Journal of Refugee Studies Vol. 00, No. 0 © The Author(s) 2023. Published by Oxford University Press.

https://doi.org/10.1093/jrs/fead062

Standard Involvement Is Not Enough: A Mixed Method Study of Enablers and Barriers in Research Meetings with Forced Migrants

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MS received December 2022; revised MS received August 2023

Although participatory approaches in health research are increasingly used, critical voices are being raised around lack of diversity among the public contributors involved. This article explores enabling and hindering factors in participatory meetings with forced migrants involved as public contributors in health research, using a convergent parallel mixed methods design including behavioural observations and questionnaires, with the aim of contributing to practices of meaningful and inclusive involvement in research. Our findings indicated that relationship-building and adapting to team development over time were key. Additionally, researcher responsivity and transparency enabled relevant contributions, but few decisions were taken. Although linguistic barriers existed and were rated higher by the researchers, engaging interpreters as co-facilitators of the meetings enabled nuanced discussions. In addition to following PPI recommendations, involving public contributors with experience of forced migration requires considering relationship-focused factors; inclusive communication, relationships and trust, and process-focused factors: where and how decisions are taken.

Keywords: patient and public involvement, forced migrants, health research, mixed methods, observations

Introduction

With more than 100 million persons forcibly displaced globally, due to causes such as conflicts and the climate crisis, strengthening health care and health research for forced migrants is a global health priority (UNHCR 2022). Even though migrants are highly diverse at the group level, the migration experience is unique and has specific social and health-related impacts (Hynie 2018). Sweden, where this study was conducted, has been one of the European countries receiving most forced migrants per inhabitant during the last decade (UNHCR 2019), but recent political changes have led to more restrictive immigration policies. Forced migrants in Sweden have significantly worse health outcomes than the general population (Public Health Agency of Sweden 2023) and have been shown to experience racism in healthcare encounters (Hamed *et al.* 2022; Bradby *et al.* 2023).

Participatory approaches have been highlighted as a way to include relevant experiences in research and knowledge production, described by Doná (2007) as a research approach which is 'collaborative and aims to achieve social change from below'. In the health sciences, participatory research activities are often termed patient and public involvement (PPI) and can be defined as research done 'with' or 'by' the public, rather than 'to', 'about', or 'for' them (INVOLVE 2012). This practice bears many similarities to participatory approaches in other fields in its strive towards ideals of empowerment, reducing inequities and increasing representation of those affected by the research in the arenas where decisions are taken (Weber 2019; King *et al.* 2022). Thus, it is an important approach to health research both for those involved and for the research. We use the term 'public contributors' for the non-academic collaborative partners participating as experts by experience, who might elsewhere be called community collaborators or patient researchers.

The evidence base for PPI in health research is growing, but there is yet much to learn, especially regarding involvement of seldom-heard groups. One such example is the forced migrant population, who often lack access to venues of decision-making and power (Vaughn *et al.* 2018; Roura *et al.* 2021). Involvement of forced migrants has been increasingly recognized as important, which is likely related to the political debate on migration (Roura *et al.* 2021). As a group, forced migrants are more likely to experience inequities, and thus more likely to experience barriers to meaningful PPI. This article is based on the assumption that PPI with forced migrants, done in a meaningful and ethical way, where the experiential knowledge has real potential to impact the research, can be a force for positive change for the forced migrant community and the research field (Weber 2019). Doná (2007), however, argues that the involvement of refugees is multifaceted and difficult to trace in the literature as it might occur in an undocumented way. Based on a case study, Pincock and Bakunzi (2021) map the

challenges for refugees involved in research, in relation to research ethics. They conclude that when uncritically applied, participatory approaches risk masking 'top-down initiatives and problematic outcomes', which is why truly participatory approaches must take into consideration existing power relations. A recent review (Filler *et al.* 2021) of refugee involvement provides a number of examples in contemporary research but concludes that involvement is often limited to certain activities and stages in the research process. The authors state that if PPI is to be maintained throughout the research process, the barriers that prevent refugee and other forced migrant communities from becoming involved need to be considered (Filler *et al.* 2021). This aligns with the conclusions in research on PPI with forced migrants (Vaughn *et al.* 2018; Roura *et al.* 2021; Smith *et al.* 2022) as well as with other groups experiencing inequities (King *et al.* 2022). As involvement of forced migrants is gaining momentum, there is now a need to understand the underlying factors to make the involvement process meaningful and mutually beneficial.

Voices within the research community also call for a development of PPI evaluation methodology. Specifically, there is a need for valid tools to evaluate PPI activities and impact (Staley 2015; Boivin *et al.* 2018a; Roura *et al.* 2021; King *et al.* 2022). Behavioural observation, the systematic recording of behaviour by an external observer, has potential to bring insight to the context, dynamics, and interpersonal relations that contribute to successful PPI (Eldh *et al.* 2020). Yet, this appears to be an underexplored approach in PPI impact evaluation research (Staley 2015; Boivin et al 2018b). A semi-structured observational approach would allow for elements of PPI efforts to be coded against a set protocol, to understand processes and interactions (Fry *et al.* 2017), and for the context-specific details to be recorded—thus providing a detailed account of context, interactions, processes, and group dynamics (Walshe *et al.* 2012; Fry *et al.* 2017).

Aim

The aim of this study was to identify patterns of enabling and hindering factors to PPI meetings with forced migrants involved as public contributors.

Methods

This is a convergent parallel mixed methods study which integrates the findings from two separate analyses: one qualitative and one quantitative. Data were collected using two tools: a questionnaire, *The Active Involvement of Users in Research Questionnaire*, and a semi-structured observation protocol, *The Active Involvement of Users in Research Observation Schedule*. Both were developed for assessment of PPI research meetings. After development and initial piloting (Warner *et al.* 2021), the protocol was revised, reducing the 12 items to 11 items, and changing the term 'advisor' to 'public contributor'. At the same time, the questionnaire was developed, with items that correspond to the protocol, to gain the meeting participants' direct perspective. The questionnaire and observation

protocol have the same structure and are organized into three domains, each containing three to four, either positive or negative, observable behaviours (Table 1). In the protocol, there is an assigned space for notes to provide examples on each behaviour and to create a rich and detailed description and space for field notes on the back of the protocol. Additionally, the observers scored each behaviour according to both quality and quantity (see Table 1). The data in this study consisted of the questionnaire responses and the data from the observation protocol: observation notes, scores, and field notes.

Study Participants

The participants in this study consisted of researchers and public contributors in four research projects in Sweden (Table 2). The inclusion criteria were health and welfare research projects focusing on the forced migrant population, with public contributors with migrant backgrounds involved; within the projects, terms like 'youth partners' or 'refugee advisors' were used. In the included projects, the public contributors were refugees, or migrant mothers in socio-economically disadvantaged areas and originated from the MENA region or Somalia. Most of the public contributor had lived in Sweden long enough to learn Swedish, while contributors in one project had arrived about 1 year earlier and communicated through an Arabic-speaking interpreter. While most of the public contributors were new to research collaborations, one public contributor had worked with a researcher before and two had met the researchers previously as study participants.

The projects were initiated and run either by researchers or by civil society organizations. Recruitment was done through the authors' networks, resulting in that three of the four included projects were connected to the authors' research group. All public contributors were part of the steering committee in the respective project. Although the project purposes were quite similar, meeting topics differed as well as at in which stage of the research process the meeting occurred. The number of participants in each meeting ranged between 3 and 18. Some meetings were steering committee meetings with international research collaborators and professional stakeholders, while other meetings were smaller workshops with just researchers and public contributors.

Data Collection

Data were collected over 2 years, in on-site, online, or hybrid meetings. Eleven research meetings were observed (Table 2). Although PPI can be done in many ways, meeting to discuss the research is a common collaborative method (Boote *et al.* 2010). Two researchers (EI and AT) conducted all but one observation, which AT conducted with another researcher. The observers were present in the room (on-site or online) but did not partake in the meeting. After the meeting, all meeting participants were asked to anonymously respond to the questionnaire, either on paper or online, using the online survey web application Research

Table 1

Items in the Observation Protocol and Corresponding Item in the Questionnaire

Item from observation protocol Scored by observer as 'low', 'moderate', 'high'[a]	Questionnaire item: public contributor Rated on Likert scale: 1 (not at all) to 5 (a lot)	Questionnaire item: researcher Rated on Likert scale: 1 (not at all) to 5 (a lot)
Domain: interpersonal relations		
Positive interactions (+)	The interactions between me and the researchers were positive	The interactions between the public contributors and the researchers were positive
Reference to public expertise (+)	The researchers made me feel my opinions were important	The researchers used phrases and body language that implied public contributors' opinions were important
Linguistic barriers to public contributor participation (−)	It was difficult to be involved because there was too much jargon or there were problems translating across languages	It was difficult for the public contributors to be involved because there was too much jargon or there were problems translating across languages
Public contributors showing a lack of engagement (−)	I found the meeting engaging	The public contributors seemed to find the meeting engaging
Domain: nature of contributions by public contributors		
Invitations to speak (+)	The researchers asked for my opinion	The researchers asked for the public contributors' opinions
Taking the initiative to speak (+)	I gave my opinion even when I was not directly asked	The public contributors gave their opinion even when they were not directly asked
Offering insights appearing irrelevant to discussions (−)	My comments were relevant to the discussion	The public contributors' comments were relevant to the discussion
Domain: how public contributors guided research development		
Challenging research ideas (+)	I challenged the research ideas in a meaningful way	The public contributors challenged the research ideas in a meaningful way

(*Continued*)

Table 1 **(continued)**

Item from observation protocol Scored by observer as 'low', 'moderate', 'high'[a]	Questionnaire item: public contributor Rated on Likert scale: 1 (not at all) to 5 (a lot)	Questionnaire item: researcher Rated on Likert scale: 1 (not at all) to 5 (a lot)
Active consideration of public contributors' ideas by the researchers (+)	My ideas influenced the planning of the research project	The public contributors' ideas influenced the planning of the research project
Ideas being ignored/treated with disregard (−)	My ideas were ignored or treated with disregard by the research team	The public contributors' ideas were ignored or treated with disregard by the research team
Decisions made without the input of public contributors (−)	Decisions were being made without input from me or the other public contributors	Decisions were being made without input from the public contributors

(+): positive item, (−): negative item.
[a]Observers were instructed to consider both quality and quantity of a behaviour.

Table 2

Research Projects in Which Research Meetings Were Observed and Questionnaire Data Collected

Research project	Public contributors	Researchers and others[a]	Meetings
1. Child mental health trial evaluating group support for refugee children experiencing symptom of post-traumatic stress	4 public contributors: refugee parents. 2 refugee youth (first meeting only)	1–10 researchers 3 professional advisors	August 2019, on-site January 2021, online June 2021, online
2. Trial evaluating two preventive psychosocial interventions aiming to promote adolescents' well-being in a school setting	2 refugee adults, 2 refugee youth.	3 researchers 4 professional advisor	November 2019, on-site October 2020, hybrid September 2021, online
3. Co-creating an online version of an intervention for youth with posttraumatic stress	3 refugee youth	2 researchers 1 professional advisor	September 2020, on-site October 2020, on-site December 2020, online June 2021, on-site
4. Project on implementing and evaluating a mentoring system for migrant mothers	2 migrant mothers	2 researchers 9 professional advisors	March 2021, online

[a]Researchers and professional advisors involved in one or more of the project meetings. How many of each were present varied across meetings.

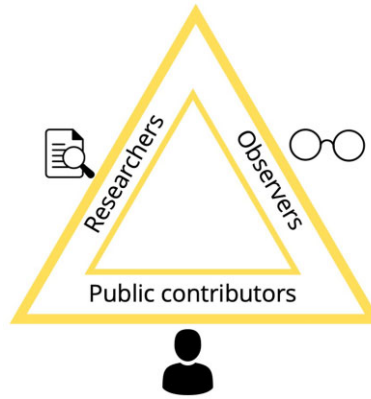

Figure 1.
The three sources used for source triangulation in the study.

Electronic Data Capture. The questionnaire was distributed in all but one meeting, where the organizer declined participation in this part of the study.

This study utilized source triangulation (Figure 1), achieved through the three groups who contributed to the study: the observers, the researchers, and the public contributors. These contributed with different perspectives, all included in the analysis (Hammersley 2008).

Data Analysis

Analysis was performed by all co-authors, led by the first author (EI). The observation data were analysed with qualitative content analysis (Graneheim and Lundman 2004). This method was used to identify patterns of enabling and hindering factors in the observation data and to explore if and how these present differently between the observed meetings. The analysis method has been previously used with observation data in a health care setting (Eldh *et al.* 2020), and similar methods are suggested by Fry *et al.* (2017) for observation data. The observation data in this study included observation notes and field notes, as well as the scoring of the items. The scores, although not qualitative, were included in the data set as scores and notes were considered two complementary parts of the observers' perspectives—they were collected by the same observer at the same meeting and thus could not be separated. First, the data were prepared for analysis by adding the two observers' data together to create one data set from each observation and then read repetitively by the first author. Although condensation of data is suggested by Graneheim and Lundman (2004), this was not deemed appropriate as the data were relatively condensed and further condensation would rather have risked removing relevant details from the data. Initial codes were developed after reading. These were assigned to the data, which was read again, leading to the identification of new codes. Although no structured longitudinal analysis was performed, data were read chronologically and patterns over time

was noted in the projects observed multiple times. Thereafter, observations were compared with each other to explore patterns between projects. Finally, themes were named and written up (Graneheim and Lundman 2004).

The questionnaire responses and how observers scored the items were summarized descriptively, using Excel and SPSS. The analysis of the questionnaire data was initiated by a Kolmogorov–Smirnov's test, to test for normal distribution of the data, which showed that this was not the case for any of the items. The Mann–Whitney *U*-test was used to compare medians between the two groups 'researchers' and 'public contributors', for each of the items separately. Both observers' scores were included in the descriptive summary. Cohen's weighted kappa, calculated including all 11 items, showed an overall substantial inter-rater agreement (0.610) between the observers' scores.

After the initial analysis, the results from the different methods were integrated. Data were integrated according to the joint display method (Creswell and Clark 2017), where convergences and divergences in the data were sought, to produce a more complete understanding. For example, questionnaire results were compared through exploring the corresponding items in the observation data, as well as across items searching for related factors. In addition, a public contributor with experience of involvement in research and from using the observation protocol provided feedback on the preliminary results.

Member Checking

When the authors had gained a preliminary understanding of the results, member checking, using an adapted version of Synthesized Member Checking (Birt *et al.* 2016), was conducted. Six study participants—two researchers and four public contributors (two refugee parents and two refugee youth)—were sent a summary of the preliminary results and then met with the first author (EI) for a discussion. Based on their input, new dimensions of the results were identified and explored in the data. Among other things, this led to an increased focus on factors surrounding relationship-building, communication, and researcher jargon.

Researcher Reflexivity

The authors are all public health researchers but adhere to different research traditions. The first author has a background in nursing and public health, has primarily worked with qualitative approaches as well as clinically with refugees and undocumented migrants in health care, non-governmental organisations, and academia. She has no personal experiences of migration. The three other authors all have experience of migration—albeit not forced migration. They have backgrounds in medicine (AS), communication (AT), and psychology (GW). All work in a child health research group and have worked in research projects on migration and health. In addition, all have worked with PPI in research settings. During the research process, the authors aimed to be attentive to how their experiences and

assumptions influenced the research, which was maintained through reflexive discussions in the team.

Ethical Considerations

This study received ethical approval by the Swedish Ethical Review Authority (Ref. 2020/03911). In all observed meetings, documented consent was attained from the meeting participants: researchers as well as public contributors and professional stakeholders. The observers introduced themselves to the meeting participants as external researchers aiming to understand the PPI collaboration process. The information given before asking for consent included the overall purpose of the observation—without details, to not risk affecting behaviour. The voluntary nature of study participation was highlighted. If one person did not wish to participate, the researchers would not go ahead with the observation. In addition, the researchers informed that whether the contributors choose to participate or not would not affect their future involvement or any related services. When possible—in all but one meeting—the participants were informed about the request to observe ahead of the meeting, giving them the opportunity to decline participation before the meeting started.

Results

In this section, the questionnaire results are presented first (Table 3), followed by the findings from the observations (Figure 2 and Table 4). After this, a section with integrated results follows, where the questionnaire and observation results are compared and synthesized.

The scores from the observation showed that overall, the positive behaviours (Figure 2) were scored higher than the negative behaviours, which were scored very low. This is elaborated on together with the three themes (Table 4) below.

Language Interpretation Central to Achieving Nuanced Discussion

The working languages in observed meetings were Swedish or English, which some of the contributors did not speak. Working with an interpreter led to a lack of direct communication that appeared difficult to overcome, as the discussion lacked the natural flow of regular conversations. Thereby, valuable nuances and elaborations were more difficult. This appeared to have been exacerbated when researchers were not used to working with interpreters, as this requires an adapted communication pattern, for example speaking in shorter sentences. One observed problem was discussions among researchers while the interpreter was translating.

> During a presentation, another researcher asks a clarifying question, and conversation starts between several researchers. Interpreter keeps almost beginning translation but has to stop when another researcher starts talking again. She can only start when conversation ends and jokes 'I'll need a minute'.

Table 3

Questionnaire Results, Rated on a Likert Scale from 1 (Not at All) to 5 (A Lot)

Questionnaire item	Researchers, $N = 32$, median (SD)	Contributors, $N = 32$, median (SD)	Mann–Whitney U test stat.	Sign. 95% CI
Interpersonal relations				
Positive interactions	5 (0.440)	5 (0.246)	416.000	$p = 0.040$*
Reference to public contributor's expertise	5 (0.716)	5 (0.369)	358.000	$p = 0.010$*
Linguistic barriers to public contr. participation	2 (0.897)	1 (0.877)	276.500	$p \leq 0.001$*
Public contributor engagement	4 (1.076)	5 (1.420)	346.500	$p = 0.014$*
Nature of contributions by public contributors				
Invitations to speak	5 (0.492)	5 (1.245)	468.000	$p = 0.839$
Taking the initiative to speak	4 (0.859)	5 (0.609)	210.000	$p \leq 0.001$*
Contributor input relevant for discussions	5 (0.483)	4 (1.402)	383.000	$p = 0.050$
How public contributors guided research development				
Challenging research ideas	4 (0.946)	4 (1.671)	473.000	$p = 0.912$
Active cons. of public contr. ideas by researchers	4 (0.964)	4 (1.105)	453.500	$p = 0.692$
Ideas being ignored/ treated with disregard	1 (0.601)	1 (0.842)	482.500	$p = 0.734$
Decisions made without the input of public contr.	1 (0.599)	1 (0.924)	425.500	$p = 0.143$

*Statistically significant according to 95% confidence interval level. p-Values below 0.050 are considered significant.

Related to this, details were sometimes lost in translation and responses therefore appeared irrelevant to the research topic. There was an apparent risk that slight misinterpretations in the communication amounted to larger misunderstandings, especially when detailed and sensitive topics were discussed.

Additionally, when comparing online and in-person meetings within the same projects, it became evident that communication changed online, for example when delays in the discussion hindered public contributors to ask for clarifications. Normal conversation patterns were disrupted, making contributors uncertain and worried about interrupting. These problems appeared exacerbated when utilizing language interpretation.

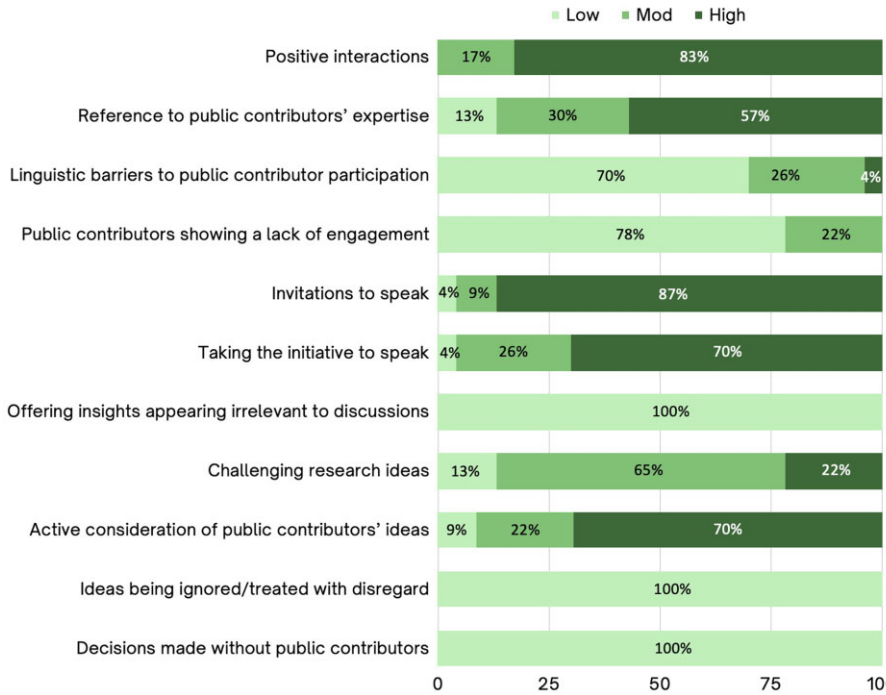

Figure 2.
How the observers rated the occurrence of behaviours during each of the 11 meetings; Low, Moderate or High.

Table 4

Themes: Enabling and Hindering Factors Identified in the Observation Notes
Language interpretation central to achieving nuanced discussion
Building relationships and adapting to team development over time
Researcher responsivity and transparency enables relevant contributions

> Public contributor A: 'I am afraid I will interrupt someone else', seems hesitant to speak up.
> Public contributor E: 'Is it my turn to talk?' Laughs. Difficult for everyone taking turns, seems to increase with interpretation.

During the meetings, it was common for researchers to use jargon or scientific terminology, for example acronyms or terms for scientific methods, which a lay person would not typically be familiar with. On several occasions, interpreters and sometimes contributors asked for clarifications and explanations of terms, showing that the language was not accessible enough.

> Researcher uses some technical terms to describe intervention group like 'light touch' and 'non clinical population' – mentioned by interpreter that she had trouble translating.

Yet, in several meetings, the moderators seemed aware of this as presentations were conducted in an accessible language. Additionally, in the observed research meetings, there were clear examples of when preparatory work with interpreters alleviated barriers and enabled the interpreters to be a positive force in the meetings. One example was an established long-term collaboration with an interpreter, in which there were significantly less communication barriers.

Interpreters might add an additional alleviating mechanism. As they are not necessarily research trained but need to understand terms to translate them, interpreters will need to identify the difficult terms—i.e. scientific jargon—figure out what they mean and translate them into something more comprehensible. Thereby, skilled interpreters, who take active responsibility for communicating comprehensible information, can function as co-facilitators of research meetings.

> Interpreter asks researcher to clarify what it means to 'join the study' or 'participate in the trial' – also what the safety protocol is, and to define PHQ-9.

Building Relationships and Adapting to Team Development over Time

Establishing a warm and personal—as opposed to a professional and strictly research-focused—relationship appeared as an important enabler for involvement over time. In early project phases when meeting participants did not yet know each other, researchers and contributors showed appreciation of meeting each other. Positive interactions were scored very high (Figure 2) and researchers often initiated these positive interactions. The public contributors were initially more self-contained but highly responsive to the social invitations from the researchers.

The observed positive interactions were expressed verbally and through body language—smiling, eye contact and showing active listening through leaning forward and nodding. Humour and laughter appeared as crucial parts of relationship-building, where both researcher and contributors generously shared jokes at their own expense, as well as finding a shared social focal point, often observed in the context of sharing a meal together. Actively socializing before and after meetings, and during breaks, was common, for example researchers offering to show contributors around in the university building. Researchers often approached the contributors as individuals, rather than as a group. This included examples of researchers and contributors striving to identify common personal aspects outside the research context, for example the challenges of parenting teenagers, or how to manage the long Swedish winter.

> Public contributor U proudly shows a photo of his daughter and others exclaim over how nice the photo is.

In projects observed multiple times, changes in the interactions were observed. Positive interaction and relationship-building was identified throughout, but even more important was the continuity of the relationship over time. While initially focusing on intense relationship-building, the interactions changed over time to a more relaxed atmosphere and reaffirming the already established relationships. Examples include researchers and contributors referring back to previous meetings and shared memories, which led to recognition and laughter.

> 'Did you not bring any sambusas?' (laughter) Referring to previous meetings.

In online meetings, the interaction was less dynamic, which might have prolonged the relationship-building process. One project opted for hybrid meetings, with meeting participants on-site and online. The contributors attending on-site interacted more in the meeting, were consulted more often and gave more input, than the contributors online.

It also appeared that the ratio between public contributors, researchers, and other stakeholders seemed related to how comfortable the public contributors were in sharing input, as well as to how open and dynamic the discussions were. In large meetings, or smaller meetings with just one public contributor, the contributors were quieter. One observed example was a meeting where one of two invited contributors did not show up, which clearly affected the meeting dynamics in a negative way. In another meeting, a refugee youth contributor who was the only young person in the meeting was quite silent, which an adult public contributor reflected on:

> 'It's normal to feel marginalised when she is the only one' said public contributor A.

This was seen in many meetings in both early and later stages of the projects. However, in one project, where the group had worked together for years and one of the contributors had a previously established working relationship with the researchers, the contributors were outspoken and seemed comfortable even when there were significantly less of them than researchers and professional stakeholders.

How to best plan and moderate a meeting to facilitate meaningful involvement appeared related to how long the team had worked together. In the beginning of a collaboration, a strict meeting agenda and an active meeting moderator appeared important to set clear expectations, increase comfort and for the contributors to grasp the boundaries they were operating within. When, on the other hand, a meeting was not properly moderated, problems occurred, such as others stakeholders interrupting public contributors, or public contributors not being consulted on matters which they could have had relevant input on.

> The speakers were always the same, the moderator did not encourage others who didn't speak to speak.

Yet, an essential task for the moderator was still to keep the discussion to the research topic. External factors such as meeting planning also appeared

important, for example which video conferencing tool to use, how the meeting room was furnished and when and how to schedule breaks. However, these factors appeared less relevant when the team had worked together for some time.

Researcher Responsivity and Transparency Enables Relevant Contributions

When the researchers were open and explicit about the research process, it appeared to be easier for the contributors to partake in a meaningful way, thereby understanding the research process functioned as an enabling factor. In several meetings when this was lacking, uncertainty was observed. First, it was not clear to the observers how researchers expressed intentions to act on contributors' ideas. The researchers used expressions such as 'That is a good idea' or 'I agree with you' but did not specify what the intended next step would be—leaving the contributors without clarifications on the overarching process and on how decisions were actually made. Second, contributors on some occasions showed hesitancy about what was expected of them, which could be a sign of not having agreed on expectations early on in the project.

> When invited to speak in breakout group, female public contributor asks clarification question: do you want to know about our experience or what we think for everybody?

Part of the solution appeared to be transparency around the research process. A good example of this was a researcher giving a visual overview of the project process. Another example was a researcher being explicit with what she did in the meeting and why, saying for example 'This is important, I will write this down so I don't forget, we will discuss this next time when we will focus on that topic'. The same researcher also stated clearly when decisions were made in the room and when she had to consult with others first. The need for transparency appeared even higher when research teams faced a new task. When one team was initiating co-writing a research article, a researcher commenced with brief contributor training.

> One researcher starts with explaining what a scientific article is, and what is requested to be an author.

Researcher responsiveness to contributor input was essential for dynamic discussions. The researchers expressed interest in contributor input through asking detailed or open questions and encouragements to share experiences and opinions. This was identified both in the high scores regarding invitations to speak (Figure 2), as well as in the observation notes. Additionally, researchers providing concrete feedback on contributor input also functioned as an enabling factor. Common examples were when researchers referred back to what contributors had said, provided examples of how previous input has impacted research, wrote down suggestions, discussed details on how to realize the suggestions, and stated an intention to discuss a suggestion with other members of the team.

> Researcher:' Ok, so you prefer a website. Tell me more. It's great that we can decide together, that's why we're here.' Continues the discussion and writes down decision.

One observed enabler related to responsiveness was that researchers were open to changing meeting plans to increase the involvement of the contributors. In one example, the moderator picked up on a contributor's idea and altered the plan for the meeting.

> Public contributor O has an idea about writing something for youth, for example a part of the article just aimed at youth. The researcher picks this up as the first suggestion, and the groups start working with it. This becomes the focus of the meeting.

Yet, another aspect of responsiveness concerned adapting the meeting format for the contributors. In one longer meeting where child contributors started showing signs of tiredness and difficulty to focus, a suggestion to play frisbee outdoors during the break was picked up by the researchers which led to laughs and renewed energy. Another project scheduled a meeting with refugee youth on a Monday morning, which caused difficulties to focus, and the next meeting was scheduled at a more appropriate time. It could also include simply adjusting the agenda:

> Researcher: 'Y (public contributor) will leave a bit earlier, let's take the important part of the discussion before then so Y can join'.

Integrated Results

The questionnaire data and observation data largely showed similar results. The items that were scored high in the observation protocol were also generally rated high ($\geq$4 out of 5) in the questionnaires, with the exceptions of a few items—this is elaborated on below. In addition, the observation notes' findings provide an in-depth understanding of the questionnaire results. In this section, we present the four areas in which combining the different methods provided additional insight to the findings.

Positive Interactions and Relationship-Building

Both researcher and migrant public contributors rated positive interactions and references to public contributors' expertise as occurring to a high degree, but the public contributors rated this significantly higher than the researchers did (Table 3). In the observation findings, this is related to the researchers making substantial efforts in making the contributors feel welcomed and relaxed, thus initiating many positive interactions, encouragements, and invitations to a less professional relationship. The researchers also acted as hosts in a traditional meaning, for example inviting the contributors to share a meal. This was especially clear in the earlier meetings. A slightly contradictory observation was that in some

meetings, the amount of researcher appreciation and invitations to speak were high—yet, the interaction and discussion was lacking, indicating that these factors are dependent on other enabling factors such as relationship-building.

Language, Interpretation, and Communication

The researchers considered the linguistic barriers to be more prominent than the migrant public contributors did (Table 3). In addition, linguistic barriers seemed to be rated slightly higher in the questionnaires by the researchers (Table 3) but scored low by the observers (Figure 2). However, interpreters and sometimes also contributors asked for clarifications and explanations of terms. Additionally, that interpreters identified difficult words and jargon and asked for them to be explained before translating might be one explanation to why the migrant contributors rated the linguistic barriers as lower. Another explanation can be that the contributors appeared to be more used to communicating through an interpreter. In projects observed over time, the work with interpreters was improved and the use of jargon appeared somewhat reduced. This points to that researchers were initially not used to working with interpreters.

Public Contributor Engagement and Input

The public contributors considered their engagement to be higher than the researchers did, according to the questionnaire ratings (Table 3). The contributors also rated taking initiative to speak to a higher degree than the researchers did (Table 3). Additionally, this appeared to be rated lower in the questionnaires (Table 3) than in the scores (Figure 2). In the observations, it was noted that lack of engagement seemed to be related to specific situations, such as long presentations or meetings on Monday mornings, which were changed for following meetings. In the observation notes, the public contributors did not appear more easily distracted than any researcher in the meeting. In addition, researchers and public contributors rated 'Contributor input relevant for discussions' high.

Decision-Making

For the questionnaire item 'Decisions made without the input of public contributors', there were no significant differences in ratings; it was scored as low in the observation protocol and rated low in the questionnaires (Figure 2 and Table 3). However, the observation notes highlighted that quite few decisions were in fact made in the meeting room, as decisions rather appeared to be made after or in-between meetings. Additionally, in the meetings, it was often unclear to the observers—and therefore likely to the public contributors—whether decisions were supposed to be taken in the meeting or not.

Discussion

Methodological Discussion

This study utilized a mixed methods approach, including source triangulation (Figure 1), using the three sources for complementary information. This increases the validity of the study. Method triangulation was not achieved to the same extent, since both the scoring data and the observation notes originated from the same observers (Hammersley 2008). Yet, the questionnaire data were retrieved via a different method. Other strengths include the fact that two observers collected data and that four different projects were included, covering a variety in project aims, meeting organization and involvement processes. In addition, we were able to identify some important processes across time in three out of four projects. We did not consider the data fit for a structured longitudinal analysis, but we see this as an interesting future research approach.

It is sometimes argued that qualitative and quantitative methods should not be mixed, as they have different underlying ontological and epistemological assumption. Mixed methods researchers, on the other hand, claim to draw from the strengths and reduce the weaknesses in both methods when addressing complex phenomena, thereby taking a more pragmatist approach to knowledge and methodology. In this study, the point of integration (Johnson and Onwuegbuzie 2004) occurred after the two separate analyses, making it possible to maintain a more post-positivist approach during the quantitative analysis, while simultaneously keeping an interpretivist approach in the qualitative analysis. Although this is a parallel study where data were collected simultaneously, the findings rely heavier on the qualitative data.

The participants in this study, researchers and public contributors, were diverse groups regarding age, gender, class, and professional background, which increases the transferability of the results. Although three of four projects were connected to the authors' research group, the individual researchers were not the same in the different projects—with the exception of two of the projects, in which two of the researchers were the same.

After data collection, we shared back a summary to the observed research team, in facilitate them making use of the findings and potentially improve their collaboration. Additionally, the insights have led to implemented changes in our own participatory processes, for example, improved facilitation of relationship-building early on in a project, new routines regarding language interpretation and increased efforts to create a common language within projects.

Behavioural observations of meetings have inherent limitations, as involvement can be carried out in several channels simultaneously in the same project. Therefore, factors outside the meetings remain invisible with the methods used in this study. This limitation was obvious regarding decision-making, which was sometimes part of the meeting but sometimes done in other channels in-between meetings. One factor, invisible in this study but previously identified in the literature as important for PPI collaborations, is how often the team members are in contact (Røssvoll *et al.* 2023).

Using an observation protocol invited both strengths and limitations. It is an established way of focusing the observer on specific behaviours of interest; yet, it might have limited the observers who then missed other factors. The protocol had been pilot tested (Warner *et al.* 2021) with promising results, but not yet validated. Therefore, refinements might be needed.

There is a need for evaluations of PPI activities not just being conducted by researchers but also by public contributors. In this study, public contributors were not involved in the data collection, but in the development of the observation protocol and questionnaire, as well as in the analysis phase. An important contribution from the public contributors giving input on the preliminary findings was highlighting transparency and processes around decision-making. Additionally, the member checking procedure contributed with valuable perspectives from both researchers and contributors, which were weaved into the analysis. Among other things, this led to an increased focus on the factors surrounding communication and researcher jargon. Two potential future research directions could be testing the observation protocol with public contributors as observers in order to refine it, and triangulating data within specific projects, preferably with the addition of qualitative data from both researchers and public contributors.

Result Discussion

The aim of this study was to identify patterns of enabling and hindering factors to PPI meetings with forced migrants involved as public contributors. The results reveal similar patterns as studies investigating PPI with other populations, for example on clarifying roles and structures for PPI, avoiding scientific jargon, the need for flexibility in the research work and the need for feedback (Wilson *et al.* 2015; Ocloo *et al.* 2021). However, a few of the findings appear specific for this population.

One area of interest regards language and communication; for this population, the added layer of language interpretation increased the complexity. That jargon and the use of interpreters were identified as barriers in the observation notes but not in the questionnaires can be explained by the observers' backgrounds; they were researchers, meaning that they might not have the right perspective to judge whether the language was too academic. However, the fact that interpreters and public contributors asked for clarifications and explanations of terms strongly strengthens this suspicion. Engaging interpreters as co-facilitators appeared as an important enabler for overcoming communication problems. This study cannot state whether the positive outcomes were related to having established a personal relation with the interpreter, or to researchers having identified an already 'good' interpreter and kept them engaged, but the importance of having an established relationship with the interpreter was emphasized by public contributors during member checking. The enabling aspect of facilitating interaction between people from different backgrounds has been previously identified in the PPI literature (Keenan *et al.* 2019). In the observations, a factor hindering accessible discussions was discussions among researchers while the interpreter was translating. This

might not have been out of disrespect for the contributors, rather researchers are used to a faster discussion pace where ideas are verbalized on the spot. Although researchers adapted their communication patterns in the subsequent meetings, this still indicates a researcher need for PPI training focused on the involved population.

A second area of interest is relationship-building. Positive interactions were rated and scored very high, as well as observed to occur to a high extent, which is likely to be important for the PPI process, for overcoming various barriers as well as for building relationships. Relationship-building is strongly related to trust, which has been identified as an important factor for PPI (Wilson *et al.* 2015; Smith *et al.* 2022). This can be assumed to have increased relevance to forced migrants, considering their increased need for trust-building processes for informed consent in research (Gehlert and Mozersky 2018). In addition, lack of in trust in government officials is both well-known (Hynes 2003) and previously identified in the context of refugee involvement in Sweden (Lampa *et al.* 2022). As seen in the observation notes, relationship-building clearly affects several other factors, making it an important overall enabler for PPI—something that has also been seen in the literature (Wilson *et al.* 2015; Keenan *et al.* 2019; Hickey *et al.* 2021; Smith *et al.* 2022). In a previous study with a longitudinal qualitative approach, it was identified that trust-building when involving refugees in research relied on prolonged involvement, over several years, as well as developing personal, rather than professional, relationships (Lampa *et al.* 2022). Participatory research with forced migrants is shaped by power; it needs to adapt to power relations between researchers and public contributors, while aiming to counteract power inequalities on a group level (Doná 2007; Pincock and Bakunzi 2021). While this was not specifically analysed in this study, comparisons with previous knowledge (Wilson *et al.* 2015; Smith *et al.* 2022) shows that building trusting relationships is essential for more equal collaborations. As relationship-building and thus trust are processes playing out over time, researchers would benefit from adapting both expectations and activities to different stages of a collaboration.

An important point of consideration was whether public contributors were in fact involved in decision-making, to make these meetings participatory and not mere tokenistic. Decisions being made without the input of public contributors were both scored as low in the observation protocol and rated low in the questionnaires. However, not many decisions were in fact made in the meeting rooms. This might to some extent be explained by the COVID-19 pandemic, as this led to smaller online meetings where not everyone involved in decision-making were present. Another factor is the issue of transparency; the observers were often uncertain which decisions were meant to be taken in the meeting. If this was not clear to the observers—who are familiar with the research setting—it was probably not clear to the contributors. Similar processes regarding the need for transparency and misconceptions about decision-making have been seen in previous studies (Wilson *et al.* 2015; Keenan *et al.* 2019; Hickey *et al.* 2021; Lampa *et al.* 2022; Røssvoll *et al.* 2023). In light of this, we suggest that PPI teams should explicitly and jointly decide where and how decisions should be made, at the onset

of each project and meeting. This could align expectations in the group as well as function as an invitation to shared decision-making when meeting participants are uncertain.

This is closely connected to the enabling factor of responsiveness, which shows the importance for researcher to dare to attempt meaningful involvement, including co-creating the actual PPI activities, even though this might mean giving up control. Allowing and encouraging public contributors to step up as decision-makers is part of the process in building a more equal partnership. This aligns with previous studies, which identified flexibility as a key to involvement (Wilson *et al.* 2015; Ocloo *et al.* 2021). Keenan *et al.* (2019) discuss the need to balance transparency and flexibility. This is also seen in our study, where explaining the research process appears important but increased flexibility around how to work together, as well as finding paths to co-creating the collaboration, might further benefit teams. In doing this, researchers need to make themselves aware of the public contributors' own agenda and preferences around level of involvement, which might not align with the researchers' agenda (Lampa *et al.* 2022). In addition to this, adopting a framework for formative evaluation of the PPI activities, including both researcher and public contributors in the aims and processes for the evaluation, would allow for the PPI activities to be evaluated and adjusted regularly throughout a project.

The results in this study are specific to PPI meetings and might not reflect involvement processes in other collaborative forms. Yet, the identified factors are mainly relationship-focused rather than process-focused, which means that they are likely to be important factors across PPI activities. The study results align with previous literature; however, the results are specific to involvement with public contributors with experiences of forced migration, a community that has been excluded from involvement and thereby from yet another arena for decision-making and empowerment. Therefore, researchers aiming to involve representatives from forced migrant population in research benefit from following existing recommendations for PPI, for example those from NIHR, Chief Scientist Office, Health and Care Research Wales & Public Health Agency (2017) as well as the insights coming out of the PPI literature (Oliver *et al.* 2015; Wilson *et al.* 2015; Smith *et al.* 2022). The results from this study highlight specific considerations to be made when involving representatives from the forced migrant population, and can serve as a basis for reflection around PPI activities.

Conclusion

In this article, enabling and hindering factors for PPI meetings with forced migrants involved as public contributors have been reported. Previous studies have shown researchers struggling to involve public contributors with a migrant background. While following general PPI recommendations is still crucial for research teams working with PPI, teams involving forced migrant contributors would benefit from carefully considering factors specific for involvement of this population. The key factors are mainly relationship-focused: to consider include

how inclusive communication can be achieved, how to best build relationships and trust within the team, but also process-focused: where and how decisions will be taken. Specific suggestions coming out of these findings include investing time in building personal rather than strictly professional relationship with the contributors, establishing long-term collaborations with language interpreters and jointly decide on a plan for decision-making at the onset of a project. Research teams—researchers and public contributors included—need to carefully plan how to continuously monitor and evaluate PPI activities, and who will be involved in this process.

Acknowledgements

The authors would like to thank the public contributors and researchers who took part in member checking, for contributing with their insightful perspectives, as well as the research group CHAP at Uppsala university for valuable advice and support.

Authors' Contributions

EI, AS, and GW contributed to the conceptualization of the study. EI and AT collected and sorted the data. EI, AS, and GW performed the analysis and contributed to writing the article. All authors read, reviewed, and approved the final manuscript.

Funding

This study was funded by the Kavli Trust (Grant ID: A-321629). The Kavli Trust has not been involved in the design of this study, nor in the data collection, analysis, interpretation, or writing of this article.

Data Availability

The datasets generated and analysed during this study are not publicly available due to the risk that individual privacy can be compromised. Parts of the data can be made available from the authors upon request.

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