Patient and public involvement with forced migrants

Exploring communication, ethics and public contributor experiences

ELIN INGE
Abstract

The topic of this thesis is patient and public involvement (PPI) in health research. Here, PPI is defined as the active involvement in key research decisions of people whose lives are at the centre of the research. Currently, there is an increased interest in and development of participatory methods. In Sweden, PPI has acquired growing attention in health research. However, the use of PPI in Sweden, as well as the structures supporting researchers and public contributors, are not yet established. The PPI field has been criticised for lacking diversity and fair representation of the researched groups. One group rarely involved as public contributors in PPI is forced migrants. Doing research with rather than about forced migrants, has the potential to alleviate asymmetries of power and knowledge, and reduce health inequities – if conducted in a meaningful way.

The overall aim was to explore patient and public involvement with forced migrants in health research. Four studies were conducted. The study designs built on and complemented each other in terms of data, analysis methods and level of detail. Study I used a longitudinal qualitative approach to track the experiences of refugee parents during their involvement in a three-year child mental health trial. In Study II, enablers and barriers to PPI meetings with forced migrant public contributors were identified using a mixed methods approach. Study III evaluated the communication strategies in a research project with refugee youth coresearchers, with a focus on epistemic injustice. In Study IV, ethical issues in PPI with forced migrants were empirically investigated and analysed using relational ethics.

The findings show similar patterns from different perspectives. PPI with forced migrants required considerations around inclusive communication, relationship-building and trust, as well as considerations around where and how decisions were made. For these processes to develop, time and a focus on relationships is required. Using relational ethics and a reflexive approach can help researchers navigate ethical PPI with forced migrants. In the Swedish setting, PPI needs to be acknowledged on an institutional level, to create conditions to work with PPI in meaningful and ethical ways.

Keywords: Patient and public involvement, forced migration, ethics, communication, epistemic injustice, empirical ethics, relational ethics, mixed methods, longitudinal research

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This is for people’s everyday knowledge
and their ability to understand and address
the issues confronting them and their communities.

This is an invitation to knit our worlds together\textsuperscript{1}.

\textsuperscript{1}Inspired by the books by Abma et al. (2019) and Brydon-Miller et al. (2003).
This thesis is based on the following papers, which are referred to in the text by their Roman numerals.


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<tr>
<td>CBPR</td>
<td>Community-Based Participatory Research</td>
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<td>ICPHR</td>
<td>International Collaboration for Participatory Health Research</td>
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<td>IOM</td>
<td>International Organization for Migration</td>
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<td>PAR</td>
<td>Participatory Action Research</td>
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<td>PHR</td>
<td>Participatory Health Research</td>
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<td>PiiAF</td>
<td>Public Involvement Impact Assessment Framework</td>
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<td>PPI</td>
<td>Patient and Public Involvement</td>
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<td>QCA</td>
<td>Qualitative Content Analysis</td>
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<tr>
<td>UK</td>
<td>United Kingdom</td>
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<tr>
<td>UNHCR</td>
<td>The United Nations High Commissioner for Refugees</td>
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<td>USA</td>
<td>United States of America</td>
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<td>WHO</td>
<td>World Health Organization</td>
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I forskningen ser vi positiva effekter av PPI på forskningsprocesser samt fördelar för de personer som involveras, vilket följs av en växande debatt kring hur PPI ska göras och vilka förutsättningar som krävs för att göra det väl. Representation och mångfald diskuteras allt mer och där har PPI fått kritik. Flyktingar involveras sällan, trots att deras erfarenheter är högst relevanta för forskning om migration och hälsa.

Syftet med avhandlingen är att undersöka hur flyktingar involveras i hälsoforskning i Sverige. I avhandlingen görs detta:

- genom involverade flyktingars egna perspektiv
- genom att undersöka faktorer som påverkar involvering
- via kommunikationsstrategier i samskapade projekt med flyktingar
- ur ett etiskt perspektiv.

Jag använder mig av kvalitativa metoder och mixed methods, med analyser av data från fokusgrupper, beteendeobservationer, enkäter, kommunikationsmaterial och fältanteckningar. I två av de fyra delstudierna har flyktingar som har erfarenhet som medforskare inom hälsoforskning deltagit i arbetet och är medförfattare till artiklar.

Den första studien gjordes under tre år och visar, ur involverade flyktingars eget perspektiv, att upplevelser och roller påverkades positivt över tid. Under projektets gång förändrades deltagarnas motivation till involvering från individualistisk till mer altruistisk. I början låg fokus på praktiska saker som
behövde lösas gemensamt, vilket möjliggjorde en djupare involvering och en social gemenskap. Tid var central; deltagarnas tillit till forskarna växte successivt under projektets gång. De upplevde att de bidrog på ett meningsfullt sätt, men såg forskarna som ansvariga för det slutgiltiga beslutsfattandet i projektet.


Den tredje delstudien undersökte kommunikationsstrategier i ett projekt med flyktingungdomar. De mest framgångsrika strategierna var interaktiva, vilket ledde till tillit och förbättrarad involvering. Att hitta ett gemensamt och tillgängligt språk var centralt, tillsammans med flexibilitet och att kommunicera i olika kanaler beroende på behov.


Sammanfattningsvis berör avhandlingen olika perspektiv på flyktingars involvering i forskning. För att etablera och upprätthålla meningsfull involvering behövs tid, kommunikation och flexibilitet. Tillit är centralt och skapas genom relationsbyggande mellan forskare och flyktingar. Etisk och meningsfull involvering med flyktingar är möjlig och har potential att göra forskning om flyktingars hälsa mer relevant. Ett etiskt förhållningssätt bör inkludera inte bara traditionella forskningsetiska perspektiv utan även relationell etik och en reflexiv praktik. För att underlätta behövs institutionellt stöd och praktiskt användbara verktyg för svenska forskare som vill arbeta med PPI.
Introduction

I started working in academia at the same time as my research group initiated its first collaboration with public contributors. This occurred in a refugee child mental health trial and both the refugee parents, invited as public contributors, and most of the researchers were new to this kind of collaboration. Our first meeting was characterised by curiosity and anticipation as well as insecurities and mismatched expectations on both sides. Over time, this grew into a warm and meaningful collaboration, mutually beneficial for researchers and public contributors. The positive experience led the research group to expand its participatory work. This, especially the process and the work we all put into growing the collaboration, also sparked an interest in how patient and public involvement (PPI) with different groups can be done in a good way – which in turn led to this PhD project.

In this thesis, I will present the findings from a PhD project exploring the involvement, in health research, of public contributors with experiences of forced migration. This is done from different perspectives: longitudinal, communicative, and ethical perspectives. In the background, I will introduce key concepts, including forced migration and PPI, as well as the ethical and theoretical perspectives underpinning the work. I will then continue by describing my methods and findings. Finally, the results and future developments in the field are discussed. But first, I want to share a quote from one of the refugee parents involved in our first collaboration with public contributors. The quote summarises the process that took us from the slightly awkward first meeting to a long and meaningful collaboration.

Moderator: What changed, from the beginning until now, what has changed?

Refugee parent public contributor: What happened is that we have gotten to know each other.
Patient and public involvement in research

The topic of this thesis is patient and public involvement (PPI) in health research. Drawing upon Abma et al. (2019), PPI is in this text defined as the active involvement in key research decisions of people whose lives are at the centre of the research. A broad definition was deliberately chosen to be able to study many forms of PPI in the health research field. An important clarification to the definition is that PPI is “research being carried out with or by members of the public rather than to, about or for them”. This commonly used definition originates from the organisation INVOLVE (2012), a leading PPI organisation in the United Kingdom (UK). It distinguishes the with from the about, meaning that it is not enough that researchers invite public representatives as advisors – research decisions also need to be taken with or by the representatives. This is necessary to avoid tokenistic approaches to PPI, where public representatives are present as advisors in a project but lack the possibility to participate in actual decision-making. I view PPI as an approach to research; a relational process in which new knowledge is produced collectively and used to guide action or change (Abma et al., 2019).

Apart from PPI, a plethora of terms are used for participatory practices (Banks & Brydon-Miller, 2019; Ocloo et al., 2021; Vaughn & Jacquez, 2020; Vat et al., 2019). Typically, the participatory practices are quite similar but the terms were developed in different research fields or geographical areas. However, even in limited settings such as health research in the Nordic countries, many different terms are used (Dengsø et al., 2023). An example of a term is citizen science (medborgarforskning), which is theoretically described in similar terms as PPI and appears to have the same underlying assumptions (Kasperowski et al., 2022). However, this is primarily used in academic fields such as environmental research, and the actual activities differ. In the example of citizen science, contributing to data collection is the most common activity for public contributors. In other academic fields, participatory action research (PAR) and community-based participatory research (CBPR) are terms used for very similar approaches to PPI, sharing many of the PPI values and practices (Lenette, 2022). In the health research field, PPI is commonly used, together with user involvement, patient engagement and other similar terms (Ocloo et al., 2021; Vat et al., 2019). Co-production is a term which often
refers to an increased level of power sharing than other collaborations (Williams et al., 2020), while *user-led research* refers to research controlled by user representatives rather than researchers. However, PPI researchers would normally include these activities in the conceptualisation of PPI. In the academic literature, including in the co-produced journals specialising in research on PPI, terms are often used interchangeably, which is representative of this dynamic and vivid research field. Typically, the participatory researcher draws upon several participatory practices and adapts their approach to their own context (Wright et al., 2013).

In this project, I have chosen to use the term *public contributor* for the individuals being involved as representatives for those whose lives are at the centre of research, i.e., a patient group, the public or a community with specific experiences. This expression is common in the PPI terminology and encompasses different ways of contributing, compared to for example *public advisor* which is limited to an advisory function. Other examples of terms used are patient partner, user representative or terms related to specific experiences, such as parent representative (Wilson et al., 2015). Although other stakeholder groups, such as professional stakeholders, have important contributions to add to research, they are not included in the term public contributor.

Included in the broad definition of PPI is the understanding that there are different levels of involvement, which range from advising about projects to leading projects. This has been visualised in several ways, famously with Sherry Arnstein’s ladder of participation from 1969 (Arnstein, 1969). This and similar visualisations are useful to show levels of involvement, in order to distinguish between for example advisory functions and equal partnerships in planning for and reporting of PPI. However, in the contemporary debate, this is sometimes connected to whether involvement is done in a “good” way, with the assumption that it is better to place the involvement activity higher up on the ladder (Hart, 2008). This can become somewhat problematic. While most participatory researchers strive to maximise involvement, this needs to be balanced against other factors, such as skills, resources and public contributors’ agendas. I argue that a more nuanced discussion on when different involvement activities are relevant and desirable would benefit the field – both from the researcher perspective and from the public contributor perspective.
Additionally, involvement activities can be performed in many different ways, throughout the research cycle (figure 1). Roles and responsibilities can also shift across projects, for example when public contributors increasingly take ownership of the project over time (Salsberg et al., 2017a; Salsberg et al., 2017b). In theory, public contributors can contribute to all stages of the research process, and all stages in the process can benefit from it in different ways. However, the practicalities around involvement vary across the stages. For example, many researchers find it difficult to work with involvement in the early stages, as they have not yet acquired funding for the project (Liabo et al., 2020). A general recommendation is to involve as early as possible to include contributors in the important early brainstorming, idea generation and decision-making around the project. Another solution for this is priority-setting initiatives, such as the James Lind Alliance (2024), where patients, carers and clinicians together publish lists of priority research areas, which are publicly available for funders and researchers to use.
The development of PPI in research

This PhD project was carried out in what Williams et al. (2020) refer to as a participatory zeitgeist, i.e., a time of increased interest in and development of participatory methods. However, the idea of participatory research is not new. Many scholars trace the roots of participatory approaches back to movements for social justice in Latin America, Africa and Asia (Abma et al., 2017; Abma et al., 2019; Lenette, 2022), where participatory approaches were initiated as a way to challenge colonial structures and the way knowledge was produced. During the 1970s, the ideas spread into academia across the globe, by thinkers such as Paulo Freire, who remains a major influence in the field, and Orlando Fals-Borda, who is often credited for conceptualising the underlying principles of PAR with his work with rural co-researchers (Abma et al., 2019; Lenette, 2022). During the same time period, the disability movement contributed with perspectives on the right to involvement under the slogan “Nothing about us without us” (Charlton, 1998).

From a more contemporary perspective, the public health care system and research institutions in the UK have been leading globally in the development of PPI in health research since the 1990s, leading to an increase in mainstream acceptance (Lang et al., 2022; Wilson et al., 2015). PPI publications from low- and middle-income countries are scarce, however, this can be attributed to publication bias (Cook et al., 2019). In 2001, the organisation INVOLVE, initiated by the Department of Health in the UK, published a review of lay involvement in health research (Baxter et al., 2001). Since then, fast development of the field has led to PPI having an established role in health research institutions and regulations, which is supported by funding bodies requiring applicants to state how they will involve public contributors (Wilson et al., 2015). In a reflection on co-production, Williams et al. (2020) warn of uncritical use of the term, where they identified use of “the language of radical power sharing to promote entrepreneurial government”. In light of the increased interest in participatory approaches and the plethora of terms used, the research community would benefit from a critical approach to participatory practices, as well as less focus on terminology and more focus on describing and evaluating participatory activities.

In the wake of this development, standards for how to conduct and report PPI were developed. Commonly used examples of this are the UK standards for PPI (NIHR et al., 2019), which were developed for a UK setting but are largely transferrable to other settings, and the GRIPP checklists for reporting of PPI (Staniszewska et al., 2011; Staniszewska et al., 2017). In addition to these, a number of frameworks have been developed, on different aspects of PPI. Greenhalgh et al. (2019) divided these frameworks into power-focused, priority-setting, study-focused, report-focused, and partnership-focused
frameworks, and concluded that most had not been widely used outside the setting where they were developed (Greenhalgh et al., 2019).

In the Swedish context, a similar development is ongoing. In the early 2000s, involvement started to be discussed in the Swedish health research community. PPI is increasingly utilised in the Nordic countries (Dengsø et al., 2023; Sand et al., 2020; Stage, 2022). In a systemic review of PPI in Europe, Scandinavia, along with the Netherlands, was identified as a region producing innovative PPI work (Biddle et al., 2021). A few Swedish examples from recent years include a community-based participatory health research project in a poor neighbourhood (Fröding et al., 2015), a project investigating sexuality and fertility among survivors of childhood cancer, where patient research partners were involved over five years, (Hovén et al., 2020) and a partnership research programme with “patient innovators” (Wannheden et al., 2023). Together, these examples of projects, where the involvement process has also been evaluated and reported, display the diversity of PPI in Sweden as well as the diversity in terms used.

Patient organisations in Sweden have been, and still are, strong driving forces in this development. One example is the Swedish Rheumatism Association (Reumatikerförbundet) which has been recruiting and training public contributors for involvement in rheumatology research for more than a decade (Persson et al., 2022). Recently, the Swedish Research Council for Health, Working Life and Welfare, a major Swedish funding body, included questions on PPI in project applications and published PPI information material directed to researchers (Kylberg at el., 2015). The need for PPI in research is highlighted in the Swedish government’s research proposition of 2020 (Forskning, frihet och framtid, 2020). An awareness is forming, but the use of PPI, as well as the structures supporting researchers and public contributors, is far from established in comparison to countries such as the UK (Dengsø et al., 2023; Sand et al., 2020).

Arguments for PPI in research

The case for PPI has been made through a number of arguments. Here, I summarise two main reasonings; the ethical argument and the methodological argument.

The ethical argument is rights-based and founded on democratic principles, and is laid out as the public having a right to be involved in decisions relating to and affecting their lives (Gradinger et al., 2015; Martin, 2008; Oliver et al., 2015; Williams et al., 2020; Wilson et al., 2015). The underlying motivations are ethical and political and associated values are empowerment,
accountability and action (Gradinger et al., 2015). This argument is often heard from rights-based organisations, such as the disability movement (Charlton, 1998) but many participatory researchers ascribe to this as well. The democratic aspects of this argument are elaborated on by Frith, who connects this to a global movement of democratic renegotiations. She argues that PPI is an initiative to widen democratic practices, as it aims to involve the public in decision-making but takes place outside conventional forms of democracy (Frith, 2023). In this way, the ethical argument frames PPI as an end in itself (Gradinger et al., 2015).

Conversely, the methodological argument frames PPI as a means to an end (Gradinger et al., 2015). It relates to the impact of PPI; that PPI improves the quality and relevance of research. This argument is based on the growing body of literature on the impact of PPI (which is covered in the section below) and includes both the benefits of PPI on research and the implementation of health services, as well as the positive impact on public contributors (Gradinger et al., 2015; Martin, 2008; Oliver et al., 2015; Williams et al., 2020; Wilson et al., 2015).

The impact of PPI

Measuring the impact of PPI has been discussed in the literature, from calls for increased and improved evaluations (for example Staniszewska et al., 2008 and King et al., 2022), to debating the purpose and methods for evaluations, and the challenges in demonstrating impact (Barber et al., 2012; Boivin et al., 2018a; Brett et al., 2014; Malterud & Elvbakken, 2020; Russell et al., 2020; Snape et al., 2014). In a position paper, the organisation International Collaboration for Participatory Health Research (ICPHR) define impact in participatory health research (PHR) as “the many forms of change that occur with, within and for those who are engaging in the research”, as well as change in the context where PHR is taking place. And, they add, impact occurs during the research project as well as after it has finished (Cook et al., 2020).

In the health research field, the literature has often referred to the impact PPI has on the research (Springett, 2017; Thompson et al., 2014). A growing number of literature reviews on PPI impact report identified benefits in priority setting, including increased relevance and research focus, and in the design of clinic trials, such as improvements of research material (Boote et al., 2010; Brett et al., 2012; Rossvoll et al., 2022; Vanderhout et al., 2023; Vat et al., 2019), as well as improved study recruitment (Brett et al., 2012; Domecq et al., 2014; Crocker et al., 2018; Ennis & Wykes, 2013; Hughes & Duffy, 2018; Vat et al., 2019). The reviews concluded that the quality and relevance of
research increased through PPI (Brett et al., 2014; Hughes & Duffy, 2018; Vanderhout et al., 2023; Vat et al., 2019).

Although the positive impacts outnumber them, reports of negative impact also exist. Vat et al. (2018), for example, report confusion around roles and methodological concerns. Challenging discussions around methodology and scientific robustness are reported (Brett et al., 2012; Malterud & Elvbakken, 2020). Increased time and resources spent are also commonly reported challenges (Blackburn et al., 2018; Domecq et al., 2014; Flynn et al., 2019; Vat et al., 2019).

Other studies – fewer but increasing – describe impact on public contributors. A systematic review (Brett et al., 2014) describes positive impact on the public contributors, including increased confidence and empowerment as well as gaining useful skills. These findings are similar to a review of family involvement in child health research (Vanderhout et al., 2023) as well as to a qualitative study, where the authors emphasise the importance of seeing PPI as a social practice with value beyond health research (Reynolds & Beresford, 2020). In a narrative synthesis review, young people involved in research experienced fulfilling relationships and a sense of achievement (Thomas et al., 2023). Public contributors in a mental health study (Werner-Seidler & Shaw, 2019), a cancer study (Thompson et al., 2014) and another review of several projects (Gibson et al., 2017) all valued the opportunity to discuss and make sense of their conditions in a non-clinical setting. However, there were also negative experiences relating to a lack of flexibility among researchers (Gibson et al., 2017), as well as a lack of preparations for tasks and being overburdened (Brett et al., 2014).

Increasingly recognised is the multitude of factors affecting the impact of PPI. Several studies have explored the contextual factors around involvement efforts, such as organisational factors within academia, and greater scrutiny of the effect of such factors on PPI impact has been called for (Ocloo et al., 2021; Oliver et al., 2015; Staley et al., 2014; Williams et al., 2020). PPI processes, including why and how PPI is conducted, have been linked to both context and impact (Boivin et al., 2014; Liabo et al., 2020; Oliver et al., 2015). This has also been identified in studies on the perspectives of public contributors (Gibson et al., 2017). A few examples of PPI enablers identified in a review of reviews (Ocloo et al., 2021), were striving for equal partnerships and distribution of power, clearly communicating roles, and ensuring financial reimbursement for public contributors. Greenhalgh et al. (2019) question, in a review of PPI frameworks, the usefulness of frameworks outside the context where they were created and instead suggest a workshop method for building an own framework for the planned participatory work in its specific context. Kristina Staley (2015) describes the importance of considering context along
with PPI processes, but adds that PPI is largely dependent on the complexities in interactions between people:

The answer to the question ‘Is involvement worth doing?’ will always be ‘It depends’. Further exploration of the contextual and mechanistic factors which influence outcomes could give a stronger steer to researchers but may never accurately predict any specific impact.

Can PPI impact be evaluated?

Many scholars have written about the challenges of evaluating PPI using traditional evaluation methods (for example Russell et al., 2020). One reason that PPI can be difficult to evaluate is the variation in perspectives on why PPI is done and what the end goal is (Frith, 2023; Springett, 2017). Another reason is the complexities around evaluating a subjective and socially constructed process (Barber et al., 2012). Springett (2017) also points out the limitations in evaluating PPI, as research projects are limited in time and many of the positive effects of PPI are long-term and difficult to measure, such as empowerment-related ripple effect. Questions raised include: What do we mean by impact? Impact on what and on who? And what happens to participatory practices when we start focusing on measurable impact?

Criticism has been raised around PPI impact evidence being anecdotal (Barber et al., 2011; King et al., 2022; Røssvoll et al., 2022; Staley, 2015), especially when mainly positive impact is reported (Tierney et al., 2016). Evaluations of PPI have been criticised for mainly consisting of case studies reported by researchers, lacking both valid assessment methodology and the public contributor perspective, leading to requests for evaluative methods for PPI in order to strengthen the evidence base (Brett et al., 2014; King et al., 2022). This critique, together with the maturation of the PPI field, led to the development of tools to assess the impact of PPI (Boivin et al., 2019). A review of PPI evaluation tools by Boivin et al. (2018b) concluded that most identified tools were developed in the last decade, 56% had been developed together with public contributors and few (7%) were tested for reliability. Most tools were developed to evaluate the engagement process (74%) and context (82%). Only 56% of the tools evaluated PPI outcomes, and of these the most common kind was self-reported impact. The authors identified a need for assessing observable impact and increased usability of PPI evaluation tools. Therefore, although the number of tools has increased rapidly, the authors identified a need for a methodological development (Boivin et al., 2018b).

In partnerships, including researcher-public contributor collaborations in PPI, group dynamics affect the collaborative process and thus the ability to achieve the intended objectives. While much of the PPI literature, e.g., Devonport et
al. (2018), acknowledges interpersonal relationships as important for participatory processes, the concept of group dynamics can add another level of understanding and analysis. Schulz et al. (2003) have reviewed and summarised the central characteristics of effective groups from previous research. These characteristics include for example shared leadership, open communication, participatory decision-making, well-organised meeting management, and trust. Schulz et al. (2003) used this to develop a questionnaire with the purpose of evaluating group processes in participatory partnerships. This led us to consider other ways of evaluating group dynamics in PPI settings. A rarely utilised way of evaluating PPI, that would lend itself well to assessing group dynamics, is behavioural observation. An example of when this has been utilised is in a trial process evaluation of involvement in priority-setting for health care (Boivin et al., 2014), where observations revealed enablers for PPI process and impact.

Representation and diversity: Who should be involved?

The PPI field has been criticised for lacking diversity and fair representation of the researched groups. This is often attributed to the habit of involving the “usual suspects” (Goedhart et al., 2021; Martin, 2008; Shimmin et al., 2017), referring to the typical public contributor: a white, well-educated person – which is similar to what academia often looks like (Nimmons et al., 2021; Oliver et al., 2015; Stage, 2022; Starling & Tanswell, 2018). Stage (2022), discussing PPI in the Danish context, argues that different prerequisites provide people with different opportunities to partake and that this risks reproducing health inequities.

The concept of diversity is sometimes used in the PPI field, together with the argument that it is important to increase diversity among those involved as public contributors (Amann & Sleigh, 2021; Oliver et al., 2015; Stage, 2022). I agree that diversity, from a societal perspective, is desirable. But from the PPI perspective, I prefer to discuss representation. As research projects often focus on a certain population and the public contributor in practice becomes the voice for that population, representation becomes a core ingredient. Therefore, it is more relevant that the public contributors are representative of the researched group, than that diversity per se is increased among the contributors. In practice, the concepts are closely connected, as improved representation often means increased diversity.

Although many researchers want to improve representation, they struggle to make this a reality. The practical experiences our team has gained from working with involvement, as well as from communicating with health researchers when mapping PPI in Swedish health research projects, led us to conclude that
although researchers might initially aim to include a representative contributor group, this is not always the end result. In the PPI literature, barriers to increased representation and diversity in involvement have been identified as multi-faceted and dependent on academic structures as well as intra- and interpersonal factors (Goedhart et al., 2021; Ocloo et al., 2021). Among the barriers identified were practical barriers to accessing diverse groups for recruitment, concerns of increased expenses for recruitment and involvement activities, and lack of flexibility, for example, researchers being used to talking about and doing research in specific ways. In addition, the academic structures such as funding, work processes and possibilities for recognition could be more facilitating (Goedhart et al., 2021; Ocloo et al., 2021).

In recent years, the PPI literature has seen more studies trying to involve seldom-heard groups. These studies often focus on one specific group. One example is involvement with children and adolescents, where researchers such as Harry Shier have made substantial contributions to the field, for example with his analytic tool for child and youth involvement (Shier, 2001; Shier, 2019). In a review of studies using co-design with indigenous and other children and young people from priority social groups, King et al. (2022) identified studies but found that quality reporting on co-design definitions, theory, and praxis was lacking.

Recently, guidance and frameworks to support the involvement of seldomly involved groups have been published. Goedhart et al. (2021) narratively reviewed the literature on involving “citizens living in vulnerable circumstances”, for example ethnic minorities. They presented a number of strategies for involving these groups in a meaningful way, but noted that these strategies are context-dependent; researchers must also reflect on their position and the research culture, and whether this needs to change. In addition to this, frameworks for involvement with specific populations have been developed, such as Lamb et al.’s (2023) framework for ethical co-production of research with victim-survivors of domestic, family, and sexual violence.

**Forced migrants**

In this thesis, I have chosen to use the term *forced migrants* to describe the population whom I focus on. The International Organization for Migration (IOM) defines a forced migrant as “a person subject to a migratory movement in which an element of coercion exists, including threats to life and livelihood, whether arising from natural or man-made causes” (International Organization for Migration, 2011). Forced migrant is thereby an umbrella term which encompasses different groups of migrants, such as refugees, asylum seekers, undocumented migrants, internally displaced people and victims of trafficking.
(Turton, 2003). These groups have different drivers for migration, and can have very different circumstances before, during and after migrating and in resettlement; they are a very diverse group with different experiences. There are however also similarities, as the migration experience and post-migration context are important determinants of migrants’ health. Forced migrants in early resettlement go through several simultaneous transitions; being new to a country and orienting themselves around a new language and culture, as well as non-migration-related transitions, such as becoming parents (Hynie, 2018).

Reasons for using this term include its broadness as well as that it recognises the vulnerability of the people it covers. The public contributors included as study participants in this thesis are all forced migrants but have different immigration statuses and have, in more than one case, altered between different immigration statuses over the course of the project. This means that in the included articles, other terms are used for study participants in that specific study. For example, in study I the study participants are referred to as refugee parents, and in study III the co-researchers are called refugee youth co-researchers.

Critiques might argue against the word forced. Turton (2003) writes that “most migrants make their decision to migrate in response to a complex set of external constraints and predisposing events”, meaning that there is almost always an element of voluntariness. This is an important statement in relation to migrants’ agency; if we portray migration, even in situations where not migrating leaves very limited opportunities for a dignified life or even a life at all, as completely reactive or forced, we remove agency. Migration, even during elements of coercion, almost always entails individual choices around if, when, where and how to migrate; migrants are far from the passive victims of circumstances the public discourse tends to portray (Turton, 2003). When talking with and about forced migrants, we must be careful in our balance between highlighting the political circumstances, drivers for migration, and the agency of individuals in migration.

**Forced migration in the Swedish context**

Historically, Sweden was a country of emigration. During the 19th century, the Swedish population suffered poverty and famine, and 1.2 million Swedes emigrated to the United States of America (USA). Since then, Sweden has been a country of immigration, both labour immigration and refugee immigration. During the 1970s, 1980s and 1990s Sweden received forced migrants, both refugees and migrants with more economic motivations, from countries such as Iran, Chile, Poland, Lebanon, Turkey and former Yugoslavia. The refugee immigration increased again after the war in Syria started. In 2015 and 2016,
more refugees than ever before were seeking refuge in Sweden; during 2016, 163,000 persons were seeking asylum in Sweden (Statistikmyndigheten SCB, 2024a). Of these, more than 35,000 individuals were unaccompanied children arriving without parents or guardians, mainly from Afghanistan (Hodes et al., 2018; Migrationsverket, 2024a). Initially, the public responded with support for arriving refugees and especially the unaccompanied children, including volunteer organisations welcoming refugees at the border, providing practical support and housing when the resources of the Migration Agency were not enough. After Russia invaded Ukraine in 2022, Sweden also received around 40,000 Ukrainian refugees (Migrationsverket, 2024b).

During late 2015 and 2016, major changes in the migration legislation, receiving of asylum seekers and support available for newly arrived refugees were implemented (Asylkommisionen, 2022). This included restrictions on permanent resident permits, giving most refugees arriving from war-torn countries temporary residence permits lasting 13 months, and limiting the possibilities to stay in Sweden for humanitarian reasons and family reunion (Asylkommisionen, 2022; Hodes et al., 2018). It also included increased identification controls at the borders, medical age assessments of asylum seekers and increased deportations. The Swedish government was open with the purpose: to decrease the number of individuals seeking asylum in Sweden. In 2017, the Migration Agency saw a decrease in asylum seekers and an increase in rejections of asylum applications (Asylkommisionen, 2022).

The years in which this PhD project was conducted, 2020 to 2024, have been characterised by a new narrative, with political suggestions and decisions to limit the support for forced migrants in Sweden. This has included limitations in financial support for asylum seekers and in the possibilities for family reunions. We have also seen political suggestions such as limiting the right to language interpreters in health care and reporting obligations for public servants when meeting undocumented migrants. Other important events include the Convention on the Rights of the Child becoming Swedish law in 2020, as well as a law granting temporary protection for Ukrainian refugees being activated in 2022. Sweden has received international attention for the treatment of refugees. The United Nations High Commissioner for Refugees (UNHCR) (2020) criticised the prolonged processes around family reunion and how Sweden treats unaccompanied minors and stateless children. Human rights organisation Amnesty International claims the political suggestions in Sweden during 2022 risk leading to human rights violations (Amnesty International, 2022).

We see migration as a cross-cutting factor, affecting all levels of the social determinants of health (figure 2). Hynie (2018) calls the post-migration context a powerful determinant of mental health. Castañeda et al. (2015) argue
that migration is “both socially determined and a social determinant of health”. In their understanding, they draw upon concepts from the social sciences such as social inequalities, discrimination, oppression and structural vulnerability. They conclude that migration should be understood as a broad determinant of health, not reduced to a stressor but rather affecting the entire living situation and possibilities for a healthy life (Castañeda et al., 2015).

Figure 2. The main determinants of health (Dahlgren & Whitehead, 1991) with conceptual additions (text and arrow in colour) by the author of this thesis. Inspired by Al-Adhami, 2023. Reprinted with the permission of the Institute for Futures Studies, Stockholm, Sweden.

About a fifth of the Swedish population is born outside Sweden (Statistikmyndigheten SCB, 2024b). In recent years, the health disparities in the Swedish population have increased (Folkhälsomyndigheten, 2019). Residents born outside of Sweden are at higher risk of a number of health issues, including dental health problems and reproductive health problems. For example, mothers born south of the Sahara and asylum-seeking mothers have higher risks for perinatal death and negative obstetric outcomes. There are large variations in the utilisation of mental health services, but some mental health problems appear more common in the foreign-born population (Folkhälsomyndigheten, 2019). Forced migrants, such as asylum seekers and refugees, seem to be more affected by mental health issues such as depression and anxiety than other foreign-born residents (Hollander & Dalman, 2020). Wellbeing is also affected; in a qualitative study with asylum-seekers residing in accommodation centres, they describe leading a “frozen life” with persistent low wellbeing, but also
strategies such as peer support (van Eggermont Arwidson et al., 2022). Non-communicable diseases, such as high blood pressure and diabetes, appear to increase with time lived in Sweden (Folkhälsovård Myndigheten, 2019). In a scoping review of migrants’ access to health care in Europe, the authors state that monitoring migrants’ health can be difficult in Sweden, as Swedish anti-discrimination legislation does not allow for registration of “ethnic” information – data on specific groups might not be possible to get (Lebano et al., 2020).

In addition to the health differences, there are socioeconomic differences. Residents born outside of Sweden have higher unemployment rates and less disposable income than residents born in Sweden (Folkhälsovård Myndigheten, 2019), which has been connected to negative health outcomes. There is also evidence of discrimination against foreign-born residents in the labour market (Erlandsen, 2023) as well as discrimination and racism within the healthcare sector (Bradby et al., 2022). A 2019 Swedish scoping review identified a need for policies to support the social participation of refugees and asylum-seekers, as this increases resilience and protects against mental health issues. Social participation, such as working or attending school, is a known protective factor (Hollander & Dalman, 2020).

Involving forced migrants in PPI

Involving forced migrants as public contributors in health research, i.e., doing research with rather than about forced migrants, has the potential to alleviate asymmetries of power and knowledge production, and reduce inequities (Krause, 2017). In a framework for refugee and migrant health in the World Health Organization (WHO) European Region, MacFarlane et al. (2022) recommend the research field of migration and health to adopt participatory research as the norm, for both practical and ethical reasons. Refugees and migrants, they argue, need to be meaningfully involved in research about their health, including in what and who is researched and how this research is designed and conducted.

When this project on PPI with forced migrants was initiated, literature on PPI with forced migrants was difficult to find. According to Doná (2007), PPI with forced migrants can be difficult to trace in the literature as it can occur in undocumented ways. Vaughn et al, in a review article from 2016 – on immigrants, not forced migrants – identified 161 articles on CBPR with immigrants in the USA. The authors noted a sharp increase in publications after 2010. In a review article from 2021, Filler et al. identified 14 articles on refugee involvement, mainly reporting involvement in research inception, community engagement and recruitment, and throughout data collection. The authors conclude refugees should be, but are not, involved in all stages of the research
process. They highlight the need for dedicated efforts to include refugees in research and enable refugee communities to take on leadership roles (Filler et al., 2021). Goedhart et al. (2021) reviewed the literature on involving “citizens living in vulnerable circumstances”. They identified four articles on refugee involvement and 13 articles on involvement with “citizens with a migration status”, which appears to be a diverse group. Although conducted around the same time, there are few overlaps in the identified articles between these reviews. This indicates a diverse field which is difficult to overview, likely due to the many terms used.

In recent years there has been an increase in publications. Roura et al. (2021) draw upon literature and researcher experiences when showing the value of involving migrants in research, including both process and outcome related opportunities. Simultaneously, they point out challenges to meaningful involvement, such as local tensions and difficulties in representativity and identification of migrant communities. In addition, operational barriers are persistent for researchers working with PPI with migrants; this includes barriers around language, compensation, consent, ethics and stakeholder priorities. The authors conclude with the need for critical scholarship and reflective PPI practices (Roura et al., 2021).

Additionally, articles reporting on processes and insights from PPI projects have contributed substantially to the field. Pincock and Bakunzi (2021) argue, in an article discussing refugee involvement in the context of refugee camps, that although participatory methods have the potential to contribute to equality, uncritically applied they instead risk masking top-down initiatives. In an earlier article on involving “hard-to-reach” migrants in healthcare research, O’Reilly-de Brún et al. (2016) report on and suggest using specific facilitation techniques such as Participatory Learning & Action in community–university research partnerships. Smith et al. (2022) report on a PAR project with refugee youth in sports. They write that participatory research with refugees requires developing trust and negotiating reciprocal partnerships, as well as working with ethics beyond the standard procedures. James (2023) writes about the ethical tensions that arose, including considerations on maintaining anonymity, in a participatory photovoice project with asylum seekers. They highlight the need for time for participatory processes. Two examples from the Swedish research community are a photovoice study in Sweden, with migrants with disabilities, using a participatory and creative method to explore these intersecting identities (Hultman et al., 2023), and a CBPR study on health promotion, reporting on empowerment processes, mutual support and improvements in health on different levels (Avery et al., 2022). In summary, the literature hosts examples of PPI with forced migrants which, individually, highlight both the opportunities, barriers and ethical risks. Simultaneously, it points out
the potential pitfalls and gaps in our shared knowledge around how meaningful and ethical involvement with forced migrants can be done.

A concept that is important in order to understand PPI with forced migrants is power dynamics. Fricker (2007) defines power as a socially situated capacity to affect what happens in social life and, importantly, control others’ actions. In her definition, power can be active or passive, and be held by an actor or be structural i.e., entangled in the social system. Roura (2021) situates power dynamics in the PPI field, in her conceptual framework of the social ecology of power in participatory research. Here, power is operating on and affecting multiple layers, from the micro level, with individual values and attitudes, to the macro level, with social and political structures. This requires different approaches, for example, reflexivity on the micro level, in order to conduct meaningful PPI and not reinforce existing inequities. Egid et al. (2021) furthers the work with a framework and highlights that a participatory approach is itself not enough to address power inequities; tools must be used systematically to address power imbalances in PPI. Ross et al. (2023) found evidence of this in a qualitative study on peer researchers’ experiences of PPI, where they saw that intersecting systems of oppression continue in the PPI collaborations along with peer researchers’ strategies and acts of resistance. In an interesting example of power dynamics in PPI, Pincock and Bakunzi (2020) discuss the experience of conducting participatory research in refugee camps. They conclude that the academic researchers are responsible for not taking advantage of the inequality in power between international researchers and local refugee co-researchers who, as an example, stayed in the camp when international researchers left “the field” and were therefore left to navigate ongoing power dynamics as the project had finished.
In this thesis, I consider ethical issues in multiple layers, both concerning the research conducted as part of this thesis and concerning ethics in PPI with forced migrants. Involving forced migrants in PPI entails unique considerations around ethics, reaching far beyond the standard applications to the Swedish Ethical Review Authority. Ethical perspectives need to be continuously considered and evaluated over the course of a research project, as ethical matters shift and change as we move through a project. In this section, I will first introduce the ethical considerations in the included studies and then proceed to introduce the ethical theories that have been used for this thesis.

In this thesis, two main ethical concerns have been identified. The first is that forced migrant study participants can – at least in the research ethics tradition – be considered subjected to increased vulnerability. Gehlert and Mozersky (2018) argue that “those who are disadvantaged or marginalized due to social circumstances and, therefore, susceptible to coercion and exploitation in medical research” should be considered vulnerable. In this group, Gehlert and Mozersky (2018) include for example ethnic minorities, individuals living in poverty and with low levels of education. Wendy Rogers (2021) terms this predicament situational vulnerability. This concept can be useful to understand how involved individuals, who are disadvantaged or marginalised due to other circumstances, risk being susceptible to exploitation in their role as public contributors. Rogers (2021) states that “situational sources of vulnerabilities are context specific and include personal, social, political, economic or environmental features affecting individuals or social groups”, and that these might fluctuate over time and context. Rogers, as well as Gehlert and Mozersky, highlight that these factors are likely to make individuals more vulnerable to be excluded from research (Gehlert & Mozersky, 2018; Rogers, 2021). Liabo et al. (2017) extends this to PPI; the increased protection warranted for “vulnerable” groups and individuals, from the research ethics perspective, risk excluding the same from involvement. They argue that this needs to be balanced with other values than protection and that it might be of increased importance for groups already excluded from different platforms of participation (Liabo et al., 2017). Cornwall (2002) adds a perspective to this when focusing on spaces for participation, rather than people, and the dynamics inherent in those spaces. She argues that inviting public contributors to
involvement can never be enough, if not considering the underlying possibilities to participate, taking into consideration the political and historical background.

Voices from the field of refugee studies also argue for greater ethical scrutiny (Block et al., 2012). When including forced migrants in research, consent procedures might need to be adjusted for genuinely informed consent, ensuring that participants do not feel compelled to participate out of fear that it would affect their asylum process or health care (Block et al., 2012; Mackenzie et al., 2007; Mollard et al., 2020). Therefore, special attention was given to consent procedures throughout this project. In all observed meetings in studies II, III and IV, study information was given in a language adjusted to variations in knowledge of Swedish and about research, and documented consent was attained from all meeting participants in the same way: researchers as well as public contributors. The invitation to participate came from me, as an external researcher, and not from researchers within the project, in an attempt to reduce feelings of being expected to participate. I presented the information about the observation and the invitation to participate to whole groups, i.e. all attendants at a meeting at the same time. This is potentially problematic, as an individual invitation provides better opportunities to ask questions. I highlighted that participation in the observation was voluntary and would not in any way affect their continued involvement in the respective research project. Adjustments to participants’ individual needs were also considered. For example, in study I, where one participant was illiterate, consent was recorded orally after a prepared statement was read aloud in the participants’ preferred language. As study I used a longitudinal approach, this also raised the issue of continuous consent (Saldaña, 2003). We approached this by asking for consent before each focus group discussion, in an attempt for the consent procedure to be continuous rather than given at just one point.

The other main ethical concern was the dual roles of the study participants. Generally, public contributors are not study participants and should therefore not automatically undergo the same ethical considerations. Yet, they are not researchers, who have the insight into research realities. However, in this project, the public contributors, along with researchers, were the focus of study i.e., also study participants. The studies in this PhD project received ethical approvals by the Swedish Ethical Review Authority (ref: 2018-382; 2020-03911; 2020-03126; 2020-06693). Although PPI activities do not require ethical approval according to Swedish legalisation, including the public contributors as study participants do – hence, ethical approvals were sought and attained.

Whether or not ethical approval is needed for participatory research is debated. The difference between a study participant and a public contributor is not
always clear and the interpretation of the law differs between fields. One consequence of this arises when publishing about participatory research, where ethical approval is sometimes requested even though the project has utilised a strictly participatory process and has therefore not applied for ethical approval. However, whether or not formal ethical approval is needed for PPI, ethical considerations need to be considered throughout, and often beyond, the PPI process (Liabo et al., 2017).

Due to the risk of confusion between the public contributor role and the study participant role, measures were taken to clarify to the contributors exactly in which situations they were also study participants. In study I, the researchers emphasized the difference before each meeting and focus group discussion. Similarly, in the behavioural observation and survey data collections in studies II, III and IV, before each meeting observation, these two roles were separated by explaining that whether or not they participated in the observation was not connected to their continued involvement in research.

Many participatory researchers argue that traditional research ethics, established in the field of bioethics, is not sufficient to discuss the ethical concerns arising in participatory research (Liabo et al., 2017; Pandya-Wood et al., 2017). This stems from that relationships are different within PPI, as compared to traditional research, leading to a need for other ethical guidance. In the PPI field, the need for reconsidering ethical guidelines has been raised in recent years (Groot & Abma, 2022). The organization ICPHR has issued ethical guidelines for participatory health research (Banks et al., 2013), which Groot and Abma (2022) used to develop a framework to support ethics work in participatory research with different populations. There is an increased need for ethical considerations when involving groups subjected to increased vulnerabilities (Groot & Abma, 2022; King et al., 2022), and these considerations will differ between contexts.

The need to work with ethical approaches surfaced along the way in this PhD project. Although the idea for an ethical approach was considered early on, it eventually became evident that ethical considerations were at the core of both working with PPI with forced migrants and researching it as a phenomenon. As this work has a strong empirical connection from both working with PPI and having collected a lot of data, we decided to use the already collected data to untangle the ethical issues we ourselves struggled with, as participatory researchers, and identified this as a need in the literature. Below, I will present the ethical approaches and theory used in this thesis.
Empirical ethics

One important perspective for this thesis is empirical ethics. According to Albert Musschenga (2005), empirical ethics entails combining empirical research with normative ethical analysis and reflection. Thereby, empirical ethics is not just a descriptive approach to ethical issues in certain contexts or praxis, but also aims to say something about the right course of action (Musschenga, 2005).

Empirical ethics is context-specific, meaning that the context in which the contemplated actions are situated needs to be taken into consideration. Musschenga (2005) argues that “if ethics indeed intends not only to prescribe actions, but also to actually guide actions, a turn to empirical ethics is inevitable”. The aim of empirical ethics is therefore to improve the context-sensitivity of ethics, without making ethics uncritical (Musschenga, 2005).

The field of empirical ethics is still relatively young and ethicists debate which exact role empirical research should have in relation to normative ethics. Most would agree that ethics, in some way, need to be empirically informed. In my understanding, empirical ethics is not only about being empirically informed in the sense of having correct facts, but concerns identifying ethical issues as they arise in different contexts. These particular contexts all entail ethical values and norms (and to some extent, practical circumstances), which come into conflict with each other and give rise to ethical issues. When this is identified, it enables a theoretical reflection on the plausibility of such issues, including values and norms.

In this thesis, the empirically based ethical issues occur in specific contexts; the contemporary Swedish context and how forced migrants exist in it, but also the academic context. Academia has similar goals globally, but operates under different organisational structures and laws. Both of these contexts raise specific ethical considerations when working with PPI with forced migrants. For this reason, we chose an empirical ethical reflection, to identify and highlight ethical issues in PPI with forced migrants, and potentially offer empirically based solutions.

Relational ethics

A second ethical approach is relational ethics. Common ethical principles in health research, such as those by Beauchamp and Childress (2013) are relevant to the research per se. However, other perspectives are needed to guide the ethical conduct of PPI processes (Martineau et al., 2020). Clandinin et al. (2018) describe relational ethics as going beyond the principle-based
approaches and acknowledging the social context of people’s lives. They argue that ethical decision-making is an unavoidable part of relationships between people in all settings, and therefore consider ethics to be embedded in relationship and commitment (Clandinin et al., 2018). Personal relationships are likely to consist of ethical commitments, entitlements and duties; we are, in that sense, primarily responsible for each other. Relational ethics concerns who we, as researchers, are and become alongside participants – or in this thesis, alongside public contributors. Therefore, what is “right” emerges in the dynamics within the relationship and is dependent on the circumstances and context. Important elements of relational ethics are respect, engagement, embodied knowledge, and attention to the context or environment (Clandinin et al., 2018).

In the PPI setting, a relational ethical approach can be used to turn the gaze towards the people that we work with and their context. While ethical principles, for example Beauchamp and Childress (2013), are important for the conduct of research, PPI requires additional ethical considerations (Martineau et al., 2020). An example of this is the principle of respect for autonomy (Beauchamp and Childress, 2013), which has been scrutinised and critiqued within the fields of contemporary feminist ethics and relational ethics. Mackenzie and Stoljar (2000) advocate for a more relationship-based approach to autonomy, which they call relational autonomy. In their argument, autonomy can never be fully realised without considering the context in which decisions are made and the relationship surrounding the decision. For example: a researcher asks a potential study participant if they consent to partaking in a study. They provide all the relevant information, verbally and written, and the potential participant is given the opportunity to ask questions. The researcher informs that participation is the potential study participant’s own choice and that no negative consequences will follow if they decline participation. The researcher has performed all the technical requirements for the potential participants to give or decline informed consent to partake in the study. However, according to Mackenzie and Stoljar (2000) this does not mean that the decision is fully autonomous; the social context and the relationship between the researcher and the potential participants will influence whether they participate or not. In this way, relationality should be recognised and considered as a potentially supportive factor for autonomy. Strengthening relational autonomy, in this example, therefore involves the researcher forming an awareness of the relationship and, based on this, providing the support needed for the potential study participant to make a meaningful and autonomous decision. Similar reasonings have been developed around other ethical principles, for example justice, which is elaborated on in the next section.
Epistemic injustice

The theory of epistemic injustice has played an important role in this work, in understanding how knowledge is produced and shared, and, more specifically, who is and who is not involved in knowledge production and sharing, which is essential to explore the role of PPI. In addition, the theory served as a lens for the findings of study III. The phrase was coined by Miranda Fricker (2007), who describes it as “a wrong done to someone in their capacity as a knower”. She aims to shed light on the ethical aspects of two epistemic practices we all engage in daily and introduce two forms of epistemic injustice. The first is the sharing of knowledge to others by telling them something, to which Fricker connects the term testimonial injustice. A person suffers testimonial injustice if they are given less credibility based on the listener’s prejudices about them, which Fricker exemplifies with cases where the police do not believe someone because they are black. Fricker introduces the ideal of a “virtuous hearer” as someone who succeeds in correcting for the influence of own or others’ prejudices in their credibility judgements, but adds that these epistemic practices occur in social settings where prejudice can be difficult to detect and correct for. The second epistemic practice is the understanding of our own social experiences. Fricker introduces the term hermeneutical injustice for the specific injustice occurring when a group lacks the terms and explanatory models for their own experiences i.e., there is a “gap in the collective hermeneutical resources” that is unequally distributed among societal groups. In these ways, epistemic injustice can make it difficult for seldom-heard groups to fully participate in knowledge production (Bhakuni & Abimbola, 2021; Fricker, 2007). Finally, Fricker notes that in order to end these epistemic injustices, there is a limit to how much individuals can correct for when the root cause is structural injustices; “the ethical is political”. This is also the core of the criticism that epistemic injustice has received. Halldenius (2020), for example, criticizes Fricker for suggesting an individual solution i.e., the virtuous hearer, when she herself described the problem as grounded in structural injustices.

Both Liabo et al. (2022) and Stage (2022) connect epistemic injustice to PPI. As Liabo et al. (2022) point out, public contributors’ experiential knowledge is different from the usual kinds of knowledge in academic settings. In order for that knowledge to find its place in a research setting and for PPI to have an impact, researchers need to create spaces – in the physical and social sense – that provide the context of epistemic justice (Liabo et al., 2022). Stage (2022), although using other terms, describes this inequality in PPI as some voices “risk being excluded or deemed less important because they are perceived to lack resources and social merits”. PPI might have a role in ameliorating hermeneutical injustice by bringing lived experiences into the rooms where knowledge is traditionally produced i.e., academia. Ideally, this leads
to experiences from otherwise seldom-heard groups, such as forced migrants, influencing the research concerning their experiences, making it more relevant and bringing this knowledge back to the group i.e., increasing the group’s collective hermeneutical resources. However, this process requires avoiding testimonial injustice which in turn, according to Fricker, requires the researchers to be virtuous hearers. Egid et al. (2021) argue that caution is advised when working on addressing epistemic injustice. Researchers must be careful to not actually perpetuate epistemic oppression. Although the PPI research field advocates for power-sharing and trust-building, adopting PPI is not sufficient in itself, especially when working with seldomly involved groups. Issues of power need to be addressed throughout, using relevant tools and actions – for example developing safe communicative spaces (Egid et al., 2021; Liabo et al., 2022). Although power was not specifically investigated in this thesis, the relationship-building and communication strategies addressing epistemic injustice are likely to have had similar effects on the pre-existing power imbalances, as these were closely connected to trust.
PPI in this project

PPI is, in this thesis, both the phenomenon under study and – to some extent – the methodology. In this project, several public contributors have been involved in a number of ways. The involvement in this project was shaped by a mix of deliberate choices and circumstances. At the onset of this PhD project, I reflected on how to meaningfully involve public contributors in a project that applied a meta-perspective on participatory research. Together with my supervisors, I made an initial decision to involve public contributors with previous experiences of PPI; their lived experience needed to come from similar processes as those we were to investigate. Importantly, we considered the practical experience of having worked with PPI essential to put theoretical ideas into a context; a participatory project exploring participatory processes is difficult for anyone to grasp, so we wanted public contributors to have tangible and practical experiences to reflect on. Additionally, we aimed to involve someone who had experience with PPI in Sweden, as the context could influence the conditions for PPI. A public contributor, Björn Sonnentheil, who had previous experience from being involved in research as a public contributor in cardiology research, was recruited through a patient organisation. His role was to provide input on aims, methods and preliminary results in the overall project and study II specifically. Björn Sonnentheil was also involved in writing and publishing a commentary in Research Involvement and Engagement (Lampa et al., 2021), but did thereafter step back from involvement for personal reasons.

As the project progressed, the focus of this thesis was directed at forced migrants, which made lived experiences of forced migration, in combination with the experience of PPI, important. An opportunity arose to develop relationships with already involved public contributors, whom I had worked with previously and had an established relationship with. Through this, Reem Aljeshy and Kalid Ibrahim became involved in the work with study III. They both have backgrounds in forced migration and were, since a few years, involved as public contributors in other projects within the research group. Due to this, they represented the perspective of being involved in research as refugee youths. More importantly, they were the natural collaborators for this specific study as they had already been involved in the project the study was evaluating; they had a unique insider perspective. They were involved in the
analysis and writing of paper III, as well as in planning science communication activities around the paper such as a press release and conference abstracts.

In the final stages of the project, Nimo Mahamed Elmi and Yasmin Cumar were involved. Both coming from a forced migration background, Nimo Mahamed Elmi has been previously involved as a public contributor and Yasmin Cumar has worked in research with recruitment and data collection. I had worked with Nimo before, while Yasmin was introduced through a researcher colleague whom she worked with. The decision to invite them was based on their experiences but also on their capacity to reflect on involvement, which I deemed essential for the ethical, and more theoretical, focus of study IV. Nimo and Yasmin were involved in the analysis and writing of paper IV. They also became involved in the development of arts-based science communication activities for the thesis results, as well as the development of a handbook on ethical PPI, which continues beyond this PhD project.

Additionally, before the PhD project commenced, two public contributors were consulted during the development of the observation protocol and questionnaire. One was an experienced public contributor in autism research who contributed based on this experience. The other contributor had a migrant background, which was deemed relevant for the project, but she did not have a background as a public contributor. Their contribution was limited to providing input on the observation protocol and questionnaire.

As a PhD student, I have learnt involvement in symbiosis with learning research. For me, these two are now intertwined, but I needed to make some compromises along the way. One example is language, where I chose to involve public contributors who could communicate in Swedish. As my research topic utilised a meta-perspective on participatory research and I was myself learning it, I decided that using a language interpreter risked being too complicated. Another example is co-writing; I hesitated to co-write academic papers together with public contributors before I had written and published academically myself.

In this thesis, different sets of public contributors have been involved. This is connected to difficulties in finding public contributors with relevant experiences, in a context where involvement of forced migrants is rare. Although none of the public contributors were involved throughout the entirety of the thesis work, we had some level of an established relationship before working together which allowed us to build on that relationship rather than starting from the beginning of our collaboration.
Rationale

PPI is increasingly utilised in health research. Common arguments for PPI include the ethical argument, founded on democratic principles, stating that the public has a right to be involved in decisions relating to and affecting their lives, and the methodological argument: that PPI improves the quality, relevance and impact of research.

The PPI field has received criticism for the lack of representation of seldomly involved groups. The involvement of forced migrants in research has the potential to solve common issues in health research and make studies more relevant, as well as to bring benefits to involved individuals and communities. However, work remains to be done to support the ethical and meaningful involvement of forced migrants. Different research approaches are needed to build an understanding of how such ethical and meaningful involvement could be carried out, including untangling the how of PPI as well as exploring the perspectives of forced migrants involved as public contributors.

In Sweden, top-down initiatives for involvement, such as demands and possibilities from funding agencies or ethics authorities have long been lacking. This has recently started to change, making right now an ideal time to understand how PPI can be utilised in a Swedish research context. In this PhD project, I aim to contribute to the field in ways that can be used by researchers and public contributors, to create opportunities for PPI with forced migrants that are meaningful and ethical.
Aims

Overall aim

The overall aim of this PhD project is to explore patient and public involvement with forced migrants.

Specific aims

I. To track the experiences and perceived impact of refugee parents during their involvement as public contributors in a three-year child mental health trial
II. To identify patterns of enabling and hindering factors to PPI meetings with forced migrants involved as public contributors
III. To evaluate the communication strategies adopted throughout a research project with refugee youth coresearchers
IV. To empirically investigate ethical issues in PPI with forced migrants.
Study design and methodology

Ontology, epistemology and researcher position

In any research, the researcher’s position is as important to the insights and process as the methodology or the theoretical assumptions; in fact, the position will influence both methodology and theory. This is even more important when the researcher inherits privileges and does not share the lived experiences of the study participants.

Being a white, cisgender, non-disabled woman, born and raised in the Swedish middle class, almost all of my positions are consistent with social privilege. As a researcher working with a population who experiences inequities and discrimination, I have to be aware that the inherent power inequalities are still very much present; they can be identified, named, discussed and to some extent ameliorated, but not removed. Importantly, the researcher must be careful that the discrimination and privileges studied are not reproduced through the research. As my research concerns processes involving both forced migrants and researchers, I am partly an outsider and partly an insider. I have no experience of refuge or migration, but much of my research relates to the academic system, which I work within. Had I migration experience, I would likely have had a different understanding of my topic and a different position towards the forced migrant study population; perhaps establishing trust and navigating norms and behaviour would have been easier. For me, this is where PPI plays an important role. A recurrent thought which guides my work with PPI, is that I am not necessarily the best person to understand or explain something. I consistently come back to the questions: Who has lived experience of this? Who is in the best position to see what is really going on here?

My choice of topic is related to my interest in social justice. I value human rights and justice highly. I was politically engaged early on and I am currently active in a human rights organisation advocating for equal access to care, where I volunteer as a nurse at a health clinic for undocumented migrants. Many of my beliefs originate from early experiences of my parents caring for children in need. They were never politically organised but open with their values on justice, community engagement and children’s rights, and actively acting upon them. I feel strongly about migrants’ rights, which originates from my work as a nurse in migration and health. There, I met so many strong and
resourceful forced migrants, but I often experienced frustration around how unequal living conditions and opportunities limited these individuals’ potential for a happy and healthy life. In this way, my agenda is, as for many participatory researchers, action-oriented.

My ontological and epistemological perspectives are shaped by my experiences and the environments where I learnt research. My academic background is in nursing and global health. In my nursing studies, I discovered qualitative research, often centred around patient experiences. The global health community, in my experience, takes a rather emancipatory, multi-disciplinary and pragmatic approach. In my PhD studies, I have been supervised by researchers from the academic fields of psychology, medicine and philosophy; one of whom had experience of PPI with other populations. I wrote this thesis in the field of public health and my research group is specialised in social medicine and child health. The public health field is diverse; it stands with one foot in a positivistic paradigm and one in the social sciences with ontological and epistemological assumptions closer to critical realism and constructionism. This thesis also ventures into ethics, which is a different academic field. More specifically, I apply empirical ethics, which stands with one foot in traditional, normative ethics and one foot in the empirical social sciences.

I approach research from critical realism and pluralistic perspectives; that reality can be captured by broad critical examination and that many different approaches can be used to acquire knowledge about it. During my PhD studies, I have worked with different approaches, as is common in the public health field. In my methodological choices, I have mainly focused on qualitative exploration. This aligns with the approach of participatory methods which challenges traditional research epistemologies, especially those valuing objectivity and seeing academic knowledge as the correct form of knowledge. In participatory research, lived experience is seen as a legitimate form of knowledge that is comparable to academic knowledge – a form of knowledge democracy (Lenette, 2022; Roura, 2021). For this reason, I find multiple methods or mixed methods useful as a way to allow different methods and perspectives to contribute to our understanding.

Participatory research has been described as a research approach, as a methodology and as an epistemology (Lenette, 2022); for many participatory researchers it is all of these things. It has been suggested that PPI can be particularly challenging for PhD students, as they need to produce a thesis within a set time and format and need supervisory and institutional support (Banks & Brydon-Miller, 2019; Coupe & Mathieson, 2020; Dawson et al., 2020; James, 2023). The same sources also describe it as very rewarding. My own experience align will all these perspectives. I find it essential that PhD students are supported by supervisors and colleagues in their participatory research.
Participatory approaches involve aspects of critical theory and considerations of power relations in the explorations and descriptions of reality and the creation of knowledge (Lenette, 2022). Participatory researchers are typically driven by ideals of social justice and achieving positive outcomes for co-researchers (Lenette, 2022). They also value relationships and “find joy in being with others” (Brydon-Miller et al., 2003). This aligns well with my own approach to participatory research. I thrive on meeting and connecting with others, especially those I can learn from and whose experiences are different from my own.

Overview of study designs and methods

While three of the studies use qualitative study designs, study II has a mixed methods design. Stemming from the explorative approach of this thesis, the study designs built on and complemented each other in terms of data, analysis methods and level of detail. The methods were chosen based on the aim of each study, of which most required qualitative methods (table 1).

The two last studies built, to some extent, on findings from the previous studies and discussions during the work with this thesis. The development of study III was guided by insights and discussions between researchers and public contributors, which unveiled the need to further understand the communication strategies used.

During analysis for studies I and II, as well as in our practical work with involvement in various projects, it became evident that a lot of the questions and points of decision-making related to ethical issues and were specific to the forced migrant population. This led to the development of study IV, where ethical issues were identified and reflected upon.
Table 1. Overview of included studies.

<table>
<thead>
<tr>
<th>Study</th>
<th>Aim</th>
<th>Study design &amp; methods</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>To track the experiences and perceived impact of refugee parents during their involvement as public contributors in a three-year child mental health trial.</td>
<td>Longitudinal qualitative study using focus group discussions. Thematic analysis.</td>
<td>Four refugee parents, involved as public contributors.</td>
</tr>
<tr>
<td>II</td>
<td>To identify patterns of enabling and hindering factors to PPI meetings with forced migrants involved as public contributors.</td>
<td>Convergent parallel mixed methods study. Data from questionnaires and behavioural observations. Content analysis and descriptive statistics.</td>
<td>Researchers and public contributors in four health research projects focusing on forced migrants.</td>
</tr>
<tr>
<td>III</td>
<td>To evaluate the communication strategies adopted throughout a research project with refugee youth coresearchers</td>
<td>Co-produced evaluation of a project with refugee youth. Data from behavioural observations and field notes. Qualitative content analysis and a readability index.</td>
<td>Refugee youth co-researchers and academic researchers.</td>
</tr>
<tr>
<td>IV</td>
<td>To empirically investigate ethical issues in PPI with forced migrants.</td>
<td>Co-produced empirical ethical exploration. Data from studies I, II and II, and field and researcher notes. Thematic analysis with an ethical lens.</td>
<td>All data from studies I, II and III.</td>
</tr>
</tbody>
</table>
Study I

Study participants and data collection

Study I was a prospective longitudinal qualitative study. The participants were four refugee parents, involved as public contributors in a research project on refugee child mental health. Data were collected in recurrent focus group discussions over three years (figure 3), to track the parents’ experiences of involvement over time (see appendix 1 for interview guide). The focus group discussions were held in Swedish, with an Arabic interpreter present. Validation of the language interpretation was conducted, to check for interpreter bias.

![Figure 3. The study process and focus group discussions.]

Analysis

Thematic analysis (Braun & Clarke, 2006), with a longitudinal approach (Saldaña, 2003), was used to analyse the focus group discussion data. When preliminary themes were identified, the analysis moved to a second step. Data were organised in a code-based time-ordered data matrix, according to content and chronological order (Miles et al., 2019). This allowed data to be read chronologically, identifying patterns over time, which led to the longitudinal themes. In addition, member checking (Birt et al., 2016) with all four refugee parents was conducted when the themes were identified but still in revision.
Results

In the analysis, six themes around the refugee parents’ experiences were identified:

- From individual benefits to societal change
- Establishing a social network – from guests to peer supporters
- Building trust takes time – from polite to candid discussions
- Laying the groundwork – overcoming practical aspects to enable involvement
- Learning from each other and growing into involvement
- We share our experiences – researchers decide what is useful

The themes all displayed some level of change across the three years of the project. This included changing motivations for involvement from an individual motivation to a more altruistic one. In the theme “Establishing a social network— from guests to peer supporters” the public contributors initially viewed themselves as guests, which transformed into utilising the group for social support. We also saw that time impacted trust positively; the trust-building processes between public contributors and researchers were based on repeated personal interactions and getting to know each other as individuals, rather than professionals. In the theme “Laying the groundwork—overcoming practical aspects to enable involvement”, we saw that practical aspects were dominant in the beginning, but that this shifted over time to allow more focus on research. The parents identified several things they learned across the project. However, that the public contributors viewed their role as sharing experiences and researchers’ roles as taking decisions around research, prevailed over time.
Study II

Study participants and data collection

Study II was a convergent parallel mixed methods study, which integrated findings from one qualitative and one quantitative analysis. The participants in this study were researchers and public contributors in four health research projects focusing on the forced migrant population in Sweden (table 2). Data were collected in eleven research meetings over two years, using two tools: a questionnaire and a semi-structured behavioural observation protocol (see appendix 2). The data consisted of the questionnaire responses and the data from the observation protocol: observation notes, scores, and field notes.

Analysis

The data consisted of the questionnaire responses and the data from the observation protocol: observation notes, scores, and field notes. The observation data were analysed with qualitative content analysis (QCA) according to Graneheim and Lundman (2004). The questionnaire responses and how observers scored the items were summarised descriptively, and the Mann-Whitney U-test was used to compare medians between groups (95% CI). Cohen’s weighted kappa was used to measure inter-rater agreement between the observers’ scores. Data were integrated according to the joint display method, to explore convergences and divergences in the data (Creswell & Clark, 2017). Member checking (Birt et al., 2016) was conducted with two researchers and four public contributors.
Table 2. Research projects in which research meetings were observed and questionnaire data collected.

<table>
<thead>
<tr>
<th>Research project</th>
<th>Public contributors</th>
<th>Researchers &amp; others*</th>
<th>Meetings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child mental health trial evaluating group support for refugee children experiencing symptoms of post-traumatic stress</td>
<td>4 public contributors</td>
<td>1-10 researchers</td>
<td>Aug 2019, on-site</td>
</tr>
<tr>
<td></td>
<td>refugee parents.</td>
<td>3 professional advisors</td>
<td>Jan 2021, online</td>
</tr>
<tr>
<td></td>
<td>2 refugee youth</td>
<td></td>
<td>June 2021, online</td>
</tr>
<tr>
<td></td>
<td>(first meeting only)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trial evaluating two preventive psychosocial interventions aiming to promote adolescents’ well-being in a school setting</td>
<td>2 refugee adults, 2 refugee youth.</td>
<td>3 researchers</td>
<td>Nov 2019, on-site</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4 professional advisors</td>
<td>Oct 2020, hybrid</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Sept 2021, online</td>
</tr>
<tr>
<td>Co-creating an online version of an intervention for youth with post-traumatic stress</td>
<td>3 refugee youth</td>
<td>2 researchers</td>
<td>Sept 2020, on-site</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1 professional advisor</td>
<td>Oct 2020, on-site</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Dec 2020, online</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>June 2021, on-site</td>
</tr>
<tr>
<td>Project on implementing and evaluating a mentoring system for migrant mothers</td>
<td>2 migrant mothers</td>
<td>2 researchers</td>
<td>Mar 2021, online</td>
</tr>
<tr>
<td></td>
<td></td>
<td>9 professional advisors</td>
<td></td>
</tr>
</tbody>
</table>

*Researchers and professional advisors involved in one or more of the project meetings. How many of each were present varied across meetings.
Results
In this mixed-methods study, the qualitative findings on barriers and enablers for involvement of forced migrants were summarised in three categories:

Language interpretation central to achieving nuanced discussion

Building relationships and adapting to team development over time

Researcher responsivity and transparency enables relevant contributions

The scores from the behavioural observations showed that positive behaviours were scored higher than negative behaviours; these were scored very low (figure 4). Five items in the questionnaires showed a statistically significant difference between researchers and public contributors (table 3). The results from the observation scores and the questionnaires were to a large extent aligning.

![Chart showing the distribution of scores for various interactions and behaviors](chart)

*Figure 4. How the observers rated the occurrence of behaviours during each of the 11 meetings; Low, Moderate or High.*
Table 3. Questionnaire results rated on a Likert scale from 1 (Not at all) to 5 (A lot).

<table>
<thead>
<tr>
<th>Questionnaire item</th>
<th>Researchers N=32 median (SD)</th>
<th>Contributors N=32 median (SD)</th>
<th>Mann-Whitney U test</th>
<th>Sign. 95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Interpersonal relations</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Positive interactions</td>
<td>5 (.440)</td>
<td>5 (.246)</td>
<td>416.000</td>
<td>p=0.040*</td>
</tr>
<tr>
<td>Reference to public contributors’ expertise</td>
<td>5 (.716)</td>
<td>5 (.369)</td>
<td>358.000</td>
<td>p=0.010*</td>
</tr>
<tr>
<td>Linguistic barriers</td>
<td>2 (.897)</td>
<td>1 (.877)</td>
<td>276.500</td>
<td>p=&lt;0.001*</td>
</tr>
<tr>
<td>Public contributor engagement</td>
<td>4 (1.076)</td>
<td>5 (1.420)</td>
<td>346.500</td>
<td>p=0.014*</td>
</tr>
<tr>
<td><strong>Nature of contributions by public contributors</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Invitations to speak</td>
<td>5 (.492)</td>
<td>5 (1.245)</td>
<td>468.000</td>
<td>p=0.839</td>
</tr>
<tr>
<td>Taking the initiative to speak</td>
<td>4 (.859)</td>
<td>5 (.609)</td>
<td>210.000</td>
<td>p=&lt;0.001*</td>
</tr>
<tr>
<td>Contributor input relevant for discussions</td>
<td>5 (.483)</td>
<td>4 (1.402)</td>
<td>383.000</td>
<td>p=0.050</td>
</tr>
<tr>
<td><strong>How public contributors guided research development</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Challenging research ideas</td>
<td>4 (.946)</td>
<td>4 (1.671)</td>
<td>473.000</td>
<td>p=0.912</td>
</tr>
<tr>
<td>Active cons. of public contr. ideas by researchers</td>
<td>4 (.964)</td>
<td>4 (1.105)</td>
<td>453.500</td>
<td>p=0.692</td>
</tr>
<tr>
<td>Ideas being ignored/treated with disregard</td>
<td>1 (.601)</td>
<td>1 (.842)</td>
<td>482.500</td>
<td>p=0.734</td>
</tr>
<tr>
<td>Decisions made without the input of public contributors</td>
<td>1 (.599)</td>
<td>1 (.924)</td>
<td>425.500</td>
<td>p=0.143</td>
</tr>
</tbody>
</table>

*Statistically significant according to 95% confidence interval level. P-values below 0.050 are considered significant.
In the questionnaires, the public contributors rated positive interactions and references to public contributors’ expertise higher than the researchers did, which in the observation notes could be seen at related to the researchers actively making efforts for the public contributors to feel welcomed and comfortable. Linguistic barriers were rated higher by the researchers than the public contributors, but the observation notes also showed that engaging interpreters as co-facilitators of the meetings enabled nuanced discussions. The observation notes showed specific occasions when meeting participants’ engagement declined, as well as that quite few decisions were in fact made in the meeting room. Involving forced migrants in PPI requires considering relationship-focused factors; inclusive communication, relationships and trust, and process-focused factors: where and how decisions are taken.
Study III

Study participants and data collection

This study was an evaluation of the communication strategies in a project where refugee youth were involved in the online adaptation of a group-based programme for youth with posttraumatic stress (figure 5). Data consisted of behavioural observations and field notes collected during the project, which lasted over 18 months, as well as team communication from emails and WhatsApp. The article was co-written by researchers and the refugee youth, who had all worked together in the evaluated project.

![Figure 5. Timeline of the project, with the PPI processes evaluated in study III marked in green.](image)

Analysis

Behavioural observations and field notes collected during the project were analysed with qualitative content analysis (Graneheim & Lundman, 2004) and a readability index (Björnsson, 1968) and discussed through the lens of epistemic injustice (Fricker, 2007). The analysis was conducted jointly by researchers and refugee youth co-authors.
Results

Four manifest categories around communication strategies and one latent underlying theme reflecting the role of trust were identified:

Categories

- Facilitating engagement through coplanning and circumstantial flexibility
- Different needs require different channels
- It's not just about the channel—facilitation skills matter
- Finding a common language opens a communicative flow

Theme

- Interactive moments facilitate trust—trust facilitates richer involvement

Different communication channels were used simultaneously in the project. They all filled a specific role, although with different purposes; for example, WhatsApp for quick messaging and social interactions, and workshops for deeper focused work. In addition to this, the researchers’ facilitation skills were essential for the collaboration, and consisted of activities such as meeting preparations and mind map exercises. Finding a common language and the right terminology around the topic of the project was essential, and included both identifying common terms and providing material in “Easy to Read” Swedish.

The refugee youth co-authors wrote advice for youth and researchers on working together, which can be found in the published article. In summary, they advise youth and researchers to show honesty, commitment and flexibility. Researchers can contribute to a welcoming and open environment through getting to know the youth and show that they genuinely want to work together, as well as help them to prepare for meetings.

At the core of the identified communication strategies were strengthening relationship-building and actively facilitating involvement. Establishing trusting relationships enabled refugee youth to share input. The communication strategies increased hermeneutical justice by contributing to a common understanding; a step towards ameliorating epistemic injustice.
Study IV

Study participants and data collection
For this study, data from studies I, II and III, as well as field notes and ethical reflection notes, were used. Themes related to ethical issues were identified in the data, as well as a number of case examples. The article was written in collaboration between researchers and public contributors with experiences of forced migration and of working with research.

Analysis
For this study, a secondary analysis on the data from studies I, II and III, as well as field notes and ethical reflection notes, was conducted using thematic analysis (Braun & Clarke, 2021). From this, themes related to ethical issues, as well as a number of case examples, were identified. These ethical issues were reflected upon in relation to PPI values (Gradinger et al., 2015) and the ethical principles by Beauchamp and Childress (2013). These themes were discussed and revised several times, based on discussions in the author team. In the discussion, relational ethics is introduced as a way to understand the identified ethical issues.

Results
Five ethical issues in PPI with forced migrants were identified:

- Treating forced migrant public contributors as a vulnerable group can inhibit autonomy
- Non-inclusive communication strategies can contribute to injustice
- Regulations around payment risk excluding the most vulnerable from involvement
- Public contributors risk being excluded from partaking in decision-making
- If trust is not established, public contributors do not feel safe sharing honest input
The first issue concerns research ethics and the obligation to protect vulnerable groups, which forced migrants are often classified as; however, researchers must balance this against the public contributors’ autonomy as well as PPI values such as partnership. The second issue is the occurrence of non-inclusive communication, which can lead to epistemic injustice being reinforced. Thereafter, issues around financial reimbursement for public contributors were identified, with difficulties for forced migrants to be equally reimbursed. We also identified a risk for forced migrant public contributors to be excluded from actual decision-making in the projects. Finally, we identified an ethical issue around the increased need for trust-building processes with the forced migrant population and the potential risk that researchers might lack awareness of public contributors’ lack of trust, as this in itself requires a certain level of trust to express.

The identified ethical issues are exemplified by case studies and discussed in relation to research ethics principles, such as those by Beauchamp and Childress (2013), and common PPI values as described by Gradinger et al. (2015). The findings align with PPI literature, but the identified ethical issues appear more prominent when involving forced migrants. The ethical issues are discussed using a relational ethics approach, which we suggest as a complement to existing ethical principles when discussing PPI ethics.
Summary of results

The aim of this PhD project was to explore PPI with forced migrants from longitudinal, communicative, and ethical perspectives. Involving forced migrants in PPI requires consideration around relationship-focused factors; inclusive communication, relationships-building and trust, and process-focused factors: where and how decisions are taken. In this thesis, I have outlined the specific prerequisites and ethical aspects of PPI with forced migrants.

The most prevalent finding coming out of this thesis concerns trust. From all the different approaches used throughout the thesis and the different groups researched and involved, the need to develop trusting relationships is always present. In addition to being a core finding, maintaining a focus on trust has continuously been highlighted by the public contributors involved in this thesis. Although trust is always essential in PPI, when drawing upon personal experiences and speaking up in a space that you might not be comfortable in, we need to acknowledge that different groups have different starting positions in the trust-building process. Involving individuals from groups that are structurally marginalised and have stronger reasons to not trust government officials requires a different approach to trust. In study I, the refugee parents describe their initial mistrust as leading back to experiences from their countries of origin and contacts with Swedish authorities. The development of trusting relationships with researchers therefore relies heavily on relationship-building, where researchers become “real people” and not government officials, in the eyes of the public contributors. This was clearly stated by the public contributors themselves in study I, identified as an enabler in study II, was part of the communication strategies in study III and – when trust was not established – was seen as a potential ethical issue in study IV.

What made the change is the way how everyone was smiling and everyone was very positive, and whenever we had questions, they were answered with a smile directly in a very welcoming way, I was very stressed that it would not go as smoothly but I felt welcome so that released all the tension and stress.

(Refugee parent, study I)

The importance of inclusive communication strategies is also reoccurring throughout the studies. While this is always essential in PPI, this issue
manifests itself differently when involving the forced migrant population. One aspect, seen in studies II and III, is the need to find a common and accessible language within the team. Another aspect, which is found in studies II and IV, is language interpretation. This can be challenging to manage in research meetings, where several languages are spoken and not all meeting participants are used to working with interpreters. Therefore, this might be a potential ethical issue. However, we also saw that when working closely together with the interpreter, they can be a positive force and contribute to a common understanding. Additionally, study III suggests that inclusive communication strategies include co-planning the communication together with public contributors, using complementary communication channels for different needs and making sure the interaction also includes social aspects. In fact, much of the content in the communication channels was social, which points to the need to build relationships within the team, and thus build trust.

Researcher: When is a good time for us to meet? I think you need some time to read before 😊

Youth: Now I have a lot to do at school 😢😢😢😢😢

So I don't really know when we can meet 😓

Researcher: Ugh yes it can be stressful at the end of the semester!!

(WhatsApp data, study II)

Another key finding concerns time. All studies reached the conclusion – from different perspectives – that investing time in the collaborations with public contributors can benefit all parties over time, including project outcomes. One example of this is how time is needed for the collaboration to develop. In study I, we found that initial issues in the collaboration were to a large extent practical. Once these were solved, the collaboration could move into more intellectual, research-focused topics. One such issue was financial reimbursement, which in study IV was also identified as a potential ethical issue for forced migrant public contributors. Another example is the building of relationships over time, which was seen across all studies.

And it should not be three years, it should be five, since the longer we’ve been here, the more we learn, more experience, more thoughts. Since, this is important, we’re not yet fully safe, deep down.

(Refugee parent, study I)
Finally, one of the most important findings, occurring in studies II and IV, concerns decision-making. “Decisions made without the input of public contributors” was consistently scored as low in the observation protocol and rated low in the questionnaires. However, this did not account for the fact that quite few decisions were made in the meeting rooms, which was identified in the observation notes. That public contributors risked being excluded from decision-making was seen as an ethical issue in study IV.
Methodological discussion

Reflections on the study design

In this thesis, different methods have been used to explore aspects of the same topic: PPI with forced migrants. Using different approaches has allowed us to view specific factors from different perspectives, moving between detailed accounts and a higher-level perspective. I consider this a strength, as the studies are pieces of the puzzle about PPI with forced migrants. However, using these various methods, which are mostly qualitative, have included a number of methodological considerations and choices.

The longitudinal approach

In this thesis, a longitudinal qualitative approach was used in study I, where we tracked the experiences of refugee parents involved in PPI over time, and to some extent in study II, where some findings were based on the repeated observations. Using a longitudinal approach was a clear strength; many of the findings were reliant on the temporal aspects, as we could see patterns unfolding over time.

Taking a longitudinal approach, as a method, has specific requirements. It requires flexibility, as circumstances are likely to change during a study (Hermanowicz et al., 2016; Saldaña, 2003). In our case, the covid-19 pandemic forced meetings online; we then altered the interview guide. Longitudinal research also requires researchers to maintain contact over time and to negotiate consent continuously. I consider it a strength that the same refugee parents, except for one person, stayed involved in the project throughout the three years; especially since refugees might, for voluntary or involuntary reasons, frequently change locations or contact information. Yet another aspect is the researcher-participant relationships, in which longitudinal approaches provide both strengths and challenges. Establishing rapport and trust with study participants is likely to be easier, when meeting several times; yet, the researcher role, which might be closer than in regular qualitative research, might be more difficult to navigate (Saldaña, 2003). To handle this, I used two strategies. First, I practiced reflexivity throughout the process. Second, I made efforts to be clear in my communication around roles and expectations, which also aimed to help maintain the difference between the standing role as public
contributors and the temporary role as study participants during the focus group discussions.

Mixed methods and multi-method approaches
In this thesis, both mixed methods and multi-methods have been used. Typically, the term mixed methods is used for designs including both qualitative and quantitative data; here, it is utilised in study II. A multi-method approach means the use of two or more data sets that are either all qualitative or all quantitative. Study III used a multi-method qualitative design, with data sets including field notes, researcher notes and documentation as well as communication data between team members. Mixed methods and multi-methods can either be designed with an explanatory, exploratory or convergent approach. Both study II and III used convergent approaches, meaning that data were collected simultaneously; one data set did not shape the other data sets, but the findings were integrated during analysis. Data integration (Creswell & Clark, 2017) is a key concept in mixed methods and refers to the point where convergences and divergences in the data are sought in order to produce a more complete understanding. In study II, this was done using the joint display methods, as suggested by Creswell and Clark (2017). This highlighted the usefulness of mixed methods, as we found the observation notes crucial for an in-depth understanding of questionnaire results. In study III, this was also done during analysis but without using a specific method. Rather, the different data sets were condensed into a description close to the data. The descriptions from the different data sets were then compared to each other, to explore convergences and divergences.

![Figure 6](image.png)

*Figure 6. The three sources for source triangulation in study II.*

Apart from combining different data sets, study II contributed with three perspectives on research meetings with public contributors with a migrant background – those from the observers, participating researchers and public
contributors (figure 6) – thus achieving source triangulation (Hammersley, 2008). Through this, the similarities and differences in their perspectives were highlighted. An example is the differences around linguistic barriers, which was rated low in the questionnaires but identified as a barrier in the observations. This highlights the usefulness of the mixed methods approach. Other strengths include the fact that two observers collected data, and that four different projects were included, covering different kinds of enablers and barriers. At a thesis level, triangulation was done through the use of different methods and sources to explore the topic of PPI with forced migrants.

Reflections on data collection

Focus group discussions

Focus group discussions, used in study I, are used to collect data on perceptions and attitudes, in groups with people with similar experiences. They are guided by a facilitator but the participants are encouraged to discuss among each other. The methodological decision to use focus group discussions was based on the aim but also on ethical and practical considerations; we thought it would be more convenient for the public contributors to continue discussing in the group they had worked with during the day than to be interviewed individually by a researcher. We had a pragmatic approach to the data collection: if all seemed tired after a day of PPI work, we kept the focus group discussion quite short.

Focus group discussions limit opportunities to share personal experiences or experiences that might not sit well with the group. However, the participants disagreed with each other more than once; that the participants knew each other can be a strength, related to longitudinal research. An aspect to reflect upon is that I facilitated about half of the focus group discussions and observed the rest. This can be either be viewed as a strength or a limitation, or both; as I knew the refugee parents, it might have resulted in increased trust or that they felt obligated to say positive things about our collaboration.

One limitation was using language interpretation, which was challenging in terms of finding good interpreters, interpreting group discussions and using interpretation in online meetings. Attempts to ameliorate these challenges included deciding together with the refugee parents which interpreters to use and to perform an interpretation validation of the recorded focus group discussions.
Behavioural observations

Behavioural observation is an established way to record behaviours, specifically behaviours the participants might not have identified themselves. We used a semi-structured observation protocol and a questionnaire (see appendix 2). The purpose was to assess group dynamics and decision-making processes in PPI meetings. The tools were developed to be used together in the setting of PPI meetings and were based on group dynamics and PPI research (Warner et al., 2019). After data collection, we shared back our findings in a summative report to the meeting organisers, as an act of reciprocity.

Using a protocol is an established way of guiding observations of intended items. As the observation protocol was structured, the observers’ attention was deliberately guided towards specific behaviours; other factors might have been missed. However, there was room for unstructured field notes in the protocol and this section was used by the observers.

The observation protocol, which public contributors had been involved in developing, had been pilot tested (Warner et al., 2019) but not yet validated, which was a limitation. A further limitation was that the observations were carried out only by researchers, who had limited insight compared to a person with experience from the role of a public contributor in research. To counteract this, a public contributor with this experience, who also had experience from using the protocol in other projects, provided feedback on the results in study II in an early stage of the analysis.

Reflections on analysis methods

Following the explorative aim of this thesis, the qualitative data were analysed using established qualitative analysis methods. Thematic analysis (Braun and Clarke, 2006; Braun and Clarke, 2021) was used in study I and IV, but combined with other approaches i.e., a longitudinal approach (study I) and an ethical reflection (study IV). In these analyses, we used a latent approach. A strength with thematic analysis, more strongly appearing in Braun’s and Clarke’s later work (2021), is its reflexive approach, which was especially useful in study IV where an ethical reflection was conducted.

In studies II and III, QCA as described by Graneheim and Lundman (2004) was used for analysis, in combination with other methods. In study II and III, the aim guided us to keep the analysis close to the data and the results “recognisable” as this would make the paper most useful for the reader. QCA has previously been used with observation data (Eldh et al., 2020) and Graneheim
and Lundman (2004) exemplify using observation data, which provided useful
guidance on how to apply the method to the data set.

The analyses in study III and IV were conducted together with public contrib-
utors, who also co-authored the manuscripts. This process was conducted
through regular analysis meetings, on-site or online, throughout the process.
We discussed the aim, how we interpreted the data and how well initial ideas
on findings reflected it. In the final stages of the process, the public contribu-
tors read the manuscript together with a summary in Swedish. Co-writing is
considered a strength and had tangible effects on the articles; the combination
of the perspectives provided both depth and transferable insights. In study III,
the idea for the underlying theme came from the public contributors and they
wrote a section of the discussion. In study IV, the co-authors were active in
forming a richer analysis and discussion. These positive experiences are sim-
ilar to other co-writing experiences; the experiential knowledge contributed to
a richer analysis (Garfield et al., 2016).

Trustworthiness

As this thesis is mainly based on qualitative approaches, I will discuss trust-
worthiness in relation to the four common criteria of trustworthiness in quali-
tative research (Shenton, 2004).

Credibility refers to the extent to which a “true picture” of the findings is pre-
sented i.e. whether the findings reflect the reality of the participants. It can be
increased by factors such as prolonged engagement and triangulation (Shen-
ton, 2004). The credibility of our findings was increased by using well-estab-
lished methods for qualitative data collection and analysis. Using a longitudi-
nal approach in study I, for example, supported credibility in that the parents
were more polite and eager to please in the initial focus groups, while in the
later focus groups they reflected back on their previous statements and ex-
plained in more depth. Triangulation, as discussed above, was achieved both
by using mixed- and multi-methods as well as source triangulation in study II;
this is considered a strength in relation to credibility. One factor that risked
diminishing trustworthiness, if not addressed, was using language interpreta-
tion in data collection (Temple, 2002; van Nes at al., 2010). However, this was
ameliorated by including a rigorous validation of the language interpretation.
A research assistant fluent in English, Arabic and Swedish listened to the re-
cordings, validated most of the interpretation and guided us to which parts
were not well translated; in addition, she transcribed and translated these parts.
Finally, member checking and co-writing contributed to credibility through
ensuring that the conclusions appeared close to the reality for those with own
experience.
Confirmability pertains to whether the findings are rooted in the data and not in the researcher’s preunderstandings. Traditionally, confirmability has been compared to the ideal of objectivity in quantitative research. This has been criticised by qualitative scholars, who rather consider the researcher’s position and preunderstandings as integral to the analysis process (Shenton, 2004). Here, reflexivity is understood as a way to position oneself in relation to the research, rather than removing the self from the research process – in the qualitative tradition, this is not seen as possible but an illusion of objectivity rooted in the positivistic research paradigm. Measures taken to strengthen this is first and foremost a reflexive practice. Reflexivity was maintained throughout the PhD years, but in different forms. I kept a journal, which was useful for my own understanding of my position in the field. Reflexivity was also conducted in conversations with other academics, several of them participatory and qualitative researchers. Triangulation, member checking and co-writing of articles together with other academics as well as with forced migrant public contributors might also have increased confirmability; other perspectives than my own have been continuously fed into the processes. However, there is a risk that confirmability was negatively affected by the longitudinal approach, as the findings depended on the relationship between the parents and the researchers more than in a cross-sectional study.

Dependability refers to the reliability and consistency of findings, and the stability of interpretation and findings throughout the research process. It is demonstrated through transparency in reporting of method procedures (Shenton, 2004). I have attempted to describe in detail the processes around the design, data collection and analysis.

Transferability of the findings refers to how relevant the findings are for other situations or contexts than the study setting (Shenton, 2004). Transferability was increased by transparency around the setting, recruitment, data collection and analysis, which would allow other researchers to apply similar methods as well as interpret the findings and recommendations. In addition, the study participants were a relatively diverse group, which could increase transferability. However, a limitation in relation to transferability is the inclusion of projects within or closely connected to my own research group, meaning that the setting is narrow. Additionally, some of the findings are processes playing out over time, which means that several factors are likely to affect public contributors’ experiences. As many of the findings are recognised in the literature, transferability to an international context is possible. However, the role of laws and institutions will differ between international contexts.

The quantitative components in study II requires different considerations. Several attempts have been made previously to assess PPI based on external measurements, such as questionnaires (Boivin et al., 2018b). Although these
can indeed be useful, inherent limitations are the lack of recognition of context and difficulties in capturing relational aspects. The semi-structured observation protocol and the questionnaire (appendix 2) were developed to capture these aspects, based on group dynamics and PPI literature (Warner et al., 2019). These tools have limitations, as do all methods. For example, they only capture processes in meetings, when a PPI collaboration is often done through multiple channels. Although the tools have not been validated, a pilot test showed good feasibility (Warner et al., 2019). Regarding reliability, the observers seemed to use the protocol in a similar way; in study II there was a substantial inter-rater agreement (0.610; calculating all 11 items together) between the observers’ scores. However, it can be questioned whether this is relevant or not; perhaps the point of having two observers is rather that they observe different things. In this thesis, the two observers were researchers. Observations conducted by a team of one researcher and one public contributor would provide interesting insights to the usefulness of the protocol. Regarding the questionnaires, accessing an insider perspective – although a brief one – from researchers and public contributors was valuable for a more complete understanding of the phenomenon.

**Member checking**

In this thesis, member checking was conducted in studies I and II. It was not conducted in studies III and IV, as these were co-written with public contributors, which made the use for member checking less relevant. In both studies I and II, the member checking contributed with significant additions to the results and conclusions. In study I, the refugee parents’ perspectives during member checking fed into the analytical discussion among authors. In study II, issues around transparency and decision-making processes in PPI were highlighted during member checking with researchers and public contributors, which led to changes in the analysis and findings.

Member checking can be done in many different ways. Activities ranging from study participants reading and correcting transcripts to scrutinizing the finished report have been described as member checking. I opted for the method of Synthesized Member Checking (Birt et al., 2016). This method is a structured approach, where synthesized themes (or the equivalent) and quotes are written up and sent to participants, who respond with their reflections which are then integrated with the findings. In this case, we adapted the procedure to our forced migrant population, who had expressed a preference to meet in person and where some of the participants were illiterate. Rather than having a written report sent out, I invited the public contributors to a meeting with a language interpreter present, where initial findings were orally presented together with quotes from the data. We discussed the themes and quotes together, while I wrote down their reflections and later included these
in the analysis. I conducted a similar member checking process with the researcher study participants.

In the context of this thesis, member checking might seem very similar to PPI. In many ways it is, as voices from the population are here taken into account in the research process – and especially in this case, where member checking was not judged necessary in the two latter studies. One difference lies in the power and decision-making. In member checking, the researcher remains the analyst and makes the decisions, but takes input from member checking into account (Birt et al., 2016). In PPI, there is an expectation to share decision-making. Making this distinction clear to the study participants, who had previously been public contributors, was a balancing act; there is a risk that the difference between the roles was not clear to the forced migrant public contributors who participated in member checking.
Discussion of findings

The studies in this thesis were all conducted in a Swedish setting. Although there has been an increasing interest in participatory processes in Sweden in recent years, there is still much uncertainty in the research community on how to involve forced migrants as public contributors.

The research milieu and the national context can either support or hinder factors contributing to meaningful PPI (Martineau et al., 2020). The Swedish context, including Swedish academia, is in many ways similar to other high-income countries. However, some of the ethical issues, such as the issue around reimbursement for forced migrant public contributors, are specific to Swedish employment laws and institutional administrative processes. This is an example of how empirical, on-the-ground, investigations of PPI can highlight context-specific factors which can manifest as barriers or enablers for meaningful PPI (Goedhart et al., 2021; Staley, 2015). Meaningful and ethical PPI with forced migrants should, of course, resemble meaningful and ethical PPI with other populations. However, there are a few important differences, which are the focus of this discussion.

Establishing trust

That establishing trust is essential is well-known both in research about forced migrants and in the PPI literature. Trust existed as a core theme throughout this thesis and appeared increasingly important when involving forced migrants. Ní Raghallaigh (2013) argues, in a study on trust among young refugees in Ireland, that mistrust is common in the population and that the reasons are embedded within these refugees’ backgrounds but – importantly – exacerbated in their current social context. Ní Raghallaigh related this mistrust back to past experiences but also being mistrusted by others. Goedhart et al. (2021) identified that mistrust in research can hinder public contributors living in vulnerable circumstances from getting involved in research. O’Reilly de Brún et al. (2016) states that this is relevant for migrants, who due to this can be very reluctant to join in any official activities.
It is worth reflecting on why trust is so important. One reason is that PPI is based on experiential knowledge which has a personal component that academic knowledge does not necessarily have; sharing something relating to own experiences can make a person vulnerable. Liabo et al. (2024) frame this as the emotional labour of public contributors and state that researchers need to create safe spaces for sharing experiential knowledge. Trusting relationships are essential for this experiential knowledge to be safely shared and received (Lenette, 2022). In addition to this, a general mistrust towards government officials is – for relevant reasons – established in groups who are, and have been historically, marginalised. This is true for forced migrants’ current circumstances in Sweden, considering the contemporary Swedish narrative and their limited opportunities for a dignified life (United Nations High Commissioner for Refugees, 2020; van Eggermont Arwidson et al., 2022).

In our findings, relationship-building was as important; trust was established when getting to know the researchers as individuals. As this happened over time and the researchers were not necessarily aware of at which point trust was established, the results suggest that keeping the same contributors involved over longer periods of time can increase trust and be beneficial for PPI.

Clear and inclusive communication

Communication, in a broad sense, is an obvious core aspect of collaboration. Communication appeared as important for PPI with forced migrants in several ways, which aligns with previous studies (Liabo et al., 2020; Goedhart et al., 2021). That a common and accessible language within the team was important was clear. This has been seen in previous studies (Ocloo et al., 2021; Roura et al., 2021) but the evaluation in study III contributed with detailed accounts and study IV identified this as a potential ethical issue. An accessible language is good for everyone, including researchers who are also not necessarily familiar with all terms and abbreviations in a field. However, communicating research in an accessible way is difficult and not a skill all researchers have acquired. PPI training for researchers would benefit from including this.

A specific circumstance in working with the forced migrant population is the potential need for a language interpreter. Language interpretation can be challenging to manage in research meetings (Temple, 2002; van Nes et al., 2010). In many health research projects, Swedish language is still an inclusion criterion; many researchers are not used to working with interpreters and interpreters are most often not trained to work with research. I recommend working closely together with interpreters, as co-facilitators, as this has potential to make them a positive force and improve the common understanding. However, engaging interpreters as co-facilitators could sometimes rather be a
There are a number of ways in which PPI can either increase or decrease epistemic injustice (Fricker, 2007; Liabo et al., 2022). Hermeneutical injustice is relevant to consider, as this can affect if and how public contributors have access to ways to describe their experiences and opinions. Finding a common language is one example of how hermeneutical injustice can be ameliorated; identifying ways of talking about research together, allows for the sharing of experiential research in a way that fits all involved and leads to an increased common understanding. Liabo et al. (2022) and Cornwall (2002) describe these allowing circumstances as creating spaces; communicative spaces or spaces that provide the context of epistemic justice.

Time as a prerequisite

In order to establish a good PPI collaboration, time is needed. Chronological time spent together to get to know each other and establish relationships, working time to do the necessary preparations and follow-ups, and time for flexibility around the work with public contributors; this is essential in building a research collaboration that is mutually beneficial. Time as a necessary component for good PPI is already recognised in the extant literature (for example in James, 2023), but the findings in this thesis suggests it might be of increased importance when working with forced migrants. In general, longer collaborations have been seen to have benefits for PPI. Time is here seen as a prerequisite for the processes needed for good PPI; for example, the findings suggest that keeping the same contributors involved over longer periods of time can increase trust and be beneficial for PPI. Salsberg et al. (2017b), saw that public contributors increased their ownership of the research over time; time is not the only component here but it is needed for other processes to run their course.

A key problem is that projects and funding are often limited in time. This applies both to chronological time, where projects are limited to a number of years, and to resource allocation, which makes researchers’ and contributors’ time for involvement activities limited. This can disrupt the possibilities to maintain collaborations with public contributors over time. To ameliorate this, structural changes in funding and institutional governance are needed, which previous studies have also seen (Martineau et al., 2020; Røssvoll et al., 2023). On the funding level, changes have started to happen; major Swedish funders are increasingly acknowledging the value of PPI and the associated requirements for time and resources, but others need to follow. On the institutional
level, PPI with forced migrants would benefit from being allocated the time needed and stability in resources to establish longer collaborations.

Where and how are decisions made?

An interesting finding in this thesis was the unclear points for decision-making. My definition of PPI is the active involvement of people whose lives are at the centre of research, in making the key decisions in research; this makes it problematic that public contributors were not always clearly involved, or even present, when decisions were made. Literature has questioned whether involving public contributors in every step of research might not be feasible or even desirable in all studies. Steffensen et al. (2022) saw that public contributors chose a role that suits them and that this might not always align with the researchers’ initial ideas. Our findings suggest that at least some of the public contributors were content with, and potentially actively had chosen, a role where they provided input and the researchers were responsible to handle that input. However, there is also evidence in the literature of the opposite scenario, where researchers are reluctant to share power with public contributors (Boaz et al., 2016).

An important conclusion to draw from this is the value of transparency in roles, expectations and decision-making. Different projects will come with different circumstances and so will public contributors. This makes general guidance difficult. Researchers initiating involvement need to carefully consider, preferably together with public contributors, in which rooms decisions will be made and who needs to be present in that room.

What is meaningful and ethical PPI with forced migrants?

General PPI guidelines and values are useful to conduct meaningful and ethical PPI with forced migrants, but a few important differences have been identified. These differences are in many ways amplified versions of known PPI challenges; the route is the same but parts of the path are more difficult to navigate. Other scholars have reflected on “good” involvement. Liabo et al. (2020) identified five values in the literature: inclusivity, partnership, purposeful involvement, transparent and valuing different kinds of knowledge. However, through discussions, they also identified characteristics that were not found in the literature: passion, enthusiasm, informal and welcoming meeting spaces and opportunities to share lived experiences (Liabo et al., 2020). These appear highly important to the relationship-focused findings of this thesis.
They also bear resemblance to the advice for refugee youth and researchers on working together presented in study III, which the refugee youth co-authors wrote. This advice displays values such as flexibility, honesty, enthusiasm, commitment and curiosity. These values are reflected in this description of the collaboration in study III, that the two refugee youth co-authors have written.

Everyone respected each other, everyone listened to each other and most importantly, we all wanted to come and had good energy.

(Study III)

According to Cornwall (2002) the dynamics inherent in academic spaces and the political and historical background of academia, affect opportunities for involvement. Therefore, while following the standard PPI guidelines is still recommended, standard involvement is not enough for involvement with forced migrants. My findings suggest that to sustain successful PPI collaboration over time, researchers need to invest time and resources in the collaboration. They need to work with continued adjustments and inclusive communication, including working together with interpreters. And importantly, they must centre relationships and trust. Goedhart et al. (2021) raises the context-dependence around how PPI should be done, and that strategies must be applied at the intrapersonal level all the way up to public policy. Liabo et al. (2020) identified six practicalities of “good” PPI: support to public contributors, capacity building, proportional involvement, communication, involvement throughout the research, and evaluation. This is in many ways consistent with the findings of this thesis, where both supportive strategies and potential and existing issues relating to similar practicalities have been identified for PPI with forced migrants.

PPI being conducted in ways that are not meaningful or ethical, risks leading to ethical issues and tokenistic approaches. However, that ethical issues occur is not in itself a sign of “bad” PPI. Ethical considerations will always need to be continuously made when working in close relationships with others; each PPI collaboration will host its own set of issues or risks, even more so when there are differences in power dynamics within the working group. This, in turn, risks leading to moral distress among participatory researchers if not handled. In order to maintain an ethical approach throughout, different reflexive approaches have been suggested in the literature. Shimmin et al. (2017) suggest a reflexive and trauma-informed approach. Abma et al. (2017) and Amann and Sleigh (2021) argue for critical reflection. When involving forced migrants, researchers can be helped in navigating these ethical concerns by using a relational ethical lens and a reflexive approach.
As researchers, we are obliged to adhere to principles of research ethics; as participatory researchers, we also need to be prepared to care for the relational aspects. Applying a relational ethical perspective to PPI work can be helpful in centring the relationships rather than the research process. Being a participatory researcher, engaging and connecting with others, always include a significant emotional budget – i.e., emotional costs and gains (Smith et al., 2022). This was evident in the data and from my own experiences of PPI. Relationships consist of ethical commitments, entitlements and duties; when we get to know each other, we accept a responsibility for each other. This raises the question: Is PPI for everyone? It is social activity at the core and requires a will to meet people where they are, on eye-level. However much guidance and support there is for PPI, it is reliant on this genuine interest in other people and a respect for the value of experiential knowledge. In many ways, participatory approaches force researchers to embrace their own vulnerability and be “able to handle a certain degree of chaos, uncertainty and messiness” (Lenette, 2022).

In the end, Abma et al. (2017) argue, what is “good” PPI is to be decided in dialogue with the different stakeholders and is often learned and created along the way. Meaningful and ethical involvement can be improved by the public contributors co-producing the PPI activities, both the aim, process and activities as well as the evaluation. An example of how to approach this is co-created formative process evaluations, guided by for example PiiAF (Public Involvement Impact Assessment Framework, 2024), where the researchers and public contributors jointly decide how to work and make a plan for both evaluations and follow-up.

Future research and development

The identified factors across all studies are relationship-focused rather than process-focused, which is expected due to the social nature of PPI. However, from the researcher perspective, focus on the processes are needed to support ethical and meaningful PPI. A development in this field can assist in understanding and managing the ethical issues that can arise, especially since many of them can be counteracted or even avoided if practical issues are solved early on.

A common question from researchers venturing into involvement is “how?”, along with a worry about things that can go wrong with involvement. Based on this, practice-oriented hands-on tools for ethical reflections in PPI is a desired development, along with training for researchers in participatory approaches. In addition, detailed accounts of PPI processes and outcomes provide useful insight and can help other researchers in their planning.
Institutional support is essential to overcome issues; many of the ethical and practical concerns are instigated by administrative procedures rather than by the researcher-public contributor collaboration. This is not unique for the Swedish context; for example, ethical issues with reimbursement have been identified in a previous study (Reynolds et al., 2021). We need to, as Williams et al. (2020) write, consider the contextual factors that lead to bad practices. We cannot assume that individual researchers can do ethical PPI in a system with so many barriers; institutional changes must come in parallel with researcher skill development. PPI must be institutionally acknowledged as a research approach, which could, for example, reduce issues around ethical clearance and funding, and provide training for researchers. Staniszewska et al. (2022) introduce the idea of a “kind revolution”. They speculate on whether we live in an era where research is changing towards being done together with communities, in a kinder and more relational way; I hope we are.

For future research endeavours, the idea about rigorous evaluations of PPI is intriguing. However, PPI will always depend on context and relationships and a focus on hard evidence can lead us down the wrong path. Nonetheless, evaluative methods such as the ones used in this thesis provided new insights. Especially the longitudinal approach, behavioural observations and co-writing; provided context is accounted for, these proved to be valuable for exploring PPI with forced migrants. Further research areas that have potential to contribute to more meaningful and ethical PPI with forced migrants are investigations into the motivations for forced migrants to become involved, and, as suggested by Gilfoyle et al. (2022), further exploration of the multiple dimensions of trust in PPI.
Conclusions

PPI with forced migrants should be guided by the same core principles as involvement with other populations. However, context needs to be accounted for when working with PPI. The context for forced migrants in Sweden is quite different from that of those usually involved in health research; they are at greater risk for a number of health issues as well as for suffering the consequences of epistemic injustice.

The findings in this thesis show that there are a number of additional considerations needed when involving forced migrants in health research. Trust-building processes need to be considered in relation to forced migrants’ position towards government officials; investing time in relationship-building with public contributors is likely to lead to positive results on many factors surrounding involvement, including trust. Establishing clear and inclusive communication is another key factor, including both channels for communication and language interpretation. This is preferably done together with the public contributors. Where and how decisions are made is another key factor; decision-making procedures need to be clear and transparent, or they risk excluding forced migrant public contributors from the actual decisions made.

PPI with forced migrants has a true potential to ameliorate epistemic injustice on an individual and systemic level, if done in a meaningful way. The findings highlight the need for time, communication and flexibility to sustain PPI collaborations over time – and the need for centring relationships in PPI work. Using a relational ethical lens and a reflexive approach, in addition to research ethics principles, can assist researchers in navigating PPI with forced migrants. In the Swedish setting, there is a need for acknowledging PPI work on an institutional level, in order to create conditions for researchers to work with PPI in a meaningful and ethical way.
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A special thank you to the penguin huddle, for keeping me warm in the occasionally harsh academic winter. Sharing journeys (PhD journeys as well as actual journeys) and tying academic friendship bracelets with you (i.e., making up exciting but unfinanced projects) has been the point of it all.

An important thank you goes to all forced migrant public contributors I have met and worked with along the way; both those named and those not named in this thesis. I am in awe of the courage, ambition and level of knowledge you have and choose to share; this has forever changed the way I think about knowledge and research.

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References


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Appendix 1

The interview guide for the focus group discussion, used in study I. This interview guide was used in the second focus group discussion. It was slightly altered across the three-year project, with questions added in the later focus group discussion.

Introduction

Thank you for coming today. We would like to talk with you about your motivations for taking part and how you feel it has gone so we can learn how to improve community involvement in our research. We would like to write about what we learn to encourage others to involve communities in their work in a meaningful way. We would like to record our conversation so we don’t miss any important comments. We won’t use any names when we write the report. There are no right or wrong answers. Please feel free to share your point of view even if it differs from what others have said. Keep in mind that we’re just as interested in negative comments as positive comments.

Opening the discussion

Tell me about your experiences from today.

Compared to last time you were here – has anything changed?

What are your thoughts about your role in the meeting?

Preparation for involvement

What did you think about the preparation material? What was helpful? What was not helpful?

Do you think that this affected you in any way? (Probes: how you felt about the meeting, your expectations on the meeting)?
Is there anything else that could be done, that would have helped you prepare for the meeting?

Introduction to focus group themes: Response to feedback on previous involvement

What did you think of the summary we made about your previous participation?

Do you think it reflected your thoughts and experiences? Was there anything we missed?

How did seeing the summary make you feel?

Impact on research

What do you think has gone well today?

What are your thoughts on your participation in the discussion?

What are your thoughts on how your input has influenced the research project?

What do you think could have gone better?

Were there any moments when you felt discouraged or hesitant to speak your mind?

Impact on individuals

How has taking part made you feel?

After taking part, do you feel more or less able to represent your interests and those of other refugees?
Appendix 2

Items in the observation protocol, *Active Involvement of Users in Research Observation Schedule*, and corresponding item in the questionnaire, *Active Involvement of Users in Research Questionnaire*.

<table>
<thead>
<tr>
<th>Item from Protocol</th>
<th>Questionnaire item: Public Contributors</th>
<th>Questionnaire obs. item: Researcher</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scored by observer as Low, Moderate, High*</td>
<td>Rated on Likert scale: 1 (Not at all) to 5 (A lot)</td>
<td>Rated on Likert scale: 1 (Not at all) to 5 (A lot)</td>
</tr>
</tbody>
</table>

**Domain: Interpersonal relations**

<p>| Positive interactions (+) | The interactions between me and the researchers were positive | The interactions between me and the public contributors 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 contributors to be involved because there was too much jargon or there were problems translating across languages |</p>
<table>
<thead>
<tr>
<th>Domain: Nature of contributions by public contributors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Invitations to speak (+)</td>
</tr>
<tr>
<td>Taking the initiative to speak (+)</td>
</tr>
<tr>
<td>Offering insights appearing irrelevant to discussions (-)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Domain: How public contributors guided research development</th>
</tr>
</thead>
<tbody>
<tr>
<td>Challenging research ideas (+)</td>
</tr>
<tr>
<td>Active consideration of public contributors’ ideas by the researchers (+)</td>
</tr>
<tr>
<td>Ideas being ignored/treated with disregard (-)</td>
</tr>
<tr>
<td>Decisions made without the input of public contributors (-)</td>
</tr>
<tr>
<td>-----------------------------------------------------------</td>
</tr>
</tbody>
</table>

(+)= Positive item, (-)= Negative item.

* Observers were instructed to consider both quality and quantity of a behaviour.
A doctoral dissertation from the Faculty of Medicine, Uppsala University, is usually a summary of a number of papers. A few copies of the complete dissertation are kept at major Swedish research libraries, while the summary alone is distributed internationally through the series Digital Comprehensive Summaries of Uppsala Dissertations from the Faculty of Medicine. (Prior to January, 2005, the series was published under the title “Comprehensive Summaries of Uppsala Dissertations from the Faculty of Medicine”.)