs. The reason for choosing the Action Research Spiral was because the spiral nature of the process aligns with the implementation stages identified within the systematic review of reviews. Furthermore, it is an established approach used within action research. An Action Research Spiral approach entails a number of stages including planning, acting, observing, revising; followed by repeating these stages to improve implementation.

In the CBPR phase, the stages of the Action Research Spiral approach were defined as:

- **Plan**- Designing the PROMs process and how they planned implementation.
- **Act & Observe**- Documenting how TSOs try to use PROMs
- **Reflect**- Reflecting on the implementation process
- **Revise Plan**- Making improvements to the PROMs process
- **Repeating the above**- The spiral element relates to TSOs repeating stages multiple times in an attempt to improve the use of PROMs within the organisation (Kemmis and McTaggart 2000).

Whilst there can be as many iterations of the spiral as desired, the intention was for the organisations to trial the PROMs, reflect on this experience and then try and use PROMs throughout the TSO. During this period, we reflected on implementation and revised the PROMs process. TSOs then continued to progress implementation after the PhD finished. Organisation B undertook the designing and trial phases before becoming part of the CBPR phase but the process they undertook reflects the Action Research Spiral process. I provide a summary of the process for each of the organisations in Table 9. When designing the CBPR phase, I had intended

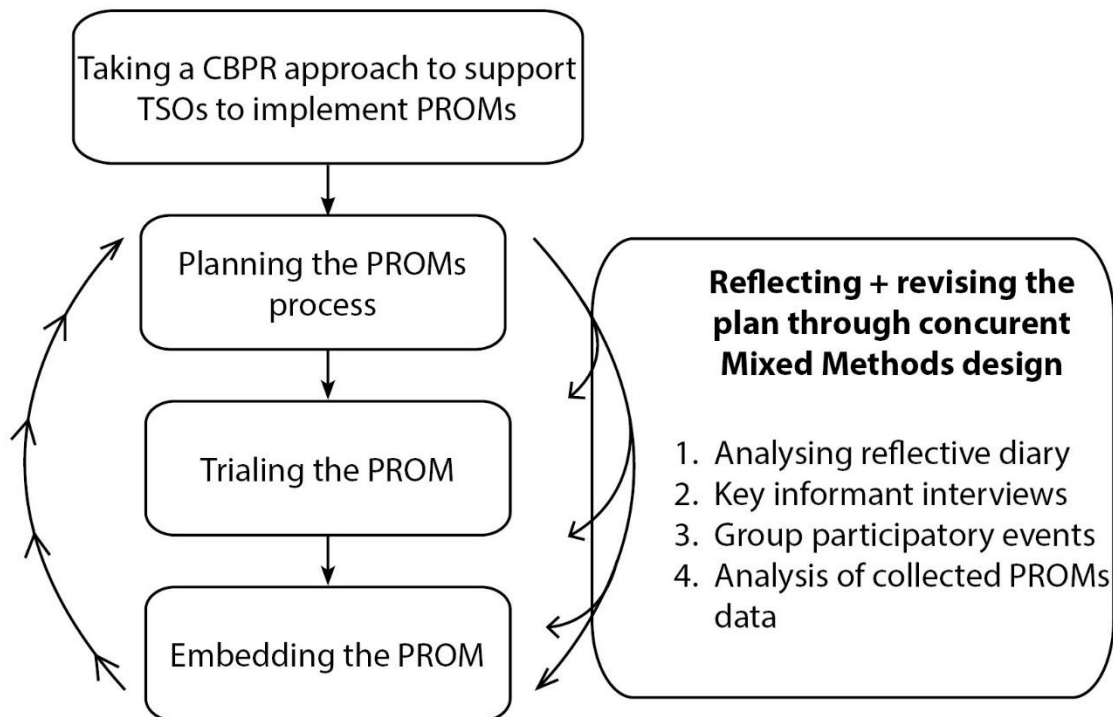
for there to be distinct stages, as per the Action Research Spiral. However, in reality the process merged, especially in relation to the TSOs making changes to their PROMs process as they were utilising the measures.

**Table 9- How the stages of the Action Research Spiral relates to the CBPR phase- Kennis and Mctaggeert- 2000**

<b>Stage of the Action Research Spiral</b>	<b>Specific element within the implementation process</b>	<b>Organisation A</b>	<b>Organisation B</b>
<b>Plan</b>	<b>Planning the implementation process</b>	I supported the TSO to plan their PROMs process during the CBPR phase.	I was part of a team supporting the TSO to design their PROMs process prior to the CBPR phase.
<b>Act &amp; Observe</b>	<b>Trialing the PROMs process</b>	The TSO trialed their bespoke outcome measure during the CBPR phase.	The TSO trialed their PROMs process before becoming part of the CBPR phase.
	<b>Using the PROM in routine practice</b>	The TSO started using the PROM within the whole organisation during the CBPR phase.	The TSO started using the PROM in routine practice before becoming part of the CBPR phase but were still undertaking this stage when they joined the CBPR phase.
<b>Reflect and Revise Plan</b>	<b>Reflecting and revising the PROMs process</b>	The TSO reflected and revised their PROMs process during the CBPR phase.	The TSO reflected and revised their PROMs process both before becoming part of the CBPR phase as well as during the CBPR phase.

How the CBPR was conducted is illustrated in Figure 9. Included in the figure are the research activities I undertook to help the TSOs learn from their experiences (this relates to the Reflect and Revise Plan element of the spiral).

**Figure 9- Taking an Action Research Spiral approach**



#### (8.7.1) Planning the implementation process (Stage 1 of Action Research Spiral)

When undertaking implementation, the TSOs had to make a number of decisions in respect to the PROMs process including:

- Designing a bespoke outcome measure
- Deciding what wellbeing activities and at which time points the measures would be used
- How the PROMs data would be collected, processed, analysed and used
- What collaboration, engagement and training would be undertaken with front-line workers and service-users
- The resources which could be invested into implementation.

I shared the learning from the literature reviews and QI phase with the Implementation Leads through having regular meetings, discussing issues over the telephone and having email exchanges. Rather than designing a PROMs process and testing it, in both organisation decisions were made about the PROMs process once they started using the measure within the wellbeing activities. Therefore there was an ongoing exchange of information between myself and the Implementation Leads throughout the phase. In the next chapter, I describe in detail the decisions made by the TSOs about the PROMs process and how I influenced implementation.

#### [\(8.7.2\) Acting- getting PROMs used \(Stage 2 of the Action Research Spiral\)](#)

The first action taken was the small scale implementation of a PROM by trialing the chosen outcome measures with a small number of front-line workers. I proposed that they did this based on my systematic review of reviews (Foster et al., 2018). The trial period differed between the two TSOs partly because of when it occurred in relation to the CBPR phase.

In Organisation A, one front-line worker used the PROM with a number of service-users to assess its acceptability during May 2019. The nature of this testing process was designed by the TSOs through me advising them that a trial period would be useful. Two front-line workers volunteered to trial the PROM but only one front-line worker actually did. This was because the second front-line worker did not feel confident enough to use the measure with service-users.

Organisation B undertook a more extensive trial process during June 2017. The TSO designed the testing period because it took place before the CBPR phase commenced. However, their decision to undertake the trial period was informed by me suggesting that they may want to test out the bespoke PROM. I made this suggestion because organisations undertaking a trial period to try out their chosen PROM was identified as a facilitator to implementation within the systematic review of reviews. Initially in June 2017, three front-line workers tested the measure with their service-users for a month. The trial period was overseen by a Masters student, who I supervised.



After trialing the PROMs, both TSOs sought to use the measures within routine practice. Following the trial phase, the intention was for the TSOs to use PROMs on an organisation-wide scale. As using the outcome measures was part of service development rather than a research activity, front-line workers did not need to seek explicit consent from their service-users to administer the measures. However, I found that rather than PROMs being used on an organisational-wide basis, the TSOs initially used the PROMs on an ad-hoc basis whilst front-line workers became more experienced in using them. I have categorised this as an ‘embedding stage’ and reflect on its role in the next chapter.

### (8.8) Reflecting (Stage 3 of the Action Research Spiral)

A key aspect of the Action Research Spiral approach is reflecting and learning from experiences (Kemmis and McTaggart 2000), which in this context relates to understanding the facilitators and barriers which arise in respect of using PROMs and identifying potential solutions. A number of methods were used to identify the learning including:

- Running group participatory events
- Key informant interviews
- Keeping and analysing a reflective diary
- Undertaking exploratory analysis of collected PROMs data.

The first three methods are described below. This is followed by an explanation of how thematic analysis was used to analyse the key informant interviews and reflective diary. I then describe the exploratory analysis undertaken of collected PROMs data. Finally, I discuss how I used a ‘following a thread’ technique to integrate the findings from the different data sources.

### (8.8.1) Group participatory events

I arranged group participatory events (subsequently called participatory events) in both organisations to provide an opportunity for people within the TSOs to inform and reflect on the implementation process. For example, front-line workers discussed the barriers they were facing with using PROMs and together identified potential solutions. Front-line workers, Implementation Leads, other members of staff and myself attended these events. The Implementation Leads decided who would attend, although attendance was partly dependent on a person's prior commitments. It was not necessary to collect formal written consent because of the participatory nature of the sessions. However, I did provide an explanation about the session and how it linked to the CBPR phase both when organising the events and at the start of each session (Pain et al., 2012). Each event lasted between an hour and an hour and a half. I facilitated the sessions but was led by what the attendees wanted to discuss.

Three events were held in Organisation A. The first two were held in November 2018 and January 2019 with the purpose of supporting front-line workers and managers to decide on the design of the PROMs process. I encouraged them to consider their previous experiences of using outcome measures and I shared the findings of the systematic review of reviews. Attendees included front-line workers, the Implementation Lead and other managerial staff. I had planned to hold just one event, but the TSO felt they needed a second event to discuss further the PROM they would use. Twelve people attended the first event and ten people participated in the second. A further event was held in December 2019 to reflect on the implementation to date and identify what improvements needed to be made to the PROMs process. The event was attended by the Implementation Lead and six front-line workers.

During the period when Organisation B was a formal partner in the study, I held a participatory event with seven front-line workers and the data manager. The event took place in October 2019 and was an opportunity for front-line workers to reflect on the PROMs process, discuss any issues they were experiencing and identify potential solutions.

I used visual methods including brainstorming during the events to capture the discussion rather than using audio recording. I felt that visual methods were advantageous as they provided a source of engagement for attendees (Lee et al., 2018). Furthermore, I was concerned that audio recording would have been detrimental to group dynamics because attendees may have perceived

this as me extracting information from them rather than us working together to identify solutions. I made detailed notes about each event within my reflective diary.

### (8.8.2) Key informant interviews

I undertook key informant interviews to gain the insights of people pivotal to implementation in each organisation. They are often used within a CBPR approach to understand an issue further and provide an opportunity to explore issues that the individual may not feel comfortable discussing within group settings (McKenna et al., 2011). Key informant interviews take the form of semi-structured qualitative interviews but differ in terms of individuals being purposefully recruited because of the unique insights they can provide (Cott et al., 2016). An example being that I interviewed a senior manager in Organisation B because they could explain how PROMs fitted into the overall strategic vision of the TSO.

Only a small number of key informant interviews were conducted because they were being used to supplement the other data sources. Within Organisation B, the Implementation Lead suggested people to interview. I identified who may be appropriate within Organisation A. The difference was because Implementation Lead B felt there were specific people who had not been involved in the participatory activities who may provide some useful insights on implementation. Potential interviewees were provided with a copy of the consent forms and Participant Information Sheet (Appendices 15 and 16). If someone was willing to participate, a face-to-face interview was organised. At the start of the interview, participants were asked to provide written consent. I audio-recorded the interviews using an encrypted digital recorder (Tessier, 2012). A unique topic guide was developed for each interview because of the specific role each participant had within their TSO (an example of one is provided in Appendix 17).

After each interview, the recording was transferred onto the University of Sheffield's secure computer data drive, using the same process undertaken in the QI phase (described in Chapter 6). A SchARR administrator transcribed the audio file. I checked the transcript for accuracy, anonymised the content and uploaded it to NVivo Version 12 ready for analysis. The transcript was then analysed using thematic analysis.

### (8.8.3) Using my reflective diary as a source of data

I kept a reflective diary (field diary) throughout the CBPR phase and decided to analyse the diary because it was a rich source of data (Friedmann et al., 2013). I used the diary to record and reflect on the study including how decisions were made within the TSO in respect to implementation, the actions taken, dynamics between stakeholders and my viewpoints. I utilised the diary for the whole period of working with Organisation A, from June 2018 to January 2020. However, I only started to document my interactions with Organisation B once they became part of the CBPR phase (June 2019). I felt using my diary was compatible with researchers using their field notes as a data source within ethnography (Phillipi and Lauderdale, 2017). A problem with using my diary was that it contained only my perspective of the CBPR phase. I addressed this issue through comparing the findings emerging from my reflective diary with the other data sources e.g. the key informant interviews.

I analysed my reflective diary in October 2019 using thematic analysis (Braun and Clarke, 2006). I needed to undertake the analysis before the CBPR phase formally finished so that I could identify the emerging findings. Before undertaking thematic analysis, I anonymised the diary by removing the names of staff and other identifiable issues. I then imported the content into NVivo Version 12.

### (8.8.4)Thematic analysis

I used thematic analysis to analyse the key informant interviews and reflective diary (Braun et al., 2019). I took this approach because it is an inductive method, where data codes are generated from the data. This was important for the CBPR phase, where the findings needed to be relevant to each TSO especially in terms of identifying learning on implementation for each organisation. Braun and Clarke's (2006) guidance was used to undertake the different stages of analysis. These encompassed:

**Familiarisation-** The first stage involved reading the transcripts and the reflective diary a number of times to understand the content. During this process, I began noting ideas about the data especially how different issues may link together.

**Coding-** The second stage involved identifying potential findings in the transcripts and diary and grouping them by commonality. Although this was largely inductive, I was influenced by the codes I used in the QI phase including the CFIR constructs.

**Searching for themes-** The third stage involved looking at the connections between the codes to develop themes and subthemes. This was done through drawing mind maps to see how the codes might link together and discussing the codes and ideas with my supervisors, advisory committee and the TSOs themselves. For example, there was a number of codes that related to the purpose and importance given to PROMs within each of the two organisations. These different codes resulted in a theme relating to the organisation's commitment to PROMs and how this had implications for implementation. As in the QI analysis, the themes went beyond the CFIR constructs and I drew upon the language used within the TSOs to name the themes.

**Reviewing the themes-** The fourth stage involved checking out whether the themes reflected the data, both in terms of the raw data but also in respect to whether the themes linked to each other and captured the entirety of the stories told within the data.

**Defining and revising the themes-** The fifth stage involved revising the themes and developing the overarching message of each theme through defining the focus of a theme using a single sentence.

**Writing the report-** The final stage involved writing up the themes including describing each theme and supporting them with quotes from the data. This part of the process was an iterative process, with the purpose of having a final document where readers not only understand the findings but also have confidence in the narrative (Braun and Clarke 2006). As this research was for a PhD, the findings were written up as a chapter for the thesis. I wrote the initial chapter and shared it with my supervisors, who then supported me to develop the write-up further. Some of this process involved revisiting the themes. Whilst traditionally the themes are meant to be finalised before the report writing stage, many researchers undergo a more iterative process to theme development because the writing process helps to identify additional insights on the linkages between the data (Sampson, 2017). The finalised write-up of the findings is included in Chapter 9.

#### (8.8.5) Exploratory quantitative analysis of the collected PROMs data

I had planned to undertake statistical analysis on PROMs data collected in both organisations and explore the following issues:

- (1) Completion rates of measures per service-user across different time points-** e.g. what proportion of service-users who completed a measure when they started attending a wellbeing activity (baseline), also completed a PROM once they attended the activity. This analysis was important to understand the extent TSOs were able to calculate whether a service-user had experienced a change in their wellbeing over time.
- (2) Whether completion rates differed between individual items on the measures-** This was to understand whether some questions on the chosen PROM were less acceptable than others which may indicate a need for changes to be made to the measure.
- (3) How completion rates differed between specific front-line workers and over time-** The purpose of the analysis was to explore whether engagement varied between individual front-line workers but also whether there was increased use of PROMs over time as front-line workers became more experienced at administering measures.
- (4) In Organisation B, whether there was consistency between participants' responses to the How are you feeling? bespoke question developed by Organisation B and the Short Warwick Edinburgh Mental Wellbeing Scale (SWEMWBS) (a validated PROM)-** This was important because bespoke questions developed by the TSOs had not undergone the psychometric testing that is usually undertaken when developing new PROMs (Roberts et al., 2012). Cohen's Kappa was used because it is a measure of agreement (McHugh, 2012). I undertook the calculation to understand whether service-users who were classed as improving on the SWEMWBS were also recorded as improving on the bespoke question developed by Organisation B.
- (5) How completion rates differed between groups of service-users such as variation between age groups and any difference between wellbeing activities attended-** The analysis would enable an understanding of whether there were some wellbeing activities and specific service-user groups where completion rates were better or worse. For example, there may be some wellbeing activities which were less suited to using PROMs.

I was only able to undertake statistical analysis of PROMs data collected by Organisation B. Organisation B had designed a bespoke PROM which included a number of validated measures such as the SWEMWBS. Additionally, the front-line workers devised a question. The PROM was used in one-to-one wellbeing activities from June 2017. Greater detail is provided about the measure and its use in the next chapter. PROMs data collected from Organisation A was not analysed because the TSO had only collected a small number of measures and not entered them into their data management system so the data was not available in a form for me to analyse. In contrast, Organisation B had been collecting and processing their bespoke measure for over a year and been inputting it into their data management system.

I undertook the quantitative analysis between October 2019 and February 2020. A data sharing agreement was put in place between Organisation B and the University of Sheffield in September 2019 to allow me access to the PROMs data. The data agreement set out the requirements for accessing, transferring, storing and using the data; and complying with the necessary governance laws and institutional policy. A member of staff in Organisation B downloaded the data, anonymised it and sent it to me analysis. I cleaned the data in Microsoft Excel then transferred it into SPSS for analysis (Field, 2009).

I only conducted the analysis detailed in points 1-4 above. It was not possible to undertake the comparison between the different service-user groups and wellbeing activities because Organisation B did not link service-user demographics or wellbeing activity data with the PROMs data. Not being able to undertake this analysis or analysis for Organisation A, resulted in less quantitative analysis than I had anticipated when I designed the CBPR phase as a mixed methods study.

The findings of the exploratory quantitative analysis were shared and discussed with Organisation B, particularly considering how the implementation process may be developed in light of the findings. The analysis of collected PROMs data was undertaken just once because of time limitations. However, it would have been useful to repeat the analysis after another 6 months to explore whether completion rates had changed.

#### (8.8.6) Integrating the CBPR findings

A ‘following the thread’ technique was used to synthesis the findings from the different sources of data within the CBPR phase (Moran-Ellis et al., 2006). The technique entailed identifying a finding in one source and exploring how it transpired in other parts of the dataset. For example, a finding from the key informant interviews was how front-line workers varied in their engagement with PROMs and this was explored in the quantitative data. The next chapter presents the overall findings of the integrated CBPR phase rather than reporting the findings of each data source separately.

#### (8.9) Changes to the CBPR Phase

The participatory nature of CBPR means that the approach and specific methods are negotiated between researchers and their community partners and are dependent on their appropriateness within the specific context (Springett et al., 2011). They may also be dependent on practical issues such as the amount of resource available for the study. Given this, I changed the number of organisations I worked with. Additionally there were three methods that I considered but did not undertake within the CBPR phase: a service-user survey, non-participant observation and Ripple Effects Mapping (REM).

I changed the number of TSOs involved within the CBPR phase. When developing the PhD, I proposed working with two organisations who were at the beginning of their PROMs implementation process. This was because learning from two organisations would provide a source of comparison. When starting the CBPR phase, I decided to work with one rather two TSO because of capacity issues. I made this decision because as I learnt more about CBPR, I realised how time consuming it would be to develop relationships and support organisations with implementing PROMs. Consequently, I initially worked with Organisation A. However as discussed previously in the chapter, Organisation A were still at the early stages of their implementation process so later in the study, I felt it would be beneficial to also involve Organisation B in the CBPR phase. As I already had a partnership with Organisation B, involving them in the study was less resource intensive than if I had worked with two TSOs throughout the CBPR phase.



When designing the PhD, I had planned an additional quantitative component: a survey of service-users about their experiences of the PROMs process. However the survey was considered inappropriate by the advisory committee. The committee felt that front-line workers find collecting PROMs a burden and an additional questionnaire would add to that burden. They also thought I would get a low response rate if I tried to get service-users to complete the survey outside of wellbeing activities. Furthermore, a finding from the QI phase was that generally service-users were compliant with completing measures and thus collecting their views was less of a priority than exploring other aspects of implementation.

I had considered using non-participant observation within the TSOs to understand further how implementation occurred. For example, I planned to observe team meetings to understand how PROMs were discussed as part of day-to-day activity. However, I decided not to conduct non-participant observation because I felt it would disrupt my rapport with the TSOs. It would have entailed a change from me contributing to team meetings, to only observing the discussions. I felt a lack of consistency in my role would be confusing for stakeholders and did not fit well within a CBPR approach.

I was going to use REM to develop with each TSO a visual map of their experiences of implementing PROMs (Chazdon et al., 2017). REM is a specific participatory technique where stakeholders meet as a group and together identify and discuss the multiple interacting factors which influence a phenomenon (Weiss, 1997). For example, we could have considered the implications of a TSO deciding that front-line workers would be responsible for processing PROMs. Through the discussion, maps are drawn to provide a visual representation of the implementation process. However, issues with the visual researchers' availability and capacity of front-line workers from Organisation B meant it was not possible to undertake REM. In Organisation B there was not the staff capacity to engage with REM. Whereas in Organisation A, we had an event arranged but the visual researcher cancelled attending so we could not go ahead with REM (but we still met and this formed one of the participatory events). It would have been difficult to have undertaken REM on my own with the group as the literature recommends having two facilitators, with one responsible for managing the discussion and one undertaking the visual mapping (Hansen et al., 2018).

### (8.10) Appraising the conduct of the CBPR phase

I appraised the conduct of the CBPR phase because this provided an opportunity for me to reflect and learn about the experience whilst also providing insight to readers about whether the study was conducted with rigor (Springett et al., 2011). Unlike in qualitative research, where Lincoln and Guba’s trustworthiness criteria dominate (Nowell et al., 2017), there are a number of potential sets of criteria for appraising participatory research. These include systems developed by Green et al., (1995), Israel et al., (2005) and the International Collaboration for Participatory (Health) Research (Springett et al., 2011). I chose to use the latter appraisal method because it draws upon previous criteria and was developed through comprehensively reviewing the literature to identify the most relevant constructs (Springett et al., 2011). These criteria encompass a number of issues to consider (described in Table 10).

**Table 10- Criteria for assessing participatory research**

<b>Criteria</b>	<b>Description</b>
<b>Participatory</b>	Whether the community partners felt involved in the study and able to influence its conduct and dissemination.
<b>Locally situated</b>	Whether the research was situated in the context where the research will bring about change in practice.
<b>A collective research process</b>	Whether the academic researchers managed to facilitate a shared decision-making group process for developing, implementing, analysing and disseminating the research.
<b>Project is collectively owned</b>	Whether the community partners felt they had some ownership of the research.
<b>Aims for transformation through human agency</b>	Whether the research enabled positive social change and has a transformational impact beyond the duration of the study.
<b>Promotes critical reflexivity</b>	Reflexivity was undertaken on the conduct on the research especially in regards to the power dynamics between the academic researchers and community partners.

<b>Produces Knowledge which is Local, Collective, Co-created, Conversational and Diverse</b>	Whether the research produced outputs which are not purely academic but are usable within the specific community context.
<b>Strives for broader impact beyond the study</b>	Considers whether the research supported learning beyond the study.
<b>Produces Local Evidence Based on Broad Understandings of Generalisability</b>	Explores whether the research considered its usability beyond the immediate context and could be useful in different contexts such as in other TSOs.
<b>Follows specific validity criteria</b>	<p>Appraises the study in respect of a number of participatory-related validity criteria including:</p> <p><b>Participatory Validity-</b> Extent stakeholders took an active part in the research process.</p> <p><b>Intersubjective Validity-</b> Extent the study was considered credible and meaningful by the stakeholders.</p> <p><b>Contextual Validity-</b> Extent research relates to the specific context.</p> <p><b>Catalytic Validity-</b> Extent the research had an impact and led to change.</p> <p><b>Ethical Validity-</b> Whether the research outcomes and changes are just and derived from the study.</p> <p><b>Empathic Validity-</b> Whether there was an increase in empathy between the community partners and the academic researchers.</p>
<b>Dialectic process characterised by messiness</b>	Acceptance that undertaking participatory research is messy and entailed an iterative process to identify findings and influence change.

I undertook an appraisal of the CBPR phase through drawing on the data from my reflective journal and by discussing the issues in Table 10 with the Implementation Leads (presented in Chapter 9). Front-line workers did not contribute to the appraisal because the focus of the group participatory meetings was on implementation rather than the conduct of the study. I reflect on this within Chapter 9.

### (8.11) Summary of the chapter

This chapter has focused on describing the methods used in the CBPR phase. Participatory approaches were used to support two TSOs with implementing PROMs and to learn further about the facilitators and barriers organisations may encounter. The next chapter presents the findings from this phase.

## Chapter 9- Using CBPR to support TSOs with implementing PROMs: The Findings

### (9.1) Outline of the chapter

The focus of this chapter is on the findings of the CBPR phase. The previous chapter explained how CBPR was used to support two TSOs to implement PROMs. This chapter includes a description of the two organisations involved, followed by an explanation of the different activities conducted during the CBPR process. The findings are presented, ordered by contextual and process related themes. Finally, I reflect on the conduct of the CBPR phase including my impact on the research and the strengths and limitations of the work.

### (9.2) Context: description of the TSOs involved in the CBPR phase

Two organisations participated in this part of the research: Organisations A and B. The organisations were similar in terms of their structure, size of their wellbeing teams, sources of funding and types of wellbeing activities they deliver. Both TSOs were neighbourhood-based community anchor organisations in different parts of the same city. Anchor organisations are based in a specific geographic area and serve the local community. Furthermore, anchor organisations provide multiple services, have a community hub within the locality and provide leadership support to smaller organisations in their area (Henderson, 2015). The TSOs served communities classed as experiencing a high level of deprivation (Sheffield City Council, No Year). The organisations are classified as large TSOs because they have an annual income greater than £1,000,000 (Charity Commission, 2020, NCVO, 2012). Alongside wellbeing activities, the TSOs provided a range of services including employment support, volunteering opportunities and community engagement. The wellbeing activities they delivered included:

- **One-to-one support of varying lengths depending on service-user needs-** E.g. advocacy, debt advice and signposting
- **One-to-one lifestyle coaching-** E.g. health trainer or mental resilience support
- **Fixed-length group activities-** E.g. confidence building or healthy eating
- **Ongoing group activities-** E.g. men's groups and craft activities
- **Health promotion events-** E.g. hosting events to raise awareness of spotting the signs of cancer.

The TSOs used a patchwork of funding to deliver the wellbeing activities. The main sources of funding were a number of contracts with the local authority and NHS. The TSOs also received one-off grants such as Organisation A winning a grant to address social isolation in the locality. Both TSOs adjusted their wellbeing activities to reflect the specific contracts available such as Organisation B developing their link worker offer in response to the NHS England Link Worker policy (NHS, 2019).

In both organisations, a manager overseeing the wellbeing activities acted as the Implementation Lead for progressing PROMs and they were my main contact. Supporting the managers were senior front-line workers, who had responsibility for overseeing the front-line workers alongside delivering activities. Each organisation had approximately 10 paid members of staff delivering wellbeing activities, although many worked part-time. For simplicity, in this chapter any reference to front-line workers includes the senior workers and front-line workers because there did not appear to be a difference between the roles when implementing PROMs. The front-line workers were based at different locations such as running activities from GP Practices or community venues.

Both organisations had previous experiences of utilising PROMs. They had tried to use measures chosen by commissioners such as PROMs associated with the national Health Trainer contract (Mathers et al., 2016). These experiences prompted both TSOs to implement their own PROMs process (explained within the findings).

### (9.3) Who was involved in the CBPR phase

It is complex to explain who participated in the CBPR phase because of the range and nature of methods utilised (detailed in the previous chapter). Much of the CBPR was conducted through informal interactions including email exchanges with Implementation Leads or me attending team meetings. It was through these interactions that decisions were made on implementation and people had an opportunity to reflect on, and improve the process. This messiness of participation is a feature of CBPR (Springett et al., 2011). However, the samples of the more formal research activities are explained in this section. These are the key informant interviews and the analysis of the collected PROMs data.

### (9.3.1) Key Informant Interviews

I interviewed five people towards the end of the research between September 2019 and January 2020. Three participants were from Organisation B and were recommended by the Implementation Lead. Two interviewees were from Organisation A, I recruited these individuals because I felt they could bring additional insight to the findings. The interviewees were the two Implementation Leads, two front-line workers and one senior manager (Table 11). The interviews generally lasted about an hour with two taking place at the university and three on the premises of the TSOs.

**Table 11- Participants in the Key Informant Interviews**

<b>Participant Code</b>	<b>Role</b>	<b>Organisation</b>
Senior Manager B	Senior Manager	Organisation B
Implementation Lead A	Implementation Lead	Organisation A
Implementation Lead B	Implementation Lead	Organisation B
Front-line Worker A	Front-line worker	Organisation A
Front-line Worker B	Front-line worker	Organisation B

I had intended to interview service-users about their experiences of using PROMs. However, the Implementation Leads were reluctant for me to do this because they felt that their service-users were generally compliant with completing PROMs and a greater barrier was engaging front-line workers. The approach taken by TSOs towards service-users during implementation is explored further within the findings.

### (9.3.2) Analysis of routinely collected data

Two sources of data were used for the analysis of Organisation B's collected PROMs data:

- **A dataset of the PROMs responses-** This included PROMs collected between March 2017 and October 2019. It included 166 service-users who had completed measures at two or more time points. This dataset was used to explore the completeness of the PROMs and consistency between questions.
- **A dataset which included dates of completion of PROMs and name of the member of staff who processed the PROM-** The dataset covered the period January 2019 to

February 2020. 324 individual service-users were included in the dataset. I used this dataset to explore the extent to which PROMs were administered such as differences between front-line workers and follow-up rates.

The quantitative analysis was more limited than anticipated due to the availability of data; I discuss this later in the chapter.

## (9.4) Presentation of findings

A number of factors were identified within the CBPR phase which appeared to influence the implementation of PROMs. Some of the findings reflected issues identified within the QI phase (as discussed within Chapter 7), whilst others highlighted how a factor played out within a specific organisational context. Furthermore, a small number of findings within the CBPR phase contradicted the QI phase. The findings of the two phases are compared throughout the chapter because the purpose of the CBPR phase was to develop the learning from the QI phase. Where the two phases are consistent, the findings from the CBPR phase have not been described in detail.

### (9.4.1) Overview of findings

As in the QI phase, there appeared to be both contextual and process related issues influencing implementation within the two TSOs. A summary of the findings is depicted within Figure 10. The TSOs were motivated to implement their own PROMs in an attempt to avoid having outcome measures imposed on them by commissioners. In the absence of being mandated to use PROMs, an organisation appeared to need to make a strategic commitment to outcome measurement and have a proactive Implementation Lead who was able to invest time and resources into the process. Alongside this, both TSOs felt that it was important to design a bespoke outcome measure in collaboration with front-line workers and to tailor the process to meet their unique organisational contexts. This approach influenced many of the other decisions and actions taken during implementation. Even with organisational commitment, a proactive Implementation Lead and use of an acceptable bespoke PROM, implementation appeared to take a considerable period of time and not all front-line workers engaged. Organisation B were further ahead with the implementation process than Organisation A, partly because they embarked on

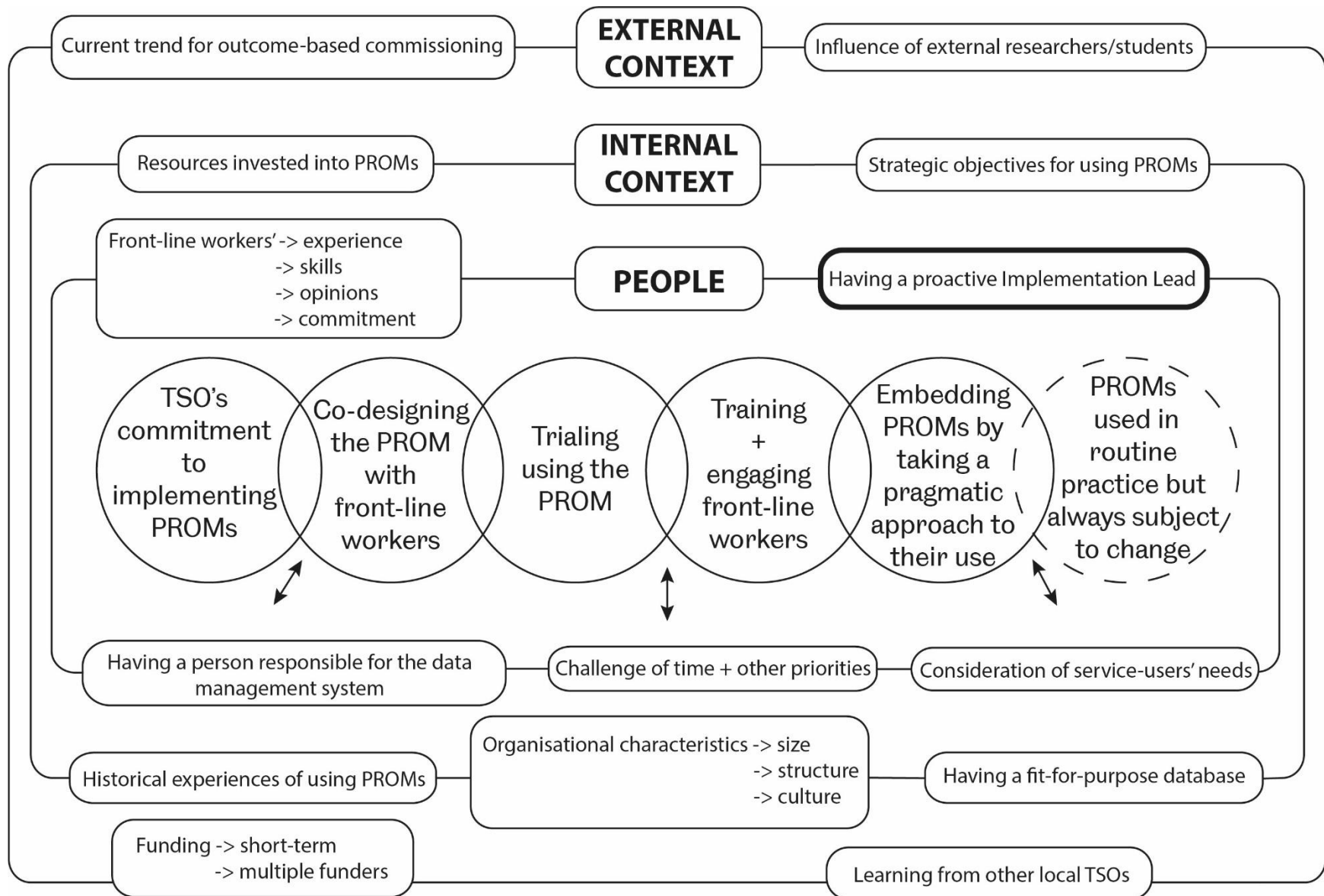


their journey earlier but also because they appeared to possess a larger number of the facilitators and address more of the barriers identified in the QI phase than Organisation A.

I considered how each finding related to the constructs of the CFIR (detailed in Appendix 18). Generally, the constructs were relevant to the findings of the CBPR phase. Although at times the experiences of the TSOs within the CBPR phase contradicted the CFIR. For example, rather than planning their implementation or designing a PROMs process, the two TSOs took a more organic approach, deciding their approaches once they started using PROMs.

The findings are presented in seven themes. The initial themes focus on context: the influence of the funding context and external support (Theme 1), the characteristics of the TSO (Theme 2) and the impact of individuals within the TSOs (Theme 3). The contextual issues appeared to influence the decisions made and actions taken during the implementation process. This included co-designing an appropriate outcome measure (Theme 4) and TSOs not pre-designing their PROMs process (Theme 5). Skilling up and engaging front-line workers to use PROMs was found to be important (Theme 6). Finally, the issues TSOs face when starting to use PROMs are explored, including the length of time implementation appears to take (Theme 7).

**Figure 10- Implementing PROMs in TSOs- Findings arising from the CBPR phase**



Footnote- Bold border- Appears essential for implementation; Dashed border- Not all TSOs reach this stage

## (9.5) Support from external sources to facilitate the implementation of PROMs

Somewhat differently from the QI phase, the two TSOs were choosing to use PROMs rather than having specific measures imposed on them by commissioners, and this influenced the organisations' processes. As found in the QI phase, external researchers and learning from other TSOs facilitated implementation.

### (9.5.1) Asserting ownership within an external funding context where PROMs are imposed through contracts

The two TSOs had to respond to the demands of multiple commissioners; they were regularly seeking new funding contracts and even within existing contracts, monitoring requirements changed. Within this context, both Implementation Leads sought to exert some control through designing a PROMs process within their organisations. The Implementation Leads hoped that commissioners would be less likely to impose a specific measure on the organisations if the TSO was already using a PROM. Both Implementation Leads discussed how they had made this decision because of the approach taken by a particular individual commissioner who funded both organisations. They explained how the commissioner had expressed an interest in local TSOs using PROMs but had not prescribed specific measures. The Implementation Leads felt that taking ownership over the process would ensure a more appropriate process for the organisation. The TSOs' decision to take this approach was what prompted them to become involved in my study.

Despite the aspiration of taking control, both TSOs acknowledged the need to be pragmatic and respond to the requirements of commissioners. During the CBPR phase, both organisations gained contracts with new commissioners who required the TSOs to use a specific measure in the wellbeing activities they funded. For example, Implementation Lead B discussed how their organisation was required to use a mental health measure within one wellbeing activity. In Organisation A, the Implementation Lead sought to incorporate the anticipated mandated questions within their organisation's measure to avoid having to use a number of PROMs within the TSO. The continually changing nature of contracts meant the TSOs faced ongoing uncertainty of what measures they would need to use and the Implementation Leads anticipated having to adapt the PROMs process to meet future requirements. For example, Implementation

Lead B discussed potentially adopting a newly prescribed PROM throughout the TSO and stopping the use of their bespoke PROM.

*“We’ve been told we are to report these outcome measures [...].so it could be rather than them [front-line workers] doing two questionnaires we might then make the decision to amend it.” [Implementation Lead B]*

#### (9.5.2) University researchers/students facilitate the implementation of PROMs

Getting support from university-based researchers/students was identified as essential by the two TSOs in the CBPR phase. Within the QI phase, I identified how some TSOs utilised support from individuals outside of the organisation because of the knowledge, additional capacity and credibility they provided. These reasons were also identified within the CBPR phase, but it was clearer that this input could be essential rather than desirable. When interviewed, both Implementation Leads and Senior Manager B felt the support from university-based researchers/students had been vital.

*“Not a chance in hell we would have done that. We could have started it off, but we would never have finished it [...] we can’t do it on our own. Really so undoubtedly and crucially we wouldn’t be able to do it without the university.” [Implementation Lead B]*

The Implementation Leads perceived the relationships as mutually beneficial because the organisations were getting support for free and, in return, the researchers/students acquired data for their studies. Through talking to front-line workers and Implementation Leads, it was apparent that engaging with researchers/students was something the TSOs did regularly as a way of increasing evaluation capacity.

Within the CBPR phase, researchers/students including myself were predominantly involved in designing the PROMs process such as identifying a measure or considering how the data may be used. This raised questions about whether TSOs would require less input from researchers/students once implementation progressed. I reflected on the issue within my diary, considering at what point TSOs were no longer dependent on the support. I was mindful of my research finishing and was concerned about whether Organisation A would continue to use PROMs because the organisation was still early on in their implementation journey. I felt more confident that Organisation B would continue progressing implementation, although

Implementation Lead B asked me to support delivery of further training to front-line workers, indicating they still valued my input.

Despite the facilitating influence of researchers/students, both organisations faced challenges when working with these external groups, such as the time commitments of researchers/students and their ability to respond to the needs of the TSO. This finding was similar to the QI phase but the extent of the time commitment by external researchers was much more evident in the CBPR phase. For example, I noted in my reflective diary how there were periods when I was not engaged with Organisation A due to other work commitments and how this delayed the formatting of the measure for a month. This was not a problem as Organisation A did not have any timescales they were seeking to meet. However, it was detrimental to progressing implementation.

#### [\(9.5.3\) Having good networks with other local TSOs enables the sharing of practice](#)

As in the QI phase, the two TSOs both received and gave support to similar local organisations, with any learning needing to be tailored to the specific TSO. The importance of adapting learning became apparent when I shared a PROM developed by a similar organisation with Organisation A, thinking they may like the measure. However, both the Implementation Lead and front-line workers felt that the PROM was not suitable for their organisation.

*“We looked at [Name of Organisation]’s evaluation form and that was helpful because we just went, that’s not what we’re trying to measure.”* [Implementation Lead A]

Additionally, the CBPR phase identified how any sharing of good practice appeared to be on a local level. This finding arose because Senior Manager B and both of the Implementation Leads explained how their networks were purely with TSOs within the same city.

## (9.6) How the characteristics of the TSO and reasons for using PROMs influenced implementation

The internal context of each organisation including their culture, structural characteristics and infrastructure appeared to influence implementation in a similar manner to the QI phase.

### (9.6.1) Strategic commitment to PROMs

Choosing to, rather than being required, to implement PROMs meant that the organisations did not have the same impetus to progress implementation. Consequently, TSOs needed to make a strategic commitment to using PROMs to prevent implementation from stagnating. In my diary, I reflected on how Implementation Lead A had been able to prioritise implementation when they thought that PROMs were required as part of a new funding contract. However, once the Lead realised that the TSO could demonstrate impact using other methods, implementing PROMs became less of a priority in comparison to more urgent work commitments. In the absence of being required to use PROMs, TSOs instead appeared to need a strategic commitment to using outcome measures. In Organisation B, Senior Manager B explained how using PROMs was part of the organisation's overall strategic commitment to become outcome rather than output focused. This commitment appeared to facilitate staff engagement and resource investment. In contrast, there did not appear to be a strategic commitment to utilising PROMs within Organisation A which had a knock-on effect on other parts of the implementation process. This included the Implementation Lead and front-line workers needing to prioritise collecting and analysing data required by commissioners such as the demographics of service-users.

*“We really liked [name of a specific measure] but we haven't got the capacity to go and [use a PROM] with people and we've got to do the [other monitoring]. So actually we haven't really got the ability to add another set of questions in, which is a shame.”*

[Implementation Lead A]

### (9.6.2) Cultural differences between the TSOs

As in the QI phase, it appeared facilitating cultural qualities included having a culture amendable to outcome measures, having good networks amongst staff and being adaptable. The culture of Organisation B appeared more amendable to implementing PROMs, with Implementation Lead A making this point by discussing how Organisation A was less process driven and saw themselves as providing a safety net for service-users rather than this necessarily resulting in an

improvement in wellbeing. In my diary, I reflected on how the differences in culture were noticeable through the differences in language used by the Implementation Leads. Within Organisation B, the Implementation Lead regularly used the terminology associated with PROMs within the academic literature such ‘PROMs’ and ‘baseline measures’. In contrast, Implementation Lead A used different terms such as ‘evaluation tool’ and ‘using the questionnaire when it felt right’.

As in the QI phase, both TSOs had a committed workforce which meant they supported each other with PROMs. However, a barrier was that front-line workers were protective of their service-users and were concerned that PROMs would be detrimental to these relationships.

*“You know we look at it from a client perspective in a sense that they come to us because they want help, the last thing they want is paperwork cos it frightens the life out of a lot of people.”* [Front-line worker A]

Similar to the QI phase, the two TSOs were used to continually adapting to new funding contracts. However, I identified in the CBPR phase that this appeared to result in a weariness amongst front-line workers as they had seen different outcome measures and monitoring come and go and thus viewed PROMs as a fad rather than as a core function of their working practices.

### (9.6.3) How the structure, size and available resources impact implementation

Similar issues relating to the size and structure of TSOs arose within the CBPR phase as in the QI phase. These included the challenges of front-line workers based within the community and organisations being of a sufficient size to invest in the PROMs related infrastructure. The Implementation Leads commented on how smaller organisations in their locality did not have scope to invest in data management systems and other infrastructure like they had. Both Leads also commented that they did face resource constraints especially in regard to not having the funding for administrative staff to process PROMs. They discussed their frustrations that commissioners were unwilling to resource the collection of PROMs which were required as part of specific funding contracts.

*“So you’ll [commissioners] end up coming back to us for reports, but you [commissioners] refuse to pay for it, yeah that’s not really that fair really, so that’s something we look at.”* [Implementation Lead B]

#### (9.6.4) Need for a fit-for-purpose data management system and a member of staff to oversee it

Front-line workers faced operational barriers using the organisations' data management systems for processing PROMs, despite the TSOs investing resources in an attempt to have a fit-for-purpose system. Both TSOs had developed data management systems to store details about individual service-users and invested in a member of staff to support the systems. The organisations had invested in these systems before they began implementing PROMs. I reflected in my diary how the data management system appeared important, especially in the context of smaller organisations in the locality who were feeling stuck with implementation because they did not have the resources or capability to develop and/or invest in data management systems.

The two TSOs within the CBPR phase took different approaches to developing a data management system because of their specific context. Organisation A had developed their system in house, using the skills of a member of staff who was employed to support the information technology. In contrast, Organisation B paid a licence fee to use an externally developed and hosted data management system. It did not appear to matter which approach was taken, providing the system was suitable for the organisation.

Front-line workers in both TSOs reported operational issues with the data management systems including the systems being slow and experiencing problems accessing the system when they were off-site such as at GP Practices. This was a barrier because it meant processing PROMs took longer. Furthermore, some less experienced front-line workers appeared to struggle with using the systems and found the PROMs process overwhelming because they did not feel confident processing the measures. Both Implementation Leads felt these front-line workers needed additional support from colleagues.

*“I think that possibly [Name of front-line worker] is on a little bit of a cusp. For her the database feels more overwhelming because she's not confident in it. So actually it would be a whole lot easier for somebody else to do it, but when she feels more comfortable with it and then she's able to do it, she'll be able to see the value of doing it.” [Implementation Lead A].*



The importance of having a person with both the technical skills and responsibility to support the use of the data management system was identified as important within the CBPR phase.

However, the precise role varied depending on the needs of the TSO. Within Organisation A, they had someone whose job role was providing technology support to the TSO. In Organisation B, the focus of the role was overseeing the data management system and use of the data. I reflected that the difference may be partly because Organisation B was further along in their implementation and wanted to make use of the collected data. Given the issues with resources discussed previously, I asked the Implementation Leads whether these data support roles were sustainable and both Leads felt the roles were critical for the organisations.

### (9.7) The skills, experience and opinions of individuals within TSOs

Consistent with the QI phase findings, there were varying levels of engagement with PROMs from different members of staff within the two participating TSOs. This appeared to be partly influenced by people's opinions and experience of PROMs.

#### (9.7.1) How varying levels of staff engagement impacted on implementation

As in the QI phase, it was found in the CBPR phase that staff varied in their engagement with PROMs but critically there needed to be a person leading the implementation (an Implementation Lead) who was able to prioritise progressing the use of PROMs. I reflected in my diary how Implementation Lead A appeared less engaged with PROMs than Implementation Lead B. This was partly due to capacity issues such as sick leave and having to prioritise other tasks e.g. funding bids. However, it was also because Implementation Lead A had fundamental concerns about whether the nature of PROMs were compatible with the values of the organisation. Thus alongside PROMs, Implementation Lead A was exploring other potential methods to demonstrate impact. In contrast, Implementation Lead B bought into the concept of PROMs and they felt this had been essential for implementation.

I *“Do you think because you have been committed to it and been kind of proactive in progressing it, that's what's kept it going?”*

P *Oh absolutely.”* [Implementation Lead B]

Within the CBPR phase, I identified how the Implementation Leads also had an external role in terms of negotiating with commissioners about the use of PROMs within performance monitoring requirements. For example, Implementation Lead A was negotiating with commissioners for the TSO to be allowed to use their own PROM because it was appropriate for the organisation.

*“I think we have the confidence to be quite forceful [...] we’ve gone no no, this is what we can give you, and we’ve tried to do a bit of a pre-emptive strike with them.”*

[Implementation Lead A]

Reflecting the findings of the QI phase, Implementation Lead B and Senior Manager B felt the TSO was now less reliant on the Implementation Lead because there had been a cultural shift within the organisation and there were now other staff responsible for PROMs such as the data manager. Organisation A appeared reliant on their Implementation Lead because they were still in the earlier stages of implementation.

In contrast to the importance of the Implementation Lead being able to prioritise implementation, there appeared to be an acceptance amongst staff that individual front-line workers varied in their engagement and it would be an ongoing challenge getting them to engage. Consistent with the QI phase, this variation was because of differences in organisational skills, experience and opinions of outcome measures.

*“There’s always certain individuals who just aren’t very good at paperwork per se whether it’s PROMS or monitoring or anything else. So I just say when I look at it again after a few months it would be the same suspects again.”* [Implementation Lead B]

#### (9.7.2) How negative previous experiences of using PROMs and concerns about validity influenced the design and use of PROMs

In both the QI and CBPR phases, staff members’ opinions of PROMs appeared to influence implementation. Within the CBPR phase, two specific issues shaped these opinions and actions: historical experiences of PROMs and concerns about validity. Both TSOs in the CBPR phase had previously struggled to implement outcome measures prescribed by commissioners because the front-line workers considered them inappropriate. This motivated the Implementation Leads to involve their front-line workers in designing a PROM suitable for their organisation.

*“So the experience of [a previous PROM] was so negative that actually, you’re not actually getting very good quality stuff because you’re just thinking, well you’re filling it in for the sake of it.”* [Implementation Lead A]

Throughout the CBPR, the term ‘validity’ was used by people in respect to the design and use of the PROM. I reflected in my diary how the concept was used in varying ways by different people but appeared to primarily relate to whether the impact of wellbeing activities could be captured within a PROM. Concern about validity was a key reason why both organisations designed their own PROM. Front-line workers and Implementation Leads wanted measures to capture how they were helping service-users to make changes in their lives and feel supported but believed this impact may not be captured within existing PROMs. Externally, Implementation Leads wanted to convince commissioners that their bespoke PROMs had greater validity than validated PROMs because they had been designed with front-line workers specifically for the TSO.

## **(9.8) Co-designing a PROM with front-line workers to ensure it is appropriate for the specific TSO**

Each TSO co-designed a bespoke PROM with their front-line workers appropriate for their specific organisation. However, neither TSO involved their service-users in the co-design process.

### **(9.8.2) Co-designing the PROM with front-line workers**

Co-designing a PROM with front-line workers was a facilitator identified in the QI phase which was also undertaken by both TSOs. Both Implementation Leads had chosen to take a collaborative approach before I became involved. The reason was because the front-line workers had struggled to use validated PROMs previously and the Implementation Leads felt involving the front-line workers in choosing a PROM would increase the likelihood that they would use the measure.

*“The PROM tool that we developed, I’m really proud of that because it was developed using staff, yourselves and all that kind of stuff, so it was something that was co-produced, so it had meaning to all those stakeholder groups.”* [Senior Manager B]

Expanding on the findings of the QI findings, front-line workers were involved in the design process as a collective because other commitments meant that not every individual could be involved. For example, I recorded in my diary how there were differences in which front-line workers attended the two group consultation meetings to design the PROM within Organisation A. The Implementation Leads primarily decided which front line-workers would be involved such as involving senior front-line workers. In my diary, I considered whether front-line workers who were resistant to PROMs should be involved because they needed to be convinced to use the measure whereas other front-line workers appeared compliant irrespective of the specific PROM. Interestingly, Organisation B's bespoke outcome measure was similar to PROMs they had previously struggled to use. I reflected in my diary how this indicated that front-line workers felt more engaged with a PROM if they were consulted on its design.

Something that became clear during the CBPR phase was taking a collaborative approach to design took a considerable period of time and did not result in all front-line workers using the PROM. For example in Organisation A, it took two group consultation meetings spread over a period of four months to decide on an outcome measure. I reflected in my diary that I had been surprised how long it had taken and that a collaborative approach might not be feasible if TSOs were required to collect data quickly. Despite their involvement in designing the measures, some front-line workers still did not use them because they had fundamental concerns about the validity of PROMs in general. This implies that a collaborative approach is a facilitator but it does not mitigate other barriers.

### (9.8.3) Designing a PROM appropriate for the TSO

The bespoke PROMs for the two TSOs differed substantially because the measures were developed to be suitable for each organisation. In terms of content, Organisation B's PROM (Appendix 19) primarily consisted of questions drawn from validated PROMs such as the SWEMWBS (Haver et al., 2015) and parts of the ASCOT (Malley et al., 2010). There was also an introductory question developed by the front-line workers about how someone is feeling. The question's purpose was to help service-users feel more comfortable with completing the measure. Furthermore, a financial wellbeing question was included because front-line workers felt that a core part of their work was supporting service-users with financial issues such as

applying for welfare payments. In contrast, Organisation A designed the questions for their PROM themselves (Appendix 20), including several which focused on a service-user's experience with the TSO (similar to a Patient Reported Experience Measure). These experience questions were asked once people received support. Some of the questions arose because Organisation A wanted to capture their impact on improving people's resilience and support networks but there were no existing PROMs which measured these issues in a way that was appropriate for the TSO. I reflected in my diary that this may indicate the need for outcome measures to be developed which focus on outcomes aligned to the objectives of TSOs. Organisation A's PROM included one validated question, this was the Office for National Statistics' (2018b) question on social isolation. This question was included because it was required by a specific commissioner. I reflected in my diary how the difference between the two organisations' PROMs was surprising because they delivered comparable wellbeing activities to similar types of service-users. I thought the differences stemmed from differences in organisational culture and viewpoints of staff about PROMs.

Despite differences in content, both TSOs prioritised having a short, clearly written and visually appealing PROM. This decision was partly because of the TSO's prior experiences of implementing lengthy questionnaires but also because I explained how I had identified that these features of PROMs appeared to be facilitators within my research. Front-line workers and Implementation Leads were adamant that any measures needed to be no longer than two sides of A4 long to reduce measurement burden. Using simple, meaningful language was important to both organisations. This arose because front-line workers felt that complex and abstract language was used in validated PROMs. Both bespoke measures included visuals such as graphics to illustrate the response options for questions because front-line workers felt that these would support service-users with completion.

*“Spoke to front-line workers at Organisation B and they feel the design of the PROM was much better than what they had to use previously and reported that service-users find the graphics useful.” [Extract from my reflective diary]*

#### (9.8.4) How the organisations considered service-users' needs but did not consult them on PROMs

The two organisations considered service-user needs but did not consult them directly. When I proposed that the TSOs may want to consult service-users, Implementation Lead A explained how their perspective was captured by involving the front-line workers because the workers lived in the local area and had friends/family who accessed the wellbeing activities. Furthermore, there was a sense within the two TSOs that PROMs were an organisational tool so it was not relevant to consult service-users.

*“So I don't think it would be, it's not relevant and it's not appropriate to ask customers about how they do that, but I do feel quite confident that the staff are embedded in the community and have got the links and the relationships with the people participating and hear a lot about the problems of other things. So I think that, I think that covers it.”*

[Implementation Lead A]

In my diary, I reflected on how the lack of service-user consultation differed from the general PROMs literature which encourages involvement. I felt the difference may be because TSO front-line workers are viewed as the peers of service-users.

#### (9.9) A lack of planning the design of the PROMs process

Rather than designing the PROMs process Organisation A, and to an extent Organisation B took a more organic process. This included making decisions about the PROMs process once the TSOs started using measures and front-line workers being asked to use the measures when it felt appropriate rather than having to follow a standard procedure. This theme focuses on how PROMs were collected, processed and the data used within the two TSOs.

##### (9.9.1) Challenges result from TSOs taking an organic approach to design

Both TSOs experienced challenges with designing the PROMs process and consequently did not have a standardised procedure for front-line workers to adhere to, but instead encouraged front-line workers to use their initiative about when to use outcome measures. This finding contrasted with the QI phase, which identified how some TSOs had a procedure for collecting PROMs. For example, rather than specifying the time points for collecting PROMs, the two TSOs asked front-line workers to use the outcome measures when they felt it was appropriate to do so with each

service-user. However, I noted in my diary how the TSOs differed in the extent and reasons for their approach. In Organisation A, the Implementation Lead encouraged front-line workers to use the PROM when it felt right. Whereas in Organisation B, front-line workers were meant to be using a PROM near the beginning of a service-user's support and towards the end but it did not have to be in the first and last appointments. This was to give front-line workers discretion to administer PROMs once they had developed rapport with a service-user, even if this meant administering the baseline measure once the service-user had started to receive support.

I noted in my reflective diary how Implementation Lead A had not developed a clear procedure, this may be partly because the organisation were still in the earlier stages of implementation (discussed in a later theme). In contrast, Implementation Lead B became less prescriptive in their approach over time. When interviewed, Implementation Lead B discussed how this was because they realised that they did not have the capacity to ensure front-line workers were adhering to a prescribed process. However, front-line workers found a lack of procedure difficult because they did not know when they should be using PROMs. This is illustrated by Front-line Worker A saying how they wanted everyone to be told what process to follow.

*“Just making sure that everyone's clear before they do leave [the training]. I know they might not be fully clear, but just that, everyone's got the same, they've been told the same.”*  
[Front-line Worker A]

Not having a defined procedure resulted in there being little consistency about when PROMs were collected, creating issues with data quality. For example, Front-line Worker A explained how they asked attendees at a wellbeing activity to complete a PROM retrospectively, based on how they were feeling when they first attended the activity (which may have been months before) and this was viewed as a baseline.

*“So it was retrospective because we weren't using it when the group set up in January and I tried to get them to think where they were when they first came, where they are now and hopefully where they're gonna be, well let's just say just before Christmas, if they want to do it again.”* [Front-line worker A]

These experiences indicate there is a case for encouraging TSOs to design a procedure for using PROMs albeit with some flexibility. This may help front-line workers use PROMs and increase the quality of data collected.

### (9.9.2) Identifying which wellbeing activities to use PROMs for

PROMs were only used in some wellbeing activities delivered by the TSOs because the nature of some activities made it more difficult to administer outcome measures, or there were other measures used within the activity. In the QI phase, I identified how TSOs may use PROMs throughout the organisation, or only in wellbeing activities where they were required to do so. In contrast, the two TSOs in the CBPR phase intentionally chose to only use the PROMs in some wellbeing activities, despite taking an organisational approach to implementation. Interviewees discussed how this was because the nature of some wellbeing activities made it difficult to identify appropriate time points for administering PROMs. This included ongoing wellbeing activities or triage services which signposted people to support. Furthermore, the TSOs were having to use commissioner mandated measures in some activities or had other measures they had historically used within specific activities. In these activities, the Implementation Leads chose not to try and implement the bespoke PROM as they did not want to risk measurement burden or create resistance to the PROM.

*“Having met with [Name of front-line worker], I am really concerned about how we will get them using the PROM within the wellbeing course. They appear keen to continue using their own measure which they feel works well and are resistant to any changes being enforced on what they feel is their project.”* [Extract from my reflective diary]

### (9.9.3) How issues with staff capacity and infrastructure caused problems with collecting and processing the PROMs

Consistent with the findings of the QI phase, the two TSOs faced staff capacity and infrastructure issues with collecting measures and processing the data. However, Organisation B invested resources and time in an attempt to mitigate these barriers. As found in the QI phase, both TSOs were collecting PROMs on paper with front-line workers supporting service-users with completion partly because the organisations did not have the resources for ePROMs. Within both TSOs, front-line workers were meant to input collected PROMs into the data management systems but reported capacity barriers so wanted administrative support.

*“Yeah admin is, can be challenging, time consuming.”* [Front-line Worker B]



When I suggested to the Implementation Leads that front-line workers felt having administrative support would help them use PROMs, both explained that their organisations did not have the resources for this and front-line workers needed to accept that processing PROMs was part of their job role. Implementation Lead A discussed how they had reassured front-line workers that they can see less service-users to give them more time for administrative tasks, although I questioned in my diary whether front-line workers themselves felt able to see fewer service-users.

*“I think that message is getting through that we need, what we need to do is quality and we need to be able to show and prove that its good and so and giving them [front-line workers] permission to take on less volume and giving them permission to have time in the office to do the paperwork and that, that is valid, whereas before I think it was just added onto.”*

[Implementation Lead A]

In Organisation A, they had not yet settled on a procedure for processing PROMs. At times the process was for front-line workers to input the collected measures into the data management system, at other times paper PROMs were filed with case notes without being inputted. This variation was because of concerns about capacity and the TSO getting used to collecting PROMs (discussed further in the embedding stage).

#### [\(9.9.4\) Developing processes for using the collected PROMs data](#)

It appeared that TSOs needed to invest time and resources in developing processes for using the PROMs data, a finding consistent with the QI phase. Following my suggestion, Organisation B invested time and resources in developing systems for using the collected PROMs data.

However, I realised when speaking with front-line workers that Organisation B had not developed provision for sharing the data with front-line workers. I recorded in my diary how this was problematic as front-line workers were feeling disengaged as did not know how the data they collected was used. This highlighted an important learning issue that TSOs need to plan how the PROMs data would be shared with all types of stakeholders. Organisation A had not started to consider how to use the PROMs data. I reflected in my diary how this was understandable because Implementation Lead A was having to prioritise collecting, processing and reporting the monitoring data which was required by commissioners. This links into the contextual issues about the reasons why TSOs are using PROMs.

Although both TSOs were using PROMs to demonstrate the impact of the wellbeing activities, over time front-line workers appeared to become interested in sharing the data with individual service-users. Front-line workers in both organisations discussed with me examples of sharing the data and wanted training and better reporting systems to facilitate this. I reflected in my diary how if front-line workers were using PROMs for care management purposes, they may engage more with PROMs. This was because the QI phase identified that the use of PROMs was sustained if people felt that using the measures was beneficial to their work.

*“Speaking with front-line workers in Organisation B felt positive as some were discussing using the PROM in their work with service-users. Others who had not done this appeared interested in understanding more about how to do this especially in terms of pulling individual reports off the database.”* [Extract from my reflective diary]

Whilst staff at Organisation B felt that they had good data reporting systems in place, I reflected in my diary how I had experienced issues with using the collected PROMs data. For example, it was only possible to generate the first and latest scores for a service-user rather than multiple time points, and scores were not linked to the individual case so further analysis such as exploring which wellbeing activities the PROMs were collected within was not possible. I discussed these issues with Implementation Lead B and they explained the data was set up to meet their needs rather than to undertake detailed analysis. I felt this highlighted how the reasons for collecting PROMs had implications throughout the implementation process.

#### **(9.10) Skilling-up front-line workers through training, peer support and supervision**

The importance of skilling-up front-line workers in collecting PROMs and using the data was identified within the QI phase and reinforced by the findings of the CBPR phase. I explained to both organisations that training front-line workers appeared a facilitator when implementing PROMs. Whilst Organisation B delivered training on PROMs, at a participatory event the front-line workers explained they needed further training on interpreting and using the data with individual service-users. Following my suggestion, Organisation B had included training on PROMs in the induction training for new front-line workers. This addressed a barrier identified in the QI phase which found that new staff may not receive training on PROMs. No training had been organised for front-line workers within Organisation A because the Implementation Lead did not feel it was a priority and that the measure was fairly self-explanatory. However, Front-

line worker A discussed how the lack of training meant that they and their colleagues were unclear about the PROMs process.

The CBPR phase built upon the QI finding of TSOs needing to provide additional support to front-line workers who were struggling with using PROMs. Using techniques they regularly employed, the Implementation Leads were keen to encourage peer support between front-line workers who were more engaged with PROMs and those who were not. This builds upon the concept of TSOs having supportive networks amongst staff. Furthermore, Implementation Lead B wanted line managers to discuss within supervision the completion rates of individual front-line workers to reinforce the message that outcome measures were part of their job role.

*“Just to see, it is still here, this is the usage, we need to keep on using it, and just to encourage the senior workers to embed that as part of their supervision, cos I actually put it on the supervision form.”* [Implementation Lead B]

The Implementation Leads felt that training would only have a limited impact because there were other reasons why some front-line workers would not engage including their opinions about PROMs (as discussed earlier in the findings). This reflects a view expressed within the QI phase that training is often cited as a barrier whereas there are other issues which need addressing.

### **(9.11) It takes time for TSOs to embed PROMs into practice and organisations experience problems with data collection**

This theme focuses on how it took time for PROMs to become embedded into a TSO and during this period there were issues with data collection especially in terms of specific front-line using PROMs.

#### **(9.11.1) Testing out the acceptability of the PROM**

Trialing the bespoke PROMs to check their acceptability appeared useful within the two TSOs. Whilst none of the organisations involved in the QI phase had a trial period, literature on implementing PROMs in healthcare services found that trialing the measure was a facilitator (Boyce 2014). In the CBPR phase, both TSOs tested their PROM based on my recommendation. The trial period was built into the Action Research Spiral (described in the methods chapter) in terms of the TSOs trying out their outcome measures to ensure they were suitable to use in the organisation. I reflected in my diary how trialing felt important because both organisations were

using bespoke measures and because front-line workers had previously found it difficult to use PROMs in wellbeing activities.

Organisation B chose to have a formal trial period where they tried their bespoke PROM for a month. This part of the implementation process was overseen by a Masters student (supervised by me) and she interviewed front-line workers about how they found the outcome measure and whether service-users were happy to complete it. The trial period within Organisation A was less extensive and instigated by myself. Two front-line workers agreed to test out the PROM within their wellbeing activities to explore whether service-users understood the questions. However, one front-line worker did not feel confident enough to use the PROM. The other front-line worker did try out the measure in one group wellbeing activity but was delayed in doing this because of other commitments. Consequently they only tried the measure with 5 attendees at the same activity rather than more extensively. Despite a smaller scale trial than anticipated, the front-line worker did feedback that the PROM appeared suitable.

*“Email exchange with {Name of front-line worker} about how the trialing period went. They had used it in the [name of wellbeing activity]. People had found it easy and straightforward. [Name of front-line workers] feels it would be suitable to use with service-users. I will encourage [Name of Implementation Lead A] to get front-line workers to start using the PROM within other wellbeing activities.” [Extract from my reflective diary]*

#### (9.11.2) How TSOs need an ‘embedding period’ where front-line workers become accustomed to using PROMs

Having an ‘embedding period’, where front-line workers became accustomed to using PROMs without being required to administer measures appeared important within the two TSOs. This phase arose when the two organisations started to use PROMs and was not identified within the QI phase. After the trial period, front-line workers were encouraged to use PROMs but the Implementation Leads did not mandate their use because they wanted front-line workers to become used to administering the PROMs. I felt that Organisation B had progressed from the embedding phase but Organisation A were still in this stage when my research finished. For example, Implementation Lead B discussed how during 2018 they encouraged front-line workers

to utilise PROMs but, to decrease the burden, the Implementation Lead themselves processed the collected measures. In 2019 there was a change in expectations within Organisation B, with front-line workers told they now needed to collect PROMs and it was also their responsibility to process the data. I reflected in my diary how Organisation A still appeared to be in the embedding period because there appeared to be no expectations for front-line workers to use the measures. The embedding period may have arisen in the CBPR phase but not within the QI phase because the two TSOs were choosing to implement PROMs rather than being required to collect the PROMs by a commissioner. This meant that the organisations had the time for front-line workers to become experienced in using outcome measures.

### (9.11.3) Issues with data collection

There appeared to be issues with data collection even when TSOs had employed the facilitators identified from the earlier phases of the PhD. As discussed throughout the findings, Organisation B appeared to have been proactive in trying to implement PROMs, such as having a proactive Implementation Lead, co-designing the measure, and delivering training. Despite these efforts, there were still issues with collecting PROMs from service-users once they received support, engaging some front-line workers, and sustaining the collection of measures. I identified these issues through analysis of the collected PROMs data in Organisation B (explored below). The datasets included in the analysis were described in Section 9.3.2 and the methods are described in Chapter 8. Deviating from my plans, I could not analyse any data for Organisation A because they were at an earlier stage of implementation and only had a small number of completed PROMs by the end of my data collection period. Consequently, the quantitative findings are based on the data from Organisation B only.

### Acceptability of individual questions

Organisation B provided a dataset of 332 completed PROMs which consisted of outcome measures completed at two time points from 166 service-users (further detail on this dataset is included in Section 9.3.2). The individual questions included on the bespoke PROM appeared to be acceptable because the completion rates for each question, at each time point, were either 100% or there were only one or two service-users who did not complete a specific question

(Table 12). The high completion rate indicated the questions were acceptable to service-users. However, it is possible that only completed PROMs were inputted onto the data management system. This is because during a participatory event, front-line workers discussed how they thought the whole PROM had to be completed for it to be inputted into the data management system.

**Table 12- Completion of individual questions**

<b>Question</b>	<b>Time point</b>	<b>Percentage completion rate (n=166)</b>
How are you feeling?	Baseline	99.4% (165)
	2 <sup>nd</sup> time point	98.8% (164)
Thinking about how much contact you've had with people you like, which of the following statements best describes your social situation?	Baseline	100% (166)
	2 <sup>nd</sup> time point	100% (166)
SWEMWBS	Baseline	98.8% (164)
	2 <sup>nd</sup> time point	98.8% (164)
How well would you say you are managing financially these days?	Baseline	100% (166)
	2 <sup>nd</sup> time point	100% (166)

Proportion of service-users completing the PROM at more than one time point

Organisation B experienced issues with collecting measures from service-users once they had received support from wellbeing activities, with less than a fifth of service-users completing PROMs at more than one time point. 313 service-users had completed a PROM at the start of attending a wellbeing activity, unfortunately the TSO could not provide me with data about how that number compares to the total number of service-users who would be eligible to complete a PROM. Therefore, it is not known how extensively the PROMs are used amongst service-users. Of the 313 service-users who had completed a PROM at the start of attending a wellbeing activity, 62 completed a second PROMs after receiving support (19.8%) between 1<sup>st</sup> January 2019 and 10<sup>th</sup> February 2020. Whilst this proportion may increase because some service-users

will still be attending an activity, the rate appears low. This is a problem because it is not possible to understand how a person's wellbeing has changed if they have only completed the measure once. The low collection rates of PROMs from service-users once they are attending a wellbeing activity reflects findings of both the QI and CBPR phases about the challenges of identifying appropriate time points. For example, front-line workers in Organisation B felt that within the advocacy services it can be difficult administering the PROM more than once because the front-line worker may only see a service-user for a small number of sessions and provide much of the support outside of appointments e.g. liaising with the Department for Work and Pensions. What is not known is whether the population of service-users who completed PROMs at more than one time point differed from those who did not. For example, whether front-line workers are focusing on collecting measures from service-users they feel have experienced an improvement in their wellbeing.

#### Variation between front-line workers

As discussed previously, there was an acceptance that front-line workers would vary in their completion rates of PROMs and this finding was supported by the quantitative data for Organisation B. It was difficult to calculate actual variation within the data provided by Organisation B because front-line workers have different sizes of caseloads. Instead, I explored whether front-line workers varied between the proportions of follow-up PROMs in comparison to baseline outcome measures. This was to get a sense of whether some front-line workers appeared better at administering PROMs at more than one time point. The information is displayed in Table 13. It is acknowledged that these calculations are based on the PROMs inputted in the data management system. So it could be that more PROMs are being collected, it is just the front-line workers have not yet processed them. However, as the data needs to be in the system for it to be analysed, it is relevant to explore this issue as a proxy of data collection rates. The completion rates varied between 8.8% and 41.9%. Six of the nine front-line workers had a higher rate than the organisation mean of 19.8%. In contrast, two front-line workers collected follow-ups for less than 10% of their service-users. The wide variation could illustrate the different types of wellbeing activities that front-line workers were involved in, or the need for TSOs to undertake targeted support for some individual front-line workers, as identified within

the QI phase. One front-line worker had not collected any baseline PROMs and only collected one follow-up measure. Their case is interesting because the front-line worker was involved in developing the bespoke measure but was resistant to PROMs generally. This raises questions of how to address a lack of engagement with front-line workers who are resistant to PROMs.

**Table 13- Collection of PROMs by front-line workers**

Front-line worker	Number of service-users with a baseline PROM* (n=281)	Number of service-users with at least one follow-up PROM (n=60)	Percentage of service-users with change data available (Organisation mean: 19.8%)	Whether the front-line worker was above or below the organisation mean
1	22	6	27.3%	Above
2	76	7	9.2%	Below
3	16	5	31.3%	Above
4	0	1	N/A	N/A
5	31	13	41.9%	Above
6	28	9	32.1%	Above
7	34	3	8.8%	Below
8	48	10	20.8%	Above
9	26	6	23.1%	Above

\*The number of baseline PROMs will be less than in other calculations because some were inputted by members of the management team and the focus of this calculation is on variation between front-line workers. Front-line workers would only input their own PROMs not anyone else's so the sample is based on front-line workers who both collected and inputted PROMs into the data management system.

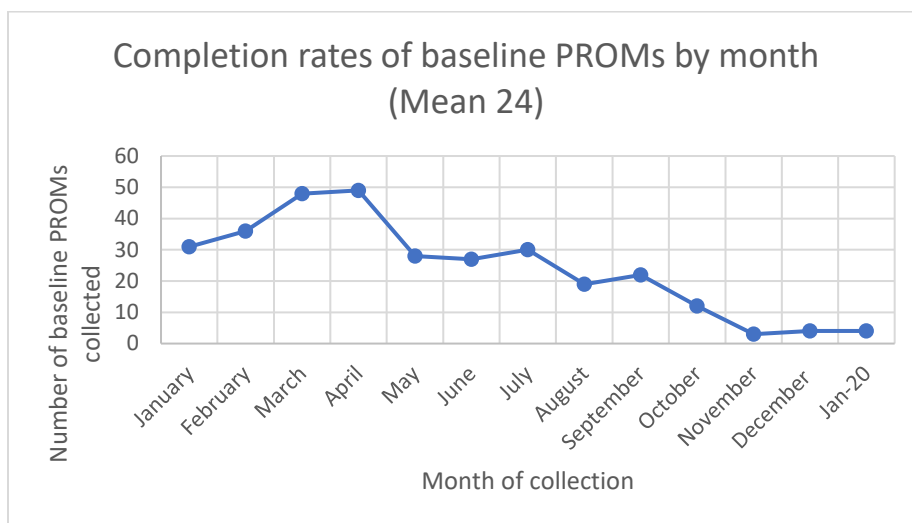
#### Change in front-line workers using PROMs over time

Rather than front-line workers becoming better at completing PROMs over time, there appeared to be issues with the ongoing collection of outcome measures within Organisation B. Within both the QI and CBPR phases, participants believed that completion rates of PROMs would improve over time as front-line workers became more accustomed to administering measures. However, the data in Organisation B did not support this belief. Of the 313 baseline PROMs collected between January 2019-January 2020 (13 months), the average monthly baseline completion rate was 24. In the first 7 months (January-July 2019), completion rates were greater than the mean. But completion rates have consistently been below average for every month since



August 2019 (Figure 11). Whilst some seasonal variation is anticipated such as holidays in August and the Christmas period, there appears to have been a reduction in the baseline PROMs collected per month over time. Some of this variation will be due to a time lag of front-line workers processing PROMs. However given the trend is ongoing, it indicates that Organisation B may need to consider further methods to encourage front-line workers to collect and process PROMs. This is relevant because even before they knew the figures, Implementation Lead B discussed how their lack of capacity had resulted in them not being as proactive in reminding front-line workers to use the PROMs. The experiences within Organisation B reflect a finding from the QI phase which emphasised the need for there to be ongoing training for front-line workers, partly to act as a reminder to administer measures.

**Figure 11- Monthly baseline completion rates in Organisation Between January 2019-January 2020**



Whilst little data was collected within Organisation A, the issue of receiving reminders to use PROMs was raised by front-line workers within the participatory meetings. For them, sporadic use of measures was not because they were resistant to the bespoke PROM. Rather, it was because of needing to remember to use the measure or not having time to use it. Front-line workers discussed needing processes in place to prompt them to use measures including having copies of the measure included with their packs of paperwork. Front-line workers acknowledged that their collection of PROMs was ‘hit and miss’ because of struggling to remember to use measures.

*“It is hit and miss with me. I can’t say, I can’t say with every client that we meet, or that I meet that I actually remember because it’s inevitable that you’ve only got a limited time with a client.”* [Front-line Worker A]

#### (9.11.4) Measurement properties of the bespoke PROM

Within the QI phase, there was disagreement about whether validated or bespoke PROMs had greater validity within TSOs in terms of measuring the change service-users may experience when accessing wellbeing activities. Organisation B chose to use a bespoke PROM which included mainly validated questions drawn from other PROMs along with one question developed by the front-line workers. Consequently, it was possible to explore whether there was consistency between responses to the How are you feeling? bespoke question and the SWEMWBS (albeit questions have been raised about the measure’s validity when used within TSOs). An analysis was undertaken to determine if a service-user was recorded as changing on one question, whether this was reflected in the other question. Of the 162 service-users, 119 had consistent responses (73.5%) in terms of recording whether their wellbeing improved, maintained or deteriorated on both questions (Table 14). There did not appear to be sufficient consistency between the questions as the Cohen Kappa’s statistic was  $k=.3$  ( $p=.000$ ), whereas an acceptable level of consistency is considered to be greater than 0.7 (McHugh, 2012).

The main source of inconsistency appeared to be service-users who maintained on the How are you feeling? question but were classed as improving or deteriorating on the SWEMWBS. One reason for the difference may be because the SWEMWBS entails answering 7 items so there is greater opportunity for service-users to express a difference in their score than on the How are you feeling? question, which consisted of one item. Irrespective of the reasons, the differences create concerns about the validity of the data collected by TSOs and whether change is captured. The comparison was only undertaken for the two questions because they are the only ones which specifically focus on wellbeing where consistency would be expected.

**Table 14- Comparison of change measures by SWEMWBS v bespoke How are you feeling? question**

		SWEMWBS			
		Improve	Maintain	Deteriorated	Total
How are you feeling?	Improve	107 (66%)	5 (3.1%)	7 (4.3%)	119
	Maintain	18 (11.2%)	1 (0.6%)	6 (3.7%)	25
	Deteriorated	7 (4.3%)	0 (0%)	11 (6.8%)	18
	Total	132	6	24	162

**(9.11.5) Implementation takes time because of delays and changes**

Implementation of PROMs appeared to take a number of years, partly because of TSOs experiencing delays due to other priorities and due to the PROMs process being subject to change because of requirements from commissioners. These insights built upon the findings of the QI phase that there may need to be ongoing improvements made to the PROMs process and implementation takes time. However, the QI phase did not identify how just how long implementation can take. For example with Organisation B, it had taken three years to get to the stage where PROMs were supposed to be collected regularly within wellbeing activities. Implementation Lead B was not surprised about the time required because they explained how a key part of the implementation journey had been encouraging culture change to enable the TSO to become an outcomes-based organisation. So in this respect, implementation was not purely about getting PROMs used.

*“At this stage it’s about creating a culture and creating infrastructure within the organisation, I think that’s the main benefit at the moment.”* [Implementation Lead B]

Implementation in both organisations was delayed at times due to other priorities, exacerbated because of the TSOs choosing to implement bespoke PROMs rather than being required to use measures by commissioners. Some of the delays were because staff within both TSOs were having to prioritise collecting and analysing data required by commissioners including the demographics of service-users.

There was a sense amongst stakeholders in the CBPR phase that implementation was never complete because of issues internal and external to the TSO. Internally, organisations felt they could always improve the use of PROMs (as identified within the QI phase). For example,

Senior Manager B discussed improving how they were using the PROMs data. Furthermore, both Implementation Leads discussed anticipating making changes to the PROMs process in the future due to commissioning requirements. I reflected in my diary how the acceptance by the organisations that they would need to develop their PROMs processes was part of the larger picture of how TSO's develop their wellbeing activities depending on the funding available. So despite the two organisations choosing to implement PROMs, ultimately it appeared they were using PROMs in response to the external funding context of outcomes-based commissioning.

## (9.12) Discussion

In this section I summarise the findings, present some of the issues arising from undertaking reflexivity and discuss the strengths and limitations of the CBPR phase.

### (9.12.1) Summary of the findings

A number of contextual and process issues were identified when supporting two TSOs to implement PROMs. The organisations were choosing to implement PROMs to demonstrate their impact in response to the external funding environment. Both relied on the support of external researchers to progress implementation. Each TSO was unique in their characteristics, level of organisational commitment and investment of resources. Having an Implementation Lead who was committed to PROMs appeared to be essential although people accepted that front-line workers would vary in their engagement. Both TSOs chose to co-design a bespoke outcome measure, which differed between the two organisations. Rather than pre-designing all elements of their PROMs process, the TSOs decided some aspects once PROMs were being used within wellbeing activities or left front-line workers to use their discretion on when to administer measures. It appeared important for there to be ongoing training for front-line workers to encourage continued use of PROMs. Having a trial period and giving front-line workers time to become accustomed to using measures was useful. However, even with the TSOs adopting a number of facilitators, there were data collection issues especially with collecting measures at more than one time point and maintaining use of PROMs. Implementation took a number of years and the PROMs process appeared to always be subject to change.

### (9.12.2) Reflexivity- How I impacted on the CBPR research

Reflecting on my impact on the research and how my perceptions evolved over time (ontological authenticity) is a key part of CBPR (Israel et al., 2005; Wallerstein and Duran, 2006; Wallerstein & Duran, 2010). I undertook reflexivity throughout the phase by keeping a reflective diary as well as discussing the work with my supervisors. In this section I discuss some of the most notable issues.

**Impact of my demographics on the power dynamics-** It was important to be aware of the power dynamics between myself and the TSOs because cultural differences cannot be eradicated (Tervalon and Murray-Garcia, 1998). I was aware I was perceived as an academic and came across as middle-class because of my accent and part of the city I lived in. I spent significant periods of time within the TSOs to improve rapport and to address the cultural barriers e.g. taking snacks to share as these provided a source of common ground for discussion and I spent time chatting to front-line workers about their lives such as holidays. I also relied on the Implementation Leads to act as gatekeepers. For example, the Implementation Leads would email the front-line workers before I approached them so that the workers were already aware of who I was and the research.

**Stance on PROMs-** I was concerned that I was perceived as promoting PROMs, whereas my stance towards them is pragmatic (as discussed in Chapter 1). When working with people within the TSOs, I emphasised how I was not expecting them to use PROMs and understood they faced challenges with using measures so wanted to learn more about their experiences. I found it important to emphasise this perspective when building relationships within the two organisations.

**Differing timescales-** A source of tension was the timescales I had planned for the CBPR phase and reality. I had planned for there to be a three month period when the PROMs process would be designed followed by the TSOs having a year of using the outcome measures. However, it took the TSOs much longer to develop a PROMs process. The difference in timescales was a source of internal tension for me because I was conscious that my funders were expecting me to undertake analysis on a year's worth of collected PROMs data. Over time, I accepted I needed to be led by the TSOs, and the time required was a finding in itself. My experience reflects a wider

challenge of needing to pre-design studies when applying for research funding whereas a key element of CBPR is responding to the evolving needs of community partners (Pyett et al., 2008)

**A lack of experience in undertaking CBPR-** I was inexperienced in using CBPR and in hindsight there were some issues which I could have handled differently. For example, I did not have a prior relationship with Implementation Lead A before we agreed Organisation A would participate in the research. In hindsight it would have been better to have spent time building up relationships and discussing our expectations and hopes about the study before deciding to work together. Over the course of the study I did become more skilled at CBPR and was fortunate to be supervised by an experienced practitioner who provided me with advice throughout the process.

**Overreliance on email-** Within academia, email is the prominent mode of communication and as a researcher I have become over reliant on sending emails rather than phoning people. In contrast, telephone or face-to-face communication is most prominent within TSOs, with front-line workers saying they access their emails irregularly. On reflection, too often I emailed people and experienced slow or non-response to emails. Over time I became better at telephoning people but it was an important area of learning and caused delays during the initial period of the CBPR.

**Balancing best practice and the needs of the TSOs-** The purpose of the CBPR phase was to support the TSOs to implement PROMs using the best practice identified in the earlier phases of the PhD. Whilst I shared the emerging learning about implementing PROMs, there were times when the organisations made decisions that contrasted with the previously identified facilitators. Often this was the product of the specific context, such as a lack of staff resources. For example, the two organisations could not invest in administrative staff to support the processing of PROMs. This felt an important difference between implementing PROMs within the ideal context and trying to implement measures within TSOs, where barriers will be encountered.

### (9.12.3) Appraising the conduct of the CBPR phase

Springett et al's (2011) criteria was used to appraise the conduct of the CBPR phase. Details of the criteria are described in the previous chapter. Several of the categories consider similar issues

so I have grouped them together to reduce repetition. The aim of the appraisal process is to facilitate reflection rather than to produce a tangible assessment of whether the research conducted was ‘good’ or ‘bad’.

**Participatory/ A collective research process/ the Project is collectively owned and**

**Participatory validity-** I led the research which at times challenged the idea of having a sense of collective ownership, which is an important principle of participatory research. The TSOs were agreeable to me leading the research activities because the organisations valued the academic credibility I provided e.g. they appreciated me analysing the PROMs data. However, whilst I sought to be led by the TSOs, I ultimately maintained ownership of the phase including pre-deciding the timescales of the project and how the research funding could be spent. Part of the reason for this was because the CBPR phase was one component of a multiphase PhD. I found it difficult to relinquish ownership because I felt I needed to complete the project within the fixed timescale of my PhD. For example, I sometimes made decisions on my own to ensure the study progressed rather than face delays by involving stakeholders. Whilst the Implementation Leads did not mind this approach, I would undertake future studies differently in regards to sharing ownership.

**Locally situated/ Contextual validity/ Produces knowledge which is local, collective, co-**

**created, conversational and diverse and Intersubjective validity-** The CBPR phase was based within two TSOs and shaped to meet the needs of each organisation. This tailoring of the approach was a key strength of the research. Throughout the study, the knowledge and outputs have been co-created including involving front-line workers in designing a bespoke PROM.

**Promotes critical reflexivity-** I undertook critical reflexivity including keeping a diary, having monthly PhD supervision meetings and discussing the research with the Implementation Leads. In hindsight, it could have been beneficial to undertake reflection with the front-line workers during the participatory events rather than purely focusing on issues relating to implementation.

**Aims for transformation through human agency /Whether the research enables positive social change and has a transformational impact beyond the duration of the study/ Strives for broader impact beyond the study/ Produces local evidence based on broad**

**understandings of generalisability and Catalytic validity-** The research has helped the two TSOs to learn more about PROMs and progress implementation. More generally, the findings from the CBPR phase have been integrated with the findings from the QI phase and literature reviews to develop overall findings (discussed in Chapter 10). These findings have been disseminated to commissioners and stakeholders from TSOs such as through developing guidance (described in Chapter 10). The learning is also being disseminated beyond the third sector such as at academic conferences. The focus of the PhD on implementing PROMs meant any change was always going to be limited to changing organisational practice rather than contributing to social change; the latter is often the ultimate aim of undertaking CBPR.

**Ethical Validity-** The findings have been derived from the study. Throughout the process I checked back with the involved stakeholders to ensure the findings resonated with their experiences. For example, I met with a number of people from Organisation A to discuss the findings in December 2019. Furthermore, the findings of the whole study were shared at a stakeholder event (described in Chapter 5).

**Empathic Validity-** My research has been running alongside a number of other studies within the university which are working with local TSOs and consequently there feels a genuine partnership between the university and the local third sector. Other researchers and I are seeking ways to continue the momentum of these partnerships now the research funding has finished. I previously worked in TSOs and this has helped my empathic validity because I understand the sector and truly believe it plays an important role within health and social care.

**Dialectic process characterised by messiness-** The CBPR phase has been characterised by messiness and I responded by taking an iterative approach to designing the study. For example, I was not able to conduct REM because of stakeholders not having capacity to attend the sessions. At times the messiness has been challenging because I have been conscious of undertaking research which reflected my funding proposal. However, over time I have learnt to accept the messiness.



### (9.13) Strengths and Limitations of the CBPR Phase

This section considers the specific strengths and limitations of the CBPR phase. In the next chapter the positives and negatives of the overall study are explored.

#### (9.13.1) Strengths of the CBPR phase

The phase had four key strengths. The main strength was co-designing the PROMs process with the two TSOs. This is in contrast to other studies where organisations have to try and implement an externally developed PROMs process. Taking a collaborative approach encapsulates a facilitator identified in the QI phase. Secondly, involving two organisations was advantageous in terms of generating knowledge on what issues appear similar or different between TSOs. Thirdly, taking a CBPR approach enabled me to identify process-related issues not identified within the QI phase such as TSOs taking a more organic approach to designing the PROMs process. Fourthly, the study had an immediate impact on practice because the TSOs increased their capabilities in respect to PROMs by incorporating the learning from the study.

#### (9.13.2) Limitations of the CBPR phase

Whilst the CBPR phase had a number of strengths, there were also 7 limitations. Firstly, having too short a timescale for the phase was a key limitation. Due to the three-year nature of a PhD, I had planned to spend eighteen months with the TSOs, anticipating this would be sufficient time to develop the PROMs process and use the outcome measures in routine practice. However, it transpired that longer was needed partly because of the length of time implementation takes but also to allow time for relationship building. For example within Organisation A, I spent the first few months of the CBPR phase developing relationships with staff.

Secondly, it was not possible to undertake the full planned statistical analysis of routine PROMs data due to the TSOs' reporting systems. I had hoped to undertake quantitative analysis on the completed PROMs, whether there was variation between different types of service-users or wellbeing activities and how comparable scores were on the bespoke questions compared to validated questions. Unfortunately no analysis was undertaken on Organisation A because the

data was not available. Within Organisation B, the analysis was limited by the TSO's reporting system. For example, demographics of service-users were not linked to the PROMs data so it was not possible to explore differences between groups of service-users. The difficulties with accessing data resulted in a much smaller quantitative component within the PhD than planned. Whilst it is acceptable to have a qualitatively dominant mixed methods design (Creswell and Plano Clark, 2018), further quantitative analysis may have enhanced the findings.

The third limitation was that the majority of my contact was with the two Implementation Leads rather than front-line workers and service-users. This is justifiable because the QI phase found that it was the Implementation Leads who played a pivotal role in implementation. However, I would have preferred for front-line workers and service-users to have greater involvement but the Implementation Leads discouraged this. For example, the Implementation Leads did not feel it was appropriate for me to interview service-users because they did not want to change the outcome measure again. Furthermore, they felt front-line workers had limited capacity so I needed to minimise how many group participatory events I held. Fourthly, both TSOs had chosen to implement PROMs rather than being required to by commissioners which created a specific context such as having the opportunity to have the time to take a collaborative approach to choosing a bespoke PROM. Different insights may have been gained if I had been supporting a TSO with implementing a PROM they were required to use.

Fifthly, I could have used a case study approach because the focus of the CBPR phase was exploring the experiences of specific TSO (Ying, 2003). For example I considered how the organisations' characteristics may have impacted on the PROMs process. However I felt that taking a case study approach was not appropriate because typically the approach is used to understand a phenomena within a specific context (naturalistic), whereas I was working with TSOs to actively influence the PROMs process (Crowe et al., 2011). Sixthly, myself and the organisations decided not to assess whether implementation had been successful using standardised criteria. The purpose of the CBPR phase was to support TSOs with implementing PROMs. In this regard, a case could be made for assessing whether implementation was successful. I did explore potential criteria which are used to assess implementation success including RE-AIM, Rogers' Diffusion of Innovation and Proctor's criteria (Glasgow et al., 1999, Rogers, 2003, Proctor et al, 2011), settling on using the latter criteria. However, when speaking

with Implementation Leads it became apparent that these criteria were not relevant to their experiences. This was because the Leads did not view the implementation of PROMs as a finite process nor were they expecting outcome measures to be used comprehensively throughout the TSO. Thus they did not feel it was appropriate to try and judge their experiences using an externally developed criterion of success.

Finally, conducting the CBPR phase as part of a PhD created challenges in terms of ownership of the study. The TSOs valued the academic input I provided to implementation and were willing for me to take the lead on the research. However because the CBPR phase was part of my PhD, I maintained greater ownership than if the study had been undertaken in different circumstances (this issue is explained in the reflexivity section above).

#### (9.14) Summary of the chapter

The CBPR phase was useful in terms of enhancing the findings emerging from the QI phase along with supporting two TSOs to progress their implementation of PROMs. A number of facilitators and barriers were identified, some were similar to the QI phase, whereas others differed or enhanced understanding on a specific issue. In the next chapter, the findings of the CBPR phase, QI phase and earlier literature review work are integrated to identify the overarching issues which appear relevant for organisations and commissioners implementing PROMs within the third sector.

## Chapter 10- Discussion Chapter

### (10.1) Outline of the chapter

This chapter focuses on integrating the findings from the different phases of the research and explores how the findings compare to existing literature. The final part of the chapter considers the implications of the study for future practice and research.

### (10.2) Integrating the findings

The overall findings of the PhD were identified through integrating the different phases of the study using a triangulation protocol approach (as described in Chapter 5). The findings from the systematic review of reviews (Chapter 3), the TSO literature review and stakeholder event (Chapter 4), the QI phase (Chapter 7) and the CBPR phase (Chapter 9) were compared using a matrix to help generate overarching findings and to understand differences between the third sector and healthcare services (Appendix 21). Specifically, I considered whether the findings were consistent (Convergence), were similar but enhanced understanding (Complementary), differed (Dissonance) or the issue was only identified in one context (Silence). I also considered how each finding linked to the CFIR constructs (included in Appendix 21). The findings arising from the triangulation protocol were discussed at the stakeholder integration event (explained in Chapter 5). The findings were positively received, with attendees feeling that they reflected their experiences.

#### (10.2.1) Model of implementation

As part of the integration process, the visual researcher and I worked together to produce a model to illustrate the implementation of PROMs in TSOs. The model of implementation builds upon the diagrams developed for each phase of the PhD (Figures 1, 3 and 10). We presented the model at the stakeholder event, using the feedback at the meeting to make improvements. The model is available from:

[https://issuu.com/niftyfoxcreative/docs/proms\\_map\\_final?fr=sMGVIYTEyOTI2ODM](https://issuu.com/niftyfoxcreative/docs/proms_map_final?fr=sMGVIYTEyOTI2ODM) . The model is more visual and places greater emphasis on facilitators than the other diagrams arising from the PhD. This is because I plan to disseminate the model to third sector stakeholders who

will want to digest the learning quickly and easily in order to take positive action. Furthermore, the model was used to inform the guidance document (discussed later). In regards to content, the main difference between the diagram produced for the systematic review of reviews (Figure 1) and this final model, is the inclusion of context related issues. During the primary research it became apparent that contextual issues influenced the implementation of PROMs within TSOs, whereas these issues were not as prominent within the systematic review of reviews. It is not known whether this is because of the unique nature of TSOs or whether previous research placed more emphasis on the design and execution of the PROMs process rather than considering implementation in the widest sense.

#### (10.2.2) Summary of the findings

The research identified how implementation appears to be an iterative process, with a number of overlapping stages and is influenced by the external and internal context, including individuals. The arising issues interacted and influenced each other. Thus, action in one part of the model could mitigate barriers which were occurring in another part e.g. if a TSO was required to use a PROM they perceived to be inappropriate, having skilled front-line workers administering the measure could enable data collection. Some factors influencing implementation acted as facilitators, others were barriers and many had the potential to be bidirectional, so either helping or hindering implementation depending on their execution. The bidirectional nature of factors is consistent with the systematic review of reviews, indicating this is relevant irrespective of the type of organisation implementing PROMs.

#### External and internal contextual issues

The external context facilitated the use of PROMs in TSOs. A major facilitator, and indeed incentive for PROMs was the need for TSOs to obtain funding in a context of austerity and outcomes-based commissioning. This funding was often contingent on organisations using PROMs, and thus the delivery of some wellbeing activities depended on TSOs managing to implement PROMs. This motivation differs for healthcare services, where the emphasis is on the use of PROMs for care management purposes. In practice, the external funding context was also

a barrier to implementation because TSOs were funded by multiple short-term contracts, each requiring different PROMs. This resulted in organisations having the challenge of a lack of consistency around requirements for PROMs because commissioners behaved differently. Furthermore, external relationships facilitated the use of PROMs. TSOs found it helpful to receive support from external researchers (including students) and advisors, alongside learning from other local organisations. Although the usefulness of this support was dependent on the learning being shaped to meet the needs of the organisation.

The unique internal context of an individual TSO influenced implementation, with some organisations having more facilitating features than others. A number of factors contributed to the internal context including the strategic commitment to PROMs, the organisation's size and structure, its culture and the resources available for PROMs. Whilst some of the internal contextual barriers faced by TSOs were not insurmountable, it appeared important to account for this context through developing a PROMs process which was suited to the specific organisation and by taking mitigating action in an attempt to overcome specific barriers the internal context could present. Although literature on the implementation of PROMs in healthcare services has identified some issues relating to internal context, this research on TSOs has placed more emphasis on the importance of the internal context and identified a greater number of issues which appear relevant.

#### People-related issues

Individuals within a TSO had a bidirectional influence on implementation depending on their views of PROMs, their skills and ability to prioritise PROMs compared to other commitments. However, these factors were not static and individuals became more or less engaged depending on their views of the appropriateness of the specific PROMs process and the training they received. This illustrates the inter-connectedness between the different components of implementation. Skilled individuals could help mitigate barriers arising from other aspects of implementation, especially proactive Implementation Leads. Utilising volunteers could increase an organisation's capacity to deliver PROMs, however most TSOs had not drawn upon this resource. Whilst the Implementation Lead was identified as a facilitator within healthcare contexts, within TSOs it appeared implementation was dependent on having an Implementation

Lead who bought into the concept of PROMs and was able to prioritise implementation over other commitments.

### Designing the PROMs process

Choosing a PROM in conjunction with front-line workers to ensure the measure was appropriate for the TSO and its service-users was a facilitator, particularly because this helped to engage front-line workers. Organisations appeared to struggle more when implementing outcome measures chosen by a commissioner. A key barrier was people within the third sector feeling there was a lack of validated PROMs appropriate for wellbeing activities, resulting in some organisations developing bespoke measures.

TSOs faced barriers with designing an appropriate PROMs process including issues with collecting, processing and using the data. This arose because of issues with staff capacity, a lack of infrastructure, organisational culture and people perceiving it was difficult to use PROMs within wellbeing activities. Examples included organisations finding it problematic to identify appropriate time points at which to administer the PROM or front-line workers not having the capacity to process collected measures. The challenges associated with designing a PROMs process meant that some organisations did not have a standardised procedure, and instead relied on front-line workers to take the initiative with utilising measures. However, as found in healthcare services, it appeared that not designing the PROMs process could be a barrier.

### Training and supporting front-line workers

Consistent with healthcare services, an important facilitator was front-line workers and volunteers receiving training and support to encourage them to use PROMs. The content of training needed to include learning on how to use PROMs and the collected data, alongside ideological training about the importance of using outcome measures. Additional to training, the engagement of front-line workers was facilitated by PROMs being included within job descriptions and front-line workers having reduced caseloads to give them more time to spend on PROMs. The latter was important because front-line workers felt a lack of capacity was a barrier to them using PROMs.

### Using PROMs in practice

Implementation appeared to take a considerable period of time and there needed to be an embedding period, to give TSOs the opportunity to make improvements to the PROMs process and for front-line workers to become more accustomed to using measures. Implementation required a sustained period of effort from the Implementation Lead alongside the organisation investing resources and encouraging staff engagement. This appeared more challenging than in healthcare services because of wellbeing activities only being funded for short periods of time and commissioners requiring data quickly and/or changing their requirements for PROMs. Even when TSOs embedded many of the facilitators, and were managing to collect PROMs, there appeared to be considerable issues with the quality of data collected. This included challenges with administering a PROM at more than one time point with individual service-users, variation in the engagement of front-line workers, ongoing support so rates of collection did not decline and questions about whether PROMs were capturing changes in wellbeing.

Whilst a number of facilitators and barriers were identified in the PhD, some TSOs were managing to implement PROMs despite not adopting all of the facilitators. This indicates that there may be some factors which are more influential than others. For example, whilst it appeared essential for TSOs to have a proactive Implementation Lead, having a trial period could be useful but was not essential. More generally, the findings raise questions about the appropriateness of using PROMs routinely within TSOs. Organisations were primarily using PROMs to demonstrate their impact to funders rather than for the care management of service-users. Furthermore, implementation required considerable investment of time and resources, which TSOs struggled with. However, even with investment, the quality of data collected by TSOs could be poor (as found in the CBPR phase of the PhD). This was especially because of uncertainty about whether PROMs capture change, either because TSOs are using a bespoke measure or the PROM has not been validated for use within the third sector. Arguably, because of the resource-intensive nature of implementation, and issues with data quality, there are fundamental questions about whether trying to use PROMs routinely within TSOs is appropriate or if other methods of demonstrating impact would be more fruitful e.g. one-off evaluations.



### (10.3) Reflections on the utility of the CFIR

The CFIR has been used to support the theorisation of the findings throughout the PhD. Using an implementation theory was important because to date, studies on implementing PROMs have generally not been underpinned by theoretical frameworks. The CFIR was very useful during the earlier stages of the PhD in terms of informing the systematic review of reviews and for coding the primary research. However, I moved beyond the CFIR constructs when developing the findings arising from the primary research. The reasoning was because some findings transcended a number of constructs and in other cases, the CFIR had limited value in helping to understand a specific finding. Furthermore, even when the CFIR construct was relevant, I chose to draw upon the language used by participants rather than using the terminology of the CFIR because the former more clearly communicated the issues relevant to TSOs. At times, I needed to supplement the CFIR with ideas from other implementation theories/frameworks to help make sense of the findings.

I detail how the CFIR constructs align with the findings in Appendix 21. There were three specific areas where there appeared to be notable differences between my findings and the constructs of the CFIR: (1) Designing the PROMs process, (2) Planning and (3) Sustainability. Factors related to *designing* the PROMs process such as which outcome measures to use and how to process collected data were prominent findings of my research. However, the CFIR had limited use for theorising the design process because there is only a construct relating to design. Consequently, the CFIR may be more useful for understanding the implementation of a pre-designed intervention. To supplement the CFIR, I drew upon the Double Diamond approach (The Design Council, 2019). This framework focuses on the need for organisations to take a collaborative, iterative approach to design. *Planning* the implementation process is a construct within the CFIR that was relevant in the systematic review of reviews, in terms of healthcare services planning implementation. However, in the QI phase I did not identify whether TSOs planned their implementation process and within the CBPR phase, I identified that TSOs took an organic approach to implementation with little evidence of planning. Finally, the CFIR has no constructs relating to *Sustainability*, whereas I identified how only some TSOs managed to make PROMs part of routine practice and that this appeared somewhat related to whether the organisation underwent cultural change. Given this, organisational change theories e.g.

Alvensson and Karreman's (2000) work on discourses within an organisation may be useful in developing a further understanding about the sustainability stage when implementing PROMs.

More generally, there appears to be a disconnect between the implementation of PROMs as a process with issues influencing each other, and the CFIR which considers constructs separately (Nilsen, 2015). Thus, it was necessary to supplement the CFIR with theories/frameworks that take a process approach to implementation including the Knowledge to Action Framework (Field et al., 2014).

#### (10.4) Comparison of findings with the existing literature

This section compares the findings of the primary research with other literature to get a sense of how the findings compare to other studies. I conducted formal literature reviews before conducting the primary research (presented in Chapter 3 and 4). Furthermore, I have sought to keep abreast of newly published literature relevant to the topic, including conducting searches in December 2019. Recent publications on using PROMs in healthcare services include Chan et al. (2019) and Gibbons and Fitzpatrick (2018). Additionally, there has been recently published resources on using PROMs within wellbeing activities. These include guidance aimed at TSOs (What Works for Wellbeing, 2019) and a report on using PROMs within social prescribing services (Polley and Richards, 2019).

##### (10.4.1) How external context and external relationships influence implementation

Participants in the study described how TSOs were primarily implementing PROMs because organisations perceived they had no choice, given the pressures of the external funding context. Sometimes organisations were required to use PROMs by specific commissioners. Alternatively TSOs decided to implement PROMs in response to the external funding context. The impact of the external funding context was not prominent in the evidence on implementing PROMs in other contexts (Foster et al., 2018). However, this 'no choice' narrative is supported by Bach-Mortensen and Montgomery (2018) in relation to TSOs and evaluation. They found TSOs were motivated to undertake evaluation because the external funding context places pressure on the third sector to effectively compete for scarce resources and justify the value of what is provided.

Lead third sector advisory organisation NCVO has warned of reduced funding available for TSOs (NCVO, 2019c), with organisations reporting they are responding to the situation by taking steps to justify the value of what they do (Harris et al., Unpublished). The pressure for TSOs to justify their value through using PROMs is demonstrated by a recent consultation on which PROMs should be used for performance monitoring within the new NHS Link Worker contract (NHS England and NHS Improvement, 2019). However, the implementation of PROMs could be improved through commissioners taking a more collaborative approach with TSOs. The importance of developing better relationships between commissioners and TSOs has been increasingly acknowledged by commissioners (ADASS' Learning Disability Policy Network and the Care Provider Alliance, 2013), indicating a collaborative context may evolve.

My research identified that external advisors/researchers could facilitate implementation, providing they took a collaborative approach with a TSO and were responsive to the organisations' specific needs. The bidirectional nature of external support has been identified in other studies on supporting TSOs, albeit not previously in relation to PROMs (Arvidson, 2009).

#### (10.4.2) How an organisations' internal characteristics and commitment to PROMs impacted on implementation

TSOs involved in the research were primarily motivated to use PROMs to justify funding. This purpose contradicts evidence from healthcare services, which emphasised the need for measures to have a care management (therapeutic) purpose (Foster et al., 2018). Thus, PROMs may serve a different purpose in the third sector than in other contexts. Despite these differences, in all types of organisations it appeared important for there to be a strategic commitment to using PROMs, a finding supported by other literature (Van Vliet et al., 2014).

Participants spoke about each TSO having a unique organisational context, which influenced the design of the PROMs process. The importance of an organisation's structural characteristics was not identified in relation to healthcare services (Foster et al., 2018). However, structural characteristics have been raised as an issue in relation to TSOs undertaking evaluation (Bach-Mortensen and Montgomery, 2018). Therefore, a TSO's characteristics should be accounted for when designing a PROMs process and undertaking implementation.

Consistent with healthcare services (Foster et al, 2018), a bidirectional issue identified in the primary research was whether TSOs invested sufficient resources into implementing PROMs. However, not all organisations are able to invest resources, with TSO managers facing a trade-off on whether to use resources on PROMs or front-line delivery (Mayne, 2017). Furthermore, as TSOs often use PROMs because of commissioner requirements, it could be argued that commissioners should resource the infrastructure needed for PROMs. Some commissioners fund TSOs to undertake evaluation (Big Lottery Fund, 2017), which could be replicated in respect of PROMs. However, Bach-Mortensen and Montgomery (2018) discussed how there was low uptake of a scheme funding resources for evaluation, which indicates that there are other barriers besides resources influencing implementation within TSOs e.g. the commitment of managers.

Having appropriate data management systems to enable the processing and use of PROMs data was a facilitator identified within the primary research and the systematic review of reviews, indicating it is a relevant facilitator irrespective of the specific context (Foster et al., 2018). Other studies have also found data management systems important within TSOs (Penn et al., 2019). However, as with this research, Penn et al. (2019) found that some TSOs may not be able to afford to invest in a sufficient data management system. Furthermore, as identified during one of the PhD's stakeholder consultation events, individuals within the TSO need to have the capacity and capability to engage with the data management system. This again highlights the interconnectedness of the different issues influencing the implementation of PROMs.

#### (10.4.3) The importance of people in the implementation process

The primary research identified how it appeared critical for TSOs to have an Implementation Lead, who was proactive in implementing PROMs. Whilst the systematic review of reviews identified the existence of this role in healthcare services (Foster et al., 2018), not all studies have discussed the need for an Implementation Lead (Snyder et al., 2011; Porter et al., 2016). Furthermore, previous literature focused on healthcare services did not emphasise how having an Implementation Lead who buys into the concept of PROMs and prioritises implementation appears to be critical. This raises questions about whether having an Implementation Lead is more essential in the third sector than in other contexts.

The PhD identified how a TSO's implementation was influenced by front-line workers because their skills, opinions and relationships interacted to impact on their engagement with PROMs. Literature from other contexts supports these findings that staff affect implementation but in turn their engagement is influenced by their perceptions of the specific PROMs process (Foster et al., 2018). However, often the guidance on implementing PROMs e.g. What Works for Wellbeing's (2019) report does not consider the human influence on implementation, concentrating instead on the design of the PROMs process. This indicates a gap between the research on implementing PROMs and the advice being given to organisations.

It emerged from the primary research in this PhD that volunteers could support the implementation, but the role of volunteers has not been identified previously in relation to PROMs. This is probably because volunteers are more prominent within TSOs than in healthcare services (Buckingham, 2012). In support of my findings, Mayne (2017) felt that volunteers can make a positive contribution to evaluation, providing they receive sufficient support. This indicates there is the potential for TSOs to involve volunteers in the PROMs process, which could increase an organisation's capacity in respect to collecting and processing measures.

#### (10.4.4) Developing a PROMs process appropriate for the specific needs and internal context of an individual TSO

##### The principles underpinning design

Taking a collaborative approach to choosing the measure was a key facilitator identified in the primary research and reflects other literature on implementing PROMs in wellbeing activities (Polley and Richards, 2019) and within other contexts (Chan et al., 2019; Foster et al., 2018; Gibbons and Fitzpatrick, 2018). However, other literature on PROMs has not identified how taking a collaborative approach entails a considerable time commitment when developing the PROMs process. It has been argued this time commitment is worthwhile because it encourages front-line workers to engage with implementation (Harris et al., Unpublished).

Both the systematic review of reviews and primary research identified how service-users' needs were usually considered by organisations when deciding the PROMs process. However, TSOs rarely appeared to consult service-users directly. The approach contradicts guidance on implementing PROMs which actively encourages involving service-users (Aaronson et al.,

2015). It is also at odds with the user-led approach usually taken by TSOs to their work (Hardwick et al., 2015). Participants in my research justified their approach because they felt front-line workers could provide the service-user perspective because they often came from the same community. Interestingly, stakeholders did not feel a lack of service-users involvement was detrimental to implementation. However, not involving service-users is at odds with the current context of patient involvement in healthcare.

### Bespoke or validated PROMs

A prominent theme arising from the primary research was whether TSOs should design their own bespoke measures or utilise validated PROMs. The issue relates to the need to choose an appropriate PROM for the wellbeing activity but also raises questions about the quality of data captured by TSOs. Whilst the evidence base on implementing PROMs in healthcare services has identified the need to choose an appropriate measure (Foster et al., 2018), previous research has not found that organisations are designing their own measures. The issue could be specific to the third sector because many of the existing PROMs have not been developed for wellbeing activities. The lack of appropriate PROMs for wellbeing activities has also been identified by Polley and Richards (2019). They felt the reason was because wellbeing activities seek to address the social determinants of health, whereas PROMs have generally focused on health outcomes related to the biomedical model of health. This indicates the need to develop new PROMs suitable for wellbeing activities delivered by TSOs. One avenue to explore would be developing item banks, where there are a range of questions available and TSOs could choose which questions they want to use within their PROM (Porter et al., 2016). An alternative method could be developing goal-based measures such as MYMOPs, where service-users set their own objectives and progress is measured on whether they have been supported to achieve the goal (Paterson, 1996). Irrespective of the specific PROM used, the primary research identified how it was important that measures are short and designed in a way to support collection e.g. including graphics. This finding is supported by other literature including Gibbons and Fitzpatrick (2018) and Philpot et al. (2018), indicating the design of the PROM is relevant irrespective of the specific context.

### Designing the PROMs process

The systematic review of reviews identified the importance of designing the PROMs process to ensure there was a clear procedure for administering and processing PROMs alongside using the collected data. Furthermore these processes needed to be straightforward, flexible and appropriate for the specific organisation (Foster et al., 2018). The importance of designing the PROMs process is somewhat supported by the findings of the primary research, inasmuch that some TSOs did not design their PROMs process and this appeared to be a barrier because front-line workers did not have a process to adhere to in respect of using measures.

The primary research identified how TSOs mainly collected PROMs through front-line workers supporting service-users to complete paper based measures. Jaharidgar et al. (2012) amongst others, support the finding because they identified how some service-users struggle to self-complete PROMs. The reliance on paper completion contrasts with the move towards ePROMs in other contexts (De Faoite, 2018). TSO managers reported not having the resources to develop ePROMs. Furthermore, the service-users interviewed were resistant to ePROMs. The reason may be because service-users within TSOs are often from lower socioeconomic groups, who typically have lower levels of digital literacy and face challenges with using ePROMs (Gibbons and Fitzpatrick, 2018). Despite this, managers in the study were interested in ePROMs because they felt it would reduce the time spent by front-line workers on processing measures. Chan et al. (2019) identified a similar trade-off, they reported how there were higher completion rates for paper based PROMs but these require greater staff resource to process. Consequently, it appears designing a PROMs process entails balancing different factors, including resources, capacity and different stakeholders' preferences.

In the primary research it was identified how TSOs found it difficult to identify and comply with time points for collecting PROMs. This finding was not identified in the systematic review of reviews (Foster et al., 2018), but has been identified in a recent study on healthcare services (Gibbons and Fitzpatrick, 2018). Furthermore, a recent trial on the benefits of welfare advice (a type of wellbeing activity) found that outcomes measures needed to be collected over a two year period to capture the impact of the support (Howel et al., 2019). This reflects concerns raised in the primary research that PROMs are not capturing the longer-term impact of TSOs on the lives of service-users. Alongside collecting measures, the primary research identified that TSOs needed to process and use the collected data but organisations often did not have sufficient staff

capacity or technology resources to undertake these tasks. This finding has also been identified within healthcare services (Hernar et al., 2019), indicating resource and capacity barriers may be relevant when implementing PROMs, irrespective of the specific context.

#### (10.4.5) Engaging and skilling up staff

Training and supporting front-line workers was identified as a facilitator within the primary research, consistent with literature in other contexts (Porter et al., 2016; Foster et al., 2018; Gibbons and Fitzpatrick, 2018; Chan et al., 2019). Furthermore, the need to train front-line workers is often recommended within guidance on implementing PROMs (Aaronson et al., 2015). This indicates that training is a key component of implementation, irrespective of the specific context. In the primary research there was an acceptance amongst participants that even after receiving training, front-line workers would vary in their engagement. The systematic review of reviews identified that this variation can create issues with staff morale if front-line workers feel colleagues are not engaging in PROMs (Foster et al. 2018). Thus the variation in engagement between front-line workers may be problematic longer-term, with TSOs needing to take additional steps to address the issue.

#### (10.4.6) TSOs experience problems when starting to use PROMs in practice and have to make improvements

TSOs experienced problems when trying to use PROMs in routine practice, resulting in organisations reflecting on, and further developing their processes. Having a trial period was found to be a facilitator in both the systematic review of reviews and CBPR phases. However, none of participants in the QI phase had experience of undertaking a trial period, indicating it may not currently be common practice within TSOs, but could be encouraged. Taking an iterative approach to implementation occurred in some healthcare services (Foster et al., 2018) and is considered good practice in intervention design (O'Cathain et al., 2019; The Design Council, 2019). Going forward, organisations should be reassured that it is normal for problems to arise when an organisation starts to use PROMs and they are likely to have to make improvements to the process.



In the CBPR phase, it was found that it took time to implement PROMs. Of concern is that Chan et al. (2019) found it took three years for PROMs to become part of an organisation's routine practice. This is challenging for TSOs, because as identified in the primary research, TSOs often receive short-term funding for wellbeing activities, an organisation may have to provide data quickly to commissioners, and commissioners' requirements for PROMs can change over time. Furthermore, not all TSOs in the primary research reached a point of sustaining the use of PROMs. Research on healthcare services has given little attention to this issue and the systematic review of reviews recommended further research on this issue was needed (Foster et al, 2018). The QI phase identified that TSOs needed to feel it was beneficial to use PROMs and undergo cultural change to sustain PROMs. Mayne (2017) reported similar facilitators in respect of sustaining evaluation within TSOs. Given the challenges of time and sustainability, it may be more apt to consider the implementation of PROMs as an ongoing process rather than a finite action, with TSOs continually needing to support staff and adapt the process.

In summary, a number of issues identified in the QI and CBPR phases were consistent with studies of healthcare services, indicating they may influence implementation irrespective of the specific context. This compatibility is not unexpected because Lewis (2002), amongst others, has argued that TSOs are sufficiently similar to other types of organisations to have shared experiences and learn from each other. Despite some similarities, the primary research identified additional factors which appeared to arise from the specific funding and organisational context of TSOs. This highlights the importance of undertaking third sector specific research and developing targeted guidance.

### (10.5) Appraising the conduct of the study

The Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018) was used to appraise the overall conduct of the study (as explained in Chapter 5). Details of the assessment are in Appendix 10. Generally, I felt the conduct of the research was undertaken to a high standard. I believed the study had an appropriate research question, methodology and the qualitative components of the study were executed well. Furthermore, there was a comprehensive integration of the findings, including the findings being grounded in the data. However, there were problems with the quantitative element of the PhD in terms of not being able to conduct all

of the planned statistical analysis and only having PROMs data from one TSO (as discussed in Chapter 9).

## (10.6) Strengths and Limitations of the study

This section focuses on the strengths and limitations of the overall study. The strengths and limitations of the specific phases of the study have been discussed in previous chapters.

### (10.6.1) Strengths

The research has seven key strengths. Firstly, the study appears to be one of, if not the first, and most comprehensive pieces of research on implementing PROMs within the third sector. Secondly, issues have been identified which appear to influence implementation which previous research has not identified. Thirdly, an established implementation theory: the CFIR was used to conceptualise emerging findings. Fourthly, having multiple phases of the research and using different methods was advantageous because each phase complemented each other by identifying unique findings and enhanced understanding of the issues arising from the other phases. For example, the benefits of taking a collaborative approach was identified in the QI phase, and in the CBPR phase, I identified the additional time this approach takes. Fifthly, participants represented a range of interest groups and organisations, enabling a variety of voices to be explored including service-users, front-line workers managers and commissioners. Sixthly, the study was conducted to a high standard when assessed using the MMAT. Finally, a consequence of the research has been capacity building, both for organisations and individuals. For example, one service-user representative used the experience of contributing to the CBPR to help her gain a paid researcher role.

### (10.6.2) Limitations

Whilst a valuable piece of research, the study does have five limitations. Firstly, I was the only researcher delivering the study, so the conduct of the research and analysis was impacted by my skills, experience and viewpoints. It would have been beneficial to have a team of researchers undertaking the study but this was not feasible given the individual nature of a PhD. Where

possible, I did involve other people within the research such as supervisors supporting the analysis, discussing the findings with the advisory committee, and involving service-users with designing the recruitment materials. Secondly, the three-year nature of the PhD resulted in a tension between having sufficient time to build up relationships with people and progressing the research to meet institutional deadlines. The importance of relationships meant many of the participants were from TSOs based within the same geographical region. The study may have benefited from the involvement of more people from different geographical areas along with interviewing individuals working for different types of TSOs including national organisations. It could have been useful to have involved organisations with a greater diversity of experiences with PROMs. This includes recruiting participants from organisations that had stopped using outcome measures and involving a TSO in the CBPR phase that was trying to implement a PROM mandated by a commissioner.

Fourthly, there was a smaller quantitative component of the PhD than intended because the necessary data was not available from the TSOs. Whilst a qualitative dominated mixed methods design is acceptable (Creswell, and Plano Clark, 2018), the study may have benefitted from having a larger quantitative component. Finally, there was a smaller amount of service-user involvement in the PhD than I had anticipated when developing the research idea. The service-user representatives had to dip in and out of the study due to personal circumstances.

Consequently, I was not able to involve the service-users representatives in supporting the analysis of the QI phase as much as I had hoped. In hindsight, a different involvement model may have been beneficial such as utilising established service-user panels of local TSOs. It also indicates that there is a need to develop an ongoing service-user involvement group for third sector research, using a similar model to the Sheffield Addiction Recovery Research Panel (Irving and Cairns, 2018).

## (10.7) Implications

### (10.7.1) Implications for practice

The research has identified a number of implications on the practice of implementing PROMs. The implications for practice are summarised in Figures 12 and 13 and were developed in conjunction with stakeholders e.g. discussing the implications of the research at the integration event (see Chapter 5). Whilst aimed at the third sector, some of the implications may be relevant to other contexts because they are consistent with findings arising from similar research in healthcare services. The implications are separated into recommendations for commissioners and recommendations for TSOs because each entity has a different role in relation to PROMs. The implications informed a standalone guidance document (discussed further below).

#### **Figure 12- Recommendations for commissioners**

##### **To facilitate implementation, commissioners could:**

- Be more transparent about how they use the data generated from PROMs. This is because TSOs are often unsure about how the collected PROMs data is used to influence decisions.
- Cultivate good working relationships with TSOs by getting to know and understand each organisation such as meeting with front-line workers.
- Collaborate with a TSO to design a PROMs process rather than pre-specify measures within funding contracts. This includes being amenable to allowing TSOs to use PROMs which are already being collected in the organisation.
- Give TSOs a grace period so they do not have to collect PROMs from the beginning of a new funding period. This would provide TSOs with time to consult front-line workers and have an embedding period.
- Consider allocating resources within a funding contract which are ring-fenced for TSOs to invest in implementing PROMs. Some commissioners allocate funding specifically for evaluation and this could be replicated for PROMs.
- It may not be feasible to use PROMs in all wellbeing activities. Therefore, consider the feasibility and whether other types of assessment studies may be more appropriate.

## Figure 13- Recommendations for TSOs

### To facilitate implementation, TSOs could:

#### Get the organisation ready to implement PROMs

- Learn from external researchers/advisors and other TSOs, but it is important to adapt any learning to the specific organisation.
- Consider the function PROMs will play within the TSO, including whether the measure will be used to inform the support delivered to service-users (care management function) or purely be used to collect data on impact.
- Consider whether the PROM will be implemented throughout the organisation or in specific wellbeing activities (not all wellbeing activities are amenable to using outcome measures).
- Allocate resources to implementation e.g. administrative support for processing PROMs.
- Identify someone within the organisation to lead and be responsible for implementation (the Implementation Lead).
- Get support from senior managers within the TSO to ensure organisational commitment to PROMs.
- Ensure there is a suitable data management system for storing PROMs data and a member of staff to support its operation.

#### Designing the PROMs process

- Engage front-line workers by consulting them on the design of the PROMs process especially involving them with choosing the outcome measure (and allow sufficient time for this).
- Ideally consult, but at least consider, the needs of service-users.
- Choose a PROM which is short and appropriate to the organisation. Some TSOs have found the Warwick Edinburgh Mental Wellbeing Scale or Outcome Star useful whereas other organisations have developed their own measure. The most appropriate PROM depends on the organisation.
- Design a PROMs process which is tailored to the organisation and specific wellbeing activity.
- Ensure service-users are supported to complete PROMs.
- Have a process for analysing and using the collected PROMs data. This includes providing feedback to front-line workers and individual service-users about changes in wellbeing over time.

#### Engaging and training front-line workers

- Engage front-line workers through providing ongoing training and support on administering the PROM, interpreting the collected data and the reasons for using PROM.
- Make PROMs part of front-line workers' job roles including discussing in supervision.
- Some front-line workers may require additional support to encourage them to use PROMs.

#### Commencing using PROMs

- Trial PROMs so any problems are identified at an early stage.
- Have an embedding phase. This provides time for people to become accustomed to using PROMs and gives an opportunity for problems to be addressed and the PROMs process improved.
- It takes time for PROMs to become part of routine practice and requires a sustained period of resource and time investment.

An objective of the PhD was to produce guidance that could be used by TSOs and commissioners to support the implementation of PROMs within the third sector. I worked with a visual researcher to develop the guidance. The guidance includes a diagram depicting the model of implementation (discussed previously) and a step-by-step guidance document to implementation. The guidance is available from:

[https://issuu.com/niftyfoxcreative/docs/proms\\_booklet\\_final](https://issuu.com/niftyfoxcreative/docs/proms_booklet_final) . The guidance was developed in conjunction with stakeholders, including one researcher using it with a TSO and providing me with feedback on how the wording needed to be less prescriptive. Recent guidance has been produced by What Works for Wellbeing (2019) on implementing PROMs that focuses on choosing measures and analysing the data. My guidance complements their work because I included a wider range of issues which TSOs need to consider when implementing PROMs. To help stakeholders benefit from both sources, I have included a link to What Works for Wellbeing (2019) within my guidance as a source of further information. I will proactively disseminate the guidance through my contacts and relevant TSO mailing lists. Furthermore, some umbrella organisations have offered to make the guidance available on their websites. More generally, I have proactively disseminated the findings of the research including at academic conferences, in peer-review articles and by giving support to individual TSOs and commissioners on utilising PROMs. I detail some of these dissemination activities in Appendix 22. I will undertake further dissemination upon completion of the thesis.

#### (10.7.2) Implications for future research

I have identified five potential issues for future research and four implications for the conduct of future studies in the field.

**Develop a new measure-** There is a need for new outcome measures specifically developed for use within TSO delivered wellbeing activities. This includes considering the utility of item banks and developing goal-based outcomes to ensure a focus on the preferences of individual TSOs and the aspirations of each service-user.

**Understand how commissioners can work collaboratively with TSOs-** The study identified the importance of commissioners taking a collaborative approach however to enable this, we need to understand further the barriers to this approach, including exploring how collected data is used to inform funding decisions.

**Explore challenges facing more diverse types of TSOs-** Further research is needed on the specific facilitators and barriers faced by different types of TSOs including those based in different localities, different sized organisations and organisations based in other countries. The latter is especially relevant to help understand which findings are specific to UK-based TSOs and which issues may be relevant irrespective of which country an organisation is situated in.

**Obtain better understanding of service-users' perspectives-** Research is needed on the information service-users want to receive on PROMs and how the collected data should be fed back to them. Stakeholders at the integration event felt this was an omission in the PhD. Furthermore, there is a need for research on using PROMs with service-users who have specific needs such as people with learning disabilities or people who have English as a second language.

**Explore how cultural change can occur in TSOs-** It appeared that undergoing cultural change could facilitate the sustained use of PROMs. However, this research did not identify how cultural change could be achieved. Drawing upon established organisational change theories could help to further understand this aspect of implementation.

### [\(10.7.3\) Implications for the conduct of research](#)

**Give sufficient time within CBPR to build relationships-** Studies using CBPR need to allow sufficient time to develop relationships with participating stakeholders. This may present challenges if someone wants to use CBPR within a PhD, given the time pressures. If a student is going to use a CBPR approach then they need to be developing relationships with potential collaborators early on in the PhD.

**Use of theoretical frameworks within research on implementing PROMs-** It is recommended that future research on the implementation of PROMs is grounded within existing theoretical frameworks including those focused on implementation or organisational change.

**Develop PROMs without licence fees-** It is important for developers of PROMs not to enforce licence fees because this can prevent people from using the measure.

**Convene a third sector service-user involvement panel-** There is a need to develop and support an ongoing third sector service-user research panel in the region who could be involved in the development and delivery of studies focused on TSOs.

### (10.8) Conclusion

The need for funding incentivises TSOs to implement PROMs. Despite this motivation, organisations face barriers to their implementation. Many of these barriers arise from the unique organisational context of TSOs including insufficient infrastructure, a lack of appropriate PROMs and belief that wellbeing activities are not amenable to measurement. However, implementation can be facilitated by a TSO having a proactive Implementation Lead, receiving support from external advisors, investing time and resources into PROMs, involving front-line workers in choosing an appropriate PROM, training staff and investing sufficient time into embedding measures into routine practice. TSO stakeholders including commissioners need greater support with implementation. Guidance has been produced based on the findings of this research. The guidance may help to improve the implementation of PROMs within TSOs.



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## Appendix 1- PRISMA Checklist

Section/topic	#	Checklist item	Reported in section
<b>TITLE</b>			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	Chapter 3 heading
<b>ABSTRACT</b>			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	N/A
<b>INTRODUCTION</b>			
Rationale	3	Describe the rationale for the review in the context of what is already known.	3.2
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	N/A
<b>METHODS</b>			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	3.4
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	3.4.2
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	3.4.3
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	Appendix 2
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	3.4.4

Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	3.4.5
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	3.4.5
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	3.4.6
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	N/A
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., $I^2$ ) for each meta-analysis.	3.4.7

## Appendix 2- Search terms used in MEDLINE

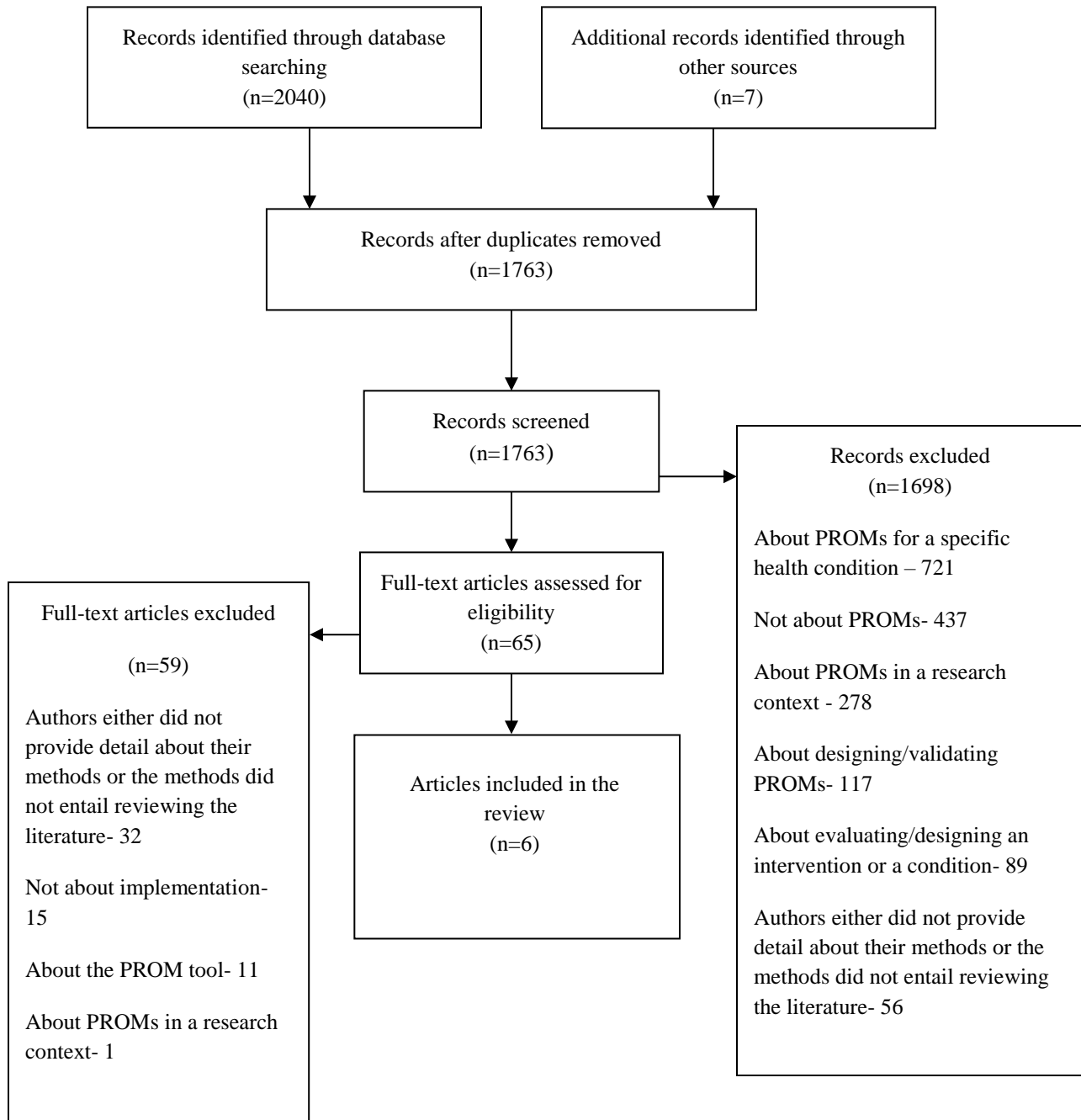
1	(prom or proms or patient reported outcom* or pros or pro or prem or prems or patient reported experience measure* or epros or epro or outcome measure*).ti.
2	clinical adj (setting* or practice*).tw
3	((routine adj2 collect* or outcome*)).tw.
4	(healthcare or social care or health care).tw.
5	Charit*.tw
6	(Voluntary sector or voluntary organi*).tw
7	Third sector.tw
8	(Grassroot* organi* or grassroot* project*).tw
9	(Community organi* or community project*).tw
10	Admin*.tw
11	Implement*.tw
12	2,3,4,5,6,7,8,9,10 or 11
13	Meta analysis.pt or meta anlysis.af
14	Review.pt
15	search:.tw.
16	13, 14 or 15
17	1 and 12 and 16
18	English.lg
19	17 and 18

### Appendix 3- Justification for the different categories of the data extraction form

Categories	Description	Rationale for each item
<b>Reference details of the review</b>	Title, authors, date and details of where published.	Reference details were included for organisational purposes but also as a point of comparison. For example, whether the authors were based in different countries which could account for any differences in implementing PROMs between the included reviews
<b>Aims and objectives of the review</b>	Information on the aims and objectives of the review	Recording the aims and objectives provided context to the review and its scope. For example, some of the reviews considered the whole implementation process in a specific clinical setting whereas other reviews focused on a specific part of the implementation process.
<b>Eligibility criteria</b>	Checklist of the inclusion and exclusion criteria and how a review met/did not meet them.	Recording how a publication met or did not meet the eligibility criteria ensured the transparency of why a review was included or not.
<b>Risk of Bias in Systematic Reviews (ROBIS) criteria</b>	Checklist of the ROBIS (the toolkit was used to assess the risk of bias of a review)	The ROBIS was used to assess the risk of bias of each included review.
<b>The parameters of the review</b>	The focus of the review in terms of the: Population, Intervention, Control, Outcome & Study type.	The scope of each review was included to provide an understanding of the specific context researched.
<b>Review method</b>	Details about the methodology used within the review.	The methodology of each review was recorded to understand how they were conducted and to inform the ROBIS assessment.
<b>Details of the individual studies a review included</b>	Information on the individual studies a review included including the author, study type, country of origin and focus of the study.	Details were recorded about the individual studies included in each review. This helped to understand the breadth of studies considered and the level of crossover between reviews. For example, whether the same individual studies were included within several reviews. This was important because a criticism of systematic review of reviews is they double count individual studies.

<b>Categories</b>	<b>Description</b>	<b>Rationale for each item</b>
<b>Issues influencing the implementation of PROMs</b>	Information was extracted on the issues identified in the reviews as influencing the implementation of PROMs.	The results and discussion of the included reviews were read and information extracted on any issues a review had identified which appeared to influence the implementation of PROMs. Contextual information on any identified factors were also recorded. For example, if the issue only arose in specific circumstances. To address differences in terminology, any factors described by the authors as influencing the implementation of PROMs were recorded, they did not have to label them explicitly as facilitators or barriers.

## Appendix 4- PRISMA Statement for the systematic review of reviews



### Appendix 5- Risk of Bias Assessment (ROBIS) of the reviews

Domain of the ROBIS	Author					
	Antunes (2014)	Bantug (2015)**	Boyce (2014)	Duncan (2012)	Greenhalgh, (2017)***	Howell, (2015)****
<b>Domain 1: Concerns regarding specification of study eligibility criteria</b>	Low	High- No description of the exclusion criteria	High- No description of the exclusion criteria	Low	Low	High- No description of the exclusion criteria
<b>Domain 2: Concerns regarding methods used to identify and/or select studies</b>	Unclear- No information on whether more than one researcher supported the search process	Low	Unclear- No information on whether more than one researcher supported the search process	Unclear- No information on whether more than one researcher supported the search process	High- Sought to identify studies which supported/challenged programme theories rather than identify all the available literature	High- No searching beyond electronic databases
<b>Domain 3: Concerns regarding methods used to collect data and appraise studies</b>	Low	High- No quality appraisal	Low	Low	High- Did not synthesis all relevant studies nor conduct quality appraisal because it was a realist synthesis	High- Lack of information on which studies were included or description of the studies. No quality appraisal
<b>Domain 4: Concerns regarding the synthesis and findings</b>	Low	Low	Low	Low	High- As did not include all relevant studies there are issues with the synthesis	High- Concerns about the synthesis for example, it was not clear which studies were included in the synthesis



	<b>Antunes (2014)</b>	<b>Bantug (2015)**</b>	<b>Boyce (2014)</b>	<b>Duncan (2012)</b>	<b>Greenhalgh, (2017)***</b>	<b>Howell, (2015)****</b>
<b>Did the interpretation of findings address all of the concerns identified in Domains 1 to 4?</b>	Probably yes	Probably no	Probably yes	Probably yes	Probably yes	Probably no
<b>Was the relevance of identified studies to the review's research question appropriately considered?</b>	Yes	Yes	Yes	Yes	Yes	Probably yes
<b>Did the reviewers avoid emphasising results on the basis of their statistical significance?*</b>	Yes	Yes	Yes	Yes	Yes	Probably no
<b>Overall risk of bias in the review</b>	Low	Unclear	Low	Low	Unclear	Unclear

‘Probably’- On the ROBIS there is the option to select ‘probably yes’, or ‘probably no’ in cases where the reviewer is not entirely sure. For example, if it appeared that a review considered the relevance of the studies it included but the review did not include all the information on this to make the reviewer certain.

\*The ROBIS considers statistical significance but because the reviews are qualitative this question should be whether a review presented all its findings rather than cherry picking the results.

\*\*Please note that Bantug (2016) was an integrative review so would not have undertaken some elements assessed by the ROBIS.

\*\*\*Please note that Greenhalgh (2017) was a realist synthesis so would not have undertaken some elements assessed by the ROBIS such as including all relevant articles.

\*\*\*\*Please note that Howell (2015) was a scoping review so would not have undertaken some elements assessed by the ROBIS such as quality appraisal.

Appendix 6- The facilitators and barriers to implementing PROMs identified in the systematic review of reviews

Domain 1- Intervention Characteristics- Issues related specifically to the intervention such as its design or cost									
CFIR Construct	CFIR Sub-construct	Antunes (2014)	Bantug (2016)	Boyce (2014)	Duncan (2012)	Greenhalgh (2017)	Howell (2015)	Examples	Facilitator/ Barrier/ Bidirectional
<b>Intervention source-</b> <i>Whether the PROM and PROMs process was internally or externally developed</i>		<input checked="" type="checkbox"/>					<input checked="" type="checkbox"/>	Involving clinicians and patients in the development of the PROM process so that it's not perceived as externally imposed.	Facilitator
<b>Evidence strength and quality-</b> <i>Stakeholders belief in the validity of PROMs</i>		<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	Knowledge about PROMs especially views on their reliability and validity.	Bidirectional
<b>Relative advantage-</b> <i>Perception that implementing PROMs is better than alternative solutions</i>		Nothing in the reviews about this concept.							

CFIR Construct	CFIR Sub-construct	Antunes (2014)	Bantug (2016)	Boyce (2014)	Duncan (2012)	Greenhalgh (2017)	Howell (2015)	Examples	Facilitator/ Barrier/ Bidirectional
<b>Adaptability-</b> <i>The extent the PROMs process can be adapted to meet local need</i>		✓		✓	✓	✓		An organisation being able to choose which PROM to use.  Flexibility to adapt the PROMs process to the particular setting and individual patient.	Facilitator  Facilitator
<b>Trialability-</b> <i>Ability to enable users to test PROMs before they are implemented fully</i>				✓				Clinicians having the opportunity to test out and become experienced in using PROMs before they are introduced fully.	Facilitator
<b>Complexity-</b> <i>Perceived difficulty of implementing and using PROMs</i>		✓	✓	✓	✓	✓	✓	Nature of a specific PROM e.g. its complexity.  The difficulty or ease of administrating PROMs.  The difficulty or ease of interpreting the scores from PROMs.  The complexity of communicating the results of PROMs because they are multi-dimensional and vary between PROMs.	Bidirectional  Bidirectional  Bidirectional  Barrier

CFIR Construct	CFIR Sub-construct	Antunes (2014)	Bantug (2016)	Boyce (2014)	Duncan (2012)	Greenhalgh (2017)	Howell (2015)	Examples	Facilitator/ Barrier/ Bidirectional
<b>Design-</b> <i>Perceptions about the quality of the design of PROMs and the PROMs process</i>		✓	✓	✓	✓	✓	✓	<p>Using a PROM which asks about relevant issues.</p> <p>PROMs not perceived as user friendly e.g. not prioritising issues for patient.</p> <p>Clinicians prefer to use PROMs once they have built up rapport with a patient.</p> <p>Patients having support to complete PROMs.</p> <p>Investing in technological solutions for collecting PROMs.</p> <p>If the process for administering a PROM is script like, it can detrimentally impact on rapport.</p> <p>Presenting PROMs data in appropriate ways e.g. the simplicity of the graphs.</p>	<p>Facilitator</p> <p>Barrier</p> <p>Facilitator</p> <p>Facilitator</p> <p>Facilitator</p> <p>Barrier</p> <p>Bidirectional</p>
<b>Cost-</b> <i>Costs of implementing PROMs</i>		✓		✓	✓	✓	✓	<p>Investment in computer systems and information management systems to support the PROMs process.</p> <p>Licence costs of PROMs.</p> <p>Opportunity cost of using PROMs- can be perceived as using consultation time which could be spent on other aspects of a patient's care.</p>	<p>Facilitator</p> <p>Barrier</p> <p>Barrier</p>

Construct 2- External settings- Impact of elements external to the organisation									
CFIR Construct	CFIR Sub-construct	Antunes (2014)	Bantug (2016)	Boyce (2014)	Duncan (2012)	Greenhalgh (2017)	Howell (2015)	Examples	Facilitator/ Barrier/ Bidirectional
		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		
<b>Patient needs and resources-</b> <i>Impact of patient needs on implementing PROMs</i>		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<b>Patients' needs</b>	
								Selecting PROMS based on the needs of patients.	Facilitator
								Having flexibility within the PROMs process to take into account individual needs.	Facilitator
								<b>Patients' knowledge</b>	
								Clinicians more willing to use PROMs if they perceive that patients' understand them.	Facilitator
								Implementation of electronic PROMs impacted by patients' technological ability.	Bidirectional
								Patients concerned about making a bad clinical decision based on them misinterpreting PROMs data.	Barrier
								Patients can struggle with interpreting PROMs data.	Barrier
								Clinicians concerned about the ability of patients to complete the PROMs e.g. literacy issues.	Barrier
								Clinicians concerned that the results may impact detrimentally on patient care.	Barrier
							Clinicians concerned that specific questions on PROMs may cause distress to patients.	Barrier	
							Clinicians feel administering PROMs can have a detrimental impact on their relationship with a patient.	Barrier	

CFIR Construct	CFIR Sub-construct	Antunes (2014)	Bantug (2016)	Boyce (2014)	Duncan (2012)	Greenhalgh (2017)	Howell (2015)	Examples	Facilitator/ Barrier/ Bidirectional
<b>Cosmopolitanism-</b> <i>Degree an organisation is networked with other organisations</i>		Nothing in the reviews about this concept							
<b>Peer pressure-</b> <i>Influence of competition with other organisations</i>		Nothing in the reviews about this concept							
<b>External policy and incentives-</b> <i>Influence of wider policy and funding on implementing PROMs</i>					☑	☑	☑	Aligning PROMs with clinical practice guidelines.  Incentivising PROMs e.g. with funding can have mixed results on implementation.  External agencies e.g. a funder imposing PROMs on an organisation.	Facilitator  Bidirectional  Barrier
<b>Construct 3- Inner settings- Impact of the organisations' characteristics</b>									
<b>Structural characteristics-</b> <i>The nature of the organisation</i>		Nothing in the reviews about this concept							
<b>Networks &amp; communications-</b> <i>The nature of networks and channels communication within an organisation</i>		Nothing in the reviews about this concept							
<b>Culture-</b> <i>The culture within an organisation</i>					☑			Having a positive team culture and the resulting normative social pressure will help engage clinicians.	Facilitator

CFIR Construct	CFIR Sub-construct	Antunes (2014)	Bantug (2016)	Boyce (2014)	Duncan (2012)	Greenhalgh (2017)	Howell (2015)	Examples	Facilitator/ Barrier/ Bidirectional
<b>Implementation climate-</b> <i>The absorptive capacity for change and shared receptivity within an organisation</i>		Nothing in the reviews about this concept specifically as the related facilitators and barriers are included in the sub-components below.							
<b>Implementation climate</b>	<b>Tension for change-</b> <i>Extent that people perceive the need for change in terms of using PROMs</i>			✓	✓	✓		Fear amongst clinicians that the results of PROMs will impact detrimentally on practice and patient care.  Clinicians can perceive that the introduction of PROMs is suggesting that their communication methods are not sufficient.	Barrier  Barrier
<b>Implementation climate</b>	<b>Compatibility-</b> <i>How much the intervention fits with the individuals' own values and existing systems</i>	✓		✓	✓	✓	✓	If PROMs can be incorporated naturally into the consultation.  PROMs more positively viewed if their purpose is as a care management tool and perceived more negatively when they are used as a performance management tool.  Use of PROMs impacted by whether a clinician perceives it within their remit to deal with any issues that arise from the PROM.  Concern that PROMs add to clinician's workload and they do not have sufficient time to administer them and manage the issues they raise.  Perception that PROMs can damage communication, narrow the focus of a consultation and be intrusive, impacting on rapport.	Facilitator  Bidirectional  Bidirectional  Barrier  Barrier

CFIR Construct	CFIR Sub-construct	Antunes (2014)	Bantug (2016)	Boyce (2014)	Duncan(2012)	Greenhalgh (2017)	Howell (2015)	Examples	Facilitator/ Barrier/ Bidirectional
<b>Implementation climate</b>	<b>Relative priority-</b> <i>Perception of the importance of implementation within the organisation</i>			✓		✓		The support provided by an organisation to use PROMs can impact on implementation.  Clinicians have to appreciate the patient’s perspective rather than purely the physiological perspective e.g. blood test results.	Bidirectional  Bidirectional
<b>Implementation climate</b>	<b>Organisations incentives and rewards-</b> <i>Incentives within the organisation to use PROMs</i>				✓	✓		Incentives do not necessarily facilitate the use of PROMs.  Issue of PROMs being used as a performance management tool with clinicians.	Barrier  Barrier
<b>Implementation climate</b>	<b>Goals and feedback-</b> <i>The extent the goals of PROMs are communicated</i>			✓				It needs to be clear what the goals of using PROMs are and that they are not contradictory.	Facilitator



CFIR Construct	CFIR Sub-construct	Antunes (2014)	Bantug (2016)	Boyce (2014)	Duncan(2012)	Greenhalgh (2017)	Howell (2015)	Examples	
<b>Implementation climate</b>	<b>Learning climate--</b> <i>The ethos within the organisation to develop their skills and try new approaches</i>	<input checked="" type="checkbox"/>						Clinicians need to feel they can influence the PROMs process and that their opinions on PROMs are valued	Facilitator
	<b>Readiness for implementation</b>	Nothing in the reviews about this concept specifically as the related facilitators and barriers are included in the sub-components below.							
<b>Readiness for implementation</b>	<b>Leadership engagement-</b> <i>Commitment and accountability of managers to implementation</i>	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>				Having sensitive and supportive leadership to motive people to use PROMs.  Managers and leaders are involved in the process and are appreciative and acknowledge the additional work PROMs bring.	Facilitator  Facilitator
<b>Readiness for implementation</b>	<b>Available resources-</b> <i>The level of resources dedicated for implementation and ongoing operations</i>	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		Providing sufficient administrative support.  Having sufficient systems in place so that clinicians can refer onto other services/offer additional support if issues are raised from the PROMs.  Sufficient investment in resources such as technology to help with the collection and analysis of PROMs.  Whether there is sufficient statistical support to appropriately analyse and interpret the PROMs data.	Bidirectional  Facilitator  Bidirectional  Bidirectional

CFIR Construct	CFIR Sub-construct	Antunes (2014)	Bantug (2016)	Boyce (2014)	Duncan (2012)	Greenhalgh (2017)	Howell (2015)	Examples	Facilitator/ Barrier/ Bidirectional
<b>Readiness for implementation</b>	<b>Access to knowledge and information- Ease of access to information and knowledge about PROMs</b>	✓	✓	✓	✓	✓	✓	<p>Delivering good training to clinicians both in terms of the reasons for using PROM and how to use them e.g. practical issues.</p> <p>A lack of clear guidance about the process can be a barrier e.g. which patients should be completing a PROM.</p>	<p>Bidirectional</p> <p>Barrier</p>
<b>Construct 4- Characteristics of individuals- How individuals impact on the process</b>									
<b>Knowledge and beliefs about the intervention- Individuals' attitudes and value placed on the intervention</b>		✓	✓	✓	✓	✓	✓	<p>Clinicians more supportive of PROMs if they perceive that PROMs have clinical utility e.g. enhancing communication.</p> <p>Managers employing clinicians who already use or are supportive of PROMs.</p> <p>Whether clinicians perceive that PROMs produce a genuine reflection of care e.g. their validity.</p> <p>Clinicians are the driving force in implementing PROMs and their values and beliefs on PROMs impact on their implementation.</p> <p>PROMs may not be valued by clinicians, who can perceive them as a tick box exercise.</p> <p>Clinicians may perceive PROMs as detrimentally impacting on their practice e.g. communication with a patient or narrowing the focus of the consultation.</p> <p>Clinicians may be resistant to having feedback from the PROMs scores and adapting their practice.</p>	<p>Facilitator</p> <p>Facilitator</p> <p>Bidirectional</p> <p>Bidirectional</p> <p>Barrier</p> <p>Barrier</p> <p>Barrier</p>

CFIR Construct	CFIR Sub-construct	Antunes (2014)	Bantug (2016)	Boyce (2014)	Duncan (2012)	Greenhalgh (2017)	Howell (2015)	Examples	Facilitator/ Barrier/ Bidirectional
<b>Self-efficacy-</b> <i>Individuals belief in their own ability to execute courses of action to achieve implementation of PROMs</i>		☑						Whether clinicians feel comfortable with using PROMs.	Bidirectional
<b>Individuals stage of change-</b> <i>Where an individual is at in terms of accepting the intervention</i>		☑			☑			Clinicians feeling they have ownership over the process.  Clinicians feeling they have personal responsibility for using PROMs.  Each individual clinician has their own emotional and cognitive processes which impacts on them using PROMs.  Clinicians can have a fear of change.	Facilitator  Facilitator  Bidirectional  Barrier
<b>Individual identification with an organisation-</b> <i>People's relationship with an organisation and their commitment to that organisation</i>		Nothing in the reviews about this concept							
<b>Other personal attributes-</b> <i>Other aspects about clinicians which can impact on implementation</i>					☑			Use of PROMs higher amongst clinicians with Masters qualifications or with clinical specialities.	Facilitator

Construct 5- Process- The process of implementing PROMs									
CFIR Construct	CFIR Sub-construct	Antunes (2014)	Bantug (2016)	Boyce (2014)	Duncan (2012)	Greenhalgh (2017)	Howell (2015)	Examples	Facilitator/ Barrier/ Bidirectional
<b>Planning-</b> <i>Extent that the implementation process is planned</i>		✓	✓					<p>Good planning and clear boundaries from the start about expectations regarding PROMs.</p> <p>Consider the implementation of processes for managing and using the PROMs data.</p>	Facilitator  Facilitator
<b>Engaging-</b> <i>Engaging staff in both the implementation and intervention</i>		✓	✓	✓	✓	✓	✓	<p>Having well-designed training.</p> <p>If PROMs are imposed then there is a greater need to be proactive in engaging clinicians.</p> <p>Engaging clinicians as a way of convincing them of the value of PROMs.</p>	Facilitator  Bidirectional  Facilitator
<b>Engaging</b>	<b>Opinion leaders-</b> <i>Individuals within an organisation that have influence on their colleagues</i>	✓						Having sensitive leadership to motivate individuals and reassure them about the value of PROMs.	Facilitator
<b>Engaging</b>	<b>Formally appointed internal implementation leaders-</b> <i>Individuals who have responsibility for implementing PROMs</i>	✓						There is a need to have someone in charge of the process of implementing PROMs.	Facilitator

<b>CFIR Construct</b>	<b>CFIR Sub-construct</b>	<b>Antunes (2014)</b>	<b>Bantug (2016)</b>	<b>Boyce (2014)</b>	<b>Duncan (2012)</b>	<b>Greenhalgh (2017)</b>	<b>Howell (2015)</b>	<b>Examples</b>	<b>Facilitator/ Barrier/ Bidirectional</b>
<b>Engaging</b>	<b>Champions- People who drive implementation</b>				<input checked="" type="checkbox"/>			Having the support and co-operation of colleagues and managers is important.	Facilitator
<b>Engaging</b>	<b>External change agents- People outside of the organisation influence the implementation of PROMs</b>	Nothing in the reviews about this concept							
<b>Executing- Carrying out the implementation of PROMs according to the implementation plan</b>		<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>		<p>Integrating a new routine into daily clinical practice takes time and effort.</p> <p>There can be issues if it is perceived that the burden of collecting PROMs is falling on one or two members of the team.</p> <p>Problems can arise when PROMs start to be used e.g. gaming of the data.</p>	<p>Barrier</p> <p>Barrier</p> <p>Barrier</p>

CFIR Construct	CFIR Sub-construct	Antunes (2014)	Bantug (2016)	Boyce (2014)	Duncan (2012)	Greenhalgh (2017)	Howell (2015)	Examples	Facilitator/ Barrier/ Bidirectional
<b>Reflecting and evaluating-</b> <i>Evaluation of the implementation</i>		☑			☑			<p>Review the implementation process and make changes as needed to the PROMs process.</p> <p>During the implementation process have open channels of communication so that everyone can provide constructive criticism.</p> <p>Leaders need to take account of the constructive criticism and address the issues raised.</p> <p>Develop an evaluation plan to assess the impact of collecting PROMs.</p> <p>Clinicians can be blamed if PROMs are not utilised but there may be multi-level determinants that can be contributing and if these are not addressed then the implementation of PROMs will continue to fail.</p>	<p>Facilitator</p> <p>Facilitator</p> <p>Facilitator</p> <p>Facilitator</p> <p>Barrier</p>

### Appendix 7- Comparing the systematic review of reviews' findings with TSO specific sources

Stage of implementation identified in the systematic review of reviews	CFIR Construct	Systematic review of reviews on implementing PROMs in healthcare services	Bach-Mortensen & Montgomery's (2018) review on evaluation in TSOs	TSO stakeholder consultation event	How the findings of the systematic review of reviews and TSO sources compared
<p><b>Stage 1- 'Purpose' – How the motivations for, and objectives of, using PROMs impact on implementation.</b></p>	<p>Organisational Incentives and Rewards</p>	<p>PROMs need to have a care management function (therapeutic purpose) whereas using them for performance monitoring reason was a barrier.</p>	<p>Whilst related to evaluation rather than PROMs, the review identified that TSOs often undertook evaluation to demonstrate their impact to current and future funders.</p>	<p>Stakeholders discussed how TSOs were generally using PROMs for performance monitoring purposes.</p>	<p><b>Dissonance</b> There appears to be differences between the use of PROMs within TSOs compared to healthcare services. TSOs used PROMs for performance monitoring purposes whereas in healthcare services, PROMs needed to have a care management purpose.</p>
	<p>External Policy and Incentives</p>	<p>A barrier to implementing PROMs was their use being incentivised by an external organisation.</p>	<p>TSOs were motivated to implement evaluation when it was required by external commissioners.</p>	<p>TSOs were implementing PROMs because funders required measures to be used.</p>	<p><b>Dissonance</b> Within TSOs, the use of PROMs may be facilitated if they were imposed by commissioners but this was a barrier in healthcare services.</p>

Stage of implementation identified in the systematic review of reviews	CFIR Construct	Systematic review of reviews on implementing PROMs in healthcare services	Bach-Mortensen & Montgomery's (2018) review on evaluation in TSOs	TSO stakeholder consultation event	How the findings of the systematic review of reviews and TSO sources compared
Stage 2- 'Designing'- How the design of the PROMs process impacts on implementation.	Adaptability Complexity Compatibility Patients' Needs and Resources Intervention Source Learning Climate	The designed PROMs process needed to be straightforward and flexible to meet service-users' different needs. Consulting front-line workers could facilitate this.	It was useful for TSOs to design their own evaluation to ensure it was feasible for the specific organisation.	Stakeholders felt the PROMs process needed to be tailored to the organisation and consulting front-line workers was advantageous to ensure the process was suitable for the TSO.	<b>Convergence</b> Both healthcare services and TSOs needed a PROMs process tailored to the specific organisation. Involving front-line workers in design could enable a more appropriate PROMs process to be designed.
	Costs Design Quality and Packaging	Choosing a PROM that is considered user-friendly, appropriate and is affordable.	Nothing written about the nature of PROMs because of the literature focusing on evaluation. However, the review identified that TSOs found it difficult to identify appropriate evaluation tools.	Need PROMs to be short, easy to use and relevant to the organisation.	<b>Complementary</b> Both TSOs and healthcare services needed PROMs to be user-friendly and appropriate. TSOs may find it difficult to identify appropriate tools, as is the case in relation to evaluation.
	Design Quality and Packaging	It was beneficial to design when PROMs would be collected and how the data would be processed, analysed and used.	Nothing written about designing the PROMs process because of the literature focusing on evaluation.	Challenges in identifying appropriate time points because of the longer-term nature of wellbeing activities and because service-users' attendance may be sporadic.	<b>Dissonance</b> In healthcare services, it appeared beneficial to design the PROMs process but TSOs found it difficult to identify an appropriate process e.g. time points.



	<b>CFIR Construct</b>	<b>Systematic review of reviews on implementing PROMs in healthcare service</b>	<b>Bach-Mortensen &amp; Montgomery's (2018) review on evaluation in TSOs</b>	<b>TSO stakeholder consultation event</b>	<b>How the findings of the systematic review of reviews and TSO sources compared</b>
<b>Stage 3- Planning the implementation process</b>	Planning	Importance of planning the implementation process.	A lack of planning can be detrimental.	Nothing was discussed in relation to planning the implementation process.	<b>Convergence</b> Need to plan implementation.
	Formally Appointed Implementation Leaders	Need to have an Implementation Lead to progress the use of PROMs.	Nothing written about having a specific individual leading implementation.	Stakeholders did not consider the need for an Implementation Lead.	<b>Silence</b> Healthcare services appeared to need an Implementation Lead to progress the use of PROMs. However, this role was not identified by TSO sources.
<b>Stage 4- 'Preparing' – Investing time and resources in preparing an organisation to implement PROMs.</b>	Engaging  Access to Knowledge and Information  Knowledge and Beliefs about the Intervention	Delivering practical and ideological training to front-line workers to facilitate engagement.	Front-line workers need to receive sufficient training.	Stakeholders discussed the need for ideological and practical training but felt the training should be on-going rather than only occurring at a discrete stage before PROMs are used in routine practice.	<b>Complementary</b> Providing front-line workers with practical and ideological training appeared relevant to both healthcare services and TSOs. However, the TSO stakeholders suggested that training needed to be ongoing rather than a discrete stage.

	<b>CFIR Construct</b>	<b>Systematic review of reviews on implementing PROMs in healthcare services</b>	<b>Bach-Mortensen &amp; Montgomery's (2018) review on evaluation in TSOs</b>	<b>TSO stakeholder consultation event</b>	<b>How the findings of the systematic review of reviews and TSO sources compared</b>
<b>(Preparing continued)</b>	Available Resources	Organisations having sufficient infrastructure to implement PROMs.	Organisations need to have sufficient infrastructure to undertake evaluation but face financial constraints to investing in the infrastructure.	Alongside funding infrastructure to support the PROMs process, TSOs a need the capacity to use the resources such as learning to use databases.	<b>Complementary</b> Both TSOs and healthcare services found it important to have sufficient infrastructure in place to facilitate the use of PROMs. However, TSOs faced barriers to developing the infrastructure including not having financial resources nor the capacity and/or capability to utilise the infrastructure.
	Leadership Engagement	Need for the managers of an organisation to be engaged.	Need for management including Board of Trustees/Management Committees to be engaged.	The stakeholders did not consider the role of management in implementing PROMs.	<b>Convergence</b> It appeared important within TSOs and healthcare services for managers to engage with PROMs.
<b>Stage 5- 'Commencing'- The issues that arise when starting to use PROMs</b>	Executing Individual Identification with the Organisation	Problems arise when an organisation starts to use PROMs.	Challenge of having the capacity to undertake evaluation.	Challenge of having the capacity to implement PROMs even after the process has been designed.	<b>Convergence</b> Both TSOs and healthcare services experienced issues when they started using PROMs.
	Trialability	Beneficial to trial out the PROMs process.	Nothing written in relation to trialing the process.	The stakeholders did not consider the issue of trialing PROMs.	<b>Silence</b> Healthcare services found it useful to trial PROMs. Trialing was not considered in the TSO sources.

Stage of implementation identified in the systematic review of reviews	CFIR Construct	Systematic review of reviews on implementing PROMs in healthcare services	Bach-Mortensen & Montgomery's (2018) review on evaluation in TSOs	TSO stakeholder consultation event	How the findings of the systematic review of reviews and TSO sources compared
Stage 6- 'Reflecting and Developing'- Reflecting on the PROMs process and making improvements	Reflection and Evaluation	Organisations need to reflect on and develop the PROMs process once they start using measures.	Nothing written in relation to the Reflecting and Developing stage.	Stakeholders discussed how TSOs need to consider any feedback on PROMs and address these issues. Stakeholders did not discuss having a formal Reflecting and Developing stage.	<b>Complementary</b> Healthcare services appeared to spend time reflecting on, and developing the PROMs process. TSOs sources discussed the need to address arising issues but this did not appear to be a formal stage.
Additional issues- External support to implement PROMs*	Cosmopolitanism  External Change Agents	The systematic review of reviews did not identify whether organisations benefitted from receiving support from external advisors or other TSOs.	Implementation was facilitated by receiving support from other organisations and external advisors.	Implementation was facilitated by receiving support from other TSOs and advisors outside of the organisation.	<b>Silence</b> TSOs appeared to benefit from receiving support from other TSOs and external advisors. This was not identified in respect of healthcare services.
Additional issues- Structural Characteristics and Culture of an organisation*	Structural Characteristics  Culture	The systematic review of reviews did not discuss issues in relation to the characteristics of the specific organisation.	Implementation appears impacted by the structural characteristics and culture of an organisation. Larger organisations can have an advantage over smaller TSOs because have greater resources. Having a culture amenable to evaluation supported implementation.	Stakeholders did not discuss the impact of the organisation on the implementation of PROMs.	<b>Silence</b> The size and structural characteristics of a TSO along with its culture may have an impact on implementation. The influence of structural characteristics was not identified in relation to healthcare services.
Additional issues- Role of volunteers in supporting implementation*	N/A	The systematic review of reviews did not discuss the role of volunteers.	Nothing written in relation to the role of volunteers.	Volunteers can support the use of PROMs but they need training and support. Not all volunteers engage in PROMs.	<b>Silence</b> TSOs may utilise volunteers to support implementation. Volunteers were not identified in healthcare services.

\*Issues were not identified in the systematic review of reviews so Silence is in relation to the systematic review of reviews not discussing an issue raised by the TSO literature/stakeholders.

## Appendix 8- Ethics approval letter to undertake the QI phase



Approved:26/06/  
2017

Dear Alexis

**PROJECT TITLE:** Exploring the facilitators and barriers to implementing Patient Reported Outcome Measures in third sector wellbeing organisations.

**APPLICATION:** Reference Number 013727

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 26/06/2017 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

- University research ethics application form 013727 (form submission date: 05/06/2017); (expected project end date: 01/07/2018).
- Participant information sheet 1031717
- Participant information sheet 1031716
- Participant consent form 1031718

The following optional amendments were suggested:

*When amendments are made please include a summary of how the recommendations have been addressed This was a really good application. Approved with suggested amendments General - As this component has NHS REC approval it may be helpful for you to have an NHS exemption letter to prevent any potential hold-ups further down the line when all the parts of the study are collated. Any mention of the X-drive should read University restricted access network folder Check the consistency of titles on the Information sheet, consent form and contact form. Giving participants the choice of not having their interview audio recorded will lead to two different types of results. Instead, let potential participants know that the interviews will be recorded (with the reason why this is done) and they can choose at that point whether to take part or not. You could simplify the explanation of those having access to the project folders and also the process for moving the recordings from the encrypted recording device to the University restricted access network folder. On the participant information sheet there should be a paragraph which refers final complaints to the Dean, e.g.: If any complaints have not been satisfactorily dealt with by the above contacts, please contact the following: Professor John Brazier, Dean of the School of Health & Related Research, University of Sheffield, Regent Court, 30 Regent Street, Sheffield S1 4DA j.e.brazier@sheffield.ac.uk*

If during the course of the project you need to documentation please inform me since written approval will be required.

Your responsibilities in delivering this research project are set out at the end of this letter.

Yours sincerely

Jane Spooner  
Ethics Administrator  
School of Health and Related Research

Please note the following responsibilities of the researcher in delivering the research project:

- The project must abide by the University's Research Ethics Policy:  
<https://www.sheffield.ac.uk/rs/ethicsandintegrity/ethicspolicy/approval-procedure>
- The project must abide by the University's Good Research & Innovation Practices Policy:  
[https://www.sheffield.ac.uk/polopoly\\_fs/1.671066!/file/GRIPPolicy.pdf](https://www.sheffield.ac.uk/polopoly_fs/1.671066!/file/GRIPPolicy.pdf)
- The researcher must inform their supervisor (in the case of a student) or Ethics Administrator (in the case of a member of staff) of any significant changes to the project or the approved documentation.
- The researcher must comply with the requirements of the law and relevant guidelines relating to security and confidentiality of personal data.
- The researcher is responsible for effectively managing the data collected both during and after the end of the project in line with best practice, and any relevant legislative, regulatory or contractual requirements.

## Appendix 9- Ethics approval letter to undertake the CBPR phase



Downloaded:  
12/03/2020  
Approved:  
26/07/2018

Dear Alexis

**PROJECT TITLE:** Implementing Patient Reported Outcome Measures in third sector wellbeing organisations: A collaborative measurement approach

**APPLICATION:** Reference Number 020700

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 26/07/2018 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

- University research ethics application form 020700 (form submission date: 25/07/2018); (expected project end date: 31/12/2019).
- Participant information sheet 1047204
- Participant information sheet 1047205
- Participant information sheet 1047206
- Participant consent form 1047207
- Participant consent form 1047208

If during the course of the project you need to documentation please inform me since written approval will be required.

Your responsibilities in delivering this research project are set out at the end of this letter.

Yours sincerely,

Jennifer Burr, Ethics Administrator, School of Health and Related Research

Please note the following responsibilities of the researcher in delivering the research project:

- The project must abide by the University's Research Ethics Policy: <https://www.sheffield.ac.uk/rs/ethicsandintegrity/ethicspolicy/approval-procedure>
- The project must abide by the University's Good Research & Innovation Practices Policy: [https://www.sheffield.ac.uk/polopoly\\_fs/1.671066!/file/GRIPPolicy.pdf](https://www.sheffield.ac.uk/polopoly_fs/1.671066!/file/GRIPPolicy.pdf)
- The researcher must inform their supervisor (in the case of a student) or Ethics Administrator (in the case of a member of staff) of any significant changes to the project or the approved documentation.
- The researcher must comply with the requirements of the law and relevant guidelines relating to security and confidentiality of personal data.
- The researcher is responsible for effectively managing the data collected both during and after the end of the project in line with best practice, and any relevant legislative, regulatory or contractual requirements.

## Appendix 10- Mixed Methods Appraisal Tool

Category of study designs	Methodological quality criteria	Responses			
		Yes	No	Can't tell	Comments
<b>Screening questions (for all types)</b>	S1. Are there clear research questions?	X			
	S2. Do the collected data allow to address the research questions?	X			
	<i>Further appraisal may not be feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.</i>				
<b>1. Qualitative</b>	1.1. Is the qualitative approach appropriate to answer the research question?	X			
	1.2. Are the qualitative data collection methods adequate to address the research question?	X			
	1.3. Are the findings adequately derived from the data?	X			
	1.4. Is the interpretation of results sufficiently substantiated by data?	X			
	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?	X			
<b>2. Quantitative randomised controlled trials</b>	2.1. Is randomisation appropriately performed?	N/A			
	2.2. Are the groups comparable at baseline?	N/A			
	2.3. Are there complete outcome data?	N/A			
	2.4. Are outcome assessors blinded to the intervention provided?	N/A			
	2.5. Did the participants adhere to the assigned intervention?	N/A			

Category of study designs	Methodological quality criteria	Responses			Comments
		Yes	No	Can't tell	
<b>3. Quantitative nonrandomized</b>	3.1. Are the participants representative of the target population?	N/A			
	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?	N/A			
	3.3. Are there complete outcome data?	N/A			
	3.4. Are the confounders accounted for in the design and analysis?	N/A			
	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?	N/A			
<b>4. Quantitative descriptive</b>	4.1. Is the sampling strategy relevant to address the research question?	X			
	4.2. Is the sample representative of the target population?			X	
	4.3. Are the measurements appropriate?	X			
	4.4. Is the risk of nonresponse bias low?		X		
	4.5. Is the statistical analysis appropriate to answer the research question?	X			
<b>5. Mixed methods</b>	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?	X			
	5.2. Are the different components of the study effectively integrated to answer the research question?	X			
	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	X			
	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	X			
	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?	X			



## Appendix 11- Example of Participant Information Sheet used in the QI phase



### Participant Information Sheet

#### Exploring the facilitators and barriers to implementing outcome measures in third sector wellbeing organisations

##### ***Introduction***

You are being invited to take part in an interview as part of a research study. You have been invited because you are currently attending or use to attend an activity ran by a charity or community organisation (called third sector organisations).

Before you decide whether you want to take part in the interview, it is important that you read this information sheet so you understand what the interview involves. You may wish to discuss it with someone else such as a friend. Please contact the researcher (contact details at the end of the sheet) if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

##### ***Why is the reason for the research?***

The reason for the research is to find out more about how people feel about completing outcome measures. By outcome measures, we mean questionnaires which ask you about your health and wellbeing. You may have been asked to complete these questionnaires when attending an activity. We want to understand more about peoples' views on completing them and their preferences for how to use them. For example whether people prefer to complete them on their own or have a worker help them.

##### ***Why have I been asked to take part?***

We have asked you to take part in an interview because you currently attend or have previously attended an activity run by a charity or community organisation.

***Do I have to take part?***

No, it is up to you to decide whether you would like to take part. If you would like further information, please contact the researcher. If you decide to take part, you can stop at any time and you do not have to give a reason. This would not affect any support you receive from an organisation.

***What will happen if I take part?***

If you take part, you can choose whether to be interviewed on the phone or in person. If the interview is in person, you can choose where the interview will take place for example at a community venue.

The interview will be informal - you will be asked a range of questions but it will be mainly a discussion about the issues you raise. We will discuss your experience of outcome measures and your preferences for completing them. The length of the interview is flexible but face-to-face interviews are likely to be about 60 minutes long. The interview will be audio-recorded. This is so that the researcher can focus on talking to you rather than taking notes.

Your real name will not be used in any subsequent written report or published material. The recordings and written notes based on these interviews will be securely stored at the University of Sheffield and recordings will be destroyed on completion of the research.

***What are the possible benefits of taking part?***

There will not be any immediate benefits to you for taking part. However, the research findings will help us to understand more about the processes charities and community organisations could use to collect outcome measures.

***What are the possible disadvantages and risks of taking part?***

There are not expected to be any disadvantages or risks to you taking part.

***Will my taking part in the study be kept confidential?***

We will follow strict ethical and legal requirements to ensure that all information about you is stored securely. We will keep your name separate from any information collected. Other people will only know that you have taking part in the research if you choose to tell them.

The only exception to this is if you disclose anything which indicates that there is the risk of harm to yourself or others. In these cases, we will explain to you that we need to inform someone and appropriate action will then be taken.

***What will happen if I no longer want to take part in the interview?***

You can choose to not take part in the interview at any time. This includes during the interview. Alternatively there may be specific questions in the interview you don't want to answer. In these cases just tell the researcher you don't want to answer them, and they will move onto another question. If you decide to no longer take part in the research, this will not affect any support you receive.

***What will happen to the results of the research study?***

The findings will be written up into a number of reports. One will be a large study report (a PHD thesis). Other reports will include guidance to community organisations and academic journal articles. If you would like, we can send you a summary of the research.

***Who is organising and funding the research?***

The study is being organised by Alexis Foster, a researcher at the University of Sheffield. This research is being undertaken as part of a PHD. The research is being funded by the National Institute of Health Research, as part of their Doctoral Research Fellowship programme (DRF-2016-09-007). Alexis has previously attended community activities and also volunteered and worked in community organisations.

***Who has reviewed the study?***

To ensure that the study is ethical, it has been reviewed by an independent ethics committee at the School of Health and Related Research, University of Sheffield.

***Further information and contact details***

If you have any questions or would like further information please contact the researcher:

- *Alexis Foster*
- *SCHARR, University of Sheffield, Regent Court, 30 Regent St, Sheffield, S1 4DA*
- *Tel: 0114 222 6129, Email: [alexis.foster@sheffield.ac.uk](mailto:alexis.foster@sheffield.ac.uk)*

If you have any concerns about the research such as how it has been conducted, please contact Professor Alicia O'Cathain. She is a senior researcher.

- *Professor Alicia O'Cathain*
- *SCHARR, University of Sheffield Regent Court, 30 Regent Street, Sheffield, S1 4DA*
- *Tel: 0114 222 0770, Email: [a.ocathain@sheffield.ac.uk](mailto:a.ocathain@sheffield.ac.uk)*

If you have any complaints about the research that have not been resolved satisfactorily by contacting the people above, then please contact Professor John Brazier. He is the Dean of the School of Health and Related Research at the University of Sheffield.

- *Professor John Brazier*
- *ScHARR, University of Sheffield, Regent Court, 30 Regent Street, Sheffield, S1 4DA*
- *Tel: 0114 222 5453, Email: [j.e.brazier@sheffield.ac.uk](mailto:j.e.brazier@sheffield.ac.uk)*

**Thank you for reading this information.**

## Appendix 12- Consent form for the QI phase



### Participant Consent Form

#### Exploring the facilitators and barriers to implementing outcome measures in third sector wellbeing organisations

Name of Researcher: Alexis Foster

**Please initial box**

1. I have read and understand the information sheet dated 30/05/2018 (v4.0) regarding the above study. I have had the chance to ask questions and the researcher has answered them.
2. I understand that my participation is voluntary and that I can stop taking part at any time, without having to give a reason. I understand that there will be no consequences of me deciding not to take part.
3. I give permission for the researcher to audio record the interview.
4. I understand that no one will be told that I am taking part in the study unless I choose to tell them. I give permission for members of the research team or the regulatory authorities to have access to my anonymised responses. I understand that people will not be able to identify me from the research results.
5. I give permission for anonymised quotes taken from my interview to be used in reports, publications, presentations and journals.
6. I agree to take part in the above study.

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

## Appendix 13- Example of a topic guide used in the QI phase

*Thank you for agreeing to take part in this interview. The interview should take less than an hour to complete.*

*Do you have any questions before we begin?*

*Can you confirm that you are happy for the interview to be recorded?*

- First of all can you tell me about your role in the organisation?- How long been there, what responsibilities does she have?
- What outcome measures are they using- which, when, how collecting, what doing with the data etc.
- How do they process and utilise the data that is collected
- Why did they start to use the PROMs? E.g. imposed by a commissioner, decided internally?
- How did they decide the process?
- Has the process changed at all following being tried and tested?
- When starting to use the PROMs, did they plan the process such as trialing it out?
- Does it feel like part of routine practice or still a challenge?
- What support are given to staff to complete?
- What training was provided to staff?
- Sometimes there can be issues engaging staff, how have things been in the organisation? What techniques have been used to try and get the staff engaged?
- What happens if a member of staff is not utilising PROMs
- How is it overseeing their collection- what issues have been raised?
- What helps the process work
- What hinders it?
- How are PROMs perceived by workers and service-users?
- What do they see the role of PROMs going forward, e.g. do they see them as a long-term practice?

## Appendix 14- How the findings from the QI phase linked to the CFIR constructs

Theme	Subtheme	CFIR construct the findings relate to	Example
<b>How external policy and funding context impacts on implementation</b>	<b>‘No choice’ but to use PROMs because of the external funding and policy context</b>	External policies and incentives	TSOs having to demonstrate their impact to gain/receive funding.
	<b>The impact of individual commissioners</b>	External change agents	A commissioner requiring a TSO to use a specific PROM.
	<b>The support of external advisors/researchers</b>	External change agents	External advisors/researchers supporting TSOs to implement PROMs.
	<b>Learning from other TSOs, or competing against them</b>	Peer pressure Cosmopolitanism	Sharing best practice amongst TSOs.
<b>How the objectives for using PROMs alongside the characteristics of a TSO impacted on implementation</b>	<b>How a TSO’s strategic objectives in relation to PROMs impacted on implementation</b>	Goals and feedback	PROMs are used to support the care management of service-users across the organisation
	<b>The impact of the size and structure of a TSO on implementation</b>	Structural characteristics Champions	Having structures within the TSO so that front-line workers have direct contact with the person responsible for implementing PROMs.
	<b>How the culture of a TSO can both facilitate and be a barrier to implementation</b>	Culture Implementation climate Networks and communications Learning climate Compatibility	Organisations being experienced at adopting new processes.

	<b>Subtheme</b>	<b>CFIR construct the findings relate to</b>	<b>Example</b>
<b>(Internal context continued)</b>	<b>The level of resources dedicated to the PROMs process</b>	Available resources Cost Relative priority	TSOs prioritising investment of resources into the implementation of PROMs.
	<b>The importance of the needs, skills and opinions of people within the TSO</b>	<b>The importance of having an Implementation Lead</b>	Formally appointed Implementation Leaders
	<b>The commitment and involvement of senior management within a TSO</b>	Leadership engagement Opinion leaders	Senior managers feel PROMs are important to implement within the TSO
	<b>The skills, experience and continuity of key staff</b>	Self-efficacy Individual stage of change Individual identification with organisation Other personal attributes	Having staff who are skilled in using PROMs.
	<b>How the needs of service-users impact on implementation</b>	Patient (service-users) needs and resources	Considering the needs of service-users when designing the PROMs process.
	<b>The role of volunteers in the PROMs process</b>	N/A	Volunteers can support the process but they need training and support.



	<b>Subtheme</b>	<b>CFIR construct the findings relate to</b>	<b>Example</b>
<b>(People continued)</b>	<b>Strong positive or negative opinions about PROMs</b>	Evidence strength and quality  Relative advantage  Knowledge and beliefs about the intervention  Tension for change  Relative priority  Opinion leaders  Compatibility	People may have concerns about PROMs but still engage with them because they want to support the TSO.
	<b>The principles underpinning the design of the PROMs process</b>	<b>Prescriptive v collaborative decision-making</b>	Intervention source  Front-line workers being involved in choosing a PROM
	<b>Having a proportionate, appropriate, straightforward and flexible design</b>	Complexity  Adaptability	Front-line workers having flexibility in how and when they administer the PROM depending on service-user.
<b>Variation between PROMs processes</b>	<b>The rationale for using specific PROMs</b>	Design quality and packaging  Cost	Decisions on whether a standardised or bespoke PROM is used.
	<b>How PROMs are collected</b>	Design quality and packaging	Collecting PROMs by paper with a front-line worker available to provide support.
	<b>The time points for administering PROMs</b>	Design quality and packaging	Choosing to collect PROMs at the start and end of when a service-users attends a wellbeing activity.
	<b>Processing the collected PROMs data</b>	Design quality and packaging	Having support staff who process and analyse data can reduce the burden on front-line workers.

	<b>Subtheme</b>	<b>CFIR construct the findings relate to</b>	<b>Example</b>
<b>(Processes continued)</b>	<b>Using the collected PROMs data</b>	Design quality and packaging	Having feedback loops so that front-line workers and service-users are provided with information on PROMs scores and how the data is being used.
	<b>Engaging and skilling up staff in using PROMs</b>	N/A  Access to knowledge and information  Organisations incentives and rewards  Engaging  Goals and feedback	Providing front-line workers with both ideological and practical training on PROMs.
<b>Using and sustaining PROMs in routine practice</b>	<b>Earlier decisions affect later stages of implementation</b>	Executing  Triability	Having a trial period to identify any issues that need addressing.
	<b>A process under constant review</b>	Reflecting and evaluating	Rarely do TSOs get the design of the PROMs process right first time and have to make improvements.
	<b>The role of culture change and job expectations on sustainability in routine practice</b>	Organisational incentives and rewards	There needs to be a shift in culture so that PROMs are seen as part of a front-line worker's role, not as something 'extra' they are doing.

## Appendix 15- Participant Information Sheet used in the CBPR phase



### Participant Information Sheet

#### **Implementing wellbeing questionnaires in third sector organisations: A collaborative measurement approach**

##### ***Introduction***

You are being invited to take part in an interview because your opinion is important to us as someone who works, volunteers or is linked with <Insert Organisation Name>. This interview will form part of a research study.

Before you decide whether you want to take part in the interview, it is important that you read this information sheet so you understand what the interview involves. You may wish to discuss it with someone else such as a friend. Please contact the researcher (contact details at the end of the sheet) if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

##### ***What is the purpose of the study?***

<Insert Organisation Name> are currently trying to use a new wellbeing questionnaire (also known as outcome measure) to capture the impact it has on its service-users. As this wellbeing questionnaire is new in the organisation, we want to understand more about people's experiences and opinions about it.

##### ***Why have I been asked to take part?***

You have been invited to take part because you are involved with <Insert organisation name>, such as working/volunteering for them, commissioning activities from them or involved in another capacity.

##### ***Do I have to take part?***

No, it is up to you to decide whether you would like to take part. If you would like further information, please contact the researcher. If you decide to take part, you can stop at any time and you do not have to give a reason. This would not impact on your relationship with <Insert Organisation Name>.

***What will happen if I take part?***

If you take part in the research, you will be interviewed either in person or over the telephone depending on your preference. If the interview is in person, you can choose where the interview will take place for example at your place of work or at the university. At the interview we will discuss your experience and opinions on the wellbeing questionnaire. The length of the interview is flexible but is likely to be about 60 minutes long. The interview will be informal- you will be asked a range of questions but this will not be a rigid question-and-answer session. The aim is to find out about your experiences and your views. The interview will be audio-recorded. This is to enable the researcher to focus on talking with you rather than having to also take notes.

Your real name will not be used in any subsequent written report or published material. The recordings and written notes based on these interviews will be securely stored at the University of Sheffield and recordings will be destroyed on completion of the research.

***What are the possible benefits of taking part?***

The research findings will help us to understand more about people's views about the wellbeing questionnaire. This information will be used to improve the process at <Insert Organisation name> and help inform other community organisations.

***What are the possible disadvantages and risks of taking part?***

There are not expected to be any disadvantages or risks to you taking part.

***Will my taking part in the study be kept confidential?***

We will follow strict ethical and legal requirements to ensure that all information about you is stored securely. We will keep your name separate from any information collected. Other people will only know that you have taken part in the research if you choose to tell them.

***What will happen if I no longer want to take part in the interview?***

You can choose not to take part in the interview at any time. This includes during the interview. Alternatively there may be specific questions in the interview you don't want to answer. In these cases just tell the researcher you don't want to answer them, and they will move onto another question. If you decide to stop taking part, the study will use any interview data collected up to that stage. If you decide to no longer take part in the research, this will not have any repercussions.

### ***What is the legal basis for processing my data?***

According to data protection legislation, we are required to inform you that the legal basis we are applying in order to process your personal data is that 'processing is necessary for the performance of a task carried out in the public interest' (Article 6(1)(e)). Further information can be found in the University of Sheffield's Privacy Notice <https://www.sheffield.ac.uk/govern/data-protection/privacy/general>.

### ***What will happen to the data collected and results of the research study?***

The audio recording from the interview will be listened to by an administrator at the University of Sheffield so that they can transcribe the interview. By transcribe, it is meant that the interview is written up in a document so that the researcher has a written account of what they and you said during the interview. Following the transcription, the researcher will remove any details in the transcript that may identify you such as your name. The transcript will then be analysed using codes and from this point, no identifiable information will be used.

The data will be stored in an access restricted folder on the University's shared network filestore and only the research team will have access to this folder

The data from the study will be retained until the completion of the research study. This will be by the end of 2024, but is likely to be sooner.

In terms of the results of the research study, the findings will be written up into a number of reports. One will be a large study report (a PhD thesis). Other reports will include guidance to community organisations and academic journal articles. If you would like, we can send you a summary of the research.

### ***Who is organising and funding the research?***

The study is being organised by Alexis Foster, a researcher at the University of Sheffield. This research is being undertaken as part of a PHD. The research is being funded by the National Institute of Health Research, as part of their Doctoral Research Fellowship programme (DRF-2016-09-007). Alexis has previously attended community activities and also volunteered and worked in community organisations.

### ***Who is the data controller for the study?***

The University of Sheffield will act as the Data Controller for this study. This means that the University of Sheffield is responsible for looking after your information and using it properly.

### ***Who has reviewed the study?***

To ensure that the study is ethical, it has been reviewed by an independent ethics committee at the School of Health and Related Research, University of Sheffield.

### ***Further information and contact details***

If you have any questions or would like further information please contact the researcher:

- *Alexis Foster*
- *ScHARR, University of Sheffield, Regent Court, 30 Regent Street, Sheffield, S1 4DA*
- *Tel: 0114 222 6129, Email: [alexis.foster@sheffield.ac.uk](mailto:alexis.foster@sheffield.ac.uk)*

If you have any concerns about the research such as how it has been conducted, please contact Professor Alicia O’Cathain. She is a senior researcher. You can also contact Alicia if you are unable to make contact with Alexis.

- *Professor Alicia O’Cathain*
- *ScHARR, University of Sheffield Regent Court, 30 Regent Street, Sheffield, S1 4DA*
- *Tel: 0114 222 0770, Email: [a.ocathain@sheffield.ac.uk](mailto:a.ocathain@sheffield.ac.uk)*

If you have any complaints about the research that have not been resolved satisfactorily by contacting the people above, then please contact Professor John Brazier. He is the Dean of the School of Health and Related Research at the University of Sheffield.

- *Professor John Brazier*
- *ScHARR, University of Sheffield, Regent Court, 30 Regent Street, Sheffield, S1 4DA*
- *Tel: 0114 222 5453, Email: [j.e.brazier@sheffield.ac.uk](mailto:j.e.brazier@sheffield.ac.uk)*

If your complaint relates to how your personal data has been handled, please contact:

- *Anne Cutler*
- *University of Sheffield Data Protection Officer*
- *Email: [dataprotection@sheffield.ac.uk](mailto:dataprotection@sheffield.ac.uk).*

If you would like further information about how to raise a complaint then please visit the University’s Privacy notice: <https://www.sheffield.ac.uk/govern/data-protection/privacy/general>. If you feel your complaint has not been handled to your satisfaction, then you can contact the Information Commissioner’s Office.

**Thank you for reading this information.**

## Appendix 16- Example of consent form used in the CBPR phase

### Participant Consent Form

#### Implementing wellbeing questionnaires in third sector organisations: A collaborative measurement approach

Name of Researcher: Alexis Foster

Please initial box

#### Taking part in the project

- (1). I have read and understand the information sheet dated 20/06/2018, Version 1.0 regarding the above study. (If no please do not proceed with this consent form until you are fully aware of what your participation in the project will mean.)
- (2). I have had the chance to ask questions and the researcher has answered them.
- (3). I agree to take part in the project. I understand that taking part in the project will involve being interviewed by a researcher.
- (4). I give permission for the researcher to audio record the interview.
- (5). I understand that my participation is voluntary and that I can stop taking part at any stage either before or during the interview without having to give a reason. I understand that any data collected up to that point will still be included in the research project. I understand that there will be no consequences of me deciding not to take part.

#### How my information will be used during and after the project

- (6). I understand my personal details, which for this study may include name, phone number, address and email address will not be revealed to people outside of the research team.
- (7). I understand and agree that my words may be quoted in publications, reports, web pages, and other research outputs. I understand that I will not be named in these outputs.
- (8). I understand and agree that other authorised researchers may use my anonymised data in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this form.

#### So that the information you provide can be used legally by the researchers

- (9). I agree to assign the copyright I hold in any materials generated as part of this project to The University of Sheffield.

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

For further information please contact the researcher;  
Alexis Foster, [alexis.foster@sheffield.ac.uk](mailto:alexis.foster@sheffield.ac.uk), 0114 222 6129

## Appendix 17- Example of a topic guide used in the CBPR phase

### Topic guide for the key informant interviews

*Will have versions of the wellbeing measure at the interview*

Please tell me about your role at the organisation

- Understand which activity/service they deliver or their link with the organisation
- Understand how long they have been undertaking that role
- Understand what made them start working at/with the organisation

Explore their experiences and viewpoints about the wellbeing measure

- Its design
- The wording of the questions
- How It is administrated

Explore how they find the process of collecting, analysing, processing and using the data generated from the wellbeing measure- Focusing on the elements relevant to the participant

Explore how involved they felt with developing the PROMs process and the impact of this on their views on the process

If appropriate, explore whether they feel they received sufficient training/support on using the wellbeing measure

Discuss how they found the implementation process- what aspects are they aware of, what their views are on it and what could be improved

Explore how sustainable they feel the collection of the wellbeing measure is- e.g. do they see its use as long-term, what processes need to be in place to enable this?

*Anything else they want to say, whether they want to be involved in the integration meetings*

*and Thank you.*



### Appendix 18- How the findings from the CBPR phase linked to the CFIR constructs

Theme	Subtheme	CFIR Construct	Example
<b>Support from external sources to facilitate the implementation of PROMs</b>	<b>Asserting ownership within an external funding context where PROMs are imposed through contracts</b>	External policies and incentives	TSOs choosing to implement PROMs in response to the external funding context.
	<b>University researchers/students facilitate the implementation of PROMs</b>	External change agents	TSOs needing the support of researchers/students to support implementation.
	<b>Having good networks with other local TSOs enables the sharing of practice</b>	Cosmopolitanism	Having partnerships with other local TSOs to share learning.
<b>How the characteristics of the TSO and reasons for using PROMs influenced implementation</b>	<b>Strategic commitment to PROMs</b>	Goals and feedback Leadership engagement Relative priority Implementation climate Relative advantage	Having an organisational commitment to measuring outcomes.
	<b>Cultural differences between the TSOs</b>	Culture Implementation climate Networks and communications Learning climate Compatibility	Staff having strong networks within TSOs where they help each other with PROMs.
	<b>How the structure, size and available resources impact implementation</b>	Structural characteristics Available resources Cost Relative priority	TSOs being sufficiently large enough so they have the infrastructure to utilise PROMs.

	<b>Subtheme</b>	<b>CFIR Constructs</b>	<b>Examples</b>
<b>(Internal context continued)</b>	<b>Need for a fit-for-purpose data management system and a member of staff to oversee it</b>	Available resources	Important to have a suitable data management system.
<b>The skills, experience and opinions of individuals within TSOs</b>	<b>How varying levels of staff engagement impacted on implementation</b>	Formally appointed Implementation Leaders Champions Self-efficacy Individual stage of change Individual identification with organisation Other personal attributes Evidence strength and quality Relative advantage Knowledge and beliefs about the intervention Tension for change Relative priority Opinion leaders Compatibility Leadership engagement	Having an individual who leads the implementation process.
	<b>How negative previous experiences of using PROMs and concerns about validity influenced the design and use of PROMs</b>	Evidence strength and quality Tension for change Knowledge and beliefs about the intervention Self-efficacy	Negative experience of validated PROMs prompted the TSOs to design bespoke measures.

Theme	Subtheme	CFIR Construct	Example
<b>Co-designing a PROM with front-line workers to ensure it is appropriate for the specific TSO</b>	<b>Co-designing the PROM with front-line workers</b>	Intervention source Engaging	Involve front-line workers in designing the PROM.
	<b>Designing a PROM appropriate for the TSO</b>	Intervention source Compatibility	TSOs designing a bespoke PROM.
	<b>How the organisations considered service-users' needs but did not consult them on PROMs</b>	Patient Needs & Resources	TSOs consider service-user needs by consulting front-line workers.
<b>A lack of planning the design of the PROMs process</b>	<b>Challenges result from TSOs taking an organic approach to design</b>	Design quality and packaging Cost Adaptability Complexity Compatibility Readiness for implementation Planning	Rather than having a pre-designed PROMs process, TSOs are deciding the process once they start using the PROMs.
	<b>Identifying which wellbeing activities to use PROMs for</b>	Design quality and packaging Compatibility	Organisations are prioritising using PROMs in wellbeing activities they feel are amenable to measurement.
	<b>How issues with staff capacity and infrastructure caused problems with collecting and processing the PROMs</b>	Design quality and packaging Cost	Front-line workers don't feel they have time to process the collected PROMs.
	<b>Developing processes for using the collected PROMs data</b>	Design quality and packaging	TSOs need to ensure collected data is shared with front-line workers.

Theme	Subtheme	CFIR Construct	Example
<b>Skilling-up front-line workers through training, peer support and supervision</b>	N/A	Access to knowledge and information Organisations incentives and rewards Engaging Goals and feedback	Providing front-line workers with both ideological and practical training on PROMs.
<b>It takes time for TSOs to embed PROMs into practice and organisations experience problems with data collection</b>	<b>Testing out the acceptability of the PROM</b>	Executing Trialability	PROMs being trialed within the TSO.
	<b>How TSOs need an ‘embedding period’ where front-line workers become accustomed to using PROMs</b>	Reflecting and evaluating Learning climate Readiness for implementation Self-efficacy Individual stage of change	TSOs need an embedding period to help front-line workers become accustomed to using PROMs.
	<b>Issues with data collection</b>	Organisational incentives and rewards Knowledge and beliefs about the intervention Complexity	Front-line workers vary in their data collection rates.
	<b>Measurement properties of the bespoke PROM</b>	Design quality and packaging	There are issues about whether bespoke PROMs are capturing change.
	<b>Implementation takes time because of delays and changes</b>	Relative advantage Relative priority	Implementation takes time because of delays and changes to the PROMs process.

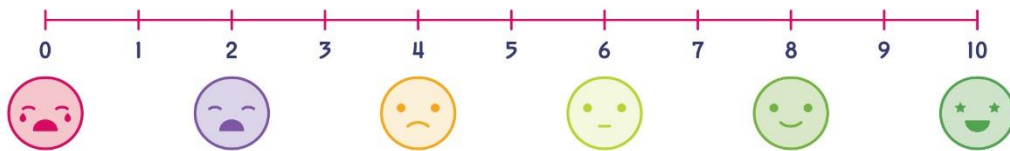
## Appendix 19- Organisation B's PROM

# WELLBEING QUESTIONNAIRE

Client name:	Staff name:
Ref number:	Service:
Date:	

### 1. How are you feeling today?

Please choose your state on the scale below.



### 2. Emotional Wellbeing

Please indicate your answer by placing a tick ✓ for the answer that best describes your feelings and thoughts over the last two weeks.

Statement	None of the time	Rarely	Some of the time	Often	All of the time
I've been feeling optimistic about the future	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been feeling useful	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been feeling relaxed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been dealing with problems well	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been thinking clearly	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been feeling close to other people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been able to make up my mind about things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

### 3. Social contacts

Thinking about how much contact you've had with people you like, which of the following statements best describes your social situation? Please indicate your answer by placing a tick ✓ in one box below.

- I have as much social contact as I want with people I like
- I have adequate social contact with people
- I have some social contact with people, but not enough
- I have little social contact with people and feel socially isolated

### 4. Financial Wellbeing

How well would you say you are managing financially these days? Please indicate your answer by placing a tick ✓ in one box below.

- Finding it very difficult 
- Finding it quite difficult 
- Just about getting by 
- Doing alright 
- Living comfortably 

## Appendix 20- Organisation A's PROM

To be completed by the worker

Name \_\_\_\_\_ Date \_\_\_\_\_

Service \_\_\_\_\_ Worker \_\_\_\_\_

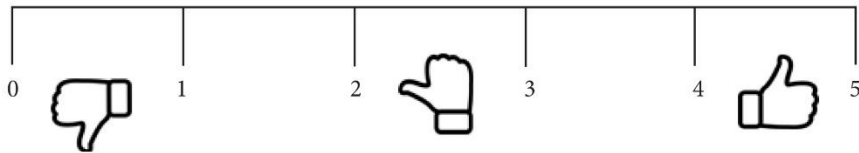
Please circle: Start Middle End

### How are you feeling? Evaluation - Follow-up

1. How are you feeling today? Please circle on the scale, with 0 being 'terrible' and 5 being 'great'.



2. How well do you cope with managing problems? Please circle on the scale, with 0 being not at all well and 5 being very well.



3. Do you know where to get help from when you have problems such as health concerns or money worries? Please circle on the scale, with 0 being don't know where to get help and 5 being always know where to get help.



4. How confident do you feel asking for help when you have problems? Please circle on the scale, with 0 being unable to ask for help and 5 being always feeling able to ask for help.



5. How often do you feel lonely? Please circle below.

Often or always      Some of the time      Occasionally      Hardly ever      Never

6. Do you feel less lonely since being supported by [redacted]

More lonely      About the same      Less lonely      A lot less lonely

Why do you think this is?

7. Do you feel more connected with your community since accessing support?

Less connected      About the same      More connected      A lot more connected

8. What, if anything has changed for you since accessing support at [redacted]

9. Is there anything [redacted] could have done better?

10. How likely are you to recommend [redacted] to friends and family, with 0 being highly unlikely and 5 being very likely?



Worker's notes.

Appendix 21- Integration table- synthesising the different phases of the research

Implementation Issue	Category	CFIR construct	Systematic review of reviews (Chapter 3)	TSO literature/ consultation event (Chapter 4)	QI Phase (Chapter 7)	CBPR Phase (Chapter 9)	Comparison between the different sources
<b>Impact of the external funding context</b>	<b>External funding and policy context</b>	External policies and incentives	Organisations were less compliant with implementing PROMs that were required or incentivised by external organisations.	Bach-Mortensen* found TSOs experienced difficulties implementing evaluation which was externally imposed.  TSO stakeholders felt organisations were motivated to use PROMs because they were required by funders	TSOs were using PROMs because they are required by commissioners or in response to the external funding context.	TSOs were implementing PROMs in response to the external funding context.	<b>Dissonance</b> External funding pressures are facilitating the use of PROMs for performance monitoring purposes within TSOs. This differs to healthcare services, where external incentives are a barrier.



	Category	CFIR construct	Systematic review of reviews (Chapter 3)	TSO literature/ consultation event (Chapter 4)	QI Phase (Chapter 7)	CBPR Phase (Chapter 9)	Comparison between the different sources
<b>(External context continued)</b>	<b>The impact of individual commissioners</b>	External Change Agents	Silence within the systematic review of reviews about the impact of individual commissioners.	TSO stakeholders discussed the influence of individual commissioners.	TSOs had to implement multiple PROMs processes because of individual commissioners taking different approaches to PROMs.	TSOs were aware of having to incorporate the requirements of different commissioners, which may change over time.	<b>Silence</b> The systematic review of reviews did not identify the influence of individual commissioners. However, the approach taken by individual commissioners was relevant to TSOs, especially having to meet the needs of multiple commissioners.
	<b>The support of external advisors/ researchers</b>	External Change Agents	Silence about having support from external advisors/ researchers	Bach-Mortensen and TSO stakeholders felt implementation was facilitated by having support from people outside of the organisation.	Extremal advisors/ researchers supported TSOs to implement PROMs but any support needed to be tailored to the specific organisation.	TSOs relied on the support of external researchers/students to support implementation and provide credibility to the process.	<b>Silence</b> The systematic review of reviews did not identify the importance of external advisors/ researchers including students, whereas TSOs benefitted from receiving external support, providing it was tailored to the specific TSO.

	Category	CFIR construct	Systematic review of reviews (Chapter 3)	TSO literature/consultation event (Chapter 4)	QI Phase (Chapter 7)	CBPR Phase (Chapter 9)	Comparison between the different sources
<b>(External context continued)</b>	<b>Learning from other TSOs</b>	Cosmopolitanism Peer Pressure	Silence within the systematic review of reviews on organisations learning from each other.	Bach-Mortensen and TSO stakeholders felt implementation is facilitated by learning from other TSOs.	TSOs learnt from other TSOs but any learning needed to be tailored to the specific organisation.	TSOs learnt from other organisations but any learning needed to be tailored to the specific organisation.	<b>Silence</b> The systematic review of reviews did not identify how organisations can learn from each other whereas TSOs found this useful, providing the learning is tailored to the specific TSO.
<b>The impact of a TSO's unique internal context</b>	<b>The impact of the reasons for using PROMs</b>	Goals and feedback	Implementation was facilitated when PROMs had a care management function.	Bach-Mortensen identified how TSOs had to prioritise implementing evaluation required by commissioners for performance monitoring reasons.	TSOs were primarily using PROMs for performance monitoring to demonstrate their impact to commissioners.	TSOs were primarily using PROMs for performance monitoring function in terms of being able to demonstrate their impact to commissioners.	<b>Dissonance</b> The systematic review of reviews identified the need for PROMs to have a care management purpose whereas PROMs generally had a performance monitoring function within TSOs.

	Category	CFIR construct	Systematic review of reviews (Chapter 3)	TSO literature/ consultation event (Chapter 4)	QI Phase (Chapter 7)	CBPR Phase (Chapter 9)	Comparison between the different sources
<b>(Internal context continued)</b>	<b>The impact of the size and structure of a TSO</b>	Structural Characteristics  Champions	Silence within the systematic review of reviews about the influence of the size and structure of organisations on implementation.	Bach-Mortensen and TSO stakeholders felt larger TSOs have an advantage over smaller organisations because they had greater resources to use for implementation.	The size of a TSO and its structure impacted on implementation, with organisations facing different challenges depending on their characteristics.	The TSOs involved in the CBPR phase were of sufficient size to invest in implementation including having data management systems and support staff. However, they faced structural barriers including front-line workers based in different locations.	<b>Silence</b> The systematic review of reviews did not discuss the impact of the characteristics of an organisation, whereas the issue was relevant in respect of TSOs.
	<b>How the culture of a TSO can both facilitate and be a barrier</b>	Culture  Implementation climate  Networks and communications  Learning climate  Compatibility	One review identified the importance of good networks amongst staff but generally the systematic review of reviews did not consider the culture of organisations.	Bach-Mortensen emphasised that culture was important in terms of whether there was a commitment to evaluation.  There was silence amongst TSO stakeholders about the influence of culture.	Some aspects of a TSOs culture facilitated implementation including having good networks amongst staff. However, other aspects were barriers.	TSOs had good networks amongst staff where they supported each other. However, their priority was to support service-users rather than spend time on administrative tasks.	<b>Silence</b> There was little in the systematic review of reviews in relation to culture whereas the culture of TSOs appeared to influence implementation- some elements facilitate and other aspects are barriers

	Category	CFIR construct	Systematic review of reviews (Chapter 3)	TSO literature/ consultation event (Chapter 4)	QI Phase (Chapter 7)	CBPR Phase (Chapter 9)	Comparison between the different sources
<b>(Infernal context continued)</b>	<b>The level of resources dedicated to PROMs</b>	Available Resources Cost Relative priority	Organisations needed to invest in infrastructure to implement PROMs.	Bach-Mortensen and TSO stakeholders identified how TSOs needed to invest in infrastructure but they faced financial constraints. Even if they made the investment, there was not always the capacity and capability to utilise the infrastructure.	TSOs needed to prioritise investing resources into PROMs including having data management systems but they may not have the finances to undertake investment.	TSOs invested into the PROMs process such as data management systems but they faced constraints e.g. not being able to fund administrators to process the data.	<b>Complementary</b> Organisations need to prioritise the investment of resources into PROMs but they also need the capacity and capability to engage with the resources.
<b>People vary in their engagement with PROMs</b>	<b>The importance of an Implementation Lead</b>	Formally Appointed Implementation Leaders	Having an Implementation Lead to progress implementation is a facilitator.	There was silence in Bach-Mortensen and amongst TSO stakeholders about the need to have an individual leading implementation.	Appeared critical to have an Implementation Lead who bought into the concept of PROMs and was committed to progressing implementation.	Appeared critical to have an Implementation Lead who bought into the concept of PROMs and was committed to progressing implementation.	<b>Complementary</b> Whilst the systematic review of reviews identified the Implementation Lead role, it appeared critical that TSOs have a proactive Implementation Lead who is able to prioritise implementation.

	Category	CFIR construct	Systematic review of reviews (Chapter 3)	TSO literature/ consultation event (Chapter 4)	QI Phase (Chapter 7)	CBPR Phase (Chapter 9)	Comparison between the different sources
<b>(People continued)</b>	The commitment and involvement of senior management within a TSO	Leadership Engagement	Need for senior managers to be committed to the implementation of PROMs.	Bach-Mortenson identified the importance of senior managers being supportive.  Silence amongst TSO stakeholders about leadership engagement.	Having senior managers supportive of PROMs was important to ensure the TSO had a strategic commitment to PROMs.	Having senior managers supportive of PROMs was important to ensure the TSO had a strategic commitment to PROMs.	<b>Convergence</b> Senior managers need to be engaged to ensure the TSO was committed to implementing PROMs.
	The importance of having a data manager/ someone with management information skills	Champions  Knowledge and Beliefs about the Intervention	Need for sufficient support staff to facilitate implementation but the systematic review of reviews did not specifically identify the need for data managers.	Silence with Bach-Mortensen and amongst TSO stakeholders about the need for data management staff but they did identify that TSOs often don't have staff with sufficient skills for undertaking evaluation.	Some TSOs invested in data managers and these organisations found it useful having someone with the technical skills to manage the PROMs data.	The TSOs each had a member of staff with technical skills to support data management.	<b>Complementary</b> It appears important to have staff supporting PROMs who have the technical skills to oversee data management systems.

	Category	CFIR construct	Systematic review of reviews (Chapter 3)	TSO literature/ consultation event (Chapter 4)	QI Phase (Chapter 7)	CBPR Phase (Chapter 9)	Comparison between the different sources
<b>(People continued)</b>	<b>The skills, experience and continuity of key staff</b>	Self-efficacy Individual stage of change Individual identification with organisation Other personal attributes	Front-line workers need to be engaged and supportive of PROMs.	Bach-Mortensen discussed the importance of front-line workers having sufficient skills.  TSO stakeholders discussed how not all front-line workers will engage with PROMs.	Front-line workers were highly skilled with service-users but varied in their skills and engagement of PROMs.	There was variation in the engagement of front-line workers because of differing levels of skills and attitudes to PROMs. This variation was accepted.	<b>Complementary</b> There is variation in the engagement of individual front-line workers because of differing skills and attitudes towards PROMs.
	<b>How the implementation of PROMs is not prioritised</b>	Relative priority	Silence within the systematic review of reviews whether implementation is prioritised by individuals.	Bach-Mortensen and TSO stakeholders emphasised that individuals within TSOs lacked capacity because of other workload priorities.	Some interviewees discussed that individuals had to prioritise other tasks rather than implementing PROMs but this was not a prominent finding.	The implementation of PROMs could be delayed because people both within and external to TSOs needed to prioritise other work commitments.	<b>Silence</b> The systematic review of reviews did not identify the issue of relative priority however this appears to be a barrier within TSOs.

	Category	CFIR construct	Systematic review of reviews (Chapter 3)	TSO literature/ consultation event (Chapter 4)	QI Phase (Chapter 7)	CBPR Phase (Chapter 9)	Comparison between the different sources
(People continued)	Considering the needs of service-users	Patients' Needs and Resources  Adaptability	Service-users' needs, especially front-line worker' perceptions of these needs should be considered when designing the PROMs process including having a flexible PROMs process.	Silence within Bach-Mortensen and amongst TSOs stakeholders about considering service-users' needs or involving them in implementation.	Most TSOs considered service-user needs rather than consulting them directly.	TSOs considered service-user needs but did not consult them because felt the front-line workers provided the service-user perspective.	<b>Convergence</b> It appears important that service-users' needs are considered but this does not usually involve consulting service-users directly. It can be useful to have flexibility within the PROMs process to account for the needs of individual service-users.
	The role of volunteers in the PROMs process	N/A	Silence within the systematic review of reviews in relation to involving volunteers in PROMs.	Silence in Bach-Mortensen about involving volunteers.  TSO stakeholders discussed how volunteers could support PROMs implementation but needed support and not all volunteers would engage.	Volunteers could support PROMs but needed sufficient training.	The TSOs did not involve volunteers but front-line workers felt volunteers could support the PROMs process.	<b>Silence</b> The systematic review of reviews did not discuss involving volunteers. In TSOs, volunteers can support the PROMs process but need sufficient training. Volunteers appear an underused resource in respect of PROMs.

	Category	CFIR construct	Systematic review of reviews (Chapter 3)	TSO literature/ consultation event (Chapter 4)	QI Phase (Chapter 7)	CBPR Phase (Chapter 9)	Comparison between the different sources
(People continued)	<b>Individuals in TSOs have strong opinions about PROMs – positive or negative- and this impacts implementation</b>	Evidence strength and quality Relative advantage Knowledge and beliefs about the intervention Tension for change Relative priority Opinion leaders Compatibility	Front-line workers opinions are changeable as are shaped by their experiences of using PROMs.	Silence in Bach-Mortensen and amongst TSO stakeholders about the opinions of individuals.	People had mixed views on PROMs and they were changeable depending on their experiences.	Negative previous experiences resulted in front-line workers being resistant to PROMs but were more accepting if they perceived the PROM as appropriate.	<b>Convergence</b> Front-line workers’ opinions are shaped by historical experiences of PROMs but also their experience of the current PROMs process.
<b>Planning</b>	<b>Planning the PROMs implementation process</b>	Planning	It is important to plan implementation	Bach-Mortensen identified the importance of planning.	Silence about planning the implementation process.	The TSOs did not plan implementation.	<b>Dissonance</b> The systematic review of reviews identified the importance of planning but TSOs did not appear to plan the implementation process. This could be a barrier.



Implementation issue	Category	CFIR construct	Systematic review of reviews (Chapter 3)	TSO literature/ consultation event (Chapter 4)	QI Phase (Chapter 7)	CBPR Phase (Chapter 9)	Comparison between the different sources
Designing a PROMs process appropriate for the specific TSO	Prescriptive v collaborative decisions on design	Intervention source	It can be beneficial to involve front-line workers in designing the PROMs process.	<p>Bach-,Mortensen emphasised the need for TSOs to be able to design their own processes</p> <p>TSO stakeholders felt front-line workers struggled most with PROMs which were imposed by commissioners.</p>	Some TSOs took a collaborative approach to design however this was not possible if a commissioner required the TSO to use a specific PROM.	TSOs took a collaborative approach to design by involving their front-line workers.	<p><b>Complementary</b></p> <p>Taking a collaborative approach to designing the PROMs process with front-line workers appears beneficial. However, this is not possible if commissioners impose a PROM process on the TSO.</p>
	Having a straightforward, appropriate, proportionate, and flexible design	Adaptability Complexity Compatibility Design Quality and Packaging	The designed PROMs process needs to be straightforward and flexible to meet the needs of different service-users and be appropriate for the organisation.	Bach-Mortensen and TSO stakeholders felt any process needed to be tailored to the organisation.	TSOs needed to have a straightforward, appropriate, proportionate and flexible design. However, having flexibility could mean PROMs were not used as much as intended.	TSOs decided the PROMs process as they used the measures. The process was flexible to meet the needs of individual service-users.	<p><b>Convergence</b></p> <p>Organisations need to ensure any PROMs processes were flexible, straightforward and compatible to the TSO, wellbeing activity and service-user.</p>

	Category	CFIR construct	Systematic review of reviews (Chapter 3)	TSO literature/ consultation event (Chapter 4)	QI Phase (Chapter 7)	CBPR Phase (Chapter 9)	Comparison between the different sources
<b>(Designing continued)</b>	<b>The rationale for using specific PROMs</b>	Design Quality and Packaging  Costs	Need to use a PROM which is relevant and suitable for the organisation. Front-line workers need to perceive the PROM as valid. Licence fees can prevent organisations using specific PROMs.	Bach-Mortensen found TSOs struggled to identify appropriate evaluation tools.  TSO stakeholders emphasised that PROMs need to be short, easy to use and relevant to the organisation.	TSOs differed in whether they use validated or bespoke measures. The PROM needed to be appropriate for the TSO but is sometimes chosen by a commissioner.	The TSOs designed their own bespoke PROM because of a lack of suitable validated PROMs.	<b>Complementary</b> Organisations need to use PROMs that are appropriate for the specific organisation & are short in length. Some TSOs are designing their own bespoke PROMs because of a perceived lack of suitable measures.
	<b>How PROMs are collected</b>	Design Quality and Packaging  Costs	Increased interest in using ePROMs	Silence in Bach-Mortensen and amongst TSO stakeholders about how PROMs are collected.	PROMs collected by paper in appointments with front-line workers because service-users needed support and there was a lack of resources for ePROMs.	PROMs collected by paper, in appointments with front-line workers.	<b>Dissonance</b> Healthcare services are increasingly using ePROMs whereas TSOs are using paper based PROMs because lack sufficient resources for ePROMs to be feasible.

	Category	CFIR construct	Systematic review of reviews (Chapter 3)	TSO literature/ consultation event (Chapter 4)	QI Phase (Chapter 7)	CBPR Phase (Chapter 9)	Comparison between the different sources
<b>(Designing continued)</b>	<b>The time points for administering PROMs</b>	Design Quality and Packaging	It was important for organisations to design which time points PROMs are collected at and to align these with existing workflows.	TSO stakeholders identified challenges in identifying suitable time points because of the ongoing nature of wellbeing activities and because service-users' attendance may be sporadic.	TSOs found it difficult to identify time points especially for ongoing wellbeing activities.	TSOs struggled to identify suitable time points and relied on front-line workers to administer the PROMs when it felt appropriate.	<b>Dissonance</b> In healthcare services, it is recommended pre-designing which time points PROMs are collected at but TSOs can struggle to identify suitable time points because of the nature of some wellbeing activities.
	<b>Processing the collected PROMs data</b>	Design Quality and Packaging  Available resources	There was a need to plan how the PROMs data will be processed.	Bach-Mortensen identified that TSOs face capability and capacity challenges with undertaking evaluation.	TSOs needed systems in place for processing the collected PROMs data but the precise system differed depending on the organisation and their resources.	TSOs struggled with processing collected PROMs because of front-line workers not having capacity.	<b>Complementary</b> Organisations need appropriate systems for processing the collected data. Front-line workers face capacity barriers with processing PROMs.
	<b>Using the collected PROMs data</b>	Design Quality and Packaging  Available resources  Knowledge and Beliefs about the intervention	It is important to design how the PROMs data will be used so that front-line workers can easily use the data when working with service-users.	Silence within Bach-Mortensen and amongst stakeholders about using the collected PROMs data.	Important for TSOs to ensure front-line workers and service-users receive feedback on the data.	TSOs needed to invest time and resources in developing processes for using the PROMs data.	<b>Convergence</b> Need to design how the PROMs data will be shared with different types of stakeholders including front-line workers and service-users.

Implementation issue	Category	CFIR construct	Systematic review of reviews (Chapter 3)	TSO literature/ consultation event (Chapter 4)	QI Phase (Chapter 7)	CBPR Phase (Chapter 9)	Comparison between the different sources
<b>Training and supporting front-line workers</b>	<b>Training and supporting front-line workers</b>	Engaging Access to Knowledge and Information Knowledge and Beliefs about the Intervention Organisations incentives and rewards Goals and feedback	It was important to deliver ideological and practical training to front-line workers.	Bach-Mortensen identified the need for training and TSO stakeholders emphasised that any training needed to be ongoing.	Front-line workers needed ongoing training which is both ideological and practical. Some front-line workers required additional training.	Front-line workers needed ongoing training and support to use PROMs.	<b>Complementary</b> Front-line workers need ongoing ideological and practical training alongside other support e.g. peer support.
<b>Implementation takes time and there are issues with data quality</b>	<b>Implementation takes time &amp; is dependent on people's capacity</b>	Executing Readiness for Implementation	Implementation takes time and issues can arise when starting to use PROMs.	Bach-Mortenson and TSO stakeholders found capacity issues were detrimental for implementation.	Implementation took time which was challenging when wellbeing activities were funded for limited periods of time.	Implementation takes over a year and capacity issues can cause delays.	<b>Convergence</b> Implementation takes a considerable period of time especially as TSOs face capacity issues.
	<b>Trialing the measure</b>	Trialability	Having a trial period to identify any issues with the measures is useful.	Silence within Bach-Mortensen and TSO stakeholders about having a trial period.	TSOs had not tested PROMs before using them.	Had some front-line workers trial the PROM.	<b>Convergence</b> Organisations can find it useful to have a trial period where they test out the proposed PROM.

	Category	CFIR construct	Systematic review of reviews (Chapter 3)	TSO literature/ consultation event (Chapter 4)	QI Phase (Chapter 7)	CBPR Phase (Chapter 9)	Comparison between the different source
<b>(Implementation issues continued)</b>	<b>Embedding period</b>	Executing	It takes time for PROMs to become part of routine practice.	Silence within Bach-Mortensen and amongst TSO stakeholders about having an embedding period.	Takes time for PROMs to become part of routine practice.	TSOs need to give front-line workers time to become accustomed to using the measures.	<b>Complementary</b> It takes time for PROMs to become part of routine practice and front-line workers need support to use measures.
	<b>A process under constant review</b>	Reflection and Evaluation	Issues arise when organisations start to use PROMs and there is a need to reflect on and develop the PROMs process.	Silence within Bach-Mortensen about needing to make improvements.  TSO stakeholders discussed the need for an organisation to respond to feedback from front-line workers.	TSOs rarely got the PROMs process right first time and had to make improvements.	TSOs continually reflected and improved the PROMs process especially as commissioners' requirements may change.	<b>Convergence</b> Issues arise when starting to implement PROMs and organisations need to reflect and develop the process.
	<b>The need for cultural change to enable the use of PROMs to be sustained.</b>	Organisational incentives and rewards	Silence within the systematic review of reviews on how to sustain the use of PROMs.	Silence within Bach-Mortensen and amongst TSO stakeholders about sustaining the use of PROMs.	Not all TSOs manage to make PROMs part of routine practice. Cultural change is needed to sustain the use of PROMs.	Took time for front-line workers to remember to complete the measures and there needed to be a change in culture.	<b>Silence</b> Not all TSOs sustained the use of PROMs and it required the organisation to undergo cultural change.

## Appendix 22- Disseminating the findings of the PhD

The aim of undertaking the research was to support TSOs, commissioners and other organisations with implementing PROMs. Consequently, I have sought to proactively disseminate the findings of the PhD. This has included traditional academic channels including publications and conferences. However, I also sought to use innovative dissemination methods in order to reach third sector stakeholders. Some of the dissemination activities are detailed in this appendix.

### **Guidance**

Guidance was produced on implementing PROMs aimed at people working in TSOs and commissioners. The guidance is available from:

[https://issuu.com/niftyfoxcreative/docs/proms\\_booklet\\_final](https://issuu.com/niftyfoxcreative/docs/proms_booklet_final)

The guidance will be actively disseminated including via mailing lists and through organisations hosting the guidance on their websites, for example Voluntary Action Sheffield (a third sector advisory organisation).

### **Publications**

Foster A, Croot L, Brazier J, Harris J & O'Cathain A (2018) [The facilitators and barriers to implementing patient reported outcome measures in organisations delivering health related services: a systematic review of reviews](#). *Journal of Patient-Reported Outcomes*. 2 (46). DOI: 10.1186/s41687-018-0072-3.

Submitted to BMJ Open in April 2020: Foster A, O'Cathain A and Harris, J. How do Third Sector Organisations or Charities providing health and wellbeing services in England implement Patient Reported Outcome Measures (PROMs)?: A qualitative interview study.

## **Conferences**

2019- National PROMs conference- Oral Presentation- “The role of Patient and Public Involvement when implementing PROMs”.

2019- International Social Prescribing Conference- Oral Presentation- “Implementing PROMs in social prescribing: A qualitative interview study”.

2018- National PROMs conference- Oral Presentation- “Identifying the facilitators and barriers to implementing PROMs: A systematic review of reviews”.

2018- ReQoL Clinical Practice Sharing Event.

## **Organisation specific training**

2019- Sharing of good practice with a number of TSO stakeholders in Devon.

2018- Development of training materials and delivering online training for link workers at the British Red Cross.

2018- Training session for staff at Rotherham, Doncaster and South Humber NHS Foundation Trust.

## **Other activities**

2019- Hosting the Social Prescribing Network twitter hour- Tweeting findings from the study, answering queries people raised and promoting awareness of the study.

2019- Blog on ReQoL Community of Practice- Implementing PROMs in practice.

2018- Knowledge mobilisation within the third sector- Teaching on the Masters in Public Health course.