



# Wider institutional research cultures and their influence on patient and public involvement and engagement in health research – An institutional ethnography

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## ABSTRACT

Focus on patient and public involvement and engagement (PPIE) is increasing in health policy and research governance. PPIE is considered by some to be a democratic right, and by others to be a way to improve health care and research outcomes and implementation. Most recently, policy makers, funders and (clinical) research institutions are making PPIE a strategic requirement for health research urging researchers to invite patients and relatives into their research activities.

Our study is based in a Danish university hospital where PPIE has been introduced as one of five strategic research goals. We investigated how researchers experienced this new practice and how their research practices connect to the wider context of the Danish health care system. Ten cases were studied during a year using observations, interviews, and document analysis. As our method of inquiry, we used institutional ethnography to look at researchers' work from their perspective and to understand how PPIE practices are part of a larger institutional research culture reaching far beyond the individual. We found that current research culture has implications for the selection of patients and relatives and for what they are asked to do. Researchers who experienced that PPIE outcomes aided their existing research practices felt motivated. Researchers who engaged patients and relatives before it was a strategy, were ideologically driven and their approaches resulted in an increased diversity of inclusion and researcher assimilation.

These findings add to the current knowledge on PPIE practices and help us understand that further development towards collaborative research practices require a change in key performance indicators and training and perhaps call for attention to our shared acceptance of knowledge generation in research.

## 1. Introduction

In the last few decades, Patient and Public Involvement (PPIE) in

health research has been promoted as a way to improve high quality and efficient health care services leading to a continuous quest for a more active role for patients and the public as consumers of health services

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and decision-makers (Fusco et al., 2020). Furthermore, funding organizations and academic journals increasingly stress the importance of PPIE in health research pushing researchers to invite patients and relatives to contribute to their research projects (Liabo et al., 2020). The solution to “more PPIE” in research has often been the creation of guidelines or frameworks, in the form of texts, key pointers, reporting tools (such as GRIPP2) etc. These have been created to aid PPIE at the request of researchers feeling they lacked skills and knowledge on “how to do PPIE” (Greenhalgh et al., 2019). As frameworks are generally broadly applicable and requires adaptation to the local context, researchers often struggle to apply those in practice (Wicks et al., 2018). Previous literature has investigated the role of the patient in research partnerships, however the role of the researcher or health care staff has received less attention (Mortensen et al., 2020). In a recent review, we found that health research partnerships are often controlled by researchers who interpret the opportunities for involving patients and relatives, for example to answer certain questions (Karlsson et al., 2023). Patients and relatives with lived experience have historically struggled to gain well defined positions within the health care system (Collins and Evans, 2007; deBronkart, 2018) and, in Denmark where this study took place, the patient perspective has often been secured via qualitative research or questionnaires. Little has been published on how PPIE is embedded in overall organizational infrastructures (Pozniak et al., 2021). There is a need to understand local context and within this context to build knowledge of how organizations working with health research should adapt in order to successfully include and patients and relatives as active partners (Fusco et al., 2020). The aim of this study is thus to investigate if and how PPIE activities work when arising due to external pressures, if the experience is different from self-initiated PPIE activities, and how these experiences may be shaped by institutional cultures.

Descriptions of collaborative research practices refer to a multitude of approaches and traditions. Harrington et al. (2020) identified 244 distinct definitions and proposed the following inclusive definition for research engagement practices: “*The active, meaningful, and collaborative interaction between patients and researchers across all stages of the research process, where research decision making is guided by patients’ contributions as partners, recognizing their specific experiences, values, and expertise*” (p. 682). This article is written with this broad and inclusive definition in mind; the term PPIE is chosen as it accommodates different cultural connotations and thus allows for a variety of forms and ways in which PPIE can be done (Locock and Boaz, 2019).

### 1.1. Institutional ethnography as a concept for investigation of institutional contexts

We used institutional ethnography (IE) as a methodology as it aims to uncover the social organization of knowledge and its mediation through texts (Malachowski et al., 2017). It focuses on revealing explicit and tacit work practices and relations between actors in institutions and thus highlights social organization as manifested in institutional discourses, textual coordination and people’s every day work (Smith and Griffith, 2022). We can thus illuminate how current PPIE practices are experienced and developed with the people involved, but also, their part in a wider institutional direction. This will help uncover institutional and contextual aspects which remain unclear. Recently, others have used IE to investigate: health care professionals’ knowledge and work practices (Cupit et al., 2020), the organization of patients’ needs (Cupit et al., 2021), and PPIE activities at a health technology assessment agency (Bidonde et al., 2021), which illustrates the usefulness of this methodological approach in the health care setting.

### 1.2. The context of a health care system

Policy on PPIE in health services has gained prominence within New Public Management and New Public Governance strategies (Brix et al.,

2020). Within such political frameworks, co-creating public services with the public can mobilize societal resources in a challenged public system and increase public value in line with the desires of citizens to be heard and have democratic rights (Ansell and Torfing, 2021). The Danish tax funded welfare model gives all citizens free access to health care. Emergence of this model can be traced back to the pre-industrial era when all social classes gained participation in parliamentary practices. The Danish health care and by extension welfare has therefore historically enjoyed a trust from citizens that it would care for them in the best way possible, implied that all citizens also have a responsibility to contribute to the upkeep of the system (Lund et al., 2021). In addition, a high degree of voluntarism involves contribution to the collective good (Lundgaard Andersen and Hygum Espersen, 2017). In recent years, Danish health policy has been oriented toward the inclusion of citizens. In 2014, a Danish national health policy document on user involvement states:

*“In a publicly financed health care system, it is an intrinsic value that citizens experience a system that is both open and democratic and that they experience being included in decisions about their own health and in decisions about how the health system of the future should work”* (Danish Ministry of Health and Prevention, 2014, p. 2 - author translation).

Subsequently, an action plan developed by the secondary health sector administration entities (the five Danish “Regions”), and The Danish Knowledge Center for User involvement (ViBIS), focused on systematizing user involvement to create “The citizen’s health system” (Danske Regioner, 2014). This included the initiation of the “Think tank for user involvement” which in 2018 produced a manifest for user involvement in the health care system (Tænketank for Brugerinddragelse, 2018). Even though user involvement has been a political focus for a decade, it is still not considered standard praxis in Denmark (ViBIS, Unknown). One way to achieve user involvement in decisions for the future health system is to include citizens in health research. In 2023, ViBIS published a report on descriptions of PPIE in health research strategies in the Regions: PPIE was mentioned in local hospital strategies when it was also mentioned in the regional strategy (ViBIS, 2023). PPIE thus seems to have been introduced in Denmark as a health system strategy echoing the overall political governance framework rather than as a response to a need from hospital staff or researchers. One such research strategy mentioning PPIE as a strategic goal is the “Together we will create the patient treatment of the future” 2021–2025, authored by Odense University Hospital (OUH) and the Clinical Department of the University of Southern Denmark (SDU). This strategy was our point of departure.

## 2. Method of inquiry

IE was developed by Canadian sociologist Dorothy Smith inspired by feminist theory, Marx, Bakhtin, and others (Widerberg et al., 2021). It focuses on the social organization of knowledge and the organizational arrangements within which an individual works stretching beyond the experience of the individual (Bisaillon and Rankin, 2013), but maintaining individual experience as the basis for analysis (Rankin, 2017a). The aim is the investigation of how people’s activities are coordinated and socially organized via texts and language across institutions gathering evidence to describe how “*disparate interests are activated or subordinated*” (Rankin, 2017a, p. 2). IE does not prescribe a certain way of collecting or analyzing data (DeVault et al., 2006). Keeping focus on the standpoint and experiences of someone within the institution should guide the analysis toward institutional structures (McCoy and Smith, 2006). Although our overall aim is to look at the institutional context in which PPIE takes place, the investigation starts from the standpoint of people). The urgency for this study arose from literature analysis (Karlsson et al., 2023), from the experiences and previous insights of the entire research team, and from informal meetings and observations with patients, relatives, and researchers at the research site. Hence, we

started with the overall problematic of “how do researchers experience (not) doing PPIE activities as part of a hospital research strategy”? Analytical inquiries after the data collection had begun showed that contradictions or tensions arose largely because researchers did not feel PPIE to be part of their “researcher DNA” (as one researcher put it). This had implications for both the researchers’ ability to see the benefit of PPIE and for the activities (work) associated with it. During the description of social processes of generalizing effects (DeVault et al., 2006), the initial problematic was further developed (Smith, 2005a) to explore the experience of being a member of the research culture and the encountering PPIE practices.

The following concepts are central to IE:

**Institutions:** Functional complexes organized around distinctive functions (such as education, health care, science etc.). These are organized in language (discourse) and are based on texts (see below). The point is not to study institutions, but how institutions come into view through people’s experiences.

**Ruling relations:** Social relations organize and regulate people’s work and knowledge, connecting the individual to a local and a translocal context (Smith, 2005b). Translocal social relations pass through local settings and shape them to dynamics that arose elsewhere (DeVault et al., 2006). Ruling relations thus create conditions for the work people do. This work is mediated through institutional texts (see below).

**Work:** “What people do intentionally, (this does not mean that they want to do it) that takes effort and time and is done under definite conditions” (Smith and Griffith, 2022, p. 41). When we understand what people do in coordination with others and how they get things done, we can promote a dialogue that potentially facilitates how this coordination takes place through sequences of action going beyond the individual.

**Texts mediating work:** Texts enable us to explore beyond the observable and are central to understand translocal social relations and organizational control over the local (Smith, 2006). Smith defines texts as “words, images or sounds that are set into a material form of some kind from which they can be read, seen, heard, watched, and so on in a particular local and observable setting while at the same time hooking up individuals consciousness into relations that are translocal” (Smith, 2006, p. 66). Texts coordinate people’s activities and must be authorized by somebody. A regulatory text is a higher order text that regulates and standardizes other texts organizing work in multiple local settings (Smith, 2006). In this case, the OUH research strategy (in turn directed by regional and national political strategies, and funders statements) coordinates local unit strategies adapted to the local setting but obliged to the overall strategic goals. Local unit strategies are activated when their goals are translated into work activities by researchers.

**Problematic:** “A problematic is a territory to be discovered, not a question that is concluded in its answer” (Smith, 2005a, p. 41). When a familiar world is disrupted by interventions from outside, people may experience difficulties in adapting. Investigation beyond initial struggles enables an exploration that is not constrained by the problems experienced by people but rather explores lines of social relations. The examination starts with peoples’ experience of working through their daily activities, and how those experiences are related to translocal relations. Finally, the exploration moves “beyond the local to discover the social organization that governs the local” (Smith, 2005a, p. 41).

### 2.1. The research team

IE advocates examining one’s personal knowledge and assumptions to truly understand the experiences of people within the social organization of an institution (Rankin, 2017a). Therefore, we describe our personal background and employment as some of us are part of (and subject to) the research strategy.

The members of the research team are patients, relatives (hereafter research partners) and researchers/clinicians. Some are affiliated with or employed by Odense University Hospital (OUH), employed by the University of Southern Denmark (SDU), or employed by the University

of Utrecht. The research partners involved have experience as patients and relatives at OUH and as members of various committees at OUH. Several members of the team have extensive experience with PPIE, with the clinical setting, and with a variety of research methods. One member was previously also involved in the creation of the OUH research strategy and with setting up a center for PPIE as part of the strategy goals. Thus, all members have preunderstandings and familiarity with PPIE in health care and research through a variety of personal or professional experiences.

### 2.2. Data sources and data collection

The study was conducted in Danish. As the research team also consists of non-Danish speakers, the analysis was partially done in English, translated by the first author. Research within OUH covers many disciplines and methods. Therefore, we planned to cover a breadth of PPIE activities and research approaches. We set up the following inclusion goals: Advisory boards and committees with PPIE activities, and research projects with PPIE activities, and within these both PPIE beginners and researchers with more extensive PPIE experience as well as both qualitative- and quantitative research, research close to and removed from the clinical setting but conducted by researchers with clinical roles. As it was not possible to follow entire research projects from start to finish, we attempted to cover all parts of a research process using different cases. Therefore, the pooled data show activities across the entire research cycle whereas an individual case will represent only part of the cycle.

### 2.3. Case selection

Ten cases were followed between March 2022 and April 2023. See Fig. 1 for overview. The scale of PPIE activities at the hospital was unknown, so the inclusion process followed an inquisitive and iterative process (Rankin, 2017b) wherein entry into the field (case A) revealed new opportunities for investigation, with the aim of understanding the problematic. Cases were selected based on main researcher experience with PPIE and on point in research cycle or board development the case would be during data collection. We obtained variation in both marginalized and privileged populations, qualitative and quantitative research, and applied and fundamental research. As IE is an iterative process, the relevance of each future case was considered as we gradually gained more knowledge during data collection. For example, funding requirements were consistently mentioned by researchers as an important reason for commencing PPIE. To follow the translocal relations controlling the researchers’ work, it became necessary to understand these funders’ requirements.

During observations, a patient or relative and a researcher were selected by the observers and invited for an interview. If interested, the individual was sent more information via email, and an appointment was arranged at the person’s workplace, at a coffee shop, or in a Zoom online conference call as per the preference of the interviewee.

### 2.4. Types of cases

**Individual projects:** Outreach to researchers at research units with known PPIE activities of various duration by the first author in a “snowball” method, in which researchers passed on knowledge of the work of other researchers. We joined meetings and activities in the individual cases over the course of the data collection period.

**Advisory boards/committees:** Attendance at research advisory boards at departments and committees organizational level known to include patients and relatives. The frequency of meetings varied, but we observed at least two meetings per group.

Case characteristics					Data collection			
Case	Project in a unit with limited experience	Project in a unit with established experience	New board	Established board	Observation	Interview with researcher	Interview with Patient/relative	Docu-ment(s)
A	pre-start					X		X
B	x							
C				X	XXX	XX	X	X
D			X		XXX	XX	X	X
E				X	XX	XX	XXX	X
F	start				X	X		X
G		start			XX	XX	XX	X
H		end				X		X
I		middle			XX	X	XX	X
J	start				X	X		
K	start				X	X	XX	X
Management						X		X
Funders						XX		X

*Observations* = participation in meetings taking place during the year of data collection.  
*Interviews* = formal interviews and informal chats before, during, and after observations.  
*Documents* = texts shared by participants or publicly available online (e.g. department research strategies, minutes, agendas)  
 Note: Case B withdrew after the initial informational conversation and hence did not provide any data.  
 "Limited experience" = a couple of PPIE activities such as initial meetings. Cases F, J, and K tried out PPIE for the first time in the current projects. Case A had previous experience from a few meetings, that had been discontinued. To protect the anonymity of all people involved (data collection from a small setting), we cannot disclose further details on health conditions or patient population.

Fig. 1. Cases and data material.

2.5. Types of data collected

We collected field notes from 15 observations, and transcripts of interviews with 14 researchers, one management staff, two funders, and 11 patients. Documents (texts) from each case were generously shared with us by the researchers and patients or relatives, or were found online. Observation- and interview guides were co-developed and piloted by the first author and research partners via test observations and mock interviews based on analysis of included texts, previous literature and contextual investigation shared above. Observations and interviews were conducted by first author and a research partner or by first author alone.

*Observations:* Before observations, we reviewed documents related to the case. These were department research strategies, invitations to the observed meetings, project protocols, committee mandates, and meeting agendas. A matrix inspired by Spradley’s nine dimensions of grand tour observations (Spradley, 1980) to support the research partner was set up (see Appendix 1). The nine steps capture the initial atmosphere, setting, place, actor, activity, actions and feelings. This is not a typical feature of IE observations, but as guidance on carrying out IE observations is rather vague, it was useful as a loose structure for research partners with no previous ethnographic experience as to how to “do” observations.

*Interviews:* A total of 28 interviews were conducted. Some interviews were more casual, occurring by approaching the interviewee directly after the observation and asking a few questions. In these cases, field notes were taken immediately afterward. Before each scheduled interview, we reviewed observational field notes and relevant documents from the case. By referring back to field notes and documents during interviews, we deepened our understanding of our observations as well as gained a detailed reflection from the interviewee about the experience of the meetings and about working with the documents (Smith,

2005). The semi-structured interview guides (see Appendix 2 and 3) were tailored to each interview situation. Hence the themes discussed where similar but varied in interviews with management, patients, relatives or researchers (i.e. for researchers: “How do you prepare the PPIE activities, and how do these activities feel compared to your other work activities?” and for patients: “How do you prepare for the project meetings?”).

*Funding organizations:* During interviews, funding requirements were frequently mentioned as a motivating factor for commencing PPIE activities. Two research funding organizations with requirements for PPIE statements were approached and informed of the study, and agreed to participate via an interview.

*Documents:* Texts from each case (project protocols, invitations, meeting agendas and website information) were analysed for activations of actions by people and links between work carried out in individual units and across the institution of OUH. We interviewed both those involved in creating the texts (management, funders and research leaders) and those who translated the text into work actions (researchers, patients, and relatives) (Smith, 2006). We asked about the underlying rationale and development for each text, and how they were activated into everyday work (DeVault et al., 2006). An attempt was made to obtain all OUH departments’ research strategies either by searching the individual department website or by contacting the department research secretary. Out of 42 departments, we obtained 18 up-to-date research strategies. These were analysed for content and description of PPIE activities by the first author and a research partner.

2.6. Process of analysis

As noted above our previous knowledge and literature search had already shaped the framing of the problematic and our attention to it

(Rankin, 2017a). In Fig. 2, we sum up the analysis process. The analysis developed as discussions between the first author and partners and between the first author and the research team. A reflexive diary was also kept by the first author throughout the data collection and analysis. Analysis is presented in a linear fashion – in reality, we shuttled back and forth between the steps as our understanding of translocal connections increased.

As an essential part of IE, we mapped the data highlighting connections between the data and visualizing the ruling and/or translocal relations (Turner and Smith, 2006). We organized texts hierarchically on the map by identifying traces of other text within them. The OUH research strategy and department research strategies quickly became the main organizing texts and are thus the focus for the textual analysis. Thus, we were able to identify in the interview transcripts comments that we believed was organized by the texts (see Fig. 3).

**Identifying an experience:** To understand how researchers experienced doing this work we indexed their experience into broad headings of “Did PPIE already: like it”, “Ok, if I must: I will try to make the best of it”, and “Can’t do it: feels irrelevant for my department”. Then, we looked beyond their immediate reactions and resulting work and looked for traces of the larger institutional rulings that may be shaping these reactions (Smith and Griffith, 2022).

**Identifying institutional processes:** In order to reach “beyond the local to discover the social organization that governs the local” (Smith, 2005a, p. 41), we continued to explore how the larger institutional rules came to shape the researchers’ work and experience. Because the data revealed tension between the work of PPIE and the higher order OUH strategy goals, we placed the analytical focus here.

**Investigating institutional processes:** By exploring the traces of ruling in the data, we found that research practices and related work are heavily influenced by ruling relations reaching across not only the Danish health research institutions but into a general scientific understanding of knowledge.

### 2.7. Ethical considerations

According to Danish law, no ethics approval is needed for this type of study (Lasseisen, 2020). We conducted the research following the Danish Code of Conduct for Research Integrity (Ministry of Higher Education and Science, 2014). Lead researchers/chairs of committees were contacted and informed of the study. Researchers, patients, and relatives from each case were sent written information about the study and its potential observations and interviews. They were requested to explicitly object if they did not want to be part of observations. Before each observation commenced, we again introduced ourselves, the project, and the option of declining participation. For formal interviews, we sent further written information about the interview process and data handling. This

information was repeated before the interviews commenced, and formal informed consent was obtained. We conducted interviews at locations preferred by interviewees. We iterated our availability for further questions or comments any time after the interviews had taken place. When interviewing patients and relatives, we iterated that taking part would have no consequences for their treatment or partnership with researchers. We managed all data with confidentiality and anonymity in compliance with the Danish Data Protection Act.

### 3. Findings

Our findings are presented as a coherent piece using all data sources interspersed with ‘exhibits’ or quotes from the data, and with mapping to create a window into informants’ experiences and the social organization of researchers’ work (Smith and Griffith, 2022; DeVault et al., 2006). In the introduction, we presented the *institution* of the Danish health care system. Here, we present the OUH research strategy as a higher order text and the experiences of the people within the institution.

#### 3.1. The research strategy

OUH performs education of students and staff, treatment of patients, and health research. The Clinical Department at SDU collaborates with OUH on education and health research, and they are both authors of the research strategy. Many staff members are in dual positions, where they teach, do clinical work, and undertake research. The research strategy is developed with inspiration from regional strategies and national health policy; it has made PPIE in all research activities one of the five strategic goals towards 2025 (Region of Southern Denmark, n.d.). The other goals are evidence-based medicine, excellent research collaborations, a strong research culture, and attractive career paths. Each unit at the hospital must publish its own strategy describing research goals for the next years. The strategy is described as “the way we work with research progression as an organization. It takes about a year to make. It includes study trips, interviews, evaluations, and desk research” (management staff). Contributors include management, researchers, and a patient and thereby manifests as a thoroughly developed organizational direction with authorization from management, staff, and patients.

The strategy states:

*“The patient’s needs, experiences, and observations from life with an illness contribute valuable knowledge and bring new perspectives into research. When patients and relatives are involved in organising and carrying out research projects in active collaboration with researchers, the focus of the research is directed towards the problems that the patient experiences in everyday life. This increases the chances of the research*

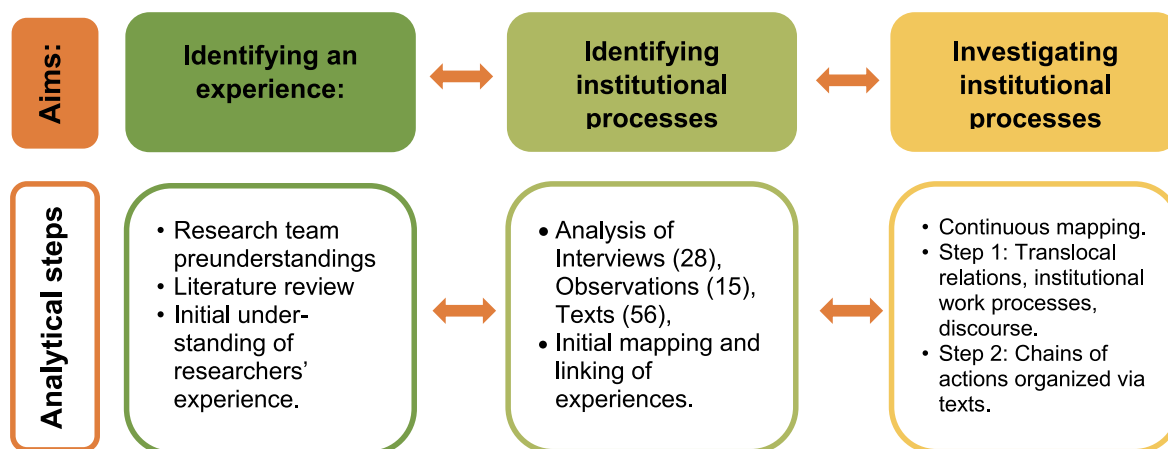


Fig. 2. Analytical process.

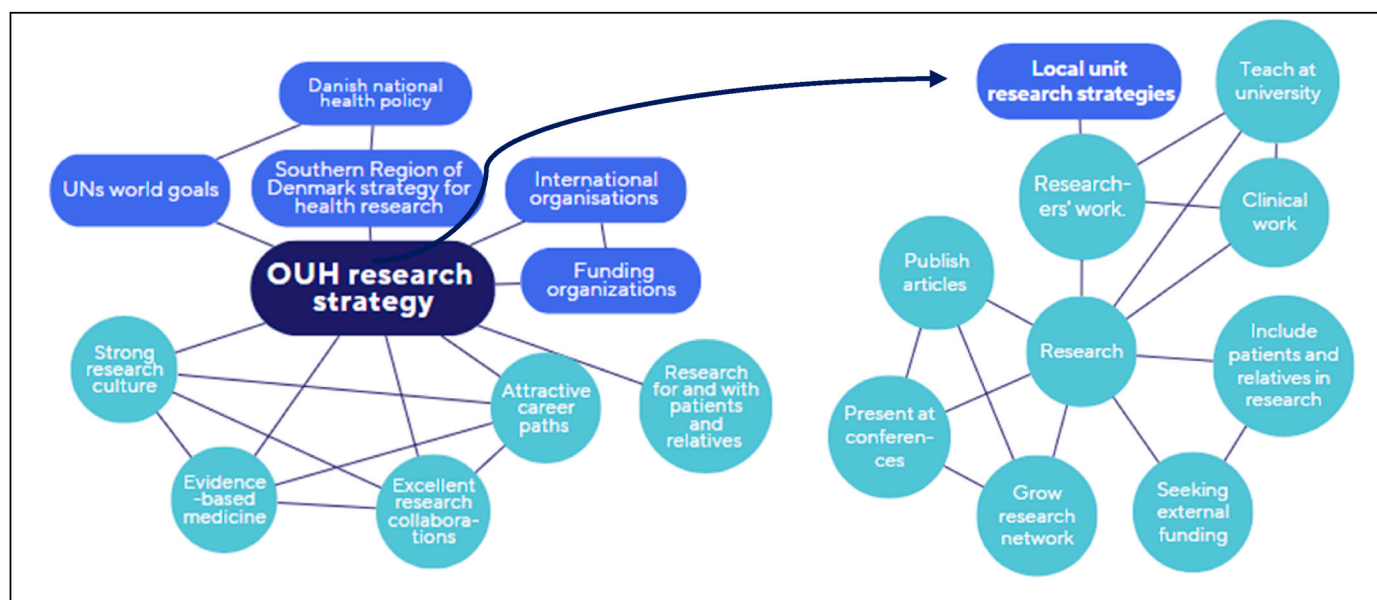


Fig. 3. Mapping the work actions within the research strategy.

being patient-centered and clinically relevant and of it reaching the clinical setting more quickly” (Region of Southern Denmark, n.d.).

PPIE appears in the strategy as a new action to be applied to current practices (see Fig. 3). It is presented as having the potential to make research more relevant to patients and easier to implement. Key goals for ‘research for and with patients and relatives’ are determining the proportion of projects with PPIE, and establishing a center for patient involvement in research.

### 3.2. The strategy as organizer of researchers’ work

The strategic research goals are ingrained in the research culture at OUH, and fulfilling the research strategy goals is a major driver. The researchers experience their daily work being highly influenced by regulations, frameworks, and rigorous research methods: “I joke about a rule regulating which foot I must put through the door first” (researcher A1).

The other goals in the strategy are more compatible with how the researchers are used to working: excellent international collaborations, attractive career paths, a strong research culture and evidence-based medicine are presented with measurable goals like publishing a certain percentage of articles in Scimago-indexed journals. These goals are more familiar to researchers and more closely aligned with the work researchers are already doing and have focused on for years. Three of six action areas for PPIE stated in the strategy document are: 1) Prioritization of research projects, 2) Communication of projects for example via lay person summaries, and 3) Funding applications. Researchers have; invited patients into research committees to discuss future and current research projects and strategies, consulting them on writing lay persons summaries and funding applications showing a strong example of the organizing potential of a higher order text. Individual unit research strategies are often developed as a replica of the OUH strategy, but they are translated to the specific unit (e.g. patient population, medical specialty). For example, a local unit strategy states: “We strive to involve the citizen from the idea phase to implementation and will assess the share of projects with citizen involvement” (Case E – author translation). Researchers strive to translate the strategy goal of increasing the proportion of PPIE activities into PPIE work. “It’s part of the whole research strategy, it’s a must-task. So I’ve tried to turn it around and say, what can we get from this. I see it as an exciting managerial task to try to make the best of it. But compared to the other tasks [in the strategy], this does not have the highest priority” (researcher E1). Researchers experience pressure to do

PPIE activities from funders and journals with PPIE statements or patients as reviewers. They are now “forced” to factor in PPIE from the start of a project. Researchers undertake new work (such as organizing meetings, finding patients, and communicating with them) to incorporate the patient perspective early in the research process, and they experience benefits like successful funding applications. This motivates more PPIE work. PPIE activities have in addition helped researchers getting their research implemented; funders or unit leaders appear to have a harder time rejecting research results endorsed by patients. When PPIE work can help the other four strategy goals, researchers see PPIE activities as meaningful and see how those activities could connect to other strategic activities.

### 3.3. The DNA of a researcher

Many researchers at OUH have training as doctors, nurses, physiotherapists, and work within specific fields of research but they have not been instructed in or had experience with PPIE activities during their training. They are educated in an epistemological tradition that makes certain statements about what kinds of knowledge are possible, adequate, and legitimate and claim a hierarchy of evidence where certain research methods are considered more sound than others. Many of them work in combined positions where they teach, conduct research, and do clinical work as part of their daily obligations. This work allocation (mentioned as such in the OUH strategy) is intended to ensure that the researched topics remain close to clinical practice: “My initial thoughts were: I talk to patients every day. I know what their challenges are. I know what they bring to the table. You have the patients’ voice in the back of your head, but without it having anything to do with the voice of the patient. It is just an interpretation”. (researcher D2).

Research methods such as participatory designs and interview studies are experienced by researchers to have been developed to capture the patient’s perspective, leaving it out of the work of researchers working within the quantitative research discipline:

“The qualitative research discipline with interviews and the likes has perhaps resulted in us thinking that the patients are heard. But the involvement is only in a fraction of the process. And it is still not regarded as really good quality research. So, maybe you have had one person in your department who have had a focus on qualitative research – typically a nurse or something – and then you felt someone dealt with that, so the others didn’t have to. So, it’s not in our DNA, it’s not in the way we were

trained. We do things the way we are trained to do. And we are used to do calculations of power". (researcher D1)

When involving patients and relatives in research councils the initiating researcher experienced resistance from other council members and find it difficult to define what the patient/relative is there to do. The institutional discourse makes researchers see PPIE as a method, and methods are something in which researchers are trained rigorously. They describe how having PPIE as a requirement helps them keep focus on patients interests but perhaps at the cost of academic research interests. PPIE potentially directs research focus away from register-based, epidemiological, and laboratory-based research. They are concerned that patients may have a harder time seeing the relevance of this type of research where implications for treatment may not be immediately clear. Researchers who did PPIE before it was a strategy all did applied clinical research. All researchers acknowledged the ideological importance of PPIE, but experienced tension between PPIE as an organizational strategic move and meeting the reality of their daily work life until PPIE activities was incorporated into existing familiar and goal-oriented work. Having to change daily work routines is experienced as difficult by all, and by researchers involved in fundamental research as very challenging.

### 3.4. The consequences of strategic organization of researchers' work

Researchers read the strategy as very clear: "It's in the strategy, it is a must-task" (researcher E1), but strategic direction on how to do it is found to be vague. The effort to find ways of creating PPIE activities, perhaps driven by an institutional discourse around research methodology and knowledge hierarchy, seems to affect the opportunities to be included. The meetings and interactions are often oriented around the questions researchers find relevant to ask the patients. In many cases, the researchers' questions dictate the input:

(Field note, research partner): *The researcher was good at following up on the questions, but actually nothing new came out of it. I think they got the answers they were looking for.*

(Field note, research partner): *The involvement is challenged by a lack of clarity as to the patient representative's role and a minimal initiative for inclusion at the meeting. Several opportunities arise for soliciting the patient's views during the meeting, but they are missed.*

Researchers experience difficulty finding patients and relatives who can represent a population and convey that population's perspective. Researchers' recruitment work includes inviting NGO's, hand picking patients and relatives from the clinic, advertising on social media, and using established patient databases at the hospital. They experience frustration when a hand-picked patient is not able to provide "the helicopter perspective" (researcher C2). The terms of reference or contracts for patients sometimes used state that patients are expected to evaluate the patient involvement in projects and layperson summaries. Although not observed to be strictly upheld, this expectation seems to be present as a reminder for the patients' role in the collaborations. The representative who can tailor the patient perspective to the needs of researchers is seen as professional who easily brings value to the collaboration.

*"If I must be honest, we get most out of the professional type. But there should be space for other types of patients too, who ask if they can peek into our world – Yes you can! Maybe they should have different roles. The ones who say: "Wow, how exciting" as observers and the professional board in the engine room who knows what's going on."* (researcher E1)

Patients who can use their previous work experience receive legitimation because of these skills – not only their lived experience.

*"We have – and I think that is a plus – our retired nurse. She has had her own mother here as a patient, so she also has the view of a relative. She is*

*sharp in letting us know if something is not ok, but she is also self-critical. So, she balances things in the right direction, where we get some professionalism."* (researcher C2)

Researchers experience that there are other "kinds" of patients whose voice they believe should be heard. They suggest using established research methods such as focus groups or Delphi surveys to include them. This disjuncture can be seen through institutionally accepted research structures giving patients the option of 1) understanding the institutional language and being invited into development of research projects; 2) not being involved in the research practice, yet being included as data through established research practices; or 3) not being part of research.

*"I think we must involve different patients in different ways. We cannot have an ordinary Joe in a council. Such a person would drown when things are in English; there are complicated texts and just the mechanics of the logic are difficult. These people also need a voice, but maybe via focus group interviews or Delphi processes where there is a specific aim or matter to work through".* (management staff)

Researchers who did PPIE activities before it was a strategy experienced PPIE as meaningful in itself: "I don't think this is about whether the ones we get are representative, it is about getting perspectives that we as researchers do not have" (researcher H1). They began because it either made sense to them or because they wanted to give previously excluded patients a voice. They learned that what works in one study with one group might not work in the next and experience collaborations as dependent on the patient's or relative's personality and expectations, and on the scope of project. "When I invite people, I invite 10 individuals who see things 10 different ways. I have to decode that pretty fast" (researcher H1).

These differences suggest that the following developments in researchers' PPIE activities could take place: When PPIE is a strategy, researchers may feel forced to begin and do minimal activities to fulfill the strategy. They learn from each activity and try a little more next time. After a few more projects they no longer see it as new work, but as a natural way to progress the research process. Researchers who started because they wanted to gain new perspectives or raise previously unheard voices also learned along the way and gained confidence in their practices but also saw it as a way of doing research which wouldn't be possible without the collaboration with patients and relatives. Some of the researchers who started PPIE to fulfill the strategy no longer find it an option not to include PPIE activities and they are actively seeking collaboration with a broader group of patients and relatives.

## 4. Discussion

Others have highlighted an epistemological division between patients and clinicians/researchers in society (Carel et al., 2017) and in PPIE practices (Bidonde et al., 2021; Jones and Pietilä, 2020; O'Shea et al., 2019). It is important to be aware of this as it divides the knowers who help set the agenda from the non-knowers whose knowledge is being consulted (Smith and Archer, 2020). We add that it seems not to be the individual researcher who regards experiential knowledge as less important (they consider patients' stories from the clinic in their research) but using experiential knowledge to inform research is a challenge for some as it cannot be accommodated into their research methodology. We note epistemological divisions also between health care professions and research tradition in the institutional discourse which may push PPIE to a peripheral position. Bidonde et al. investigated PPIE activities in a Canadian Health Technology Assessment agency, and similarly found that structures for patient input result in the impression of it being of less value, and in the involvement of a select group (Bidonde et al., 2021). Patients appear in our data as a category rather than people with individual experiences. Looking at the category as a social relation in which people act (Smith, 2009) allows us to see

that researchers use their research data collection skills when including patients, who do not readily bring a helicopter view. All people are active agents, but they act within (in)visible ruling relations (Smith, 2005b). Researchers are both ruled by the local (the research strategy) and by the trans-local (their research training), and ruling because they execute the research methods, they are familiar with in PPIE activities thus helping to uphold the institutional ruling relations. The more PPIE-experienced researchers got, the less they saw patients and relatives as a category but saw a need for the researcher to decipher what support the individual patient or relative needed.

Two approaches have previously been identified based on the locus of involvement: a so-called consumerist approach to improve and streamline research, and an ideological democratic approach involving a patient’s right to be included in research that impacts their situation (Beresford, 2020; Beresford, 2002). As Fig. 4 demonstrates, seeing PPIE through researcher’s work and as part of a context, brings a new dimension to this discussion as a consumerist approach may (partially) be rooted in unfamiliarity on the part of researchers as well as in the research- and knowledge culture they are part of. Whilst participating researchers agree that ideologically, PPIE is the right thing to do, they search for the quickest and cheapest (finances and time) route to comply with the strategy and to obtain funding – because there are many requirements they must meet in their daily work. Researchers who did PPIE before it was a strategic goal maintained an ideological approach of wanting to give patients a voice and of needing to learn from experiential knowledge.

The experienced difference between PPIE and other strategy goals results in work conflicts (how is limited time best spent), reflecting an international research culture in which researchers are valued by and rewarded for publications produced and the ranking of the journals. Measuring researcher credentials solely by quantifiable measures like number of publications will naturally organize researchers’ attention towards this. There is some movement away from “metric oversimplification of scholarly achievement” (Schmidt et al., 2021) - see for example: The Declaration on Research Assessment ([www.sfdora.org](http://www.sfdora.org)) or the discussion of narrative resumes (Fritch et al., 2021), but not in a systematic way within most research communities, and this is not reflected in the OUH research strategy goals. Researchers (speaking from a qualitative and quantitative background) explained that involving patients is not in their DNA because it is not how they learned to do things. Philosopher Thomas Kuhn called this ‘normal science’ (Rouse, 1998): researchers acting within the rules of research they know and are accustomed to. They are trained in research methods it took them years

to learn. It becomes part of their lexica - or vocabulary. To counter this, PPIE could be introduced during researcher training (Karlsson and Janssens, 2023). Pozniak et al. highlight another solution which have evolved over time in a smaller setting of a research center: several of their researchers have dual roles as patients/relatives and use both professional training and lived experience in their work (Pozniak et al., 2021). This approach could address epistemic divisions if a dual role can be seen as bridging, but based on our data on the desired professional qualifications of patients, care must be taken to not push patients without researcher training further to the margins.

We suggest that ruling relations and context heavily influence PPIE and the ranges of actions within activities. It may not just be a case of researchers having to learn new ways of creating research, but a case of a need for culture change locally, institutionally and internationally. In countries with decades of experience (like the UK and Canada), PPIE is still not embedded within the general way of doing research (Beresford, 2020, 2002; Richards et al., 2023) perhaps because the larger institutional aspects have been missing. We hope our study will serve to demonstrate that there may be a greater need to focus on changing institutional research cultures.

### 5. Conclusion

Using the explorative nature of IE to investigate the social organization of PPIE within an institution, this study illustrates researchers’ experiences of doing PPIE work as part of a strategy. Researchers increased their PPIE activities little by little once they experienced successes, slowly inviting a larger group of patients and relatives. Researchers found it challenging as they didn’t feel it as part of their DNA or as something that aligned with their other work obligations. Other institutional goals are experienced as conflicting with PPIE, and this had implications for the way researchers sought to fulfill the strategy and for the chosen PPIE activities. Researchers who involved patients and relatives before it was a strategy did so because they felt it was needed to create the research. This allowed for a wider participating population where the work associated with making PPIE successful was unquestioned. The study also illustrates the need for institutional culture changes, for focusing on different key performance indicators, and a different approach to researcher training. We suggest that, understanding PPIE as part of a wider context is necessary to reach goals of embedding PPIE at the core of health research institutes.

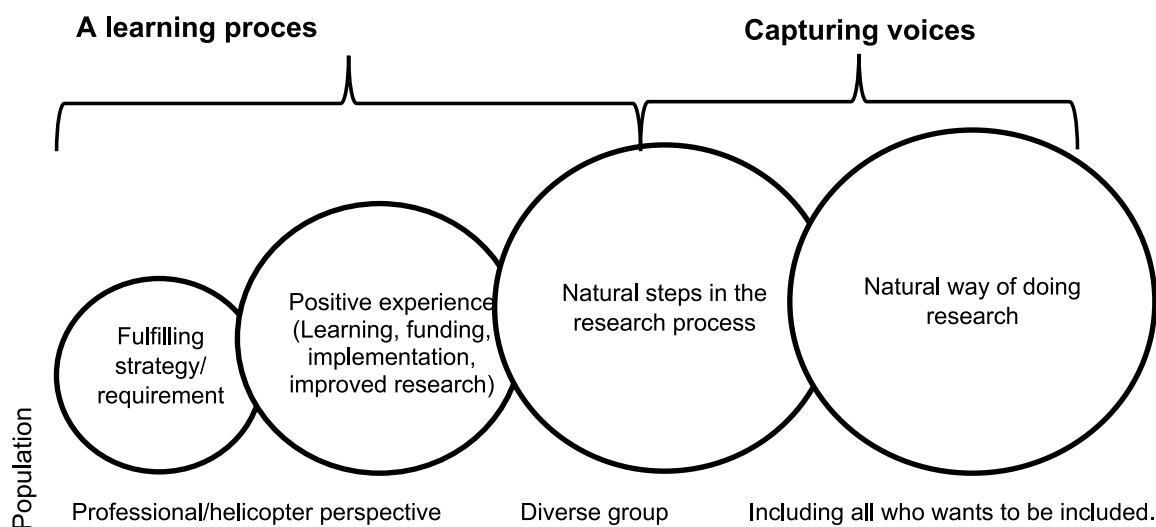


Fig. 4. Model of researchers’ entry into PPIE activities.



### 5.1. Strengths and limitations

The use of IE is a strength, as it allows to uncover necessary elements in PPIE. IE is a non-directional approach which leaves much up to researchers' interpretation and their ability to see experiences from a certain standpoint. Our research team of research partners and researchers provided several perspectives on the analysis.

The study was conducted within one setting, in which there are local factors unrepresentative for other settings, but IE allowed us to find translocal factors we believe to be of influence elsewhere. We encourage similar approaches in different research settings and locations to highlight differences and similarities.

We present only the views of researchers who also have clinical duties. We saw research activities at the hospital without direct clinical application, such as economic assessments, but we excluded them, as they may experience different challenges. We have not presented the views of patients and relatives – we plan to do so in an upcoming publication.

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### CRedit authorship contribution statement

**Anne Wettergren Karlsson:** Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Resources, Validation, Visualization, Writing – original draft. **Anne Kragh-Sørensen:** Conceptualization, Formal analysis, Investigation, Validation, Visualization, Writing – review & editing. **Kirsten Børgesen:** Conceptualization, Formal analysis, Investigation, Validation, Visualization, Writing – review & editing. **Karsten Erik Behrens:** Conceptualization, Formal analysis, Investigation, Validation, Visualization, Writing – review & editing. **Torben Andersen:** Conceptualization, Formal analysis, Investigation, Validation, Visualization, Writing – review & editing. **Karen Margrethe Maglekær:** Conceptualization, Formal analysis, Investigation, Validation, Visualization, Writing – review & editing. **Mette Juel Rothmann:** Conceptualization, Resources, Supervision, Validation, Visualization, Writing – review & editing. **Marjolijn Ketelaar:** Conceptualization, Resources, Supervision, Validation, Visualization, Writing – review & editing. **Esben Nedenskov Petersen:** Conceptualization, Resources, Supervision, Validation, Visualization, Writing – review & editing. **Astrid Janssens:** Conceptualization, Methodology, Project administration, Resources, Supervision, Validation, Visualization, Writing – review & editing.

### Data availability

The data that has been used is confidential.

### Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.socscimed.2024.116773>.

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