

Exploring Key Themes of Patient and Public Involvement (PPI) in Swedish Health Research Documents

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ABSTRACT

Introduction: Patient and Public Involvement (PPI) has become an important part of health research, but the existence of many different frameworks and guidelines for the process and the lack of consensus has led to fragmented procedures and terminology. There are currently no national guidelines for PPI in Sweden, and an overview of current PPI related documents could aid in the development of a common framework.

Aim: The aim of this study was to explore the key themes in PPI related documents created by Swedish health research actors as well as explore any similarities and differences between them.

Methods: A thematic analysis of PPI related documents created by Swedish health research actors was conducted.

Results: The result of this study includes five themes constructed from the data: *the entanglement of culture and structure within PPI, the importance of flexible systematic procedures, laying the foundation for collaboration in PPI, the appraisal of knowledge and education and ethical aspects of PPI.* The similarities found are illustrated by the themes as they were constructed based on similarities and patterns found between the documents. The main differences found include terminology used for collaboration and PPI itself, differences in emphasis put on ethical considerations depending on actors involved and different guidelines for financial compensation.

Conclusions: The key themes highlight the many similarities that exist between the documents, and considering these along with the differences can aid in constructing a common framework for PPI in Swedish health research.

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ABBREVIATIONS

PPI Patient and Public Involvement

EUPATI European Patient's Academy for Therapeutic Innovation

TA Thematic Analysis

SALAR Swedish Association of Local Authorities and Regions

1 INTRODUCTION

Background

In the past few decades, Patient and Public Involvement (PPI) has become an integral part of health research. Patients contribute with a unique perspective and experiential knowledge that adds to and complements the professional knowledge of researchers when developing and conducting research (Hewlett et al., 2006). The notion of ‘nothing about us without us’ (Charlton, 2004) is applicable to PPI as “a more collaborative and reciprocal partnership approach with patients has the potential to ensure that research undertaken matters to a wider tranche of society and involves those who stand most to benefit from it” (Hoddinott et al., 2018, p. 14). It is important to note that PPI in this context refers to involvement of patients and the public in the research process itself and not patients as participants that contribute with data to clinical trials for example. Within the process of PPI, the patient takes on an active role as opposed to being a passive recipient of the research results post hoc (Liabo et al., 2018). The active participant of PPI refers to patients, service users, members of the public, patient representatives, family members and carers for example (Hoddinott et al., 2018). Hereon after, this group will be referred to as patients as a way of differentiating them from professional research actors such as individual researchers, research institutes, pharmaceutical companies, universities and state- and regional agencies.

In a study conducted by Baines & Regan de Bere (2018), essential and desirable principles of PPI was identified through a systematic review, as well as by using the Delphi technique with PPI experts, including both patients and researchers. Essential principles, with >75% agreement among the participants, included working in equal partnership, communication and sharing knowledge and power for example. Desirable principles, that did not reach >75% agreement, included aspects such as evaluation and empowerment. The authors also direct attention to the fact that research regarding PPI often is based on the opinions and experiences of professionals rather than patients, whereas their study includes the perspectives of both patients and professionals. Results showed an initial lack of consensus regarding essential and desirable aspects among the experts and the authors mention the complexity of reports on PPI in current studies, and specifically the impact of different contexts (Baines & Regan de Bere, 2018). The definition and procedures of PPI are constantly under development but there exist some frameworks that are more frequently referred to in literature. One of these is NIHR INVOLVE, a program started in the UK in 1996 that “aims to advance the role of PPI in all phases of the research process, including research prioritisation, design, conduct and dissemination” (Gray-Burrows et al., 2018, p. 858). One example of PPI within health research can be found in a study by Skovlund et al. (2020). The authors conducted a clinical trial to measure the effect of questionnaires as dialogue tools between patients with metastatic melanoma and care providers and included five patients throughout the whole research process. This entailed co-selecting of questionnaires during the design phase, but also separately

analyzing the results to see if patients and researchers agreed in their analysis. The researchers mention that they did agree but that the patients also added a distinct perspective and different vocabulary, compared to the researchers, to explain the results (Skovlund et al., 2020).

One of the most widely applied theoretical models for PPI research and development is Arnstein's Ladder of Citizen Participation (Arnstein, 1969). The model was initially developed to illustrate the shift of power that takes place between decision makers and members of the public due to participation within democratic processes (Van Der Scheer et al., 2017), and it has later been related to the PPI process in health- and healthcare research (Pii et al., 2019). The rungs of the ladder, moving from manipulation and consultation to partnership and citizen control, depict the redistribution of power with Arnstein equating power with participation (Arnstein, 1969). Some researchers have criticized the model and its focus on hierarchy and shifting power, calling it an over-simplification of citizen participation (Tritter & McCallum, 2006). However, the Ladder of Citizen Participation is still a foundational and influential model within PPI research and the development of PPI frameworks. For instance, in a recent study by Bergholtz et al. (2024) the authors found that "some of the frameworks that are being applied for PPI in healthcare quality improvement, community-based initiatives and the education of healthcare professionals have clearly evolved from Arnstein's ladder."

At this point it is also necessary to create a distinction between PPI in healthcare and health research. Even though similarities exist, Modigh et al. (2021) also point out the differences, such as legal regulations but also overall purposes. Healthcare can be described as services aimed at treating illness and maintaining health for example, and PPI can take place in areas related to different types of decision-making, both at policy level but also in patient-provider interactions. Health research, also called medical or clinical research, is a process that aims to methodically contribute with knowledge that will improve health, identify risk factors, and develop treatments and public health interventions for example. PPI can take place in all phases of the health research process, from the initial development to reporting results (Modigh et al., 2021). Previous research by Bergholtz et al. (2024) has provided a systematic overview of PPI in healthcare, not including PPI in health research. This study will therefore focus on PPI as it relates to health research specifically, to expand the knowledge within this area.

PPI in health research – an overview

Previous research has examined procedures for PPI as it relates to different health research areas and methods. In a study by Pii et al. (2019), different aspects, such as methods, purposes, challenges and recommendations, of PPI in cancer research was explored. The authors found that one of the barriers to making methodological or procedural recommendations for PPI within the research process is that methods vary considerably and that the reporting of PPI in studies often is inconsistent and unspecific (Pii et al., 2019). This can also be illustrated by the fact that there exist a plethora of PPI frameworks and

guidelines for research that are often used mainly within a single local context (Greenhalgh et al., 2019). Furthermore, a study by Tanay et al. (2023) elucidates the significance of doctoral students and young researchers being exposed to PPI early in their training. The authors mention the importance of early education for researchers on PPI, specifically regarding why it is important, how it is utilized and therefore working toward a universal understanding of PPI.

Additionally, it is important to also highlight research that explores patient's experiences of PPI in health research. Gorbenko et al. (2022) conducted a study exploring patient's perspectives of impact measurements that are used for PPI within the biopharmaceutical industry. Results showed that patient's find impact measurements for patient involvement important as a palpable measure of contribution leads to a sense of achievement and claim to the outcome. This is confirmed by the fact that Hovén et al. (2020) found, in a study including both patients and researchers, that patients find it important that the input they contribute with is noticeable. Also, Shahid et al. (2022) conducted a scoping review of literature that examines assessment of PPI in research. Within their study, the authors included and consulted two patients that have experience with participating in research. The participants "expressed a desire for an accessible lay resource to help people like them (i.e., citizens) be a meaningful part of research and stated that such a resource would vastly improve their comfort level with participating in research" (Shahid et al., 2022, p. 14). The courses provided by EUPATI could be described as such a resource.

EUPATI, or European Patient's Academy for Therapeutic Innovation, is an online educational platform that aims to supply patients with the knowledge necessary to contribute to health research, such as pharmaceutical research and health economical evaluations (EUPATI Sverige, 2024a). A platform such as EUPATI also raises questions of the different types of knowledge contributed by actors within PPI processes. Research has traditionally been described as a process of generating knowledge that is characterized by the un-biased and objective position of the researcher that possesses professional expertise within a specific area (Beresford & Russo, 2020). The experiential knowledge that patients contribute with could be considered to challenge this ideal:

The introduction of experiential knowledge into research that came about with PPI, to which traditional research principles grant less value and credibility, can be seen to be at odds with such thinking. Experiential knowledge is understood as knowledge that comes from lived experience rather than from professional training or research and experiment. (Beresford & Russo, 2020, p. 163)

The different knowledge being possessed by patients and researchers may not only affect the research being conducted during PPI but also the creation of frameworks that guide the process itself. Different understandings of the research process, and which knowledge should be prioritized, can be expected to inform the creation of guidelines for PPI. Patient's taking part of scientific knowledge as it relates to health research, through sources such as EUPATI, is one way of developing the process of PPI. But the

process, and its guidelines, also needs to be evaluated from different perspectives, such as different cultural contexts between countries (Beresford & Russo, 2020). In 2021, EUPATI Sverige (2024b) launched the Swedish version of the educational platform and thereby provided Swedish patients with tools to contribute to health research. Previous literature has explored PPI practices in the Nordic countries (Dengsø et al., 2023) but there is a limited amount of research exploring PPI in health research specifically in a Swedish context.

PPI in a Swedish context

The Swedish government's 2024 proposition for research and innovation mentions the importance of Patient and Public Involvement in health research related to precision medicine and women's health for example. However, the proposition does not detail the process or scope of involvement, and it also does not define the roles of the different involved actors (Prop. 2024/25:60). There are currently no official national guidelines or a common framework for PPI within a Swedish context, meaning that different health research actors depend on internal documents for collaboration with patients and members of the public. This includes corporate actors such as pharmaceutical companies but also state agencies, patient organizations, universities and research institutes. Guidelines is sometimes referred to as more general recommendations and a framework more comprehensive and systematic structures (Wang et al., 2018). Both terms will be used in this study as the specific need for either guidelines or a framework is still unclear within a Swedish context and the terms are often used closely in relation to each other or even synonymously (Greenhalgh et al., 2019).

The proposition also mentions the importance of research on prevention and public health. Specifically in relation to risk factors for ill health that can be addressed through interventions and the measurable health inequities between different groups in society. Furthermore, the proposition states that "research is also needed on civil society's efforts and cooperation with public actors in relation to the preventive work of public health" (Prop. 2024/25:60, p. 112). Research exploring the public's involvement and cooperation with actors working towards promoting health, and health related research in general, is needed as the lack of a common framework for PPI could result in miscommunication in collaborations, meaning that differences in definitions and procedures surrounding PPI could affect research outcomes (Dengsø et al., 2023).

The lack of national guidelines for PPI in a Swedish health research context creates uncertainty regarding which framework to follow as well as the roles of the participants. It is important to clarify however that a framework may need to be adapted based on different research contexts. Having national guidelines for PPI to promote effective, safe and satisfying collaborations for better research and to promote health does not imply that one size fits all. Having one overarching framework as opposed to multiple internal documents, however, could help prevent miscommunication and further clarify the process and roles of

both patients and researchers. A common framework could also act as a reference for evaluating the process of PPI in health research and developing it further. To aid in the development of national guidelines for PPI in health research in Sweden, it is necessary to explore the key themes of PPI mentioned in current documents. It is also crucial to examine similarities and differences between documents regarding PPI among key actors in Swedish health research. Health research actors, in this context, refers to all actors involved in the process of health research including researchers, pharmaceutical companies, research institutes, state- and regional agencies, universities, patients and patient organizations.

2 AIM

This study aims to explore key themes and examine what similarities and differences exist between internal documents and statements regarding PPI of different health research actors in Sweden. This could assist in future development of national guidelines for PPI in Sweden, based on the possible similarities as well as the potential to discuss and attend to any possible differences. By building on previous research examining PPI in health research, this study will contribute with an overview of PPI related documents among different actors within Swedish health research specifically, an angle of research that has not yet been extensively explored. As the overarching goal of this study is to examine key themes, similarities and differences in PPI related documents of actors in Swedish health research, the research questions that will be answered within this study are:

1. What are the key themes in PPI related documents among health research actors in Sweden?
2. What similarities and differences exist between PPI related documents among the different actors?

3 METHODS

To answer the research questions of this study, a thematic analysis of PPI related documents created by Swedish health research actors was conducted. The following chapter gives an account of the philosophical assumptions and theoretical framework underlying this study, how data collection and analysis was performed as well as ethical considerations.

Philosophical assumptions and theoretical framework

With the aim of contributing with an overview of the key themes of PPI related documents within Swedish health research, as well as explore similarities and differences, it is important to clarify the philosophical assumptions and theoretical framework that are underlying this study. This is crucial to note as the researcher's assumptions inform both theories and methods used in analyzing the data, and may therefore have an impact on the communicated results (Creswell & Poth, 2018; Malterud, 2001). In terms of ontological assumptions, or the nature of reality, in this qualitative study, multiple realities are assumed to exist and the different perspectives within the documents will be reported through the findings. Epistemological assumptions, or the assumptions of what counts as knowledge (Creswell & Poth, 2018), is not only relevant to the researcher's knowledge but in this context also the knowledge of actors within the PPI process. As previously mentioned, patients and researchers can be said to contribute with different types of knowledge, experiential and professional respectively (Beresford & Russo, 2020). Devaluing of certain knowledge, such as the experiential knowledge of patients, can be described as *epistemic injustice*:

PPI in research thus raises the uncomfortable issue of including experiential knowledge centrally and on equal terms with other kinds of knowledge. It means working towards achieving epistemic justice and ensuring that everybody can contribute to creating a general knowledge base and that perspectives of entire social groups are no longer excluded from that process. (Beresford & Russo, 2020, p. 163)

As existing guidelines for PPI have been developed by actors possessing both experiential and professional knowledge, such as actors within pharmaceutical companies or patient organizations, this is important to be aware of during the analysis of similarities and differences in the documents. The discussion of knowledge is also relevant to the theoretical framework of this study, which could be described as social constructivism. This framework assumes a position that challenges the idea of objective knowledge and instead assumes that knowledge is constructed within a social context (Detel, 2001; Kim, 2024). The existing guidelines of PPI can be said to have been constructed based on interactions between actors and creates meaning for the roles of patients within the process (Creswell & Poth, 2018). Acknowledging the social constructivist nature of the guidelines and descriptions of PPI is

important both when exploring similarities and differences but also when discussing the future construction of a common framework.

Data collection

To answer the research questions, the data utilized in this study consists of reports, informational brochures, web pages and other types of internal documents stating guidelines, frameworks and procedures for PPI within operations of different Swedish health research actors. During an initial overview of available documents, it became apparent that several actors did not have publicly available documented guidelines for the PPI process. Therefore, a wide variety of documents were included to ensure that any text produced by a Swedish health research actor that included discussions about PPI and its procedures were incorporated into the analysis. The sampling strategy could be described as opportunistic (Creswell & Poth, 2018) as websites and documents of different health research actors were used to locate additional documents. For example, collaborating partners of EUPATI Sverige were used as a reference for collecting documents as they are active within PPI in Swedish health research. EUPATI Sverige collaborates with a wide variety of actors ranging from pharmaceutical companies, regions (self-governing local authorities), research institutes and patient organizations (EUPATI Sverige, 2024b). Also, two patient advisors with experience of the PPI process contributed with their knowledge of existing documents created by key actors, and the role of the patient advisors within this study is specified further under ethical considerations. Additionally, the search function on websites of various Swedish health research actors were utilized to acquire documents by using search words related to PPI such as *patientsamverkan* (patient collaboration), *patientmedverkan* (patient involvement) and *brukarmedverkan* (service user involvement). Although an opportunistic sampling strategy was used, the search for documents was broad and comprehensive, aiming to include all available documents on PPI created by Swedish health research actors rather than only a sample. However, it is important to note that some documents may have been overlooked or been published after the analysis was conducted. The inclusion criteria for included documents were that the document is publicly available, the document includes aspects related to the process of PPI in health research and were developed by a Swedish health research actor.

In total, 23 documents were included for analysis (see Table 1). The term document encompasses (within this study) guidelines, frameworks, reports, regulations, statements, informational brochures, web pages and any internally produced text related to PPI by a Swedish health research actor. Therefore, the documents differ in length and scope. Included documents were created by a variety of actors; government bodies and agencies (n=6), patient organizations and non-profit organizations (n=6), regions (n=2), industry associations for health research companies (n=2), a university (n=1) and documents created as a collaboration between several different actors (n=6). Some of the documents include

information and procedures related to healthcare and other processes but only sections that discuss PPI within health research was included in the analysis.

Table 1. Documents included in analysis, in alphabetical order (n=23)

| Document ID | Actor/author | Title (<i>translation</i>) | Type of document | Pages | Date | Source |
|--------------------|---------------------|---|-------------------------|--------------|-------------|----------------------|
| #1 | Blodcancerförbundet | Personspecifikation för Patientpanelen <i>(Person Specification for the Patient Panel)</i> | Informational document | 3 | n.d. | Link |
| #2 | EUPATI Sverige | EUPATI Sveriges rekommendationer för hur patientinvolvering organiseras <i>(EUPATI Sverige's Recommendations on How to Organize Patient Involvement)</i> | Informational document | Web page | n.d. | Link |
| #3 | Forska!Sverige | Agenda för hälsa och välbefinnande <i>(Agenda for Health and Prosperity)</i> | Report | 80 | 2023 | Link |
| #4 | Forska!Sverige | Agenda för hälsa och välbefinnande – Granskningsrapport 2022–2024 <i>(Agenda for Health and Prosperity – Assessment Report 2022–2024)</i> | Assessment report | 53 | 2025 | Link |

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|----|--|---|---|----|------|----------------------|
| #5 | Forska!Sverige | Hälsodata – till er tjänst! – Tre krafttag för att omsätta hälsodata till patientnytta <i>(Health Data - At Your Service! - Three Actions to Turn Health Data into Patient Benefits)</i> | Report | 76 | 2024 | Link |
| #6 | Forte (Kylberg et al.) | Brukarmedverkan – Forskning med och om brukarmedverkan <i>(Service User Involvement – Research with and about Service User Involvement)</i> | Report | 8 | 2015 | Link |
| #7 | Forte | Forskning möter samhälle – Fortes förslag till forskningspolitik 2017–2027 <i>(Research Meets Society –Forte's Proposals for Research Policy 2017–2027)</i> | Proposal for the Government's research politics | 13 | 2015 | Link |
| #8 | Forum Spetspatient (Sara Riggare et al.) | Spetspatienter – En ny resurs för systemförbättring <i>(Expert patients – A New Resource)</i> | Report | 48 | 2020 | Link |

| | | | | | | |
|-----|---|---|-------------------------|----------|------|----------------------|
| | | <i>for System Improvement)</i> | | | | |
| #9 | Funktionsrätt Östergötland | Att arbeta med forskningspartner – Så här gör du som forskare om du vill arbeta med forskningspartner (<i>Working with research partners – What to do if you as a researcher want to work with research partners</i>) | Informational Web page | Web page | n.d. | Link |
| #10 | Lif & Handikappsförbunden/ Funktionsrätt Sverige | Handbok – Samarbete mellan Handikappförbunden och Läkemedelsbranschen (<i>Handbook – Collaboration between Disability Associations and the Pharmaceutical Industry</i>) | Handbook | 24 | 2012 | Link |
| #11 | Lif | Läkemedelsbranschens etiska regelverk (<i>The Ethical Regulations of the Pharmaceutical Industry</i>) | Ethical Regulations | 100 | 2022 | Link |
| #12 | Regeringskansliet | Bättre tillsammans – Förslag till en | Proposal for a national | 694 | 2024 | Link |

| | | | | | | |
|-----|---|---|------------------------|----------|------|----------------------|
| | | uppdaterad nationell cancerstrategi <i>(Better together – Proposal for an Updated National Cancer Strategy)</i> | cancer strategy | | | |
| #13 | Region Örebro län | Till dig som vill bidra i forskningsprojekt med din erfarenhet som patient, brukare eller närstående <i>(For Those Who Want to Contribute to Research Projects with Their Experience as a Patient, Service User or Family Member)</i> | Informational Brochure | 2 | n.d. | Link |
| #14 | Reumatikerförbundet | Om forskningspartners <i>(About Research Partners)</i> | Informational Web page | Web page | n.d. | Link |
| #15 | SAMKA/Samverkan 2.0 (Clareborn et al.) | Patient- och närståendesamverkan för bättre forskning och hälso- och sjukvård <i>(Patient and Related Party Engagement for</i> | Report and guidelines | 60 | 2023 | Link |

| | | | | | | |
|-----|---|--|------------------|----|------|----------------------|
| | | <i>Better Research and Healthcare)</i> | | | | |
| #16 | Samverkansnämnden, Uppsala-Örebro Sjukvårdsregion | Strategi för forskning inom hälso- och sjukvård 2018–2024 <i>(Strategy for Research in Healthcare 2018–2024)</i> | Strategic Agenda | 5 | n.d. | Link |
| #17 | Svenska Covidföreningen | Att utforma studier för patienter med PEM – en guide till dig som forskare <i>(Designing studies for patients with PEM - a guide for researchers)</i> | Guidelines | 15 | 2025 | Link |
| #18 | Swelife | Swelifes strategiska agenda <i>(The Strategic Agenda of Swelife)</i> | Strategic Agenda | 25 | 2021 | Link |
| #19 | TLV | Myndighetsgemensam vägledning för ersättning vid patient-, brukar och närståendemedverkan <i>(Inter-Agency Guidance on Reimbursement for Patient, Service User and Related Party Involvement)</i> | Guidelines | 6 | n.d. | Link |

| | | | | | | |
|-----|--|---|------------------------|----------|------|----------------------|
| #20 | Universitetssjukvårdens forskningscentrum | Verksamhetsberättelse 2023 (<i>Annual report 2023</i>) | Annual Report | 27 | 2024 | Link |
| #21 | Uppsala University Research Group Child Health and Parenting (Inge et al.) | Handbok för samskapande forskning (<i>Handbook for Co-Creative Research</i>) | Handbook | 32 | n.d. | Link |
| #22 | Vetenskap och Allmänhet | Medborgarforskning – Vetenskap & Allmänhets definition (<i>Citizen Research – Vetenskap & Allmänhet's Definition</i>) | Informational Web page | Web page | 2024 | Link |
| #23 | Vetenskapsrådet | Forskningsöversikt 2023 – Klinisk behandlingsforskning (<i>Research Overview 2023 – Clinical Treatment Research</i>) | Report | 25 | 2023 | Link |

Data analysis

To analyze the collected data, a thematic analysis (TA) of documents related to PPI was performed. As thematic analysis “is a method for identifying and analyzing patterns of meaning (themes) in qualitative data” (Clarke & Braun, 2014, p. 1948), this method is appropriate for the aim of exploring key themes as well as similarities and differences between documents regarding PPI among Swedish health research actors. Clarke & Braun (2014) describe thematic analysis as a method that can be used with a wide variety of theoretical frameworks, such as those related to constructivism. When choosing to utilize

thematic analysis as a method it is therefore also essential to clarify more specifically what analytical steps are taken, as TA can be described as an umbrella term. Some schools of TA attempt to bridge quantitative and qualitative research and in some cases utilizes already existing codebooks for the analytical process. This type of TA assumes a position of consensus and “correct” analysis of codes, as well as aims to control for research bias and influence from the researcher (Braun et al., 2019). This school of TA is not relevant to this study as the underlying philosophical assumptions and interpretive framework take on a social constructivist approach and assumes the subjectivity of knowledge. The documents that were analyzed within this study were constructed by actors with different experiences of the PPI process and exist within different contexts of health research and therefore do not call for a “correct” interpretation. The overall aim of this study is to create an overview of the key themes related to PPI within these documents, as well as similarities and differences between them, as the meanings may inform future work toward a common framework. This agrees with the school of *reflexive TA*:

The aim of coding and theme development in reflexive TA is not to “accurately” summarize the data, nor to minimize the influence of the researcher subjectivity on the analytic process, because neither is seen as possible nor indeed desirable. The aim is to provide a coherent and compelling *interpretation* of the data, grounded in the data. (Braun et al., 2019, p. 848)

The author of this study has previous knowledge and insights into the PPI process, due to conducting research within this area, which contributed to the analysis. Within the school of reflexive TA this is considered a resource and the method emphasizes “the active role of the researcher in the knowledge production process” (Braun et al., 2019, p. 848). The knowledge of the researcher interacted with the knowledge within the analyzed documents and contributed to the construction of new knowledge. The researcher also has experience as a patient and therefore possesses experiential knowledge and an insight into the perspective of the patient, which contributed to the analysis. Apart from the researcher’s interpretation of the data, the subjectivity of the data itself is also emphasized (Braun et al., 2019). The different actors and their prioritizations affect the content of the documents and therefore the themes and meanings constructed. As previously mentioned, this is important to note as a future common framework would include meanings from several actors and be created within this context of social constructivism.

The process of reflexive TA that was utilized within the analytical process of this study will now be described through the six steps developed by Clarke & Braun (2014). The first step included familiarization with the material as all collected documents were imported to the reference software Zotero. Familiarization in this context meant immersion into the data by reading the documents whilst taking casual notes and notice of any possible connections and patterns in the data without assigning any labels (Braun et al., 2019). Excerpts from the data pertaining to PPI were translated from Swedish to English and put in an extraction table to prepare for the second step which was coding the data. Before coding, some linguistic choices had to be made as the data was translated. One such choice was deciding

on using the translation *patient and related party/parties' involvement* for the term *patient- och närståendesamverkan*. This choice indicates that the word *närstående* does not only refer to direct relatives of a patient but any close related party. It was decided to translate the excerpts before analysis to ensure that the results presented did not change meaning between analysis and presentation but stayed consistent through language and words used to code and construct themes.

The second step included generating codes for the excerpts. For this process an inductive orientation was adhered to, meaning that the analysis started from the data, bottom-up, and no theoretical model for PPI was utilized during this step of the process (Braun et al., 2019). Adhering to an inductive orientation during analysis does not mean that the researcher acts as a blank slate in the process, as they possess previous knowledge and exist in a social context, but rather that the analysis is data-led and no theoretical model or concepts are used as a foundation for coding (Willig et al., 2017). Instead, the results of this study will be discussed in relation to existing models. Most codes generated were semantic (more surface-level and explicit) but there was also some codes that captured latent meaning (more conceptual or implicit) that contributed to the next step of constructing the themes and subthemes (Braun et al., 2019).

Constructing initial themes was the third step performed and included revisiting the excerpts and generated codes to identify patterns in the data. This also included identifying similarities and differences between the documents. The codes were grouped together and in some cases a code even became a candidate theme or subtheme. The themes can be described as constructed rather than discovered as “themes are constructed by the researcher, based around the data, the research questions, and the researcher’s knowledge and insights” (Braun & Clarke, 2022b, p. 35).

The fourth step entailed developing the themes further, and in some cases discard themes, as they were checked against the coded excerpts and the whole dataset. During this step, the themes were also considered in relation to each other and a preliminary thematic map was constructed. Additionally, the supervising professor of this study and one patient advisor agreed to check some of the coding and candidate themes. This was done to encourage further development and processing of the themes through discussion, rather than assessing the quality of the analysis. To ensure quality for reflexive TA it has been recommended for the researcher to engage in reflexivity regarding their own position and expectations throughout the whole process, as the subjectiveness of the researcher contributes to the construction of themes that is to be presented as results of the analysis. The author of this study continuously kept notes throughout the process which is encouraged to deepen reflexivity (Braun & Clarke, 2022a).

Finally, the last two steps included refining and naming the themes and writing up the results (Braun et al., 2019). During the fifth step of refining and defining the themes, some subthemes were removed or

combined, and themes were renamed to better illustrate the patterns found within the data. The thematic map was also refined to clearly illustrate the themes and their relation to each other. The final step included presenting the themes in a narrative structure that highlighted the patterns in the data and to answer the research questions. The research questions were continuously revisited throughout the entire analytical process and some adaptations were considered. This mainly pertained to the fact that the analysis resulted in the similarities identified being incorporated into the construction of themes. Therefore, the presented key themes also illustrate the identified similarities between the documents. The research question regarding similarities and differences was still considered relevant as this question is answered by the results of this study, through the themes as well as identified differences.

Ethical considerations

As the documents used within this study are public and do not contain sensitive information, no ethical approval was necessary. However, it is still important to consider the ethical impact of this research regardless. One of these considerations include the presentation of actors within the PPI process (Braun & Clarke, 2022a). Patient and Public Involvement in health research is a process that includes a variety of actors with varying degrees of influence over the process itself. This is important to consider when analyzing possible similarities and differences in guidelines between the actors but also when presenting the results, as they could impact the construction of a common framework and therefore processes the actors are involved in.

As this research project discusses the concept of PPI, the author of this study could be considered the professional research actor within this context. Including an actor representing patient or public actors is relevant not only from an ethical standpoint, but also as it is valuable to the development of the research and validation of the results. Therefore, two participants that have experience of being patient co-researchers acted as patient advisors during the duration of this project. Due to the limited timeframe and resources of this study, a process that fully utilizes a PPI framework in every step of the research was not feasible. However, the NIHR INVOLVE framework and UK standards were consulted and adhered to as much as possible. These frameworks were chosen as there currently exist no common guidelines for PPI in Swedish health research, but NIHR INVOLVE is an often-mentioned resource within PPI literature (Wilkinson et al., 2024). At least one of the patient advisors was involved throughout all phases of the research process, from the initial development of the study to data collection, analysis, presenting the results and discussion. To further highlight the contribution of the patient advisors, one discussion led to a linguistic change where the term stakeholders was replaced by key actors. The term stakeholders exist in a historical context of colonialism and is often not properly defined (Reed et al., 2024). Opting for the term key actors is a move away from the word stakeholders but it is also a clearer description for the most prominent actors within Swedish health research.

4 RESULTS

To present the results of this study, each constructed theme will be presented with excerpts from the analyzed documents to illustrate the patterns found within the data. Additionally, a thematic map (see Figure 1) was constructed during the analysis and gives an overview of the themes and subthemes that are presented. The thematic map and themes presented aim to answer the research question regarding the key themes in PPI related documents among health research actors in Sweden.

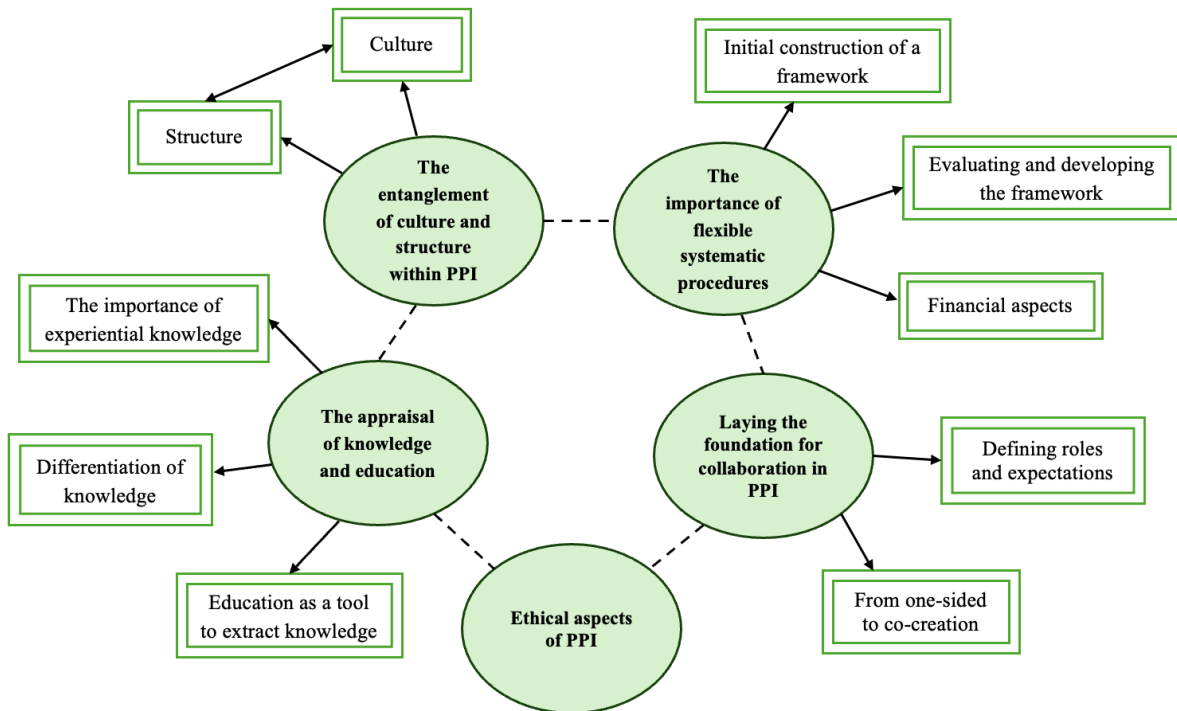


Figure 1. Thematic map

The entanglement of culture and structure within PPI

The first theme that was constructed from the documents was named *the entanglement of culture and structure within PPI*. This theme builds on patterns found in the data elucidating how the culture developed within the process of PPI, and among its participants, informs the structure and vice versa. To illustrate this entanglement, the concepts of culture and structure within PPI first needs to be clarified further. The notion of culture and structure is, in the context of this study, based on how the terms are used within the documents included in the analysis:

There is a need for cultural and structural change in research and healthcare around patient and related parties engagement. Structural change means that organizations need to review their leadership, administration, financial systems and the way they work. Cultural change largely

concerns the mindsets and attitudes of individuals. Structure and culture need to interact and complement each other to get the most out of working together. (Document #15)

Structure refers to the literal structures for PPI available within a health research actor's organization:

Without a structure, for example in the form of processes, IT systems, allocated working hours, budgets, management systems and adapted leadership, collaboration becomes burdensome both administratively and in terms of time. (Document #15)

This sentiment is reoccurring in PPI related documents of Swedish health research actors:

For successful implementation in all aspects of research, patient engagement structures and processes need to be systematically designed. (Document #3)

Culture is described as the mindsets and attitudes of individuals, such as researcher's attitudes toward patient participants:

[...] the researcher must be very open and adapt to different circumstances and different people. (Document #21)

But it is also apparent in how culture is developed within the actual process of PPI that individuals are taking part in. Such as developing a culture of trust:

Expect much of the initial collaboration to be social and personal. Be generous and share. Becoming people to each other, instead of professions or roles, is important for us to trust each other in the collaboration. Trust in each other is important for both researchers and co-researchers. (Document #21)

Creating a culture of trust early in the process is deemed important to the structure of PPI:

Co-creative research is largely based on trusting relationships between researchers and co-researchers. Laying the foundation for this is particularly important at the beginning. (Document #21)

The culture that permeates the structure and process of PPI is important, but the available structure also informs the culture that is developed among the collaborators:

A structure for collaboration is therefore necessary to develop a long-term sustainable culture of collaboration. (Document #15)

For this theme, the codes generated during the analysis were split into two subthemes of culture and structure. However, several of the codes could be placed under both subthemes which further illustrates

the entanglement of culture and structure in PPI. One example of this is how the code *communication* is relevant to both the culture and structure of PPI:

The most important thing is that communication is good and clear. Everyone involved should feel heard and appreciated. (Document #21)

Having a well-functioning communication structure within the process of PPI fosters a culture of communication where participants feel heard. This culture in turn informs the structure and thereby illustrates the entanglement of culture and structure in PPI:

Strive for all participants to contribute as equal actors to foster a culture of collaboration and mutual respect, for example in the planning of work, travel, commitment and compensation. (Document #2)

A culture of collaboration permeates the PPI structure:

The research process is characterized by being carried out together with users, with continuous feedback for mutual reflection and action between the parties as an important principle. (Document #6)

Another aspect that is highlighted within the documents is the fact that PPI is a collaboration between two or more actors that do not necessarily adhere to similar internal guidelines for PPI and other collaborative processes:

To facilitate possible collaboration, the parties involved should familiarize themselves with the organizational/company structure of the other parties. Organizations and companies can operate very differently in terms of, for example, decision-making processes. (Document #10)

Bridging the structure and culture of at least two different actors is considered difficult when collaboration through PPI is carried out on a case-by-case basis:

It is common for collaborative initiatives to be temporary interventions carried out in the form of projects, for example, rather than actions implemented in a permanent way in existing structures and systems. This means that any impact will also only be temporary. Structural changes are needed in the short term and can lead to cultural changes in the longer term. (Document #15)

The notion of culture and structure being entangled within PPI is apparent in how the temporary nature of collaboration, and lack of a common framework, is described as a hindrance for cultural change within the process of PPI.

The importance of flexible systematic procedures

The second theme, *the importance of flexible systematic procedures*, further highlights how the importance of a common framework is expressed in the documents through three different subthemes: *initial construction of a framework*, *evaluating and developing the framework* and *financial aspects*. This theme builds on the reoccurring mentioning of not only the importance of systematic procedures, but also of a common framework for PPI being adaptable to different health research contexts.

Initial construction of a framework

The subtheme *initial construction of a framework* is based on the concurrence of actors calling for the construction of a national policy for PPI:

We propose that the government commissions the research councils and Vinnova, in collaboration with patient representatives, to develop a national policy for patient participation in calls and research support linked to clinical research. (Document #3)

However, several actors are called upon to be responsible for the practical construction of a national policy depending on which part of the research process is attended to:

The Swedish Association of Local Authorities and Regions (SALAR) [...] should develop a national policy for patient participation in the planning, implementation and evaluation of clinical research. In addition, follow up that the regions create a structure for patient collaboration based on this policy. (Document #3)

There are both state- and regional level actors mentioned as possible candidates for constructing a common framework, but it is also emphasized that patients should be involved in the construction process.

Another recurring aspect pertaining to the construction of a framework is the emphasis on flexibility and acknowledging that this is a prerequisite for a common framework to function within the context of PPI:

Studies show that flexible collaboration models that can be adapted to specific conditions and needs are more useful. It is unrealistic that one framework or toolbox could be applied to all contexts. At the same time, it is important to emphasize that overlapping initiatives and constantly reinventing the wheel have an erosive effect on collaboration. (Document #15)

This excerpt does not only express the importance of flexibility and adaptability of a common framework but also the erosive effect that utilizing many different frameworks may have on collaboration. Different frameworks that are employed among actors also contributes to different terminology used:

Important knowledge gaps to fill are: More well-defined and consistent terminology; Theoretical grounding; Better knowledge of which users should be involved depending on the question and

application area; Continued development of valid methodology for evaluating research with user participation. (Document #6)

Apart from the initial construction of a common framework, the importance of continuous evaluation and development of the collaboration process is also a recurring subject within the documents.

Evaluating and developing the framework

The flexibility of a common framework is not only discussed in relation to constructing a framework that is adaptable to different research contexts but also throughout the process of collaboration:

We suggest using the framework in a formative way: returning to the framework at regular intervals during the project. The team then reflects together again to identify new ethical issues and consider improvements. (Document #21)

The subtheme of *evaluating and developing the framework* is therefore another example of the importance of flexible systematic procedures:

Evaluate frequently to identify success factors and challenges and introduce improvements for long-term effectiveness and relevance. (Document #2)

Apart from a framework that guides the actual process of PPI, there is also mentions of guidelines for how the PPI process should be evaluated and measured to aid in the development of the process:

We propose that the government commissions the appropriate authority to develop a national standard for measuring patient involvement in the design of clinical research and participation in research studies. (Document #3)

Guidelines for evaluation is deemed important, but it is also highlighted how additional guidelines should aid in the process of development and not be a hindrance:

An important aspect of evaluation and integration can be the development of policy documents and documentation. However, it is important to design these in such a way that they do not become another obstacle on the way to good collaboration. (Document #15)

There are many aspects to include within a common framework for PPI and the importance of flexibility and therefore being able to continuously, and systematically, develop it is mentioned by several actors within the data.

Financial aspects

The subtheme of *financial aspects* highlights another important aspect, namely the financial compensation of patient participants:

Review the budget so that expenses, co-researchers' working hours and researchers' time for co-creative work can be financed. Review the organization's procedures so that it is possible to provide financial compensation to co-researchers. (Document #21)

There exist different guidelines for financial compensation among actors such as pharmaceutical companies and state agencies, but a common thread is the importance of having systematic procedures and agreements in place:

Compensation for work performed shall be reasonable in relation to the scope of the assignment. The time spent, the amount of compensation and how the compensation is regulated must be stated in the written agreement. (Document #11)

The importance of flexibility is also apparent in discussions of financial compensation in PPI, specifically in relation to participant's financial situation:

However, flexibility and dialogue may be required on the appropriate form of compensation for involvement, especially if the group of patients or related parties you want to engage with are on income support or sickness benefit. (Document #15)

Laying the foundation for collaboration in PPI

A flexible common framework for the PPI process contributes with a map to follow but to practically utilize it during collaboration within different health research contexts is the base for the third theme of *laying the foundation for collaboration in PPI*.

Defining roles and expectations

A continuation of the importance of a common framework is utilizing it in the beginning of the process to lay the foundation for a well-functioning collaboration:

The framework is introduced in the first meeting with researchers and co-researchers. Each question in the four steps is addressed in the conversation, which lays a good foundation for a common understanding of the project and collaboration. (Document #21)

The subtheme of *defining roles and expectations* is based on how this is deemed important to avoid misunderstandings and engaging patients early in the process is also emphasized:

Engage patients and related parties as research partners early in the research process to get help through all phases. (Document #8)

There is also emphasis on the fact that the actual process of defining the objectives and expectations for the collaboration should be a collaborative effort in itself:

The work should start with defining aims and objectives and establishing a process for joint evaluation and monitoring. Policy documents can support this process, but their development should also be based on a co-creative perspective. (Document #15)

This is a common thread throughout the data:

Develop the aims and objectives of patient involvement in the project together. (Document #2)

As PPI involves actors with different backgrounds working together, the initial definition of roles is stressed:

At the beginning of a collaboration, there is always a need to clarify expectations and roles, answer questions and get to know each other. (Document #21)

Not only for the effectiveness of the project but also to avoid unnecessary conflict:

It is important to bear in mind that role conflicts can arise in any collaboration, and it is therefore necessary that the objectives, roles, responsibilities and rules of the collaboration are clear from the outset. (Document #11)

Throughout the documents it is also possible to identify what the role of a patient entails:

They [patients] can help identify areas of need for the development of clinical research, they can be involved in policy development, in the design of and participation in studies. (Document #3)

Focus is put on how patients can contribute to the research study design and directly increase relevance for the target demographic of the conducted research:

Patient and related parties involvement can take place in different parts of the research process to increase relevance for patients by, for example, giving patient representatives and civil society the opportunity to provide input on study design, research applications and implementation. (Document #12)

There is also emphasis on how patient participants can help in communicating science, research results and information to other patients and the public by, for example, making the information more accessible linguistically:

For example, research partners can ensure that the information is linguistically adapted to the public, that it contains the information patients want to know before participating in a study, that it is well described, and that the questions are interpreted the way the researchers want. (Document #14)

Another aspect that is mentioned in relation to why it is important to define roles before the collaboration is the issue of power imbalance:

If the purpose, roles and expectations are clearly defined, the risk of power imbalances is reduced.
(Document #15)

By initially making it clear what the collaboration will entail for all parties involved, and at what level or in what phases of research collaboration will take place, the risk of power imbalance may be reduced.

From one-sided to co-creation

Deciding at what level and in which phases of health research PPI will take place is the base of the second subtheme, *from one-sided to co-creation*. The language that is used for PPI within the different documents oscillates between consultation, collaboration and co-creation. These terms are not only used to describe different levels of PPI that can take place but also to critically reflect on the process of PPI:

Engagement with patients or related parties is sometimes criticized for being tokenistic and not genuine. This may have to do with the fact that engagement is often implemented at a purely consultative level, i.e. only collecting or disseminating information to patient and related party representatives, without involving them further in any decision-making process or follow-up.
(Document #15)

The issue of tokenism is referred to throughout the data, to describe PPI that is symbolic rather than actively participatory, and some actors make a distinction between the different levels of involvement and advocate for co-creation specifically:

Samverkan 2.0 aims at co-creation rather than consultation, i.e. co-creating with patients and families rather than for them. (Document #15)

One actor even notes that there are levels to co-creation depending on the role of the patient participant or co-researcher:

There are different levels of co-created research. Co-researchers can possess anything from an advisory role in a project led by researchers to leading the project themselves. A common way to be a co-researcher is to have a seat on the steering committee of a research project, where all important decisions about the research are made. (Document #21)

The move from one-sided consultation to collaboration and co-creation is deemed an area that needs further improvement:

The development of patient and related party participation is an area for development with a need for continued work in the various parts of the research process to develop collaboration and achieve a shift from participation to co-creation. (Document #12)

Co-creative research is described to utilize the knowledge of all participating actors.

The appraisal of knowledge and education

The process of PPI can be said to be built on an exchange of knowledge and co-creation of new knowledge. How different knowledge is valued by actors and utilized in the process of PPI is the basis of the theme *the appraisal of knowledge and education*.

The importance of experiential knowledge

The experiential knowledge of patients and how it contributes to research is highly valued based on the documents included in the analysis:

Through patient engagement in clinical research, individualized treatment and precision medicine can become even better as it is based on the needs, knowledge and wishes of the individual, combined with new research advances. (Document #3)

The range of experiential knowledge is highlighted and deemed invaluable which further illustrates the subtheme *the importance of experiential knowledge*:

In Sweden, there is a long tradition of working through patient associations. Through their interest groups and members, the organizations have knowledge ranging from general experiences to deep diagnosis-specific knowledge. This is invaluable in research contexts. (Document #3)

The importance of experiential knowledge is also illustrated by the fact that the knowledge of patients is described as a resource which cannot be obtained without communicating with the patients themselves:

Research partners have a knowledge of rheumatic disease that is not available from textbooks, publications or medical consultations. They are experts in what it is like to live with the disease and can therefore bring a different perspective to the research. (Document #14)

It is recommended for researchers to express the value of patient's experiential knowledge:

Value patients' experiences. Identify, document and encourage people's contributions. Provide feedback on the results of their involvement and show them how much they are appreciated. (Document #17)

Differentiation of knowledge

Patient's experiential knowledge is highly valued, but the subtheme *differentiation of knowledge* also illustrates how patient's experiential knowledge is separated from that of researchers' professional knowledge:

They [patients] are seen as experts on their own life situation - in the same way that scientists are experts on science. (Document #21)

There is a differentiation of knowledge but there is also an emphasis on the equal value of knowledge possessed by patients and researchers:

Involving service users in the analysis process can help strengthen the validity of the study, as the service user's subjective experiences and perceptions are taken as equivalent to the researcher's expert knowledge. Where the researcher is based on their formal knowledge, the service user can contribute with their own and others' experiences and perceptions. (Document #6)

The differing knowledge is described as a resource:

Properly managed, this type of contrast adds innovative dimensions to research. (Document #6)

Despite this sentiment recurring in the documents, the equal value of different knowledge is not described as a common thread throughout all PPI contexts and there is also recurring mentioning of a power imbalance, specifically in relation to knowledge:

There is thus a power imbalance in terms of which party possesses the most highly valued knowledge, with the most highly valued expertise usually being that of the profession. Many forget that expertise can take many different forms. Patients' expertise can be of different kinds that are relevant to different parts of a collaborative process, for example in research. Patients and related parties bring to the table, in addition to their knowledge and experience of their/their loved one's illness, also experiences, skills and knowledge from working life and education that should be mapped and utilized. (Document #15)

The type of knowledge that is assumed to be valued higher is that of the researcher and the role of acknowledging this power imbalance is appointed to them:

Another important point is that the researcher must be aware of the balance of power. Everyone involved may feel that their knowledge and experience is as important as the knowledge of the researcher. (Document #21)

However, one actor also points out the importance of researchers not feeling left out and further emphasize that the two types of knowledge build on each other:

Reciprocity in collaboration is thus of great importance so that researchers and clinicians do not feel excluded or reduced to bystanders. Lived experience does not replace other perspectives and competencies in a research or care team - it complements and broadens them. (Document #15)

Researchers and patient participants bring their knowledge into collaborations and this knowledge is not described as static but continues to accumulate and develop throughout the process through mutual learning.

Education as a tool to extract knowledge

There exists a consensus within the data that the experiential knowledge of patients is highly valuable but further education on the research process is deemed necessary in some cases to further or better utilize their knowledge. This training does not only include gaining an understanding of the research process but also addresses the roles within the collaboration:

The education provides basic knowledge of, among other things: Different steps in the research process, scientific approach, research methodology, research ethics, what it means to be a research partner in a research group, opportunities and challenges in the collaboration between researchers and research partners, research funding, searching for and evaluating scientific information. (Document #9)

Providing additional education for patient participants is motivated by how it can improve the research being conducted through PPI:

Educated patients help to improve the quality of research, identify what to evaluate, broaden the research questions and facilitate the recruitment of patients for studies. (Document #3)

It is also described as a facilitator for the PPI process:

The committee recommends that specific education on clinical trials be developed for patient representatives, to facilitate and improve their involvement in clinical research. (Document #23)

Several different actors provide education for patient participants, and it is also presented as a tool of empowerment:

To empower participating patients so that they can participate in an informed and active way, they should have undergone EUPATI Sverige's education. (Document #2)

The importance and availability of education for patient representatives is a recurring theme among the documents but one actor also calls for education for researchers:

The committee recommends developing education for researchers on how to collaborate with patient representatives in the planning and conduct of clinical trials. (Document #23)

One actor contributes with an additional perspective to the effects of educating patients:

There is often a shift in representativeness or perspective when lay people are transformed into patient or related party experts. This can happen through their increased knowledge of, for example, the healthcare system or the research system, which means that the boundaries between the different identities can become blurred. (Document #15)

Providing education on the research process and PPI process to patients and researchers is described as a tool to better the collaboration, but a blurring of roles and identities is also a possible result.

Ethical aspects of PPI

The final theme, *ethical aspects of PPI*, highlights the importance of ethical considerations when different actors with various degrees of power and influence over the research process collaborate. This theme is apparent throughout the data in how it is stressed that the process of PPI should be inclusive, accessible, prioritize representation and avoid tokenistic measures. Avoiding tokenism and reflecting over the utilization of patient's contributions is one ethical aspect that is mentioned. Also, considering possible conflict related to differing knowledge and training:

Scientific and ethical conflicts may arise due to differences in understanding and competence between researchers and service users. (Document #6)

Another important aspect mentioned is the fact that participating in a research project through PPI is not equally feasible for patients as the work often takes place during work hours:

It is often relatively resourceful individuals who can get involved as patient representatives, as many believe that it requires having plenty of time and relatively good finances. (Document #12)

This also relates to the importance of representation which is frequently mentioned throughout the data:

The need to reflect the breadth of the population is highlighted by practitioners for a relevant and robust representation in patient participation. (Document #12)

Researchers are urged to consider how they can increase the diversity of patient co-researchers to broaden the representation of experiences. Lack of representation is also connected to power imbalance between actors:

A further power imbalance arises if representativeness fails, so that certain groups are under-represented. (Document #15)

Within the documents, representation is also related to accessibility for different diagnostic groups:

A further aspect is differences in representation between different diagnostic groups, with weaker representation for some of the diagnoses with the poorest prognosis. (Document #12)

One actor expresses the importance of addressing this early in the process:

A key group is patients who are particularly frail or seriously ill. Studies show that their contributions include improved study design and more relevant research, but that there are particular challenges in collaborating, as their availability and flexibility may be less than others. It is therefore important to assess particular risk factors in terms of representativeness from the outset and to be prepared to take steps to address any problems that arise. (Document #15)

Accessibility is therefore not only related to inclusion and representation but also the process of PPI itself being accessible:

Ensure accessibility and inclusion for all patient groups, including people with disabilities or special needs. (Document #2)

Further ethical considerations such as independence of actors are discussed specifically regarding collaborations between pharmaceutical companies and patients or patient organizations:

It is the common intention of the parties that the collaboration shall be conducted in a responsible and meaningful manner so that the independence of each party in relation to the other is not compromised or called into question from a legal or ethical point of view. (Document #10)

Having publicly documented agreements and therefore being transparent about the collaboration is also encouraged:

Agreements between organizations and pharmaceutical companies should be made available to third parties. Transparency applies to all agreements, whether they are ongoing, completed or relate to future projects. (Document #11)

Transparency is also mentioned in relation to the PPI process itself and transparent communication:

Be open, honest and transparent about your approach. Be clear about resource constraints and other limitations. (Document #17)

There are many ethical aspects mentioned in relation to PPI and this theme has highlighted the importance of ethical considerations throughout the process.

Similarities and differences

The second research question of this study explores the similarities and differences between PPI related documents of Swedish health research actors.

The themes as similarities

Regarding similarities, the themes themselves illustrate these as the themes were constructed by including similarities and patterns found throughout the documents. The key themes are therefore used to highlight the similarities within the data. This includes the importance of; having a well-functioning structure for PPI that influences (and is influenced by) a culture of communication and mutual respect, utilizing a common but flexible framework for the PPI process and continuing to develop this, laying the foundation for the process early by defining roles and agreeing on the level of collaboration that will take place, being aware of how different knowledge is valued and utilized, and considering ethical aspects throughout the process. The themes do not only elucidate the similarities between the documents, but the thematic map (see Figure 1) is constructed to also illustrate the connection between the themes. This interconnectedness highlights the importance of considering the similarities, the different themes, collectively when constructing a common framework. For example, this excerpt connects the importance of systematic procedures with defining roles and the value of experiential knowledge:

Systematic and strategic collaboration with patient associations clarifies their role in relation to research, enabling patient-centered research that addresses crucial perspectives that only a patient or family member can contribute with. (Document #3)

Another actor relates the issue of one-sidedness in PPI to the fact that education for PPI is mainly directed toward patient participants:

It may also be that information only flows in one direction. An example of this is if it is only the patient, the family representative or the resident who should be educated or receive information. In a surprising number of cases, there is no flow in the other direction. (Document #15)

Another similarity, recurring among the documents, is the emphasis on the attitude of actors toward each other's knowledge:

There must therefore be an openness about how the group views each other's expertise. Once this is addressed, it is also possible to contribute to increasing each other's knowledge and expertise by creating shared learning. (Document #15)

This connects the themes, or more specifically subthemes, of culture and differentiation of knowledge. Also, the attitude of the researcher is related to well-functioning co-creative research:

Certain characteristics are common in co-creative researchers. These characteristics contribute to doing co-creative research well. One is a genuine joy in meeting other people and learning about their realities. The other is a belief in people's knowledge and their ability to identify and solve the problems they see in their own everyday lives. (Document #21)

These excerpts have illustrated that the themes are not only representative of similarities between the documents, but that the themes themselves are also connected.

Differences

One of the most noticeable differences found between the documents is the use of different terminology related to PPI and the levels of patient involvement. Some actors mainly use the terms consultation and collaboration:

Any collaboration (cooperation, consultation and/or any form of financial support, and regardless of value transfer or not) between a pharmaceutical company and an organization/patient/relative should, generally, be regulated in written agreements signed by both parties before the collaboration/activity is carried out. (Document #11)

Whereas others put a significant emphasis on co-creation:

Samverkan 2.0 focuses on co-creation rather than consultation, i.e. co-creating with patients and families rather than for them. (Document #15)

The term collaboration is used generally to describe the process of PPI and the collaboration that takes place between researchers and patients, whereas the terms consultation and co-creation or co-creative research are used when more specifically referring to different levels of collaboration. Differences in terminology also applies to words used for PPI itself, with words such as patientsamverkan (patient collaboration), patientmedverkan (patient involvement) and brukarmedverkan (service user involvement) being used.

Another difference includes ethical aspects and how ethical regulations are more pronounced in relation to collaborations between pharmaceutical companies and patients or patient organizations compared to state agencies or regional actors. A document created by both a pharmaceutical industry organization and a patient organization addresses this:

Some critics argue that an overly close relationship with the pharmaceutical industry could jeopardize the credibility and independence of these organizations. Is this criticism justified? We believe that sharing experiences between different actors in society is important. When it comes to our members' collaboration, we actively work to ensure that the independence and impartiality of the parties are not called into question through, among other things, regulations, discussion and this Handbook. (Document #10)

An additional difference found is the fact that there exist multiple guidelines for financial compensation, where the levels of participation generally act as a guide for remuneration:

The guidance assumes that a certain level of activity in the assignment to the participant justifies a certain level of reimbursement. This principle already exists in several local reimbursement policies, but there is no consensus on how to define the activity levels. (Document #19)

The issue of financial compensation for patients that depend on sickness benefit is also an area that is considered and utilizing different methods for compensation is described as one solution. The differences presented in this section can therefore also be related to the importance of flexible but systematic procedures and although financial aspects is a subtheme that connects the documents, it also has aspects that differ between them.

5 DISCUSSION

The aim of this study was to explore the key themes in PPI related documents produced by Swedish health research actors, as well as the possible similarities and differences between them. The key themes found within the documents include *the entanglement of culture and structure within PPI, the importance of flexible systematic procedures, laying the foundation for collaboration in PPI, the appraisal of knowledge and education and ethical aspects of PPI*. The similarities found are illustrated by the themes as the themes constructed include the patterns and similarities that were found throughout the data. The main differences found include terminology used for collaboration and PPI itself, differences in emphasis put on ethical considerations depending on actors involved and different guidelines for financial compensation. The results will now be discussed in relation to previous research and implications for the future will also be considered.

Coherence in guidelines for the PPI process and its development

The existence of many different guidelines and frameworks for PPI (both in Sweden and globally), although often similar, has led to a lack of coherence and efficiency in the area of Patient and Public Involvement (Deane et al., 2019). Actors within the analyzed documents of this study call for the development of national guidelines for PPI but there is no clear consensus regarding which actor or actors should be responsible for this initiative. Including a wide range of actors in this development may seem counterintuitive, but could aid in preventing the fragmentation with all included actors contributing to one common framework instead of several different ones (Harrington et al., 2020). This could also address the need for a flexible framework and guidelines that are adaptable to collaborations between many different sorts of health research actors and health research contexts.

The need for systematic procedures and a common framework does not only apply to the practical process of PPI but also systematic ways of measuring, evaluating and developing the process further. There exist many different methods for measurement and evaluation of PPI and previous research has found a need for standardized guidelines within this area as well (Shahid et al., 2022). One of the results of this study includes the difference of terminology used between the health research actors regarding collaboration through PPI and this has also been described as a challenge in relation to evaluating the process, where standardization can aid in improving the methods of evaluation (Shahid et al., 2022). It is also important that the evaluation itself encompasses the perspectives and goals of all included actors. Additionally, the methods do not only include evaluation of the process and goals of PPI but also the culture, by assessing perceived empowerment of participants, respect and support (Shahid et al., 2022). This agrees with the theme of entanglement between culture and structure in PPI and indicates that a common framework for PPI should not only be a guide for the process but also be a tool for evaluating and developing it and the culture that permeates it.

The term culture is in this context used in agreement with how it is used among Swedish health research actors to describe attitudes of individuals and how this contributes to the culture within the process of PPI. Developing a framework for PPI could seem unambiguous and mainly include the practical process of collaboration, but the framework would also lay the foundation for the culture of collaboration. The theme of entanglement of culture and structure is illustrated by how the actors included in this study describe how the structure for communication can foster a culture of openness, feeling heard and appreciated. This sentiment is also apparent in existing literature exploring PPI within different research contexts; also finding that trust, empowerment, honesty and transparency is the basis for well-functioning collaboration and that this culture should be established early in the process together with roles and expectations (Arumugam et al., 2023; Dews et al., 2023). The documents of Swedish health research actors encourage early engagement of patients and patient involvement throughout all phases of research. Establishing roles and expectations is generally recommended to avoid tokenism but also to start building a culture of trust and mutual respect early as this is something that may take time to build (Dews et al., 2023; Hovén et al., 2020). Despite recommendations, previous studies have found that there is a lack of examples of PPI that takes place in all phases of research (Pii et al., 2019). A common framework that encourages, or even requires, early involvement of patients in the research process and throughout all phases of it should therefore be considered.

Reflecting on PPI models, levels of participation and shifting the focus to knowledge

The conducted analysis had an inductive approach and therefore no model for PPI was utilized when exploring the data and constructing the themes (Braun & Clarke, 2022a). However, it is still important to consider the results against existing models that could help guide the development of a national framework for PPI in Sweden.

One of the most referred to models for PPI, although not initially developed for PPI but democratic processes in general, throughout the past decades is the Ladder of Citizen Participation (Arnstein, 1969). This model is illustrated by a ladder for levels of participation and relates them to the level of power over decision-making held by citizen participants as they move up the ladder. The ladder moves from the lowest rung that is manipulation and non-participation, to consultation and degrees of tokenism, partnership and the highest rung that is citizen control (Arnstein, 1969). Levels of participation are also mentioned throughout the documents within this analysis, with words like consultation, cooperation, collaboration and co-creation being used to indicate what type of participation is to take place. Arnstein's model has been criticized for its tunnel vision focus on hierarchy and how it moves the imbalance of power from one actor to another, from researcher to citizen participant, or patient in this context (Tritter & McCallum, 2006). Other literature suggests a shift from purely focusing on power and levels of involvement and toward what the involvement actually entails in terms of utilizing the knowledge and experiences possessed by the actors (Stewart & Liabo, 2012; Tritter & McCallum, 2006). The theme

within this study that pertains to the appraisal of knowledge and education is built on the actors' emphasis on the value of experiential knowledge, the differentiation between knowledge possessed by patients and researchers, shared learning and co-creation of new knowledge. The level of participation is relevant, one included actor considers it important for addressing power imbalances, but it is also important to consider what takes place within these levels of participation in terms of knowledge exchange and co-creation. When utilizing a future framework to agree on a level of participation it is therefore also essential to consider how knowledge will be communicated and utilized. The documents analyzed include a wide range of terms for PPI and the different levels of involvement, but a common thread is the focus on the knowledge that is being communicated, exchanged and co-created throughout the process.

This study assumes a position of social constructivism, assuming that knowledge is constructed within a social context and not a universal truth (Detel, 2001). This does not only include the knowledge possessed by the actors involved in PPI, but also the co-created knowledge that is created through the PPI process and even the creation of a future framework. It is also applicable to the themes within this study, where the author interacted with the knowledge and information within documents constructed by Swedish health research actors, and new knowledge was constructed (Braun & Clarke, 2022a). The focus on power in Arnstein's model does not escape the discussion of knowledge, and the notion of power imbalance due to the valuing of different knowledge is recurring in the results of this study. Researcher's knowledge in the form of professional knowledge and practice is commonly viewed as rigorous and objective compared to the experiential knowledge possessed by patients and lay people (Beresford & Russo, 2020). The devaluing of experiential knowledge, which can be described as epistemic injustice (Beresford & Russo, 2020), is mentioned within the results as an area that needs to be addressed and emphasis is put on attitudes toward and respecting each other's knowledge and explicitly expressing the value of patient's knowledge, for example. Working toward epistemic justice would also entail "ensuring that everybody can contribute to creating a general knowledge base and that perspectives of entire social groups are no longer excluded from that process" (Beresford & Russo, 2020, p. 163).

Although there exists a power imbalance in terms of the view on knowledge, the focus of future guidelines should not necessarily be on shifting power (such as in Arnstein's model) but rather on ensuring that patients' experiential knowledge and researchers' professional knowledge are valued equally or at least on clarifying how different knowledge will be utilized early in the process. Models moving toward this approach have been presented in previous research:

We propose an alternative model to the hierarchy which places research at the centre and acknowledges the different areas of expertise which contribute to and improve research relevance and quality. If different types of expertise are recognized, the mode of involvement becomes

secondary, because the model for scientific inquiry will itself incorporate expertise which lies outside of the scientists' repertoire. (Stewart & Liabo, 2012, p. 249)

A common framework that does not only consider levels of participation, but also clearly creates a structure (and therefore culture) where the knowledge of all actors is utilized to create new knowledge, could address the issues of power imbalance at least to some extent. An example of this would be the education offered to patient participants that is mentioned in several of the analyzed documents. Only one actor urges for education or training for researchers in relation to the PPI process. This result agrees with recent literature that discusses how researchers also can utilize training or put in an effort to work well with patient participants (Jacques-Aviñó et al., 2022; Pii et al., 2019). Educating patients on the research process allows them to meet researchers in their knowledge and improve research. An area to consider could therefore be how researchers can improve their ability to meet patients in their knowledge with respect and sensitivity, as experiential knowledge may include difficult topics related to illness and health.

Further ethical considerations and addressing the differences

Apart from addressing power imbalances and the utilization of knowledge, other ethical aspects that are considered by Swedish health research actors include representation and accessibility. The importance of including different diagnostic groups but also considering social determinants such as economic stability is a common thread throughout the documents and in previous research (Pii et al., 2019). Not having the financial stability to participate in PPI during work hours creates an issue of representation and emphasis is also put on the process of PPI itself being accessible for those with different illnesses and disabilities. The recurring mentioning of representation and accessibility throughout the documents, and existing research, indicates a need for addressing these issues clearly within a common framework for PPI.

The similarities found through the themes of this study identifies areas of agreement and can aid in the development of national guidelines for PPI. Additionally, the inclusion of the research question exploring differences in documents created by Swedish health research actors was motivated by the possibility of addressing these differences when developing a common framework. The use of different terminology for PPI and the processes within it was one of the main differences found, both within the results but also through previous research (Mc Menamin et al., 2022). Ethical aspects were considered throughout most documents, but documents created by and for collaboration between pharmaceutical companies and actors such as patients and patient organizations included stricter regulations. Existing literature has alluded to the fact that the public may lack trust in the pharmaceutical industry (Dews et al., 2023) and this could be one of the reasons for the emphasis on independence between the actors in the ethical regulations.

The final difference presented from the documents was the fact that several of the Swedish health research actors have different guidelines for financial compensation for PPI. Levels of participation and time spent participating is commonly used to determine remuneration and previous research also mentions the use of vouchers and some patients preferring to volunteer (Hoddinott et al., 2018). The issue of patients receiving financial compensation whilst receiving sickness benefit is expressed in the results and this raises the question of how the differences should be addressed in a common framework. Future research and actors developing national guidelines should consider if all differences need to be reduced or if they could be a sign for where there is need for flexibility. Existing literature has shown that different use of terminology can be a hindrance for PPI (Shahid et al., 2022) and future research should explore if this is the case in regard to ethical regulations and financial compensation within a Swedish context.

Moving toward a common framework for PPI in Swedish health research

The results of this study, related to previous research, creates a picture for the next steps needed to develop national guidelines for PPI in a Swedish health research context. The themes constructed from the data highlight the similarities between the actors but also differences that need addressing or point toward need for flexibility within the framework. A recurring sentiment, both in the included documents of this study but also existing literature, is flexibility and the fact that a framework or guidelines for PPI does not work as a one size fits all (Baines & Regan de Bere, 2018). However, utilizing a common framework could both contribute to further effectiveness within the PPI process and “commitment to citizen engagement in research by funding bodies, research institutions, and scientific journals could create a shift in research culture promoting use of standardized practices, helping citizen engagement move away from tokenism into an efficient and unified process” (Shahid et al., 2022, p. 15). Additionally, a clarification of the terms framework and guidelines as they relate to PPI is needed to specify what type of procedural document should be constructed to unify the PPI process in Swedish health research.

Based on the results, as well as previous research, the author of this study recommends that key actors within Swedish health research begins the construction of national guidelines or a common framework for PPI in health research, and that this is conducted as a co-creative process together with patients. The common framework should provide a clear guide for the process of PPI, establish an open and respectful collaborative culture, utilize agreed upon terminology and be adaptable to collaborations between different actors. This could not only improve the effectiveness of PPI and research being conducted by involving those that the research impacts but also contribute to an established culture within Swedish health research where patients and their knowledge is valued and utilized to the extent of researchers’.

Strengths and limitations

Despite the broad and comprehensive data collection, it is possible that some documents relevant to this analysis may not have been included and therefore did not contribute to the construction of themes, similarities and differences found in the results. However, this study aimed to be exploratory and initiate a first overview of key themes in PPI related documents among Swedish health research actors and contribute to further research, thus supporting the development of national guidelines for PPI.

Additionally, the documents included differ in date of creation and may be outdated or not representative of current internal procedures or guidelines. The documents are also a variation of reports, handbooks and informational brochures, meaning that they have different purposes which may affect the content and therefore the comparison between them. The sample of documents included from regions and pharmaceutical companies were only n=2 respectively and as these actors are prominent within Swedish health research there is a risk that they are underrepresented in the results compared to their importance to PPI. However, all relevant documents that could be found from these actors were included to ensure highest possible representation.

Also, some of the documents included in this analysis were significantly more extensive than others, such as reports compared to informational brochures or websites. This led to some documents being overrepresented in the results section. While all documents were included in the analysis and added to the construction of themes, the more extensive documents contributed a greater number of excerpts to the results due to their richness of content. However, it was still considered important to include all types of documents related to PPI in a Swedish health research context to create an accurate overview of the current situation. Additionally, the documents that contributed with the largest proportion of excerpts in the results were those created in collaboration between several health research actors, therefore not only contributing with the perspective of one actor. The length of a document is also not necessarily related to overrepresentation as the longest document of over 600 pages only contained a few pages related to PPI in health research.

Regarding strengths of this study, previous literature has mentioned that research about the PPI process often is conducted from the perspective of professional research actors and regulators (Baines & Regan de Bere, 2018). This study does include PPI related documents from actors such as pharmaceutical companies, research institutes and state agencies, but also from patient-led organizations and initiatives, thus including a wide range of health research actors to represent both the professional and patient perspective of PPI. Additionally, the inclusion of two patient advisors introduces the patient perspective within the research process of this study as well and their experiential knowledge of taking part in PPI is another strength that contributed to this study.

An additional strength pertains to the method and methodology used. Utilizing thematic analysis with a social constructivist assumption allowed for the construction of themes that illustrate patterns and

similarities between PPI related documents of Swedish health research actors and therefore aided in answering the research questions. Other methods were also considered, such as discourse analysis, but for an initial overview of Swedish PPI documents and guidelines a thematic analysis was appropriate to explore more semantic meanings (surface-level and explicit) within the documents (Braun et al., 2019). However, some more implicit or latent meanings were also identified, and an interesting next step could be exploring Swedish PPI documents with a method such as discourse analysis to delve deeper into the discourses of knowledge and power.

6 CONCLUSION

This study has contributed with an overview of the key themes and similarities between PPI related documents created by Swedish health research actors, as well as explored the differences between them. This can aid in guiding future research as well as the initiative to construct national guidelines for PPI in Swedish health research. The themes elucidate the fact that there does exist many similarities between the actors' PPI procedures and values for collaboration through PPI, which bodes well for the construction of a common framework. The differences found can also aid in the construction as they illustrate the need for a framework that is adaptable to many different health research contexts and actors within this area. The result of this study suggests that a well-functioning framework for PPI in Swedish health research needs to be overarching, unified in terminology and structure, that contributes to a culture of trust and respect for different knowledge, accessible and adaptive to different contexts as to not be a hindrance but truly aid the process of PPI.

7 PUBLIC HEALTH PERSPECTIVES/IMPLICATIONS

The 2024 proposition for research from the Swedish government calls for more research regarding the public's involvement and collaboration with actors related to public health and health research such as that of women's health (Prop. 2024/25:60, n.d.). This study contributes with an overview of the status of the involvement of the public in health research in Sweden and suggestions for steps moving forward.

Apart from the argument of the patient and public perspective improving research, it is also mentioned as a way of working toward health equity (Prop. 2024/25:60, n.d.). Representation and accessibility are important aspects discussed in the PPI related documents included in this study and a lack of this could be considered a public health issue, where health research is conducted without those whose health is affected:

As for the roles of the public, it is important to note that “the public” encompassed a wide variety of population groups that did not have the same opportunities to be involved in participatory processes. Eventually, only some agents of the public held had power and only to a certain extent: organised social groups (e.g., a patient organisation) and individuals in a position of power that belong to traditionally privileged population groups (e.g., individuals with high education). (Jacques-Aviñó et al., 2022, p. 10)

The recurring mentioning of power, both within the results of this study but also existing research on PPI, is an indication for future public health research where power structures should be explored more thoroughly to be able to address them during the construction of a national framework for PPI. The connection that is made between knowledge and power imbalance is also worth exploring further, as a way of developing the PPI process, and is something that has been explored to some extent within a healthcare context (Baptista et al., 2017), but not extensively related to health research and PPI.

When conducting future research, it is also important to continue considering and discussing the terminology used. This study included studies and documents using words such as guidelines, framework, policy and standards, which are sometimes used synonymously but should be specified when developing a common process to follow. Also, the differences and similarities between terms such as participatory research and PPI should be explained and explored further to clarify how the public can be involved in research concerning their health. Finally, this study was conducted in a Swedish context, but similar research may be necessary within a global context and other national contexts where health research actors work in different ways, to broaden the public health relevance.

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