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## How do Third Sector Organisations or Charities providing health and wellbeing services in England implement Patient Reported Outcome Measures (PROMs)?: A qualitative interview study

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3 **How do Third Sector Organisations or Charities providing health and**  
4 **wellbeing services in England implement Patient Reported Outcome**  
5 **Measures (PROMs)?: A qualitative interview study**  
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# How do Third Sector Organisations or Charities providing health and wellbeing services in England implement Patient Reported Outcome Measures (PROMs)?: A qualitative interview study

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## Abstract

**Objectives:** To identify the facilitators and barriers to implementing Patient Reported Outcome Measures (PROMs) in third sector organisations (TSOs) delivering health and wellbeing services.

**Design:** A qualitative interview study. Participants were recruited using purposive, opportunistic and snowballing methods. Framework analysis was used.

**Setting:** TSOs including charities, community groups and not-for-profit organisations in England, United Kingdom.

**Participants:** Thirty interviewees including service-users, TSO front-line workers and managers, commissioners of TSOs and other stakeholders such as academic researchers.

**Results:** TSOs primarily used PROMs because of pressures arising from the external funding context. However organisations often struggled to implement PROMs, rarely getting the process right first time. Facilitators for implementation included having an Implementation Lead committed to making it work, investing resources in processes and taking a collaborative approach to designing the PROMs process. The latter helped to ensure an appropriate PROMs process for the specific TSO including choosing a suitable measure and planning how data would be collected, processed and used. There was a dilemma about whether TSOs should use standardised measures, for example the Warwick Edinburgh Mental Wellbeing Scale or design their own PROM. Not all TSOs sustained the collection and reporting of PROMs over time because this required a change in organisational culture such as PROMs becoming part of front-line workers' job specifications.

**Conclusions:** TSOs are implementing PROMs in their wellbeing services but face challenges. This study identified a number of facilitators which could help TSOs and commissioners implement PROMs. Some of the findings are consistent with the experiences of more clinical services so appear relevant to the implementation of PROMs irrespective of the specific context.

### **Strengths and Limitations**

- First piece of published research specifically focusing on the implementation of Patient Reported Outcome Measures (PROMs) in third sector organisations.
- Identified a number of findings useful to commissioners and TSOs to improve the implementation of PROMs.
- Some of the findings may be relevant to healthcare services.
- It would have been useful to interview more people from larger TSOs and from organisations who had stopped using PROMs.

### **Introduction**

PROMs (Patient Reported Outcome Measures) are standardised questionnaires which measure Patient Reported Outcomes such as a person's health, wellbeing or symptoms (1-3). If a person answers a questionnaire at two or more time points, for example before and after receiving support, scores can be compared to understand whether there is any change. Examples of PROMs include the Warwick Edinburgh Mental Wellbeing Being Scale (WEMWBS) (4) and the Office for National Statistics Wellbeing questions (5). PROMs' scores can be used on an individual service-user level as a care management tool or the scores of multiple service-users can be combined to evaluate the impact of a service (1). Increasingly, policy makers advocate the use of PROMs. For example the United Kingdom's (UK's) PROMs programme mandates hospitals used PROMs for hip and knee replacements (6). And in the United States of America, the Patient Reported Outcomes Measurement Information System (PROMIS) is being implemented (7).

Healthcare organisations often experience problems when using PROMs so studies have sought to identify the facilitators and barriers to implementation. Identified facilitators include choosing PROMs which are appropriate and can have a therapeutic purpose, designing a PROMs process which is straightforward, having an Implementation Lead, engaging and training staff, trialing PROMs and refining the process if initial issues arise (8-11). These factors could become barriers if not undertaken by an organisation. For example, staff may not use PROMs if they do not receive sufficient training or find the data collection process complex.

To date, research on implementing PROMs has focused on clinical services and not considered PROMs usage within third sector organisations (TSOs) (8). TSOs, also known as charities, voluntary or community organisations are increasingly commissioned to deliver health and

wellbeing services (forth-known as wellbeing services) within the UK (12-14) through initiatives such as social prescribing, advocacy services and community allotments (15,16). However, wellbeing services are usually funded on a short-term basis, with TSOs having to demonstrate their impact on the health and wellbeing of service-users to justify further funding (17). PROMs are one approach that TSOs use to demonstrate their impact. However, little is known about how to implement PROMs within TSOs and a recent review recommended research was needed (8) because it is not clear how transferable known facilitators and barriers to implementing PROMs are to TSOs. This is because TSO-delivered wellbeing services differ from clinical services as they are often run more informally, support is from peers rather than healthcare professionals, attendance may be long-term, and service-users may access multiple services within a TSO rather than receiving one specific intervention (18-20). Given this gap in knowledge, the study aimed to identify the facilitators and barriers to implementing PROMs in TSOs.

## **Methods**

### **Design**

A qualitative interview study of multiple stakeholders was undertaken for an in-depth exploration of different TSOs' experiences of implementing PROMs in England (21).

### **Participant Recruitment**

Participants who had different connections to the use of PROMs in TSOs were recruited including service-users, front-line workers and managers, commissioners and other relevant stakeholders for example academic researchers. Further detail is provided in Table 1. Recruitment was undertaken through using a range of sampling strategies including purposive, opportunistic and snowballing approaches (22). Purposive sampling involved targeting people because of their professional roles, such as approaching commissioners who funded TSOs. Opportunistic sampling entailed promoting the study through networks including visiting wellbeing services. Finally, snowballing was used because some interviewees recommended other people to approach. Thirty-five people were invited and five individuals did not respond so were not interviewed. Potential interviewees were provided with a Participant Information Sheet and Consent Form when making initial contact and written consent was collected before individuals were interviewed. Recruitment stopped after 30 interviews because the sample was suitably diverse, the information power was high (23) and saturation had been reached on some central themes (24).

## Data collection and analysis

Semi-structured interviews were used so that similar questions could be asked of all participants whilst also providing scope to explore arising issues (25). AF undertook all interviews, predominately conducting them face-to-face, using telephone interviews when geographical distance was prohibitive. Participants chose the location of the interview- usually this was at the TSO. Topic guides were used which included questions on what measures were used and why, engaging and training staff, available resources, how data was used, whether implementation had been successful and attitudes towards PROMs. The guides were tailored to each interest group.

The interviews were audio recorded, transcribed verbatim and imported into NVivo Version 11 (26). Framework analysis was undertaken, entailing the steps of Familiarisation, Identifying a Thematic Framework, Indexing, Charting and Mapping and Interpretation (27). Transcripts were read for familiarisation. The Thematic Framework was developed from findings of a systematic review on implementing PROMs (8) and constructs of the Consolidated Framework for Implementation Research (CFIR) (28). The framework was further developed to account for additional issues identified within the transcripts (29). Data was coded to the framework. During the Mapping and Interpretation stages of analysis, the themes evolved beyond the CFIR because many of the findings covered several CFIR constructs. The analysis was primarily undertaken by AF, with AOC and JH each coding an early transcript for team discussion and providing substantial input into the analysis.

## Patient and Public Involvement

Service-users were actively involved in the study including supporting the development of the research, designing the recruitment materials such as Participant Information Sheets, advising on the recruitment strategy and reviewing the topic guides. AF consulted the service-users at each stage of analysis to help with interpreting the findings.

## Ethics committee approval

The study was approved by the School of Health and Related Research Ethics Committee (Ref: 013727).

## Findings

### Participant characteristics

Thirty people were interviewed, which included at least five people per interest group (designated by their current role in relation to TSOs) to enable different perspectives to be explored (Table 1). Participants were involved in different sized TSOs including neighbourhood



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3 based organisations and national TSOs. Interviewees were primarily located in the North of  
4 England (n=24). The majority of interviews were face-to-face (n=22), with eight by telephone.  
5 Interviews were generally an hour long, although the majority of service-user interviews were  
6 shorter (average length 25 minutes) because they did not have views about organisational issues.  
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**Table 1- Characteristics of the sample**

<b>Participant type</b>	<b>Number interviewed</b>	<b>Mode of interview</b>	<b>Geographical location</b>	<b>Type of organisation</b>	<b>Other information</b>
<b>Service-users-</b> people who attend wellbeing activities	5	Face-to-face- 5 Phone- 0-	North- 5 Central- 0 South- 0	National TSO- 0 Regional TSO- 0 City level TSO- 4 Neighbourhood TSO- 1	
<b>Front-line workers-</b> people who deliver the wellbeing activities, providing support to attendees	6	Face-to-face- 5 Phone- 1	North- 5 Central- 0 South- 1	National TSO- 0 Regional TSO- 3 City level TSOs- 0 Neighbourhood TSO- 3	
<b>TSO Managers-</b> people who oversee wellbeing activities and have management responsibilities within the TSO	8	Face-to-face- 7 Phone- 1	North- 7 Central- 1 South- 0	National TSOs- 1 Regional TSOs- 1 City level TSO- 5 Neighbourhood TSO- 1	
<b>Commissioners-</b> People working for organisations which fund TSOs to deliver wellbeing activities and who are responsible for ensuring organisation abide by the contract	6	Face-to-face- 1 Phone- 5	North-4 Central- 0 South- 2	Local Authority- 2 NHS- 1 Non-statutory funder- 3	
<b>Stakeholders-</b> People external to TSOs who support them to implement PROMs	5	Face-to-face- 4 Phone- 1	North- 4 Central- 0 South- 1	N/A	Carer/volunteer- 1 Researcher/policy advisory- 2 Developer of PROMs' data management systems- 1 Statutory service Implementation Lead- 1

## **Overview of factors influencing implementation of PROMs**

Multiple factors appeared to influence implementation, some related to the internal and external context of TSOs, whilst others arose from the process of using PROMs. Figure 1 encapsulates these issues. Table 2 describes how the identified issues link to the CFIR constructs. Whilst each factor is presented separately, in practice they interacted and influenced each other, acting as facilitators or barriers depending on how an organisation approached the issue. For example the choice of PROMs influenced front-line workers' opinions of measures and whether they used the PROM.

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**Table 2- How the findings from the qualitative interviews linked to the CFIR constructs**

Theme	CFIR Construct	Example
<b>External context: PROMs are compulsory</b>	External policies and incentives	TSOs using PROMs to demonstrate their impact to gain/receive funding.
<b>Organisational commitment: Organisational culture and investment can facilitate PROMs</b>	Culture Implementation climate Networks and Communications Learning climate Compatibility Available resources Cost Relative priority	TSOs prioritising investment of resources into the implementation of PROMs.
<b>Staffing: Strong leadership and buy-in from staff can facilitate PROMs</b>	Self-efficacy Individual stage of change Individual identification with organisation Other personal attributes Patient (service-users) needs and resources Evidence strength and quality Relative advantage Knowledge and beliefs about the intervention Tension for change Relative priority Opinion leaders Compatibility	Having someone within a TSO instigating and leading implementation.

Theme	CFIR Construct	Example
<b>A collaborative approach improves the appropriateness of the PROMs process</b>	Intervention source Complexity Adaptability	Whether front-line workers and service-users are consulted about the design of the PROMs process.
<b>A dilemma: standardised PROMs or bespoke measures?</b>	Design quality and packaging Cost	A TSO choosing to design their own measure because they feel existing standardised wellbeing PROMs were inappropriate.
<b>Developing systems for processing and using the data generated from administering PROMs</b>	Design quality and packaging Cost	Investing in data management systems to process the collected PROMs data.
<b>The need for ongoing, practical and ideological training for staff using PROMs</b>	Access to knowledge and information Organisational incentives and rewards Engaging Goals and feedback	Providing front-line workers ongoing training on PROMs.
<b>Sustaining the use of PROMs in routine practice: a long term iterative process</b>	Executing Triability Reflecting and evaluating Organisational incentives and rewards	Rarely do TSOs get the design of the PROM's process right first time and have to make improvements to it.

### External context: PROMs are compulsory

A dominant narrative was interviewees believing TSOs have no choice but to engage with PROMs due to funding requirements. Interviewees from all the interest groups discussed how TSO's funding came from time-limited contracts and grants. In a national context of Austerity, and the trend for Outcomes-based commissioning, TSOs were required to measure benefits of funded services and show value for money. Many commissioners required TSOs to collect PROMs as a condition of funding contracts. This was challenging for organisations because they were funded by multiple commissioners so had to incorporate all of their specific requests in

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3 respect of PROMs. Additionally TSO managers needed PROMs data to support future funding  
4 applications. Front-line workers and service-users complied with completing PROMs because  
5 they understood that funding was needed to enable wellbeing services to continue. Indeed some  
6 service-users felt compelled to complete PROMs in order to access services.  
7

8  
9 *“The reality is that you know money is getting tighter and tighter. Whether its*  
10 *grants or contracts [...] the only way you’ll attract funding is to be able to*  
11 *show that you make a difference and that you have an impact.”*  
12 *[TSO Manager 4]*  
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15 Not all interviewees signed up to a ‘no choice’ narrative. They pointed out that individual  
16 commissioners took different approaches to PROMs and that there was a lack of transparency in  
17 how the data generated from measures actually influenced funding decisions.  
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### 20 21 22 **Organisational commitment: Organisational culture and investment can facilitate PROMs**

23 The organisational characteristics of culture and willingness to invest resources into PROMs  
24 appeared to affect the success of implementation. Interviewees felt that the culture of TSOs had a  
25 bidirectional influence on PROMs. Facilitating aspects included organisations being proactive in  
26 adopting new working practices and having good networks amongst staff, where front-line  
27 workers supported each other with using measures.  
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31 *“I think as an organisation we are quite good at being fluid, you know and*  
32 *having a go at things and seeing if they work.” [TSO Manager 4]*  
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35 However some interviewees felt that collecting PROMs detrimentally affected the dynamic of  
36 wellbeing services especially group social activities or when a service-user was receiving short  
37 term advocacy support.  
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39 TSOs prioritising investment of sufficient resources in implementation was considered to be a  
40 pertinent issue by interviewees. This included investing in data management systems and support  
41 staff to process PROMs, and training front-line workers. However TSO managers raised  
42 concerns about sustaining investment because they did not consider resourcing PROMs to be  
43 part of their core costs. For example, one manager was uncertain about continuing to fund their  
44 organisation’s data manager.  
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47  
48 *“Funds are tight for us and it’s one of those roles that I look at and think ‘is it a*  
49 *bit of a luxury?’ On the other hand, I do know that we’ve won funding because*  
50 *of the quality of the data that we’ve been able to provide to people so it’s a real*  
51 *balancing act.” [TSO Manager 3]*  
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### Staffing: Strong leadership and buy-in from staff can facilitate PROMs

The needs, skills and opinions of managers, front-line workers and other people within a TSO could impact on implementation. Interviewees discussed the importance of having an Implementation Lead, that is someone who took responsibility for implementing PROMs and offered strategic and operational management of the processes.

*“Cos when I first came it [the PROM] was just ad-hocly written into funding bids, thinking that they 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]*

Challenges arose if no one within a TSO acted as Implementation Lead or when the Lead did not engage with PROMs. For example, one manager explained she had not progressed implementation because she did not consider PROMs a priority.

Interviewees felt that front-line workers generally tried to engage with PROMs even if they considered the measures to be inappropriate and invalid. Negative opinions arose from workers feeling their service-users' lives were complex and positive changes may not be captured by an overall assessment of wellbeing. Additionally, front-line workers believed the language used in measures was too complex for their service-users. Despite this, front-line workers discussed engaging with PROMs out of loyalty to their TSO and because they believed collecting PROMs could generate further funding, keeping them in a job. Despite being willing, some front-line workers struggled to use PROMs as they were concerned that administering measures would damage their relationships with service-users because of the seeming irrelevancy of these measures in the context of the serious difficulties people were facing.

*“But people who are coming to me with the social issues such as they can't pay their rent or universal credit [...] 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]

### A collaborative approach improves the appropriateness of the PROMs process

The 'designing stage' of implementing PROMs where a TSO decides which PROMs to use and how to use them, appeared to be critical to the implementation process. Interviewees felt that taking a collaborative approach to ensure the design was appropriate, proportionate and straightforward was important. Collaboration involved commissioners working with, rather than imposing a PROMs process on an organisation and TSO managers consulting front-line workers and service-users. Consulting front-line workers and service-users was often reported as not occurring in our sample, with interviewees explaining that if PROMs had been imposed by commissioners, then there was little scope to consult service-users and front-line workers. Participants felt externally imposed PROMs processes were often inappropriate for an



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3 organisation's specific service-users, resulting in some TSOs struggling to collect PROMs.  
4 However some organisations overcame the challenge through taking mitigating action in other  
5 parts of the implementation process. For example one TSO was required to collect a PROM they  
6 considered inappropriate but were managing to administer the measure through skilled front-line  
7 workers engaging service-users. In another TSO, they implemented one PROM throughout the  
8 whole organisation and then negotiated with commissioners to be allowed to use their  
9 implemented outcome measure. Even if TSOs managed to collect imposed PROMs, interviewees  
10 questioned the quality of data generated.  
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14 *"It's the sort of people that I'm using it on, it's fundamentally flawed anyway*  
15 *cos some of them I have to, I deal with a lot of people who can't read or can't*  
16 *write or got dementia and that makes it irrelevant because they, you say the*  
17 *question and they say ' ooh what number oh I think it was a three', but they have*  
18 *no comprehension of what I've asked them."* [TSO Front-line worker 1]  
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21  
22 Interviewees explained that TSOs needed to ensure the designed PROMs process was  
23 straightforward and proportionate to the specific service-user group and organisation. For  
24 example front-line workers discussed how they had to complete multiple PROMs which caused  
25 measurement burden and they wanted the process reduced to a single measure.  
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### 28 29 **A dilemma: standardised PROMs or bespoke measures?** 30

31 Interviewees differed on whether their TSOs used standardised PROMs or had designed their  
32 own bespoke measure. Organisations using standardised PROMs generally utilised wellbeing  
33 measures, with WEMWBS being the most used measure within the sample. Other measures  
34 included the Outcome Star and Office for National Statistics 4 Wellbeing Questions. Reasons  
35 given for using standardised PROMs included interviewees believing it enhanced credibility of  
36 measurement and enabled comparison with other services. Some interviewees designed their  
37 own bespoke measure because they did not feel existing measures were appropriate for their  
38 context. Bespoke PROMs often drew upon established wellbeing frameworks such as Five Ways  
39 to Wellbeing. Factors influencing the choice of PROM included the preferences of  
40 commissioners and Implementation Leads, experiences of similar TSOs, and needing to avoid  
41 the license fees associated with using certain PROMs.  
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46 *"Sometimes you think 'ooh it would be good to have a validated tool in terms*  
47 *of being able to compare yourself to that organisation' and things like that and*  
48 *it's something we definitely have thought about... but it doesn't mean they're*  
49 *right and it doesn't mean they're going to work for you."* [TSO Manager 7]  
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## Developing systems for processing and using the data generated from administering PROMs

TSOs planning how measures would be collected and the data processed, analysed and used, appeared to facilitate implementation. PROMs were generally collected by front-line workers supporting service-users to complete paper versions within face-to-face appointments. Some interviewees had unsuccessfully tried to use digital methods or asked people to complete PROMs independently before appointments; the service-users interviewed were also resistant to these approaches. Interviewees from all the interest groups discussed the difficulty in identifying appropriate time points for collecting PROMs in some wellbeing services, especially when service-users attended on a long-term or sporadic basis. Having sufficient time and resources within the organisation to process collected PROMs was also highlighted as a challenge. Some TSOs in the sample had invested in staff to perform these tasks and/or in data management systems. Unfortunately, this could create additional challenges if the system was not fit for purpose.

*“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]*

A number of managers felt that they had good systems in place to ensure the PROMs results were fed back and used by front-line workers and service-users. However several front-line workers and service-users complained about not receiving feedback such as how individual users’ scores had changed, which was detrimental to their engagement with PROMs. Although it was also the case that not everyone wanted to discuss the data because they did not feel PROMs were relevant.

*“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]*

## The need for ongoing, practical and ideological training for staff using PROMs

Training front-line workers appeared to be important for facilitating the implementation of PROMs. Interviewees discussed how training should be both practical in terms of learning how to use measures, and also ideological so front-line workers understood the rationale for using PROMs. Managers and front-line workers felt that training needed to be ongoing including refreshers in team meetings and additional training given to individual front-line workers who were not engaging in PROMs.

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*“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]*

### **Sustaining the use of PROMs in routine practice: a long term iterative process**

Rarely did TSOs get the PROMs process right first time, resulting in front-line workers struggling to collect measures. Consequently organisations had to further develop the PROMs process, sometimes by making fundamental changes such as using a different measure. Other organisations only needed to make small refinements, for example by improving staff training.

*“We thought ‘well we’ll give this [the PROM] a go because it’s been given to us’. But we doubt it’s going to 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.’” [TSO Front-line worker 2]*

Having a trial period was suggested by one front-line worker as a potential way of overcoming these initial problems but none of the interviewees had tried this. It took time for PROMs to become part of routine practice, and although this had occurred in some TSOs, not all organisations in the sample had reached this point. For example one manager believed that the whole process relied totally on her. Interviewees felt that the long-term use of outcome measures was facilitated by TSOs undergoing organisational culture change so that they perceived PROMs as beneficial for the organisations and front-line workers having PROMs incorporated into their job roles. For example, several TSO managers spoke about setting PROM related performance objectives for staff.

*“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]*

In contrast, the length of time it took to implement PROMs was considered a barrier because wellbeing services rely on short-term funding. A couple of TSO managers in the sample discussed addressing this issue through developing an organisational wide PROMs process.

## **Discussion**

### **Summary of findings**

TSOs primarily used PROMs because of pressures arising from the external funding context. However, organisations often struggled to implement PROMs, rarely getting the process right first time. Facilitators for implementation included having an Implementation Lead committed to making it work, investing resources in processes, and taking a collaborative design approach. The latter helped to ensure an appropriate PROMs process for the specific TSO including

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3 choosing a suitable measure and planning how data would be collected, processed and used.  
4 There was a dilemma about whether TSOs should use standardised measures like the WEMWBS  
5 or design their own measure. Not all TSOs sustained the collecting and reporting of PROMs over  
6 time because this required a change in organisational culture.  
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### 10 **Strengths and limitations**

11 The study's strengths are that it is the first published research on implementing PROMs in TSOs,  
12 the research considered the whole implementation pathway, and different interest groups were  
13 interviewed. The research would have benefitted from having more interviewees from larger  
14 TSOs and from organisations that had stopped using PROMs.  
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### 20 **Context of other research**

21 Several factors identified were consistent with findings of studies based in healthcare settings  
22 whereas other issues appeared unique to TSOs, arising from their specific external and internal  
23 context. Key similarities related to designing the process, engaging staff and needing to improve  
24 the PROMs process. Implementation in both TSOs and healthcare settings appeared to be  
25 facilitated by organisations co-designing an appropriate and straightforward PROMs process,  
26 and planning how data would be collected, processed and analysed (8, 30, 31). The importance  
27 of having skilled and engaged staff who received sufficient training was consistently identified in  
28 studies based in different healthcare settings (8, 9, 31). Organisations experiencing problems  
29 when starting to use PROMs and needing to make improvements to facilitate sustainability has  
30 also been consistently documented (8). The similarity in findings between TSOs and healthcare  
31 settings is understandable because it has been proposed they are sufficiently alike to learn from  
32 each other (32).  
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38 However some findings appeared to be unique to TSOs or more prominent. Firstly, TSOs were  
39 motivated to use PROMs to demonstrate their impact because of the sector's specific funding  
40 context, whereas research based in healthcare settings focuses on using PROMs to improve  
41 patient care (8). Second, TSOs were having to implement PROMs imposed on them by  
42 commissioners rather than having the scope to design their own process, which contrasts with  
43 good practice guidance on implementing PROMs (33). This research found that having an  
44 Implementation Lead was fundamental. Some but not all previous studies identified the  
45 importance of the Lead. However, previous research did not place as much importance on the  
46 role as TSOs have. Third, TSOs were developing their own measures, unlike in healthcare  
47 settings. This could be because no existing PROMs have specifically been designed for TSOs,  
48 indicating new measures may be required. However it raises questions about the validity of data  
49 being collected as bespoke measures have not undergone psychometric testing. TSOs were  
50 generally using paper-based PROMs which is at odds with the shift towards electronically  
51 collected measures (34). The variation may be because of concerns about the digital literacy of  
52 people accessing TSOs (31, 35).  
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## Implications

When implementing PROMs, commissioners and TSOs need to consider co-designing a process which is appropriate for a specific organisation and their service-users. It appears to be important that TSOs have an Implementation Lead and invest sufficient resources in processes and training. Commissioners could facilitate this by allocating funding for PROMs implementation as part of their funding contracts. Organisations should anticipate problems when initially implementing PROMs and be proactive in addressing these.

There were some TSOs which managed to implement PROMs despite not having all the facilitators described here, raising questions about whether certain facilitators are more fundamental than others or whether some barriers can be minimised by facilitators. The relative importance of different facilitators and barriers needs further research. The struggle to find suitable PROMS could be addressed by developing and validating a measure specifically for wellbeing services.

To conclude, TSOs are trying to use PROMs because they feel they have no choice but often struggle with implementation. Having an Implementation Lead, designing an appropriate process, training staff and taking mitigating action to address potential barriers can facilitate implementation.

## Contributorship statement-

AF undertook all the recruitment, interviews and analysis alongside writing the article.

AOC coded a transcript and provided ongoing advice into the conduct of the study and significant input into the analysis. AOC provided substantial feedback on the drafts of the article.

JH coded a transcript and provided ongoing advice into the conduct of the study and significant input into the analysis. JH provided substantial feedback on the drafts of the article.

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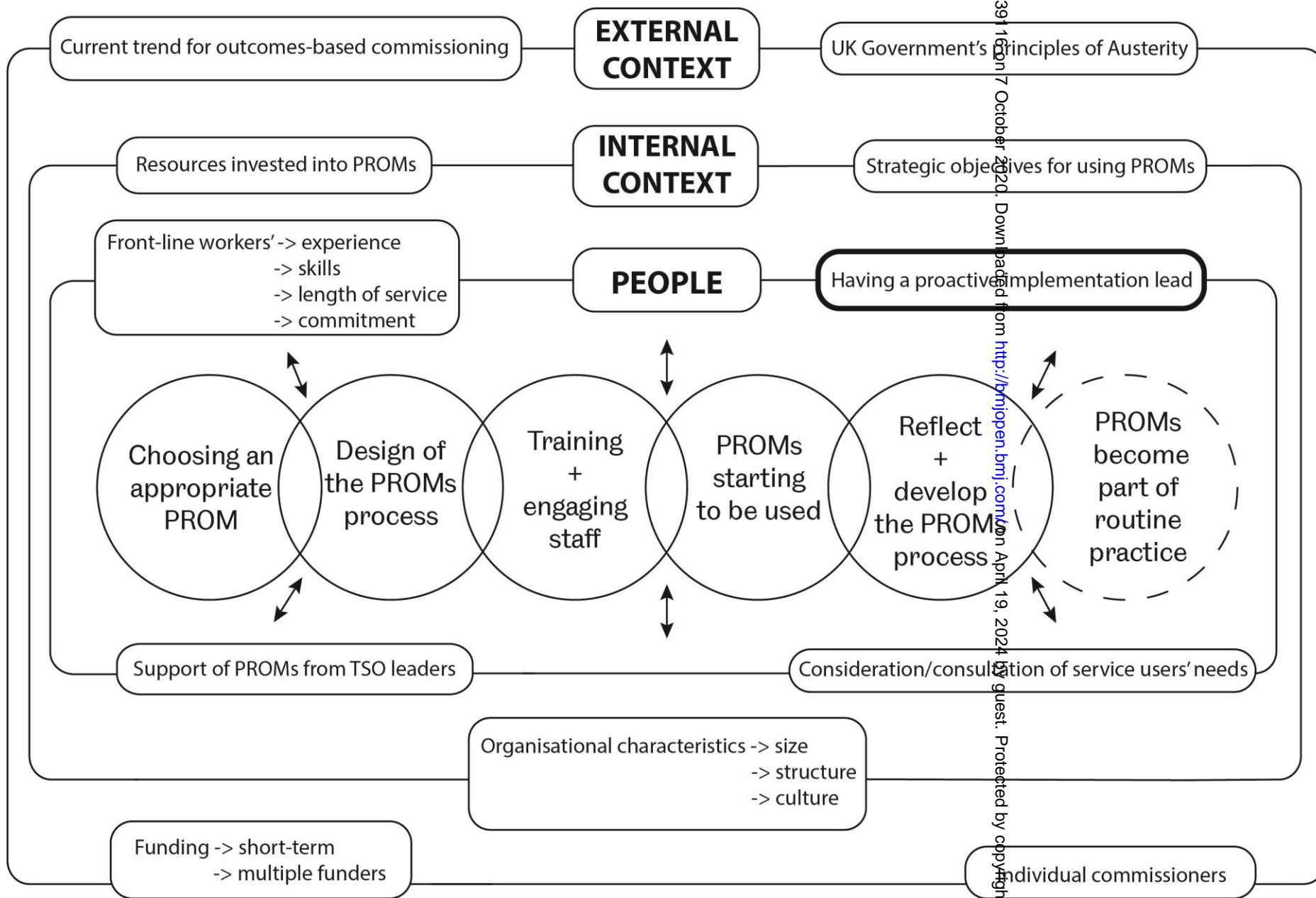
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## How do Third Sector Organisations or Charities providing health and wellbeing services in England implement Patient Reported Outcome Measures (PROMs)?: A qualitative interview study

### Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No. Item	Guide questions/description	Reported on Page #
<b>Domain 1: Research team and reflexivity</b>		
<i>Personal Characteristics</i>		
1. Inter viewer/facilitator	Which author/s conducted the interview or focus group?	5
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	In the author information
3. Occupation	What was their occupation at the time of the study?	In the author information
4. Gender	Was the researcher male or female?	N/A
5. Experience and training	What experience or training did the researcher have?	In the author information
<i>Relationship with participants</i>		
6. Relationship established	Was a relationship established prior to study commencement?	4
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	4
8. Interviewer characteristics	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	N/A
<b>Domain 2: study design</b>		
<i>Theoretical framework</i>		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	5
<i>Participant selection</i>		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	4
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	4
12. Sample size	How many participants were in the study?	4
13. Non-participation	How many people refused to participate or dropped out? Reasons?	4

<i>Setting</i>		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	5
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	N/A
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	7
<i>Data collection</i>		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	5
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	No
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	5
20. Field notes	Were field notes made during and/or after the interview or focus group?	NA
21. Duration	What was the duration of the interviews or focus group?	6
22. Data saturation	Was data saturation discussed?	4
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	N/A
<b>Domain 3: analysis and findings</b>		
<i>Data analysis</i>		
24. Number of data coders	How many data coders coded the data?	5
25. Description of the coding tree	Did authors provide a description of the coding tree?	5
26. Derivation of themes	Were themes identified in advance or derived from the data?	5
27. Software	What software, if applicable, was used to manage the data?	5
28. Participant checking	Did participants provide feedback on the findings?	N/A
<i>Reporting</i>		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Yes
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Yes
31. Clarity of major themes	Were major themes clearly presented in the findings?	Yes
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes

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## How do Third Sector Organisations or Charities providing health and wellbeing services in England implement Patient Reported Outcome Measures (PROMs)?: A qualitative interview study

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3 **How do Third Sector Organisations or Charities providing health and**  
4 **wellbeing services in England implement Patient Reported Outcome**  
5 **Measures (PROMs)?: A qualitative interview study**  
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# How do Third Sector Organisations or Charities providing health and wellbeing services in England implement Patient Reported Outcome Measures (PROMs)?: A qualitative interview study

## List of tables, figures and supplementary files

- Table 1- Participant characteristics
- Table 2- How the arising findings link to the Consolidated Framework for Implementation Research constructs
- Figure 1- Factors which appear to influence the implementation of PROMs in TSOs
- Supplementary file- COREQ checklist

## Abstract

**Objectives:** To identify the facilitators and barriers to implementing Patient Reported Outcome Measures (PROMs) in third sector organisations (TSOs) delivering health and wellbeing services.

**Design:** A qualitative interview study. Participants were recruited using purposive, opportunistic and snowballing methods. Framework analysis was used.

**Setting:** TSOs including charities, community groups and not-for-profit organisations in England, United Kingdom.

**Participants:** Thirty interviewees including service-users, TSO front-line workers and managers, commissioners of TSOs and other stakeholders such as academic researchers.

**Results:** TSOs primarily used PROMs because of pressures arising from the external funding context. However organisations often struggled to implement PROMs, rarely getting the process right first time. Facilitators for implementation included having an Implementation Lead committed to making it work, investing resources in data management systems and support staff and taking a collaborative approach to designing the PROMs process. The latter helped to ensure an appropriate PROMs process for the specific TSO including choosing a suitable measure and planning how data would be collected, processed and used. There was a dilemma about whether TSOs should use standardised wellbeing measures, for example the Warwick Edinburgh Mental Wellbeing Scale or design their own PROM. Not all TSOs sustained the collection and reporting of PROMs over time because this required a change in organisational culture to view PROMs as beneficial for the TSO and PROMs becoming part of front-line workers' job specifications.

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3 **Conclusions:** TSOs are trying to use PROMs because they feel they have no choice but often  
4 struggle with implementation. Having an Implementation Lead, designing an appropriate  
5 process, investing resources, training staff and taking mitigating action to address potential  
6 barriers can facilitate implementation. Some of the findings are consistent with the experiences  
7 of more clinical services so appear relevant to the implementation of PROMs irrespective of the  
8 specific context.  
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### 11 **Strengths and Limitations**

- 12 • First piece of published research specifically focusing on the implementation of Patient
- 13 Reported Outcome Measures (PROMs) in third sector organisations (TSOs).
- 14 • Identified a number of findings useful to commissioners and TSOs to improve the
- 15 implementation of PROMs.
- 16 • Some of the findings may be relevant to healthcare services.
- 17 • It would have been useful to interview more people from larger TSOs and from
- 18 organisations who had stopped using PROMs.
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### 30 **Introduction**

31 PROMs (Patient Reported Outcome Measures) are standardised questionnaires which measure  
32 Patient Reported Outcomes such as a person's health, wellbeing or symptoms (1-3). If a person  
33 answers a questionnaire at two or more time points, for example before and after receiving  
34 support, scores can be compared to understand whether there is any change. Generic PROMs  
35 which measure a person's overall health include the EQ-5D (1) and SF-36 (4). Examples of  
36 PROMs which focus on wellbeing include the Warwick Edinburgh Mental Wellbeing Being  
37 Scale (WEMWBS) (5), the Office for National Statistics Wellbeing questions (6) and the  
38 Personal Wellbeing Measure (7). PROMs' scores can be used on an individual service-user level  
39 to inform their support or the scores of multiple service-users can be aggregated to evaluate the  
40 impact of a service (1). Policy makers and healthcare services are increasingly attempting to  
41 implement PROMs because they can improve communication between clinicians and service-  
42 users, resulting in improved care and outcomes (8,9). Furthermore, aggregated PROMs are used  
43 by commissioners to hold services to account for offering health benefit. For example the United  
44 Kingdom's (UK's) PROMs programme mandates that hospitals use PROMs for hip and knee  
45 replacements (10). And in the United States of America, the Patient Reported Outcomes  
46 Measurement Information System (PROMIS) is being implemented (11). Despite the intent to  
47 use PROMs, healthcare services can struggle with implementation, resulting in low completion  
48 rates (12).  
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53 Implementation is defined as the process from a service deciding to use PROMs to when they are  
54 part of routine practice (13). To improve implementation, researchers have sought to identify  
55 potential facilitators and barriers (14-17). To date, this work has been undertaken in clinical  
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services. A recent systematic review of reviews (14) identified a number of facilitators including using PROMs to tailor a service-user's care, the importance of choosing an appropriate measure and the need to design a straightforward process for collecting, analysing and using the PROMs data. Furthermore, having an Implementation Lead to progress implementation and engage and train staff is necessary. The review also identified that organisations need to reflect and develop the PROMs process if problems arise. Importantly, the review identified that many of these issues were bidirectional, in terms of becoming barriers if not undertaken by an organisation. For example, staff may not use PROMs if they find the data collection process complex. Other studies have identified similar facilitators and barriers (15-17), with some questioning whether organisations have sufficient resources to invest in the PROMs infrastructure (18) and whether the use of measures is sustained (19).

Generic implementation theories such as the Knowledge to Action framework (20) or the Consolidated Framework for Implementation Research (CFIR) (21) may also be useful for identifying issues affecting the use of PROMs. A recent review of PROMs utilised the CFIR (14), showing how previous PROMs research had not considered the influence of an organisations' characteristics or external influences on implementation, even though these are considered relevant within implementation theories (21).

To date, research on implementing PROMs has focused on clinical services and not considered PROMs usage within third sector organisations (TSOs) (14). TSOs, also known as charities, voluntary or community organisations are increasingly commissioned to deliver health and wellbeing services (called 'wellbeing services' in this paper) within the UK (22-24) through initiatives such as social prescribing, advocacy services and community allotments (25,26). Often TSOs receive short-term funding to deliver their services, with organisations having to demonstrate their impact on the health and wellbeing of service-users to justify further funding (27). PROMs are one approach that TSOs use to demonstrate their impact. However, little is known about how to implement PROMs within TSOs and a recent review recommended research was needed (14) because it is not clear how transferable known facilitators and barriers to implementing PROMs in clinical services are to TSOs. This is because TSO delivered wellbeing services differ from clinical services as they are often run more informally, support is from peers rather than healthcare professionals, attendance may be long-term, and service-users may access multiple services within a TSO rather than receiving one specific intervention (28-30). Given this gap in knowledge, the study aimed to identify the facilitators and barriers to implementing PROMs in TSOs.

## **Methods**

### **Design**

A qualitative interview study of multiple stakeholders was undertaken for an in-depth exploration of different TSOs' experiences of implementing PROMs in England (31).



## Participant Recruitment

Participants who had different connections to the use of PROMs in TSOs were recruited including service-users, front-line workers and managers, commissioners and other relevant stakeholders for example academic researchers. Further detail is provided in Table 1. Recruitment was undertaken through using a range of sampling strategies including purposive, opportunistic and snowballing approaches (32). Purposive sampling involved targeting people because of their professional roles, such as approaching commissioners who funded TSOs. Opportunistic sampling entailed promoting the study through networks including visiting TSOs. Finally, snowballing was used because some interviewees recommended other people to approach. Thirty-five people were invited and five individuals did not respond so were not interviewed. Potential interviewees were provided with a Participant Information Sheet and Consent Form when making initial contact and written consent was collected before individuals were interviewed. Recruitment stopped after 30 interviews because the sample was suitably diverse, the information power was high (33) and saturation had been reached on some central themes (34).

## Use of the CFIR

We used the CFIR in this study because it amalgamates a number of implementation theories (13), has been used in a previous review of PROMs (14) and provides a framework of 36 constructs which may influence implementation, structured around five different domains. These include (21):

- Outer setting- Factors outside of the organisation e.g. External policies and incentives
- Inner settings- Characteristics of an organisation e.g. its Culture and Structural characteristics
- Characteristics of individuals- How people influence implementation e.g. front-line workers' Knowledge and beliefs about the intervention
- The intervention- The PROMS process e.g. its Complexity and Adaptability to the specific context
- Process- Factors relating to getting PROMs used such as Planning and Reflecting and evaluating implementation.

## Data collection and analysis

Semi-structured interviews were used so that similar questions could be asked of all participants whilst also providing scope to explore arising issues (35). AF undertook all interviews, predominately conducting them face-to-face, using telephone interviews when geographical distance was prohibitive. Participants chose the location of the interview- usually this was at the TSO. The topic guides incorporated the CFIR constructs by asking about which measures were used and why, Staff engagement, Knowledge and beliefs about PROMs, Available resources and Reflecting and evaluating implementation. The guides were tailored to each interest group.

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3 The interviews were audio recorded, transcribed verbatim and imported into NVivo Version 11  
4 (36). Framework analysis was undertaken, entailing the steps of Familiarisation, Identifying a  
5 Thematic Framework, Indexing, Charting and Mapping and Interpretation (37). Transcripts were  
6 read for familiarisation. The Thematic Framework was developed from findings of a systematic  
7 review on implementing PROMs (14) and constructs of the CFIR (21). The framework was  
8 further developed to account for additional issues identified within the transcripts (38). Data was  
9 coded to the framework. During the Mapping and Interpretation stages of analysis, the themes  
10 evolved beyond the CFIR because the findings often transcended several constructs and it was  
11 important to utilise the language of the participants. The analysis was primarily undertaken by  
12 AF, with AOC and JH each coding an early transcript for team discussion and providing  
13 substantial input into the analysis.  
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### 19 **Patient and Public Involvement**

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21 Service-users were actively involved in the study including supporting the development of the  
22 research, designing the recruitment materials such as Participant Information Sheets, advising on  
23 the recruitment strategy and reviewing the topic guides. AF consulted the service-users at each  
24 stage of analysis to help with interpreting the findings.  
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### 29 **Ethics committee approval**

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31 The study was approved by the School of Health and Related Research Ethics Committee (Ref:  
32 013727).  
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### 36 **Findings**

#### 37 **Participant characteristics**

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39 Thirty people were interviewed, which included at least five people per interest group  
40 (designated by their current role in relation to TSOs) to enable different perspectives to be  
41 explored (Table 1). Participants were involved in different sized TSOs including neighbourhood  
42 based organisations and national TSOs. Interviewees were primarily located in the North of  
43 England (n=24). The majority of interviews were face-to-face (n=22), with eight by telephone.  
44 Interviews were generally an hour long, although the majority of service-user interviews were  
45 shorter (average length 25 minutes) because they did not have views about organisational issues.  
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**Table 1- Characteristics of the sample**

<b>Participant type</b>	<b>Number interviewed</b>	<b>Mode of interview</b>	<b>Geographical location</b>	<b>Type of organisation</b>	<b>Other information</b>
<b>Service-users-</b> people who attend wellbeing activities	5	Face-to-face- 5 Phone- 0-	North- 5 Central- 0 South- 0	National TSO- 0 Regional TSO- 0 City level TSO- 4 Neighbourhood TSO- 1	
<b>Front-line workers-</b> people who deliver the wellbeing activities, providing support to attendees	6	Face-to-face- 5 Phone- 1	North- 5 Central- 0 South- 1	National TSO- 0 Regional TSO- 3 City level TSOs- 0 Neighbourhood TSO- 3	
<b>TSO Managers-</b> people who oversee wellbeing activities and have management responsibilities within the TSO	8	Face-to-face- 7 Phone- 1	North- 7 Central- 1 South- 0	National TSOs- 1 Regional TSOs- 1 City level TSO- 5 Neighbourhood TSO- 1	
<b>Commissioners-</b> People working for organisations which fund TSOs to deliver wellbeing activities and who are responsible for ensuring organisation abide by the contract	6	Face-to-face- 1 Phone- 5	North-4 Central- 0 South- 2	Local Authority- 2 NHS- 1 Non-statutory funder- 3	
<b>Stakeholders-</b> People external to TSOs who support them to implement PROMs	5	Face-to-face- 4 Phone- 1	North- 4 Central- 0 South- 1	N/A	Carer/volunteer- 1 Researcher/policy advisory- 2 Developer of PROMs' data management systems- 1 Statutory service Implementation Lead- 1

## **Overview of factors influencing implementation of PROMs**

Multiple factors appeared to influence implementation, some related to the internal and external context of TSOs, whilst others arose from the process of using PROMs. Figure 1 encapsulates these issues. In Table 2, we explain how each theme relates to the CFIR constructs. The majority of the CFIR constructs were identified in the data. The main exception was Planning, with interviewees not discussing whether their TSO planned the implementation process.

Each of the factors influencing implementation is presented separately within the findings, however in practice they interacted and influenced each other, acting as facilitators or barriers depending on how an organisation approached the issue. For example, the choice of PROMs influenced front-line workers' opinions of measures and whether they used them.

Table 2- How the findings from the qualitative interviews linked to the CFIR constructs

Theme	The CFIR constructs identified within the interview data	Example
<b>External context: PROMs are compulsory</b>	External policies and incentives	TSOs using PROMs to demonstrate their impact to gain/receive funding.
<b>Organisational commitment: Organisational culture and investment can facilitate PROMs</b>	Culture Implementation climate Networks and communications Learning climate Compatibility Available resources Cost Relative priority	TSOs prioritising investment of resources into the implementation of PROMs.
<b>Staffing: Strong leadership, buy-in from staff and support from external advisors can facilitate PROMs</b>	Self-efficacy Individual stage of change Individual identification with organisation Other personal attributes Patient (service-users) needs and resources Evidence strength and quality Relative advantage Knowledge and beliefs about the intervention Tension for change Relative priority Opinion leaders Compatibility External change agents	Having someone within a TSO instigating and leading implementation.

Theme	The CFIR constructs identified within the interview data	Example
<b>A collaborative approach improves the appropriateness of the PROMs process</b>	Intervention source Complexity Adaptability	Whether front-line workers and service-users are consulted about the design of the PROMs process.
<b>A dilemma: standardised PROMs or bespoke measures?</b>	Design quality and packaging Cost	A TSO choosing to design their own measure because they feel existing standardised wellbeing PROMs were inappropriate.
<b>Developing systems for processing and using the data generated from administering PROMs</b>	Design quality and packaging Cost	Investing in data management systems to process the collected PROMs data.
<b>The need for ongoing, practical and ideological training for staff using PROMs</b>	Access to knowledge and information Organisational incentives and rewards Engaging Goals and feedback	Providing front-line workers ongoing training on PROMs.
<b>Sustaining the use of PROMs in routine practice: a long term iterative process</b>	Executing Triability Reflecting and evaluating Organisational incentives and rewards	Rarely do TSOs get the design of the PROM's process right first time and have to make improvements to it.

### External context: PROMs are compulsory

A dominant narrative was interviewees believing TSOs have no choice but to engage with PROMs due to funding requirements. Interviewees from all the interest groups discussed how TSO's funding came from time-limited contracts and grants. In a national context of Austerity, and the trend for Outcomes-based commissioning, TSOs were required to measure benefits of funded services and show value for money to demonstrate accountability. Consequently, TSOs were subject to external policies where commissioners required TSOs to collect PROMs as a

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3 condition of funding contracts. This was challenging for organisations because they were funded  
4 by multiple commissioners so had to incorporate all of their specific requests in respect of  
5 PROMs. Additionally TSO managers needed PROMs data to support future funding  
6 applications. Front-line workers and service-users complied with completing PROMs because  
7 they understood that funding was needed to enable wellbeing services to continue. Indeed some  
8 service-users felt compelled to complete PROMs in order to access services.  
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11 *“The reality is that you know money is getting tighter and tighter. Whether its*  
12 *grants or contracts [...] the only way you’ll attract funding is to be able to*  
13 *show that you make a difference and that you have an impact.”*  
14 *[TSO Manager 4]*  
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18 Not all interviewees signed up to a ‘no choice’ narrative. They pointed out that individual  
19 commissioners took different approaches to PROMs, healthcare services were not having to use  
20 PROMs to justify funding and that there was a lack of transparency in how the PROMs data  
21 influenced funding decisions.  
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### 25 **Organisational commitment: Organisational culture and investment can facilitate PROMs**

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27 The organisational characteristics of culture and willingness to invest resources into PROMs  
28 appeared to affect implementation. Interviewees felt that the culture of TSOs had a bidirectional  
29 influence on PROMs. Facilitating aspects included organisations being proactive in adopting  
30 new working practices and having good networks amongst staff, where front-line workers  
31 supported each other with using measures.  
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34 *“I think as an organisation we are quite good at being fluid, you know and*  
35 *having a go at things and seeing if they work.” [TSO Manager 4]*  
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39 However some interviewees felt that collecting PROMs detrimentally affected the dynamic of  
40 wellbeing services especially group social activities or when a service-user was receiving short  
41 term advocacy support.  
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43 TSOs prioritising investment of sufficient resources in implementation was considered to be a  
44 pertinent issue by interviewees. This included investing in data management systems and support  
45 staff to process PROMs, and training front-line workers. However TSO managers raised  
46 concerns about sustaining investment because they did not consider resourcing PROMs to be  
47 part of their core costs. For example, one manager was uncertain whether they could continue to  
48 fund a data manager.  
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51 *“Funds are tight for us and it’s one of those roles that I look at and think ‘is it a*  
52 *bit of a luxury?’ On the other hand, I do know that we’ve won funding because*  
53 *of the quality of the data that we’ve been able to provide to people so it’s a real*  
54 *balancing act.” [TSO Manager 3]*  
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## Staffing: Strong leadership, buy-in from staff and support from external advisors can facilitate PROMs

The needs, skills and opinions of TSO managers and front-line workers as well as support from external advisors may influence implementation. Interviewees discussed the importance of having an Implementation Lead, that is someone who took responsibility for implementing PROMs and offered strategic and operational management of the processes.

*“Cos when I first came it [the PROM] was just ad-hocly written into funding bids, thinking that they 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]*

Challenges arose if no one within a TSO acted as Implementation Lead or when the Lead did not engage with PROMs. For example, one manager explained how they did not consider PROMs a priority so had not invested time in progressing implementation.

Interviewees felt that front-line workers generally tried to engage with PROMs even if they considered the measures to be inappropriate and invalid. Negative opinions arose from workers feeling their service-users' lives were complex and positive changes may not be captured by an overall assessment of wellbeing. Additionally, front-line workers believed the language used in measures was too complex for their service-users. Despite this, front-line workers discussed engaging with PROMs out of loyalty to their TSO and because they believed collecting PROMs could generate further funding, keeping them in a job. However, some front-line workers struggled to use PROMs as they were concerned that administering measures would damage their relationships with service-users because of the seeming irrelevancy of these measures in the context of the serious difficulties people were facing.

*“But people who are coming to me with the social issues such as they can't pay their rent or universal credit [...] 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]

External advisors providing support with implementation were valued by some TSO managers because these interviewees did not feel they had the capacity or knowledge themselves. For example, one manager discussed how an external advisor designed the TSO's data management system.



### A collaborative approach improves the appropriateness of the PROMs process

The ‘designing stage’ of implementing PROMs where a TSO decides which PROMs to use and how to use them, appeared to be critical to the implementation process. Interviewees felt that taking a collaborative approach to ensure the design was appropriate, proportionate and straightforward was important. Collaboration involved commissioners working with, rather than imposing a PROMs process on an organisation and TSO managers consulting front-line workers and service-users. Consulting front-line workers and service-users was often reported as not occurring in our sample, with interviewees explaining that if PROMs had been imposed by commissioners, then there was little scope to consult service-users and front-line workers. Participants felt externally imposed PROMs processes were often inappropriate for an organisation’s specific service-users, resulting in some TSOs struggling to collect PROMs. However some organisations overcame the challenge through taking mitigating action in other parts of the implementation process. For example one TSO was required to collect a PROM they considered inappropriate but were managing to administer the measure through skilled front-line workers engaging service-users. In another TSO, they implemented one PROM throughout the whole organisation and then negotiated with commissioners to be allowed to use this measure. Even if TSOs managed to collect imposed PROMs, interviewees questioned the quality of data generated.

*“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 they, 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]*

Interviewees explained that TSOs needed to ensure the designed PROMs process was straightforward and proportionate to the specific service-user group and organisation. For example front-line workers discussed how they had to complete multiple PROMs which caused measurement burden and they wanted the process reduced to a single measure.

### A dilemma: standardised PROMs or bespoke measures?

Interviewees differed on whether their TSOs used standardised PROMs or had designed their own bespoke measure. Organisations using standardised PROMs generally utilised wellbeing measures, with WEMWBS being the most used measure within the sample. Other measures included the Outcome Star and Office for National Statistics Wellbeing Questions. Some interviewees believed standardised measures were more credible and using them enabled comparison with other organisations. Other interviewees designed a bespoke measure because they felt that existing PROMs were not appropriate for their context. Bespoke PROMs often drew upon established wellbeing frameworks such as Five Ways to Wellbeing. Factors influencing the choice of PROM included the preferences of commissioners and Implementation

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3 Leads, experiences of similar TSOs, and needing to avoid the license fees associated with using  
4 certain measures.  
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7 *“Sometimes you think ‘ooh it would be good to have a validated tool in terms*  
8 *of being able to compare yourself to that organisation’ and things like that and*  
9 *it’s something we definitely have thought about... but it doesn’t mean they’re*  
10 *right and it doesn’t mean they’re going to work for you.” [TSO Manager 7]*  
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## 12 13 **Developing systems for processing and using the data generated from administering** 14 **PROMs** 15

16 TSOs planning how measures would be collected and the data processed, analysed and used,  
17 appeared to facilitate implementation. PROMs were generally collected by front-line workers  
18 supporting service-users to complete paper versions within face-to-face appointments. Some  
19 interviewees had unsuccessfully tried to use digital methods or asked people to complete PROMs  
20 independently before appointments; the service-users interviewed were also resistant to these  
21 approaches. Interviewees from all the interest groups discussed the difficulty in identifying  
22 appropriate time points for collecting PROMs, especially when service-users attended the TSO  
23 on a long-term or sporadic basis. Having sufficient time and resources within the organisation to  
24 process collected PROMs was also highlighted as a challenge. Some TSOs in the sample had  
25 invested in staff to perform these tasks and/or in data management systems. Not investing in  
26 systems meant that paper-based PROMs could be collected but the data not processed or used.  
27 However this could also happen if the systems were not fit for purpose.  
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32 *“We’ve set up a management information system and part of that system is to*  
33 *record outcomes and it’s just a new piece of technology, it’s a new way of*  
34 *doing things. It’s really you know looking at it now, and thinking maybe we*  
35 *didn’t get the right one because it’s just so time consuming and staff are just*  
36 *really resistant to it.” [TSO Manager 4]*  
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40 A number of managers felt that they had good systems in place to ensure the PROMs results  
41 were shared with and used by front-line workers and service-users. However several front-line  
42 workers and service-users complained about not receiving feedback such as how individual  
43 users’ scores had changed. Front-line workers and service-users found this frustrating because it  
44 meant they could not use the data to inform a service-user’s care, making them less likely to  
45 engage with PROMs, affecting their sustainability.  
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48 *“When they gave me the second form to fill in I felt happier and said ‘oh now*  
49 *I’ll know if I’ve improved or not’. But when I ask for the result [...], ‘no this*  
50 *was for the records and I can’t access them’. I felt like I’d wasted my time*  
51 *thinking that I will know my score.” [Service-user 5]*  
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## The need for ongoing, practical and ideological training for staff using PROMs

Training front-line workers appeared to be important for facilitating the implementation of PROMs. Interviewees discussed how training should be both practical in terms of learning how to use measures, and also ideological so front-line workers understood the rationale for using PROMs. Managers and front-line workers felt that training needed to be ongoing including refreshers in team meetings and additional training given to individual front-line workers who were not engaging in PROMs.

*“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]*

## Sustaining the use of PROMs in routine practice: a long term iterative process

Rarely did TSOs get the PROMs process right first time, resulting in front-line workers struggling to collect measures. Consequently organisations had to further develop the PROMs process, sometimes by making fundamental changes such as using a different measure. Other organisations only needed to make small refinements, for example by improving the data management system or staff training.

*“We thought ‘well we’ll give this [the PROM] a go because it’s been given to us’. But we doubt it’s going to 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.’” [TSO Front-line worker 2]*

Having a trial period was suggested by one front-line worker as a potential way of overcoming these initial problems but none of the interviewees had tried this. It took time for PROMs to become part of routine practice. Interviewees felt that the long-term use of outcome measures was facilitated by front-line workers having PROMs incorporated into their job roles and TSOs undergoing organisational culture change so that they perceived PROMs as beneficial for the organisation such as the data being used to inform a service-user’s care or to help generate funding. For example several TSO managers spoke about setting PROM related performance objectives for staff.

*“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]*

In contrast, the length of time it took to implement PROMs was considered a barrier because TSOs rely on short-term funding. A couple of TSO managers in the sample discussed addressing this issue through developing an organisational wide PROMs process.

## **Discussion**

### **Summary of findings**

TSOs primarily used PROMs because of pressures arising from the external funding context. However, organisations often struggled to implement PROMs, rarely getting the process right first time. Facilitators for implementation included having an Implementation Lead committed to making it work, investing resources in processes, and taking a collaborative design approach. The latter helped to ensure an appropriate PROMs process for the specific TSO including choosing a suitable measure and planning how data would be collected, processed and used including developing the supporting infrastructure such as data management systems. There was a dilemma about whether TSOs should use standardised measures like the WEMWBS or design their own measure. Not all TSOs sustained the collecting and reporting of PROMs over time because this required a change in organisational culture so that PROMs were viewed as useful to the organisation.

### **Strengths and limitations**

The study's strengths are that it is the first published research on implementing PROMs in TSOs, the research considered the whole implementation pathway, and different interest groups were interviewed. The research would have benefitted from having more interviewees from larger TSOs and from organisations that had stopped using PROMs.

### **Context of other research**

Several factors identified were consistent with findings of studies based in healthcare settings whereas other issues appeared unique to TSOs, arising from their specific external and internal context. Key similarities related to designing the process, engaging staff and needing to improve the PROMs process. Implementation in both TSOs and healthcare settings appeared to be facilitated by organisations co-designing an appropriate and straightforward PROMs process, and planning how data would be collected, processed, analysed and used including sharing it with front-line workers and service-users (14,19,39). The importance of having skilled and engaged staff who received sufficient training was consistently identified in studies based in different healthcare settings (14,15,19). Organisations experiencing problems when starting to use PROMs and needing to make improvements to facilitate sustainability has also been consistently documented (14). The similarity in findings between TSOs and healthcare settings is understandable because it has been proposed they are sufficiently alike to learn from each other (40).

However, some findings appeared to be unique to TSOs or more prominent. Firstly, TSOs were motivated to use PROMs to demonstrate their impact because of the sector's specific funding context, whereas research based in healthcare settings focuses on using PROMs with individual service-users to tailor their care (14). Second, TSOs were having to implement PROMs imposed

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3 on them by commissioners rather than having the scope to design their own process, which  
4 contrasts with good practice guidance on implementing PROMs (41). This research found that  
5 having an Implementation Lead was fundamental. Some but not all previous studies identified  
6 the importance of the Lead. However, previous research did not place as much importance on the  
7 role as TSOs have. Third, TSOs were developing their own measures, unlike in healthcare  
8 settings. This was because some interviewees did not feel that existing PROMs developed for  
9 other settings were transferable to TSO, making it difficult to sustain their use (42) and measures  
10 specifically designed for TSO are needed. The use of bespoke measures raises questions about  
11 the validity of data being collected as these PROMs have not undergone psychometric testing.  
12 TSOs were generally using paper-based PROMs which is at odds with the shift towards  
13 electronically collected measures (43,44). The variation may be because of concerns about the  
14 digital literacy of people accessing TSOs (19,45).  
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### 21 **The utility of the CFIR**

22 Using the CFIR enhanced our understanding of the range of issues which influence  
23 implementation, especially considering the impact of the external context and an organisations'  
24 characteristics. Without using the CFIR, we would not have identified potentially relevant issues  
25 which have arisen in respect of PROMs. For example interviewees did not discuss planning  
26 implementation, raising questions about whether TSOs take an organic approach to  
27 implementation. However, the CFIR had less utility in respect of exploring designing the  
28 PROMs process and sustaining their use. A further limitation is that each CFIR construct is  
29 independent but we identified how implementing PROMs was a process, with the different  
30 constructs influencing each other.  
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### 37 **Implications**

38 When implementing PROMs, commissioners and TSOs need to consider co-designing a PROMs  
39 process which is appropriate for a specific organisation and their service-users. This includes  
40 choosing an appropriate measure alongside deciding suitable ways to collect, process, analyse  
41 and use the PROM data. It appears to be important that TSOs have an Implementation Lead and  
42 invest sufficient resources in processes and infrastructure such as electronic data systems and  
43 training. Commissioners could facilitate this by allocating funding for PROMs implementation  
44 as part of their funding contracts. Organisations should anticipate problems when initially  
45 implementing PROMs and be proactive in addressing these.  
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49 There were some TSOs which managed to implement PROMs despite not having all the  
50 facilitators described here, raising questions about whether certain facilitators are more  
51 fundamental than others or whether some barriers can be minimised by facilitators. The relative  
52 importance of different facilitators and barriers needs further research. The struggle to find  
53 suitable PROMs and sustain the use of PROMs could be addressed by developing and validating  
54 a measure specifically for TSOs.  
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To conclude, TSOs are trying to use PROMs because they feel they have no choice but often struggle with implementation. Having an Implementation Lead, designing an appropriate process, investing resources, training staff and taking mitigating action to address potential barriers can facilitate implementation.

### **Contributorship statement-**

AF undertook all the recruitment, interviews and analysis alongside writing the article.

AOC coded a transcript and provided ongoing advice into the conduct of the study and significant input into the analysis. AOC provided substantial feedback on the drafts of the article.

JH coded a transcript and provided ongoing advice into the conduct of the study and significant input into the analysis. JH provided substantial feedback on the drafts of the article.

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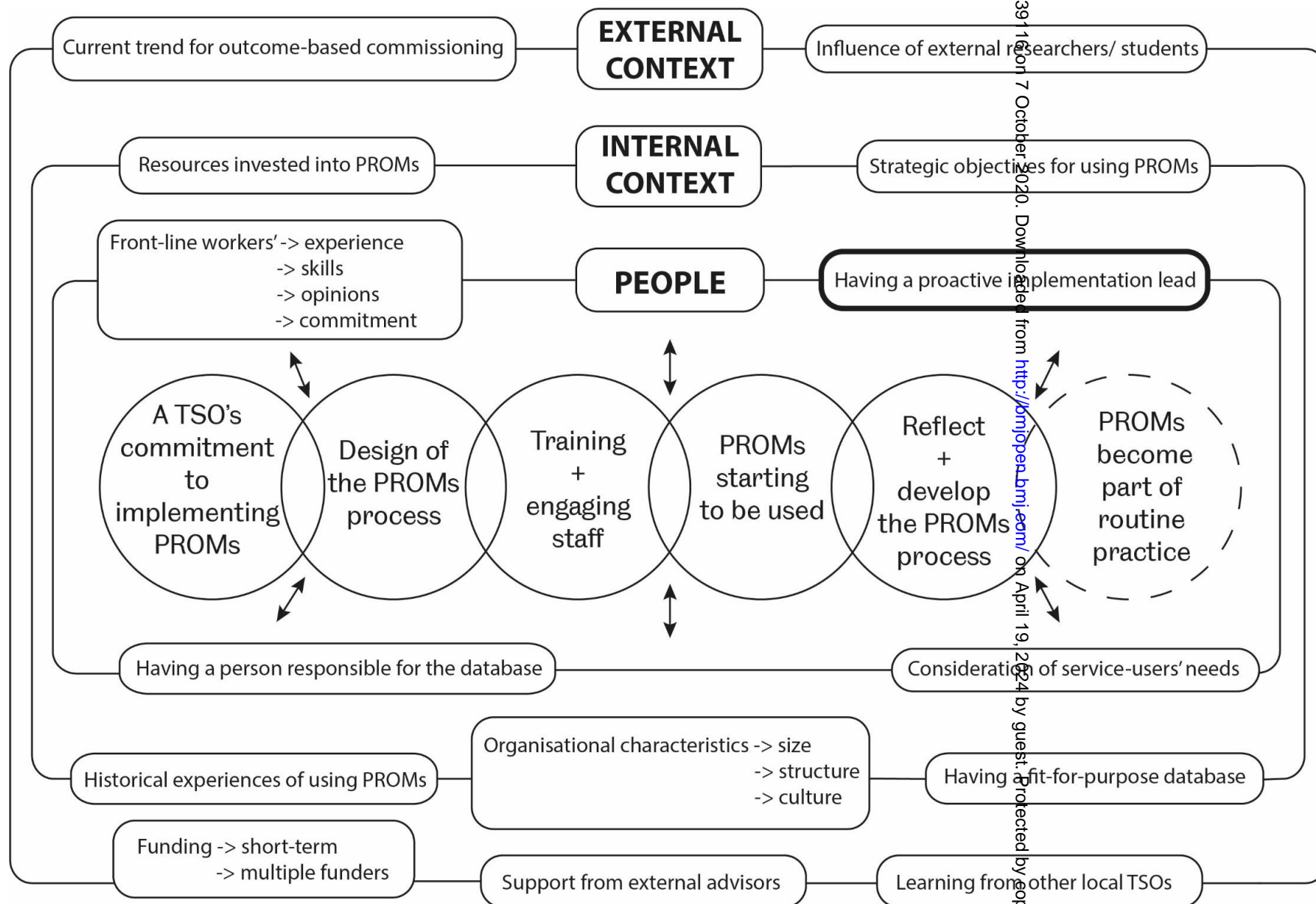
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Figure 1- Factors which appear to influence the implementation of PROMs in TSOs



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## How do Third Sector Organisations or Charities providing health and wellbeing services in England implement Patient Reported Outcome Measures (PROMs)?: A qualitative interview study

### Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No. Item	Guide questions/description	Reported on Page #
<b>Domain 1: Research team and reflexivity</b>		
<i>Personal Characteristics</i>		
1. Inter viewer/facilitator	Which author/s conducted the interview or focus group?	5
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	In the author information
3. Occupation	What was their occupation at the time of the study?	In the author information
4. Gender	Was the researcher male or female?	N/A
5. Experience and training	What experience or training did the researcher have?	In the author information
<i>Relationship with participants</i>		
6. Relationship established	Was a relationship established prior to study commencement?	5
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	5
8. Interviewer characteristics	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	N/A
<b>Domain 2: study design</b>		
<i>Theoretical framework</i>		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	6
<i>Participant selection</i>		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	5
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	5
12. Sample size	How many participants were in the study?	5
13. Non-participation	How many people refused to participate or dropped out? Reasons?	5

<i>Setting</i>		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	5
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	N/A
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	6
<i>Data collection</i>		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	5
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	No
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	6
20. Field notes	Were field notes made during and/or after the interview or focus group?	NA
21. Duration	What was the duration of the interviews or focus group?	6
22. Data saturation	Was data saturation discussed?	5
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	N/A
<b>Domain 3: analysis and findings</b>		
<i>Data analysis</i>		
24. Number of data coders	How many data coders coded the data?	6
25. Description of the coding tree	Did authors provide a description of the coding tree?	5
26. Derivation of themes	Were themes identified in advance or derived from the data?	6
27. Software	What software, if applicable, was used to manage the data?	6
28. Participant checking	Did participants provide feedback on the findings?	N/A
<i>Reporting</i>		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Yes
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Yes
31. Clarity of major themes	Were major themes clearly presented in the findings?	Yes
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes

# BMJ Open

## How do Third Sector Organisations or Charities providing health and wellbeing services in England implement Patient Reported Outcome Measures (PROMs)?: A qualitative interview study

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## **How do Third Sector Organisations or Charities providing health and wellbeing services in England implement Patient Reported Outcome Measures (PROMs)?: A qualitative interview study**

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- Implementation Science
- Organizational innovation

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# How do Third Sector Organisations or Charities providing health and wellbeing services in England implement Patient Reported Outcome Measures (PROMs)?: A qualitative interview study

## List of tables, figures and supplementary files

- Table 1- Participant characteristics
- Table 2- How the arising findings link to the Consolidated Framework for Implementation Research constructs
- Figure 1- Factors which appear to influence the implementation of PROMs in TSOs
- Supplementary file- COREQ checklist

## Abstract

**Objectives:** To identify the facilitators and barriers to implementing Patient Reported Outcome Measures (PROMs) in third sector organisations (TSOs) delivering health and wellbeing services.

**Design:** A qualitative interview study. Participants were recruited using purposive, opportunistic and snowballing methods. Framework analysis was used.

**Setting:** TSOs including charities, community groups and not-for-profit organisations in England, United Kingdom.

**Participants:** Thirty interviewees including service-users, TSO front-line workers and managers, commissioners of TSOs and other stakeholders such as academic researchers.

**Results:** TSOs primarily used PROMs because of pressures arising from the external funding context. However organisations often struggled to implement PROMs, rarely getting the process right first time. Facilitators for implementation included having an Implementation Lead committed to making it work, investing resources in data management systems and support staff and taking a collaborative approach to designing the PROMs process. The latter helped to ensure an appropriate PROMs process for the specific TSO including choosing a suitable measure and planning how data would be collected, processed and used. There was a dilemma about whether TSOs should use standardised wellbeing measures, for example the Warwick Edinburgh Mental Wellbeing Scale or design their own PROM. Not all TSOs sustained the collection and reporting of PROMs over time because this required a change in organisational culture to view PROMs as beneficial for the TSO and PROMs becoming part of front-line workers' job specifications.

**Conclusions:** TSOs are trying to use PROMs because they feel they have no choice but often struggle with implementation. Having an Implementation Lead, designing an appropriate process, investing resources, training staff and taking mitigating action to address potential barriers can facilitate implementation. Some of the findings are consistent with the experiences of more clinical services so appear relevant to the implementation of PROMs irrespective of the specific context.

### **Strengths and Limitations**

- First piece of published research specifically focusing on the implementation of Patient Reported Outcome Measures (PROMs) in third sector organisations (TSOs).
- Identified a number of findings useful to commissioners and TSOs to improve the implementation of PROMs.
- Some of the findings may be relevant to healthcare services.
- It would have been useful to interview more people from larger TSOs and from organisations who had stopped using PROMs.

### **Introduction**

PROMs (Patient Reported Outcome Measures) are standardised questionnaires which measure Patient Reported Outcomes such as a person's health, wellbeing or symptoms (1-3). If a person answers a questionnaire at two or more time points, for example before and after receiving support, scores can be compared to understand whether there is any change. Generic PROMs which measure a person's overall health include the EQ-5D (1) and SF-36 (4). Examples of PROMs which focus on wellbeing include the Warwick Edinburgh Mental Wellbeing Being Scale (WEMWBS) (5), the Office for National Statistics Wellbeing questions (ONS4) (6) and the Personal Wellbeing Scale (PWS) (7). PROMs' scores can be used on an individual service-user level to inform their support or the scores of multiple service-users can be aggregated to evaluate the impact of a service (1). Policy makers and healthcare services are increasingly attempting to implement PROMs because they can improve communication between clinicians and service-users, resulting in improved care and outcomes (8,9). Furthermore, aggregated PROMs are used by commissioners to hold services to account for offering health benefit. For example the United Kingdom's (UK's) PROMs programme mandates that hospitals use PROMs for hip and knee replacements (10). And in the United States of America, the Patient Reported Outcomes Measurement Information System (PROMIS) is being implemented (11). Despite the intent to use PROMs, healthcare services can struggle with implementation, resulting in low completion rates (12).

Implementation is defined as the process from a service deciding to use PROMs to when they are part of routine practice (13). To improve implementation, researchers have sought to identify potential facilitators and barriers (14-17). To date, this work has been undertaken in clinical

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3 services. A recent systematic review of reviews (14) identified a number of facilitators including  
4 using PROMs to tailor a service-user's care, the importance of choosing an appropriate measure  
5 and the need to design a straightforward process for collecting, analysing and using the PROMs  
6 data. Furthermore, having an Implementation Lead to progress implementation and engage and  
7 train staff is necessary. The review also identified that organisations need to reflect and develop  
8 the PROMs process if problems arise. Importantly, the review identified that many of these  
9 issues were bidirectional, in terms of becoming barriers if not undertaken by an organisation. For  
10 example, staff may not use PROMs if they find the data collection process complex. Other  
11 studies have identified similar facilitators and barriers (15-17), with some questioning whether  
12 organisations have sufficient resources to invest in the PROMs infrastructure (18) and whether  
13 the use of measures is sustained (19).  
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18 Generic implementation theories such as the Knowledge to Action framework (20) or the  
19 Consolidated Framework for Implementation Research (CFIR) (21) may also be useful for  
20 identifying issues affecting the use of PROMs. A recent review of PROMs utilised the CFIR  
21 (14), showing how previous PROMs research had not considered the influence of an  
22 organisations' characteristics or external influences on implementation, even though these are  
23 considered relevant within implementation theories (21).  
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26 To date, research on implementing PROMs has focused on clinical services and not considered  
27 PROMs usage within third sector organisations (TSOs) (14). TSOs, also known as charities,  
28 voluntary or community organisations are increasingly commissioned to deliver health and  
29 wellbeing services (called 'wellbeing services' in this paper) within the UK (22-24) through  
30 initiatives such as social prescribing, advocacy services and community allotments (25,26).  
31 Often TSOs receive short-term funding to deliver their services, with organisations having to  
32 demonstrate their impact on the health and wellbeing of service-users to justify further funding  
33 (27). PROMs are one approach that TSOs use to demonstrate their impact. However, little is  
34 known about how to implement PROMs within TSOs and a recent review recommended  
35 research was needed (14) because it is not clear how transferable known facilitators and barriers  
36 to implementing PROMs in clinical services are to TSOs. This is because TSO delivered  
37 wellbeing services differ from clinical services as they are often run more informally, support is  
38 from peers rather than healthcare professionals, attendance may be long-term, and service-users  
39 may access multiple services within a TSO rather than receiving one specific intervention (28-  
40 30). Given this gap in knowledge, the study aimed to identify the facilitators and barriers to  
41 implementing PROMs in TSOs.  
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## 48 **Methods**

### 49 **Design**

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51 A qualitative interview study of multiple stakeholders was undertaken for an in-depth  
52 exploration of different TSOs' experiences of implementing PROMs in England (31). The  
53 Consolidated criteria for reporting qualitative research checklist (COREQ) was used to guide  
54 reporting (32) (Supplementary file).  
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## Participant Recruitment

Participants who had different connections to the use of PROMs in TSOs were recruited including service-users, front-line workers and managers, commissioners and other relevant stakeholders for example academic researchers. Further detail is provided in Table 1. Recruitment was undertaken through using a range of sampling strategies including purposive, opportunistic and snowballing approaches (33). Purposive sampling involved targeting people because of their professional roles, such as approaching commissioners who funded TSOs. Opportunistic sampling entailed promoting the study through networks including visiting TSOs. Finally, snowballing was used because some interviewees recommended other people to approach. Thirty-five people were invited and five individuals did not respond so were not interviewed. Potential interviewees were provided with a Participant Information Sheet and Consent Form when making initial contact and written consent was collected before individuals were interviewed. Recruitment stopped after 30 interviews because the sample was suitably diverse, the information power was high (34) and saturation had been reached on some central themes (35).

## Use of the CFIR

We used the CFIR in this study because it amalgamates a number of implementation theories (13), has been used in a previous review of PROMs (14) and provides a framework of 36 constructs which may influence implementation, structured around five different domains. These include (21):

- Outer setting- Factors outside of the organisation e.g. External policies and incentives
- Inner settings- Characteristics of an organisation e.g. its Culture and Structural characteristics
- Characteristics of individuals- How people influence implementation e.g. front-line workers' Knowledge and beliefs about the intervention
- The intervention- The PROMS process e.g. its Complexity and Adaptability to the specific context
- Process- Factors relating to getting PROMs used such as Planning and Reflecting and evaluating implementation.

## Data collection and analysis

Semi-structured interviews were used so that similar questions could be asked of all participants whilst also providing scope to explore arising issues (36). AF undertook all interviews, predominately conducting them face-to-face, using telephone interviews when geographical distance was prohibitive. Participants chose the location of the interview- usually this was at the TSO. The topic guides incorporated the CFIR constructs by asking about which measures were

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3 used and why, Staff engagement, Knowledge and beliefs about PROMs, Available resources and  
4 Reflecting and evaluating implementation. The guides were tailored to each interest group.  
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7 The interviews were audio recorded, transcribed verbatim and imported into NVivo Version 11  
8 (37). Framework analysis was undertaken, entailing the steps of Familiarisation, Identifying a  
9 Thematic Framework, Indexing, Charting and Mapping and Interpretation (38). Transcripts were  
10 read for familiarisation. The Thematic Framework was developed from findings of a systematic  
11 review on implementing PROMs (14) and constructs of the CFIR (21). The framework was  
12 further developed to account for additional issues identified within the transcripts (39). Data was  
13 coded to the framework. During the Mapping and Interpretation stages of analysis, the themes  
14 evolved beyond the CFIR because the findings often transcended several constructs and it was  
15 important to utilise the language of the participants. The analysis was primarily undertaken by  
16 AF, with AOC and JH each coding an early transcript for team discussion and providing  
17 substantial input into the analysis.  
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## 22 **Patient and Public Involvement**

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24 Service-users were actively involved in the study including supporting the development of the  
25 research, designing the recruitment materials such as Participant Information Sheets, advising on  
26 the recruitment strategy and reviewing the topic guides. AF consulted the service-users at each  
27 stage of analysis to help with interpreting the findings.  
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## 32 **Ethics committee approval**

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34 The study was approved by the School of Health and Related Research Ethics Committee (Ref:  
35 013727).  
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## 39 **Findings**

### 40 **Participant characteristics**

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42 Thirty people were interviewed, which included at least five people per interest group  
43 (designated by their current role in relation to TSOs) to enable different perspectives to be  
44 explored (Table 1). Participants were involved in different sized TSOs including neighbourhood  
45 based organisations and national TSOs. Interviewees were primarily located in the North of  
46 England (n=24). The majority of interviews were face-to-face (n=22), with eight by telephone.  
47 Interviews were generally an hour long, although the majority of service-user interviews were  
48 shorter (average length 25 minutes) because they did not have views about organisational issues.  
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**Table 1- Characteristics of the sample**

<b>Participant type</b>	<b>Number interviewed</b>	<b>Mode of interview</b>	<b>Geographical location</b>	<b>Type of organisation</b>	<b>Other information</b>
<b>Service-users-</b> people who attend wellbeing activities	5	Face-to-face- 5 Phone- 0-	North- 5 Central- 0 South- 0	National TSO- 0 Regional TSO- 0 City level TSO- 4 Neighbourhood TSO- 1	
<b>Front-line workers-</b> people who deliver the wellbeing activities, providing support to attendees	6	Face-to-face- 5 Phone- 1	North- 5 Central- 0 South- 1	National TSO- 0 Regional TSO- 3 City level TSOs- 0 Neighbourhood TSO- 3	
<b>TSO Managers-</b> people who oversee wellbeing activities and have management responsibilities within the TSO	8	Face-to-face- 7 Phone- 1	North- 7 Central- 1 South- 0	National TSOs- 1 Regional TSOs- 1 City level TSO- 5 Neighbourhood TSO- 1	
<b>Commissioners-</b> People working for organisations which fund TSOs to deliver wellbeing activities and who are responsible for ensuring organisation abide by the contract	6	Face-to-face- 1 Phone- 5	North-4 Central- 0 South- 2	Local Authority- 2 NHS- 1 Non-statutory funder- 3	
<b>Stakeholders-</b> People external to TSOs who support them to implement PROMs	5	Face-to-face- 4 Phone- 1	North- 4 Central- 0 South- 1	N/A	Carer/volunteer- 1 Researcher/policy advisory- 2 Developer of PROMs' data management systems- 1 Statutory service Implementation Lead- 1



## **Overview of factors influencing implementation of PROMs**

Multiple factors appeared to influence implementation, some related to the internal and external context of TSOs, whilst others arose from the process of using PROMs. Figure 1 encapsulates these issues. In Table 2, we explain how each theme relates to the CFIR constructs. The majority of the CFIR constructs were identified in the data. The main exception was Planning, with interviewees not discussing whether their TSO planned the implementation process.

Each of the factors influencing implementation is presented separately within the findings, however in practice they interacted and influenced each other, acting as facilitators or barriers depending on how an organisation approached the issue. For example, whether front-line workers used a PROM depended on whether they felt the choice of measure was appropriate in terms of its length, the relevance of the questions and the accessibility of the language.

**Table 2- How the findings from the qualitative interviews linked to the CFIR constructs**

Theme	The CFIR constructs identified within the interview data	Example
<b>External context: PROMs are compulsory</b>	External policies and incentives	TSOs using PROMs to demonstrate their impact to gain/receive funding.
<b>Organisational commitment: Organisational culture and investment can facilitate PROMs</b>	Culture Implementation climate Networks and communications Learning climate Compatibility Available resources Cost Relative priority	TSOs prioritising investment of resources into the implementation of PROMs.
<b>Staffing: Strong leadership, buy-in from staff and support from external advisors can facilitate PROMs</b>	Self-efficacy Individual stage of change Individual identification with organisation Other personal attributes Patient (service-users) needs and resources Evidence strength and quality Relative advantage Knowledge and beliefs about the intervention Tension for change Relative priority Opinion leaders Compatibility External change agents	Having someone within a TSO instigating and leading implementation.

Theme	The CFIR constructs identified within the interview data	Example
<b>A collaborative approach improves the appropriateness of the PROMs process</b>	Intervention source Complexity Adaptability	Whether front-line workers and service-users are consulted about the design of the PROMs process.
<b>A dilemma: standardised PROMs or bespoke measures?</b>	Design quality and packaging Cost	A TSO choosing to design their own measure because they feel existing standardised wellbeing PROMs were inappropriate.
<b>Developing systems for processing and using the data generated from administering PROMs</b>	Design quality and packaging Cost	Investing in data management systems to process the collected PROMs data.
<b>The need for ongoing, practical and ideological training for staff using PROMs</b>	Access to knowledge and information Organisational incentives and rewards Engaging Goals and feedback	Providing front-line workers ongoing training on PROMs.
<b>Sustaining the use of PROMs in routine practice: a long term iterative process</b>	Executing Triability Reflecting and evaluating Organisational incentives and rewards	Rarely do TSOs get the design of the PROM's process right first time and have to make improvements to it.

### External context: PROMs are compulsory

A dominant narrative was interviewees believing TSOs have no choice but to engage with PROMs due to funding requirements. Interviewees from all the interest groups discussed how TSO's funding came from time-limited contracts and grants. In a national context of Austerity, and the trend for Outcomes-based commissioning, TSOs were required to measure benefits of funded services and show value for money to demonstrate accountability. Consequently, TSOs were subject to external policies where commissioners required TSOs to collect PROMs as a

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3 condition of funding contracts. This was challenging for organisations because they were funded  
4 by multiple commissioners so had to incorporate all of their specific requests in respect of  
5 PROMs. Additionally TSO managers needed PROMs data to support future funding  
6 applications. Front-line workers and service-users complied with completing PROMs because  
7 they understood that funding was needed to enable wellbeing services to continue. Indeed some  
8 service-users felt compelled to complete PROMs in order to access services.  
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11 *“The reality is that you know money is getting tighter and tighter. Whether its*  
12 *grants or contracts [...] the only way you’ll attract funding is to be able to*  
13 *show that you make a difference and that you have an impact.”*  
14 *[TSO Manager 4]*  
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18 Not all interviewees signed up to a ‘no choice’ narrative. They pointed out that individual  
19 commissioners took different approaches to PROMs, healthcare services were not having to use  
20 PROMs to justify funding and that there was a lack of transparency in how the PROMs data  
21 influenced funding decisions.  
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### 25 **Organisational commitment: Organisational culture and investment can facilitate PROMs**

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27 The organisational characteristics of culture and willingness to invest resources into PROMs  
28 appeared to affect implementation. Interviewees felt that the culture of TSOs had a bidirectional  
29 influence on PROMs. Facilitating aspects included organisations being proactive in adopting  
30 new working practices and having good networks amongst staff, where front-line workers  
31 supported each other with using measures.  
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34 *“I think as an organisation we are quite good at being fluid, you know and*  
35 *having a go at things and seeing if they work.” [TSO Manager 4]*  
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39 However some interviewees felt that collecting PROMs detrimentally affected the dynamic of  
40 wellbeing services especially group social activities or when a service-user was receiving short  
41 term advocacy support.  
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43 TSOs prioritising investment of sufficient resources in implementation was considered to be a  
44 pertinent issue by interviewees. This included investing in data management systems and support  
45 staff to process PROMs, and training front-line workers. However TSO managers raised  
46 concerns about sustaining investment because they did not consider resourcing PROMs to be  
47 part of their core costs. For example, one manager was uncertain whether they could continue to  
48 fund a data manager.  
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51 *“Funds are tight for us and it’s one of those roles that I look at and think ‘is it a*  
52 *bit of a luxury?’ On the other hand, I do know that we’ve won funding because*  
53 *of the quality of the data that we’ve been able to provide to people so it’s a real*  
54 *balancing act.” [TSO Manager 3]*  
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### **Staffing: Strong leadership, buy-in from staff and support from external advisors can facilitate PROMs**

The needs, skills and opinions of TSO managers and front-line workers as well as support from external advisors may influence implementation. Interviewees discussed the importance of having an Implementation Lead, that is someone who took responsibility for implementing PROMs and offered strategic and operational management of the processes.

*“Cos when I first came it [the PROM] was just ad-hocly written into funding bids, thinking that they 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]*

Challenges arose if no one within a TSO acted as Implementation Lead or when the Lead did not engage with PROMs. For example, one manager explained how they did not consider PROMs a priority so had not invested time in progressing implementation.

Interviewees felt that front-line workers generally tried to engage with PROMs even if they considered the measures to be inappropriate and invalid. Negative opinions arose from workers feeling their service-users' lives were complex and positive changes may not be captured by an overall assessment of wellbeing. Additionally, front-line workers believed the language used in measures was too complex for their service-users. Despite this, front-line workers discussed engaging with PROMs out of loyalty to their TSO and because they believed collecting PROMs could generate further funding, keeping them in a job. However, some front-line workers struggled to use PROMs as they were concerned that administering measures would damage their relationships with service-users because of the seeming irrelevancy of these measures in the context of the serious difficulties people were facing.

*“But people who are coming to me with the social issues such as they can't pay their rent or universal credit [...] 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]

External advisors providing support with implementation were valued by some TSO managers because these interviewees did not feel they had the capacity or knowledge themselves. For example, one manager discussed how an external advisor designed the TSO's data management system.

### **A collaborative approach improves the appropriateness of the PROMs process**

The ‘designing stage’ of implementing PROMs where a TSO decides which PROMs to use and how to use them, appeared to be critical to the implementation process. Interviewees felt that taking a collaborative approach to ensure the design was appropriate, proportionate and straightforward was important. Collaboration involved commissioners working with, rather than imposing a PROMs process on an organisation and TSO managers consulting front-line workers and service-users. Consulting front-line workers and service-users was often reported as not occurring in our sample, with interviewees explaining that if PROMs had been imposed by commissioners, then there was little scope to consult service-users and front-line workers. Participants felt externally imposed PROMs processes were often inappropriate for an organisation’s specific service-users, resulting in some TSOs struggling to collect PROMs. However some organisations overcame the challenge through taking mitigating action in other parts of the implementation process. For example one TSO was required to collect a PROM they considered inappropriate but were managing to administer the measure through skilled front-line workers engaging service-users. In another TSO, they implemented one PROM throughout the whole organisation and then negotiated with commissioners to be allowed to use this measure. Even if TSOs managed to collect imposed PROMs, interviewees questioned the quality of data generated.

*“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 they, 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]*

Interviewees explained that TSOs needed to ensure the designed PROMs process was straightforward and proportionate to the specific service-user group and organisation. For example front-line workers discussed how they had to complete multiple PROMs which caused measurement burden and they wanted the process reduced to a single measure.

### **A dilemma: standardised PROMs or bespoke measures?**

Interviewees differed on whether their TSOs used standardised PROMs or had designed their own bespoke measure. Organisations using standardised PROMs generally utilised wellbeing measures, with WEMWBS being the most used measure within the sample. Other measures included the Outcome Star and ONS4. Some interviewees believed standardised measures were more credible and using them enabled comparison with other organisations. Other interviewees designed a bespoke measure because they felt that existing PROMs were not appropriate for their context. Bespoke PROMs often drew upon established wellbeing frameworks such as Five Ways to Wellbeing. Factors influencing the choice of PROM included the preferences of commissioners and Implementation Leads, experiences of similar TSOs, and needing to avoid the license fees associated with using certain measures.



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*“Sometimes you think ‘ooh it would be good to have a validated tool in terms of being able to compare yourself to that organisation’ and things like that and it’s something we definitely have thought about... but it doesn’t mean they’re right and it doesn’t mean they’re going to work for you.” [TSO Manager 7]*

## **Developing systems for processing and using the data generated from administering PROMs**

TSOs planning how measures would be collected and the data processed, analysed and used, appeared to facilitate implementation. PROMs were generally collected by front-line workers supporting service-users to complete paper versions within face-to-face appointments. Some interviewees had unsuccessfully tried to use digital methods or asked people to complete PROMs independently before appointments; the service-users interviewed were also resistant to these approaches. Interviewees from all the interest groups discussed the difficulty in identifying appropriate time points for collecting PROMs, especially when service-users attended the TSO on a long-term or sporadic basis. Having sufficient time and resources within the organisation to process collected PROMs was also highlighted as a challenge. Some TSOs in the sample had invested in staff to perform these tasks and/or in data management systems. Components of data management systems included having the function to store details of PROMs scores and systems to report individual service-user and amalgamated PROMs scores such as through visual dashboards. TSOs not investing in data management systems meant that paper-based PROMs could be collected but the data not processed or used. However this could also happen if the systems were not fit for purpose.

*“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]*

A number of managers felt that they had good systems in place to ensure the PROMs results were shared with and used by front-line workers and service-users. For example, some interviewees spoke about being able to generate dashboards from their data management systems so that front-line workers and service-users could view their PROMs scores. However several front-line workers and service-users complained about not receiving feedback such as how individual users’ scores had changed. Front-line workers and service-users found this frustrating because it meant they could not use the data to inform a service-user’s care, making them less likely to engage with PROMs, affecting their sustainability.

*“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*



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3 *thinking that I will know my score.” [Service-user 5]*  
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## 8 **The need for ongoing, practical and ideological training for staff using PROMs**

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10 Training front-line workers appeared to be important for facilitating the implementation of  
11 PROMs. Interviewees discussed how training should be both practical in terms of learning how  
12 to use measures, and also ideological so front-line workers understood the rationale for using  
13 PROMs. Managers and front-line workers felt that training needed to be ongoing including  
14 refreshers in team meetings and additional training given to individual front-line workers who  
15 were not engaging in PROMs.  
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18 *“Me and my manager did one [team meeting] about the importance of*  
19 *monitoring and where it comes from and what it means and the cycle of it and*  
20 *why we do it....just to refresh thinking.” [TSO Manager 7]*  
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## 23 **Sustaining the use of PROMs in routine practice: a long term iterative process**

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25 Rarely did TSOs get the PROMs process right first time, resulting in front-line workers  
26 struggling to collect measures. Consequently organisations had to further develop the PROMs  
27 process, sometimes by making fundamental changes such as using a different measure. Other  
28 organisations only needed to make small refinements, for example by improving the data  
29 management system or staff training.  
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32 *“We thought ‘well we’ll give this [the PROM] a go because it’s been given to*  
33 *us’. But we doubt it’s going to work and fairly quickly by the end of the first*  
34 *quarter we were on our knees with it saying ‘we’ve got to change it.’ [TSO*  
35 *Front-line worker 2]*  
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39 Having a trial period was suggested by one front-line worker as a potential way of overcoming  
40 these initial problems but none of the interviewees had tried this. It took time for PROMs to  
41 become part of routine practice. Interviewees felt that the long-term use of outcome measures  
42 was facilitated by front-line workers having PROMs incorporated into their job roles and TSOs  
43 undergoing organisational culture change so that they perceived PROMs as beneficial for the  
44 organisation such as the data being used to inform a service-user’s care or to help generate  
45 funding. For example several TSO managers spoke about setting PROM related performance  
46 objectives for staff.  
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50 *“It’s in the bones, we could all leave and it would still be in the bones. I think*  
51 *it’s sort of, we’ve been on at it long enough now that it’s just, yeah part of our*  
52 *DNA and people know this is just what we do.” [TSO Manager 6]*  
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3 In contrast, the length of time it took to implement PROMs was considered a barrier because  
4 TSOs rely on short-term funding. A couple of TSO managers in the sample discussed addressing  
5 this issue through developing an organisational wide PROMs process.  
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## 9 **Discussion**

### 10 **Summary of findings**

11 TSOs primarily used PROMs because of pressures arising from the external funding context.  
12 However, organisations often struggled to implement PROMs, rarely getting the process right  
13 first time. Facilitators for implementation included having an Implementation Lead committed to  
14 making it work, investing resources in processes, and taking a collaborative design approach.  
15 The latter helped to ensure an appropriate PROMs process for the specific TSO including  
16 choosing a suitable measure and planning how data would be collected, processed and used  
17 including developing the supporting infrastructure such as data management systems. There was  
18 a dilemma about whether TSOs should use standardised measures like the WEMWBS or design  
19 their own measure. Not all TSOs sustained the collecting and reporting of PROMs over time  
20 because this required a change in organisational culture so that PROMs were viewed as useful to  
21 the organisation.  
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### 29 **Strengths and limitations**

30 The study's strengths are that it is the first published research on implementing PROMs in TSOs,  
31 the research considered the whole implementation pathway, and different interest groups were  
32 interviewed. The research would have benefitted from having more interviewees from larger  
33 TSOs and from organisations that had stopped using PROMs.  
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### 39 **Context of other research**

40 Several factors identified were consistent with findings of studies based in healthcare settings  
41 whereas other issues appeared unique to TSOs, arising from their specific external and internal  
42 context. Key similarities related to designing the process, engaging staff and needing to improve  
43 the PROMs process. Implementation in both TSOs and healthcare settings appeared to be  
44 facilitated by organisations co-designing an appropriate and straightforward PROMs process,  
45 and planning how data would be collected, processed, analysed and used including sharing it  
46 with front-line workers and service-users (14, 19, 40). The importance of having skilled and  
47 engaged staff who received sufficient training was consistently identified in studies based in  
48 different healthcare settings (14, 15, 19). Organisations experiencing problems when starting to  
49 use PROMs and needing to make improvements to facilitate sustainability has also been  
50 consistently documented (14). The similarity in findings between TSOs and healthcare settings is  
51 understandable because it has been proposed they are sufficiently alike to learn from each other  
52 (40).  
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3 However, some findings appeared to be unique to TSOs or more prominent. Firstly, TSOs were  
4 motivated to use PROMs to demonstrate their impact because of the sector's specific funding  
5 context, whereas research based in healthcare settings focuses on using PROMs with individual  
6 service-users to tailor their care (14). Second, TSOs were having to implement PROMs imposed  
7 on them by commissioners rather than having the scope to design their own process, which  
8 contrasts with good practice guidance on implementing PROMs (42). This research found that  
9 having an Implementation Lead was fundamental. Some but not all previous studies identified  
10 the importance of the Lead. However, previous research did not place as much importance on the  
11 role as TSOs have. Third, TSOs were developing their own measures, unlike in healthcare  
12 settings. This was because some interviewees did not feel that existing PROMs developed for  
13 other settings were transferable to TSO, making it difficult to sustain their use (43) and measures  
14 specifically designed for TSO are needed. The use of bespoke measures raises questions about  
15 the validity of data being collected as these PROMs have not undergone psychometric testing.  
16 TSOs were generally using paper-based PROMs which is at odds with the shift towards  
17 electronically collected measures (44,45). The variation may be because of concerns about the  
18 digital literacy of people accessing TSOs (19,46).  
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### 26 **The utility of the CFIR**

27 Using the CFIR enhanced our understanding of the range of issues which influence  
28 implementation, especially considering the impact of the external context and an organisations'  
29 characteristics. Without using the CFIR, we would not have identified potentially relevant issues  
30 which have arisen in respect of PROMs. For example interviewees did not discuss planning  
31 implementation, raising questions about whether TSOs take an organic approach to  
32 implementation. However, the CFIR had less utility in respect of exploring designing the  
33 PROMs process and sustaining their use. A further limitation is that each CFIR construct is  
34 independent but we identified how implementing PROMs was a process, with the different  
35 constructs influencing each other.  
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### 42 **Implications**

43 When implementing PROMs, commissioners and TSOs need to consider co-designing a PROMs  
44 process which is appropriate for a specific organisation and their service-users. This includes  
45 choosing an appropriate measure alongside deciding suitable ways to collect, process, analyse  
46 and use the PROM data. It appears to be important that TSOs have an Implementation Lead and  
47 invest sufficient resources in processes and infrastructure such as electronic data systems and  
48 training. Commissioners could facilitate this by allocating funding for PROMs implementation  
49 as part of their funding contracts. Organisations should anticipate problems when initially  
50 implementing PROMs and be proactive in addressing these.  
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53 There were some TSOs which managed to implement PROMs despite not having all the  
54 facilitators described here, raising questions about whether certain facilitators are more  
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3 fundamental than others or whether some barriers can be minimised by facilitators. The relative  
4 importance of different facilitators and barriers needs further research. The struggle to find  
5 suitable PROMS and sustain the use of PROMs could be addressed by developing and validating  
6 a measure specifically for TSOs.  
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9 To conclude, TSOs are trying to use PROMs because they feel they have no choice but often  
10 struggle with implementation. Having an Implementation Lead, designing an appropriate  
11 process, investing resources, training staff and taking mitigating action to address potential  
12 barriers can facilitate implementation.  
13

### 14 15 16 **Contributorship statement-**

17 AF undertook all the recruitment, interviews and analysis alongside writing the article.

18  
19 AOC coded a transcript and provided ongoing advice into the conduct of the study and  
20 significant input into the analysis. AOC provided substantial feedback on the drafts of the article.  
21

22  
23 JH coded a transcript and provided ongoing advice into the conduct of the study and significant  
24 input into the analysis. JH provided substantial feedback on the drafts of the article.  
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32  
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39

40  
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44

45  
46 **Data sharing statement-** The interview data is not available to share as would breach the  
47 conditions of the Ethics Committee which granted approval.  
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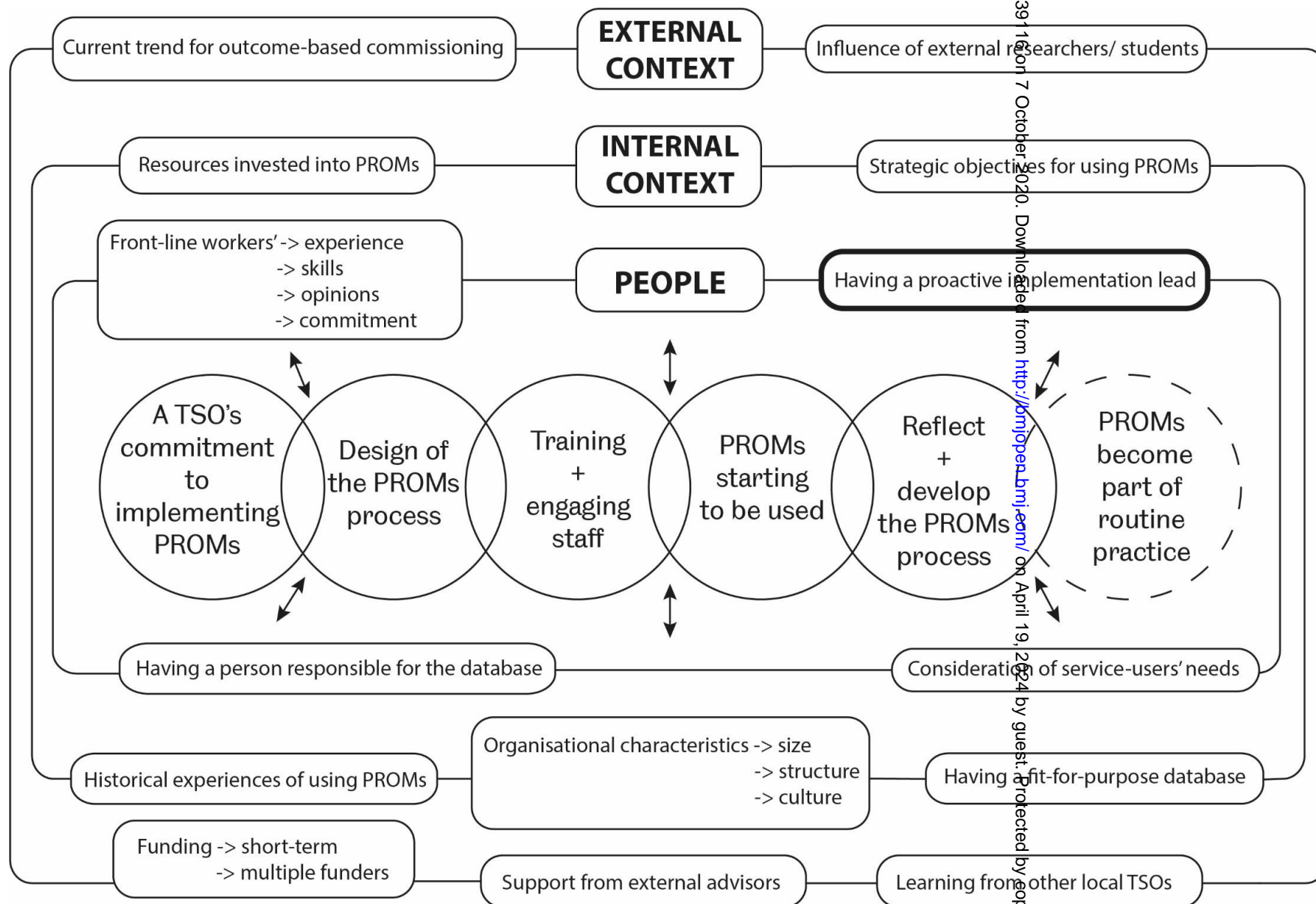


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Figure 1- Factors which appear to influence the implementation of PROMs in TSOs



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## How do Third Sector Organisations or Charities providing health and wellbeing services in England implement Patient Reported Outcome Measures (PROMs)?: A qualitative interview study

### Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No. Item	Guide questions/description	Reported on Page #
<b>Domain 1: Research team and reflexivity</b>		
<i>Personal Characteristics</i>		
1. Inter viewer/facilitator	Which author/s conducted the interview or focus group?	5
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	In the author information
3. Occupation	What was their occupation at the time of the study?	In the author information
4. Gender	Was the researcher male or female?	N/A
5. Experience and training	What experience or training did the researcher have?	In the author information
<i>Relationship with participants</i>		
6. Relationship established	Was a relationship established prior to study commencement?	5
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	5
8. Interviewer characteristics	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	N/A
<b>Domain 2: study design</b>		
<i>Theoretical framework</i>		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	6
<i>Participant selection</i>		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	5
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	5
12. Sample size	How many participants were in the study?	5
13. Non-participation	How many people refused to participate or dropped out? Reasons?	5

<i>Setting</i>		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	5
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	N/A
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	6
<i>Data collection</i>		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	5
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	No
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	6
20. Field notes	Were field notes made during and/or after the interview or focus group?	NA
21. Duration	What was the duration of the interviews or focus group?	6
22. Data saturation	Was data saturation discussed?	5
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	N/A
<b>Domain 3: analysis and findings</b>		
<i>Data analysis</i>		
24. Number of data coders	How many data coders coded the data?	6
25. Description of the coding tree	Did authors provide a description of the coding tree?	5
26. Derivation of themes	Were themes identified in advance or derived from the data?	6
27. Software	What software, if applicable, was used to manage the data?	6
28. Participant checking	Did participants provide feedback on the findings?	N/A
<i>Reporting</i>		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Yes
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Yes
31. Clarity of major themes	Were major themes clearly presented in the findings?	Yes
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes