SSM - Qualitative Research in Health 9 (2026) 100734



Contents lists available at ScienceDirect

SSM - Qualitative Research in Health

journal homepage: www.journals.elsevier.com/ssm-qualitative-research-in-health



The rise of patient and public involvement in health research in Denmark – a qualitative study of funder's policies and practices☆

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ARTICLE INFO

Keywords:
Research funders
Health research
Field theory
Patient and public involvement
Participatory practice
User involvement
Legitimacy

ABSTRACT

Patient and public involvement (PPI) aims to produce knowledge and improve health services by involving patients, citizens, and stakeholders in various processes, including research. Research funders are centrally positioned to influence how PPI is understood in a given context and legitimise how it is done. This article investigates the rationales used by research funders to encourage PPI in Danish health research, and the possible implications for how PPI is performed by health researchers. Building on Collyer's (2018) conceptualisation of the healthcare sector as a field and her focus on the social action of central actors, we explore 1) the origin of research funders in Denmark, 2) funders rationales for encouraging PPI and 3) how research funders may shape PPI in Danish health research. A thematic analysis was performed based on interviews with 7 senior managers at seven research funding organisations in addition to strategic documents about PPI retrieved from these funders. We find that these rationales presented by research funders reflect predominantly technocratic rationales for PPI. Less emphasis was given to democratic justifications for PPI. Most funders supported PPI as part of their efforts to accumulate organisational legitimacy and credibility within the research infrastructure and among their members as patient organisations. Funders' relationship with the wider healthcare and academic systems plays a part in determining their framing of PPI, and, that the cultural (re)production of PPI across national borders is highly likely to shape what PPI 'is' and 'becomes' in Denmark, requiring reflections to not repeat international experiences and critiques.

1. Introduction

Internationally, the involvement of patients and other members of the public in health research as contributors (as collaborators not just participants) is increasingly expected– and, in some cases, even mandatory (Patrick, 2016). A scoping review notes the historical basis of this phenomenon, considering that traditional models for public management has long been criticized for operating a 'democratic deficit', (Facer & Enright, 2016). This is also true for health research (Madden & Speed, 2017). Accordingly, it has been argued that an exclusion of patient and other members of the public from strategic decisions concerning research aims and conduct has contributed to the emergence of a 'relevance gap' between health research and its practical application, despite calls to enhance the societal impact of health research (Durose et al., 2012, p. 7). A subsequent report described the response to this critique as representing a 'participatory turn' in research during 2010 and the following years, 'opening up new relationships between publics, professionals, audiences, artists, citizens and policy makers in all areas of public life' (Facer & Enright, 2016).

In some contexts, the adoption of PPI in health research has been

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https://doi.org/10.1016/j.ssmqr.2026.100734
Received 9 October 2024; Received in revised form 28 August 2025; Accepted 19 February 2026
Available online 26 February 2026
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particularly notable (Palmer et al., 2019). A case in point is the UK, where state institutionalization of PPI played an in important role early on (O. Williams, Robert, et al., 2020a). The National Institute for Health Research (NIHR) in the UK defines PPI in research as research "being carried out 'with' or 'by' members of the public not just 'to', 'about' or 'for' them" (INVOLVE 2020). This is also the definition of PPI we adopt in this article. The NIHR launched their PPI mission in 2006 and have, since then, played a leading, international role in developing ways for health researchers to work together with patients and other members of the public informed by social science critique of existing PPI theories and practices (Locock & Boaz, 2019; Locock et al., 2017; O'Shea et al., 2017). However, funders, researchers, and the public increasingly expect health and social care research to at the very least involve patients and citizens in decision-making processes (National Institute for Health Research, 2018.).

Existing studies have established that research funders are centrally positioned to shape the legitimacy of PPI in health research (den Oudendammer et al., 2019; Elberse, 2012; van Bekkum, 2016; van Bekkum & Hilton, 2014). If PPI is internationally acknowledged as necessary for the development of more inclusive and inequity-oriented healthcare, the role of research funders in promoting PPI is therefore important to explore. This article focuses on the role of research funders in encouraging PPI in a particular national setting, namely, Danish health research. We investigate the rationales used by research funders to encourage PPI and discuss the possible implications for how PPI is performed in Denmark. The aim is to provide in-depth, empirical knowledge about PPI in Danish health research. However, as part of the wider 'participatory turn', the Danish experiences are also of international relevance. By international comparison, PPI in Danish health research is still relatively immature. Unlike some other countries (e.g. in the UK), no national organisation responsible for promoting PPI in health research exists in Denmark. Accordingly, the shaping of PPI occurs in a heterogenous, organisational landscape where research funders play a particularly important role.

The remainder of this article is structured as follows: First we provide an insight into the benefits and challenges of PPI in health research, next we present our theoretical framework, afterwards we introduce the Danish context more to describe the development of PPI. Here after, the methods section is presented which leads to the analysis divided into three sections on 1) the origin of research funders in Denmark, 2) funders rationales for encouraging PPI and 3) how research funders may shape PPI in Danish health research. We end the paper by summarizing our analysis and discuss the implications of these along with international critique of PPI, which Danish funders can learn from to avoid supporting harmful PPI in health research.

Denmark is often considered one of the most equal societies globally (OECD, 2015). Nonetheless, while Denmark remains a high-income country with extensive redistributive income policies and a comprehensive tax-funded healthcare system, inequalities persist (Bambra, 2012; OECD, 2015; Vrangbaek, 2020). Further, the attribution of social value based on based on economic and cultural capital (Prieur et al., 2020), can shape *who* is invited into PPI Danish health research (Stage, 2023).

As the international adoption of PPI has been uneven, this article outlines the role of Danish research funders (e.g., private, public, patient organisations etc) in shaping what PPI is becoming in Denmark and explores how institutional histories, norms, and motives of funders influence (shape) how PPI is (comes to be) understood and implemented in particular ways as the international adoption of PPI has been uneven, this study provides an opportunity to empirically explore a shift in a field of knowledge production within one international case (Denmark) during the wider 'participatory turn'. We will return to the importance of learning from international critiques of PPI for the theory and practice of PPI in Denmark at the end of the paper.

2. Review: The benefits and challenges of PPI in health research (and the role of research funders in promoting it)

Internationally, scholars and policymakers have highlighted the benefits of PPI by validating research that includes PPI and making research processes and outputs more relevant to those outside of academia (Beresford, 2013; Glasby & Beresford, 2006). As mentioned, UK initiatives have been leading in developing PPI based on the understanding that researchers and academic institutions often have "blind spots" and that the priorities of researchers not necessarily reflect what is most important to the patients (Nygaard et al., 2019). Consequently, the development of health services and interventions may not fully reflect the communities they are intended to serve.

International studies outside Denmark show that research funders in many countries encourage or even mandate PPI in health research, while some funders also involve citizens in their own work (den Oudendammer et al., 2019; Elberse, 2012; Saunders, Crossing, et al., 2007; Saunders, Girgis, et al., 2007; Teunissen et al., 2013; van Bekkum, 2016; van Bekkum & Hilton, 2014; Russell et al., 2019). By controlling access to grants, funds, and prestige in various research settings, funders possess what Greenhalgh and colleagues (2021) can "scientific capital" (Greenhalgh et al., 2021). This means that funders distribute capital within a given field of research while also shaping ideals of relevant through the requirements they pose. Accordingly, research funders are centrally positioned to influence how PPI is performed in a given context. Yet, if funders convey vague ideals about PPI it may contribute to legitimising sub-optimal or even detrimental PPI approaches, such as extractive practices or tokenistic involvement(Brandsen et al., 2018; Cluley et al., 2021; Green, 2016; Ocloo & Matthews, 2016; Stage, 2022; Williams et al., 2020a). However, studies of PPI in research commissioning also warn that highly structured commissioning systems can carry a risk of tokenism if, patients and other members of the public are not meaningfully involved in commissioning activities or their actual influence is difficult to determine (Caron-Flinterman et al., 2005; Oliver, 1996; Tembo et al., 2019). Consequently, a mismatch can arise between what patients, clinicians and local communities identify as important topics of research and what is actually being researched (Crowe et al., 2015).

Researchers have also warned that the possible benefits of PPI are often left unrealised as a result of tokenism, poor practice and selective recruitment is commonplace; often failures are indicative of inequitable PPI processes and practices that risk exacerbating existing inequalities (Beresford, 2020, 2021; Brett et al., 2014, 2014; Stage, 2022; Williams et al., 2019). Tokenism refers to instances when the goal of PPI is adopted formally but the actual opportunities of patients and other members to gain influence remain very limited (Ives et al., 2013). Reflecting this view, scholars have noted that decision-making power (i.e. who is involved and which influence do they exercise?) - tends to reside with health professionals as perceived 'experts', whilst systems and processes fail to be adapted to address the power imbalances and facilitate equitable participation of citizens in research (Ives et al., 2013; Ocloo et al., 2021; Ocloo & Matthews, 2016). Further, it has been demonstrated that recruitment practices may contribute to a lack of diversity in PPI initiatives – with contributors representing predominantly white, middle-class, and older adults (Beresford, 2013; Church et al., 2002; Martin, 2008, 2011; Ocloo & Matthews, 2016; Stage, 2023).

Recent research has emphasized the importance of PPI initiatives being fit for purpose, that is, the level and mode of involvement should match the specific objectives of a given PPI initiative (Caron-Flinterman et al., 2005; Crowe et al., 2015; Oliver, 1996; Tembo et al., 2019). Yet, there are warnings with highly structured involvement can create tokenism if, patients and other members of the public are not meaningfully involved and mismatch between what patients, clinicians and local communities defines as areas of importance.

Finally, scholars argue that too much emphasis has been dedicated to the challenges, individual perspectives, and associated expenses of PPI

without sufficient acknowledgement of the existence and persistence of structures, contexts, and cultures within academia and healthcare that hinder more inclusive and collaborative practices (Boylan et al., 2019; Locock et al., 2017; Stage, 2022; Williams et al., 2019, 2020). This article seeks to address this imbalance by attending to the social shaping of PPI as it occurs through the discursive practices of research funders. We develop this theoretical perspective in the following section.

3. Theoretical perspective: The social shaping of PPI

When exploring the role of research funders in promoting PPI, we follow central, theoretical tenets of Collyer's work on changes in healthcare system (2018). Collyer (2018) emphasises the need to examine the social actions undertaken by central actors in a given field to understand how novel configurations of knowledge production arises in this field (F. M. Collyer, 2018). In relation to PPI, such novel configurations refer to change from a, mainly academically driven approach to health research to a more inclusive and collaborative research practice. Following Collyer (2018), such changes results from contestations or struggles to define values and objectives should guide knowledge production, and how the relationship between research institutions and members of the public (including patients and caregivers) are to be understood. In this sense, research funders can be understood not simple as a site where PPI is 'Implemented' but rather as a central actor in the field where PPI is defined and shaped in particular ways through contestation and struggle (Bourdieu, 1986). Others scholars have used Collyer's understand struggle between professions, (Hindhede & Larsen, 2019), patient trajectories (Bystrup et al., 2022) and gatekeeping (F. M. Collyer et al., 2017; Willis et al., 2016) along with studies on class differences in PPI in health research (Stage, 2022, 2023). In our context it means that, PPI is not a universal standard but a contested outcome shaped by the social action of central stakeholders, such as research funders.

Importantly, national stakeholders do not operate in a vacuum but are influenced by their international relationships. Therefore, the field of Danish health research is not entirely confined by geographical borders but involve also relationships with international actors, such as NIHR or PCORI. To understand how research funders in Denmark may shape PPI in health research, it is therefore also important to attend analytically to their relationships with acquiring knowledge from international actors. Moreover, research funders may differ in their approach to PPI. Tellingly, a recent review of PPI in Nordic healthcare research has exposed a lack of agreement and called for a shared definition of PPI (Dengsø et al., 2023). Accordingly, it is important to explore similarities and differences in how the funders justify and operationalise PPI in a given field.

To structure our analysis we take inspiration from three generic questions formulated by Collyer to understand what drives healthcare reform (2018): "where do these groups come from, what motivates the individuals in these groups to act in the way they do, and how does their action produce changes in the structure of the healthcare system?" (F. Collyer, 2018, p. 116). In the context of this study these questions translate into: 1) What are the origins of various research funders?, 2) Which rationales do the funders use to encouraging PPI? and 3) How might these rationales shape the development of PPI in health research?

4. Background: The rise of PPI in Danish healthcare

A recent review of PPI by Dengsø and colleagues (2023) shows a growing development of PPI in Nordic health research from 1992 to 2023 This is reflected by an increased publication of both scientific articles and gray literature on PPI and increased emphasis on PPI by research funders (Dengsø et al., 2023). Still, PPI is relatively new to the Danish healthcare sector, compared to the UK, USA, Canada, and Australia. In 2014 the Danish Ministry of Health developed a policy on patient-centered healthcare together with the five Danish regions who are responsible for healthcare delivery (Finderup et al., 2022; Forsk2025, n.d.; Selby et al., 2022; Staley et al., 2019, p. 23; Zealand, 2019). Despite calls for more knowledge about and evaluation of PPI in health research (Hørder, 2017; Sundhedsstyrelsen, 2022, p. 53), national guidelines are lacking. Health researchers and funders in Denmark have therefor sought guidance from international peers.

Reflecting developments in PPI internationally, several research policies and health institutions in Denmark highlight different rationales for PPI. We draw on an overall distinction between what we may call a 'technocratic' and a 'democratic' rationale (Martin, 2009; O. Williams, Sarre, et al., 2020). Firstly, a 'technocratic' rationale refers to a perception of PPI, where involvement is primarily seen as a pragmatic way to produce health services and research that respond better to the needs of services users; if health care should be designed to meet the needs of patients, then logically patients should be consulted about their needs. A technocratic rationale may be expressed in various ways that convey slightly different but potentially overlapping goals, including ambitions of making health more 'relevant' to patients, improve its 'quality', make it more 'efficient', or 'impactful'. A 'democratic' rationale reflects a view of PPI as primarily a matter of egalitarianism that can help limit the 'democratic deficits' in the public administration and increase the legitimacy of public decision-making; the public should have the right and means to contribute to decision-making processes relating to *public* services (Boaz et al., 2021; Martin, 2008; Metz et al., 2019; Robert et al., 2021; Williams et al., 2020a). A democratic rationale can also be expressed in various ways, including the ambition of making health research more 'legitimate', 'ethically sound', and 'inclusive', and to foster 'patient empowering', secure 'representation', and reduce 'inequity'. The technocratic or democratic rationales are not mutually exclusive and can be expressed by the same stakeholders. Indeed, often those who use a democratic rationale to advocate for more involvement will do so in part because they want to improve service provision and patient experience Yet, they are worth distinguishing analytically because they convey slightly different conceptions of *who* should be involved in health research and *why*. Whereas the technocratic rationale reflects a tradition of *user* involvement originating in industrial innovation (von Hippel, 1976), the democratic rationale rests on a Habermasian ideal of deliberative democracy (see Weale, 2016).

Reflecting the void of a centralised approach to PPI, local research networks have been organised in Denmark adopting the language of PPI prominent in other countries along with work that advise health researchers on an individual level, how to work their PPI initiatives (Finderup et al., 2021, 2022; Skovlund et al., 2020). Still, researchers from the Nordic countries express challenges in relation to PPI (AM et al., 2020, p. 45; Sand et al., 2020; Pii et al., 2019). A national umbrella organisation for patient associations shares knowledge about involvement (ViBIS, 2013), yet have only recently begun to focus on PPI in health research.

Leading authorities on PPI are researchers from both medical and social science background, along with patient association, yet they are not in Denmark part of a national organisation with a unified definition of PPI. In this scattered organisational landscape without a centralised approach to PPI, research funders can shape interpretations of what PPI means in their respective contexts. While this might facilitate PPI initiatives that are 'fit for purpose', it also raises concerns about a lack of oversight over potentially improper practices (e.g. tokenism and exploitation). Further, it carries a risk that PPI initiatives will reflect the priorities of funding agencies and healthcare professionals rather than the priorities patients and other members of the public.

5. Data and methods

The study is based on semi-structured interviews with senior managers at seven different research funding agencies in Denmark in combination with analysis of 20 strategic documents on PPI retrieved those funders. According to Danish legislation, research ethics approval is not

required for qualitative research (only biomedical research is assessed). However, the study was conducted in line with general guidelines in Denmark of good research practices (Danmark & Uddannelses- og Forskningsministeriet, 2014).

To learn about the research funder's approaches to PPI, a purposive sampling in terms of seeking out multiple perspectives was employed (Clark et al., 2021). Because the landscape of research funders in Denmark is heterogenous and the approach to PPI is likely to differ between funders, we strived to secure representation of diverse types of funders, attending to the *ownership* (public vs. private), *focus* (singular illness vs. health more generally), *size* (10-100+), and *leadership* (board of professionals vs. patients or carers) of the organisations (Table 1).The recruitment of informants was undertaken by the first author, initially through email and, if requested by the funders, a follow-up phone call to discuss the purpose of the interview and how data would be used and anonymised. In the larger research agencies, this process also served to find out who would be able to talk about PPI.

Applying a snowball strategy (Clark et al., 2021), the first author asked informants about advice on other research funders that would be relevant to include. For example, one informant from a patient organisation, point out another patient organisation that had had incorporated PPI experience from the UK and from whom they had learned from. In a subsequent interview it became clear that representatives from the other patient organisation had visited the UK and invited UK speakers to seminars in Denmark. Such practices of knowledge exchange provided important insights into how knowledge about PPI travels internationally as research funders acquire knowledge and seek to navigate and foster changes in health research. All the approached research funders positively to the invitation and all of the funders agreed to meet, although with an effort to anonymize their interviews. To accommodate their work commitments, the main author arranged face-to-face interviews and travelled to their workplace. In one instance, this enabled an informant to include two colleagues in the interview who had specialised know about PPI (as experienced researcher and consultant on user involvement). All the interviews were undertaken during 2020-2022 and recorded with consent of the informants. The interviews lasted 30-90 min.

To further substantiate the empirical basis of the study, we retrieved a total of twenty documents on PPI from the same funders (Table 2). The documents included official policies published on funders website in addition to internal documents on PPI accessed through the informants. For example, guidelines for reviewers on criteria for PPI in health research, which are not described in the analysis due to agreement with funders. At the time of writing, some of the policies expressed in retrieved documents are now out of date. However, they represent the conceptions of research funders at the given time. Importantly, the perspectives conveyed by the senior managers and in strategic documents are likely to reflect the ideas of PPI as conceived by the funders. Hence, it is outside the scope of this analysis to explore how PPI is actually done in practice or how patients and others members of the public experience PPI initiatives promoted by the funders.

Table 2
Overview of strategic documents on PPI from funders.

Doc ID	Category	Title/summary	Year published
#1	Research strategy	Research strategy for 2020-2025. Mission driven research	2020
#2	Strategy document	Research Council	2019
#3	Policy	Terms of reference for the Research Council	2019
#4	Recruitment document	Terms of reference for the Research Council	2019
#5	Research strategy	Research at the forefront 2019-2022	2019
#6	Evaluation	Synthesis report of the mid-term evaluation of research policy	2017
#7	Policy	Policy for health research 2015-2018′	2014
#8	Policy	For Citizens Strategy 2022-2025	2022
#9	Research call	Health Sciences Research Fund call 2021 for funds in 2022	2020
#10	Guidelines for applicants	The Health Sciences Research Fund 2022/23	2022
#11	Research	Evaluations criteria of research	2020
#12	Policy	Strategy and goals	2022
#13	Research Policy	Research Policy 2018-2022	2018
#14	Report	Research in the region 2022	2022
#15	Newsletter	The elderly and their families are consulted	2021
#16	Expert appraisal	Expert appraisal of project	2020
#17	Webpage	Purpose and strategy |	2022
#18	Webpage	How to apply for a grant	2022
#19	Webpage	User involvement in research	2022
#20	Webpage	Support for research in 2023	2022

A semi structured interview guide was developed. The guide included both a theoretically informed questions (deductive approach), where senior managers were asked to define and talk about how they understand PPI in health research, and how it mattered within their funding processes, and what their funding' organisation's motivations were for promoting PPI in grant applications. Whereas open questions invited informants to speak more broadly about PPI (inductive approach). Inspired by Collyer (2018), the theoretically informed questions focused on the origin of research funders, their rationales for engaging with PPI, and their visions of how PPI might change the landscape of health research. Acknowledging the relational dimension of the field concept we also asked about whom funders sought inspiration from and how they sought to learn about PPI. The inductive part of the interview guide concerned broad questions about the role of PPI in

Table 1
Characteristics of the funders and informants.

Informant ID	Ownership (private/public)	Interviewees role in organisation	Patient organization member count	Organization size (staffemployed staff)	Focus (singular disease/ broadly)	Annual amount of funding
#1	Private patient organisation	Research leader	+100,000	+100	Singular, illness-specific	4 million euros
#2	Public health institution	Director, and research leader	Not relevant	25 (local - +100 national)	Singular, illness-specific	1,5 million local region, 7,5 on a national level
#3	Private business fund	Research program leader	Not relevant	+100	Singularresearch program but have different programs	150-200 million euro
#4	Private patient organization	Research leader, responsible for PPI and with experience of PPI	+100,000	+100	Singular, illness-specific	50-60 million euros
#5	Public institution with a fund	Research consultant	Not relevant	+100	Broad	1-2 million euros
#6	Private fund	Research leader and program manager	Not relevant	50-60	Broad	50-60 million euros
#7	Public Fund	Director	Not relevant	10	Broad	7 million euros

health research, and how citizens and other members of the public were involved in their organisation and the research they commissioned.

5.1. Analytical approach

The first author wrote initial analytical memos after the interviews describing emerging themes (Andrews et al., 2013). Subsequently, the identified themes were developed into codes and interview transcripts along with documents were coded thematically by the first author using NVivo14. The codes reflected the theory-driven interest of the authors in the rationales for encouraging PPI, their origins, the relationships of funders with international experts in PPI, and potential shaping of PPI in the health research landscape (deductive approach). However, new themes also emerged from the interviews and were turned into codes (inductive approach). For example, the theme of organisational legitimacy was identified during interviews and subsequent memo writing, and later systematically through the coding. The documentary analysis catalogued and highlighted different justifications for and operationalisation of PPI in research expressed in the documents. After the coding, the data extracted from the interviews and documents were in more depth following a thematic analysis approach (Clark et al., 2021, pp. 538–540). The thematic approach encompassed an exploration of the institutional histories, norms, and rationales that might influence how PPI comes to be understood and implemented (Bowen, 2009; Stuhlfauth et al., 2021), and was thus informed by our theoretical framework by creating knowledge about diverse positions of funders and relating their knowledge and practices of PPI to each other. We placed an emphasis on the rationales associated with PPI in the analysis of both documents and interviews, different themes were established by triangulating data from interviews and documents (Miles et al., 2013). In the analysis of both documents and interviews, we put emphasis on the different rationales associated with PPI. The main author drafted the article based on ongoing discussion and readings with UK co-authors and their editing of the paper. Afterwards the new draft was sent to the Danish co-authors, who edited and added their comments before the main authors revised the whole paper again.

Using the theoretical framework from Collyer as part of our thematic analysis, along with our open reading of the material, the following themes and subthemes were analysed. We described the broader themes 1) What are the origins of various research funders?, 2) Which rationales do the funders use to encouraging PPI? and 3) how might the ways funder theorise and practice involvement, shape the development of PPI in research in the healthcare sector. Subthemes of theme two were identified as “democratic rationale” and “technocratic rationale”. Subcategorizations of the technocratic rationale included components expressed in statements concerning that involvement make health research more ‘relevant’, ‘quality’, ‘accountability’ ‘efficient’, and ‘impactful’. On the other hand, subcategorization of the democratic rationale entailed components, expressed in statements concerning that involvement make health research more ‘legitimate’, ‘ethical sound’, ‘inclusive’, ‘representation’, ‘inequity’ ‘empowerment’. As part of theme three, we identified a subtheme ‘testing the waters’, which explains a mechanism of evaluation of the applications readiness to practice involvement, which only one funder out of seven practiced.

The analysis is structured by the following three questions, as mentioned earlier: 1) What are the origins of various research funders? 2) Which rationales do the funders use to encouraging PPI? and 3) how might the ways funder theorise and practice involvement, shape the development of PPI in research in the healthcare sector? Quotes were translated to English by the authors for this article.

6. Results: Funders' approach to PPI in Danish health research

In the following section we demonstrate how funders theory and practice of PPI in health research are shaped by a predominantly technocratic rationale for encouraging it. We focus on funders perspective on the rationales of using PPI and attempt to outline some of the reconfigurations among Danish funders, who endorse patient involvement in the development of health care research. There are other perspectives present in understanding funder's role and value of research within the broader emphasis on involvement. Still, the effort towards greater involvement is clear and plays an important role in steering health research towards citizen's needs.

The findings are presented using the aforementioned structure of Collyer's guiding questions as they relate to the theorisation and practice of PPI by research funders in the Danish healthcare sector. They are as follows: 1) where do research funders come from 2) what are funders' rationales for advocating for PPI and 3) how might the ways funders theorise and practice PPI shape the development of PPI in research in the healthcare sector? We use the terminology of PPI throughout even though it was not the term all used to describe the involvement of citizens and contributors in health research. In several cases, the language of user involvement and PPI was mentioned in funders' documents and senior management statements. The use of PPI represents a shift in thinking, viewing PPI as being more than end users of health research, with broader engagement and involvement being important from initial idea generation throughout the research cycle. Although PPI is an international and English term, it is being adopted in Denmark, with subtle changes influencing the prioritization and development of new knowledge.

6.1. The origin of research funders in Denmark

Unlike the UK with the state-sponsored NIHR Centre for Engagement and Dissemination (formerly NIHR INVOLVE) focused on PPI with a clear goal for public participation in health(care) research (Williams et al., 2020a), Denmark lacks an equivalent organisation-supported organisation promoting PPI in research or an authoritative, national definition of, or guidance on PPI in research. Rather, funders in Denmark constitute a heterogenous group of organisations and given that these organisations fund most of the research, they can act with a high degree of autonomy define and practice PPI in different ways.

Research funders in Denmark have different origins. Some originate from patient associations driven by an interest in advancing the quality of life and treatments of people with particular diseases. Others originate from public institutions that promote basic research with a particular focus on theoretical and methodological innovation but also some learning towards meeting problems from practice, while others again are research foundations established by the owners of large, Danish corporations typically exhibiting a focus on product innovation and other forms of applied research, some does also constitute major public health institution with a focus on meeting in their healthcare services and meet the needs of the citizen they serve. This variety in the origin of research funders provide for differing research priorities and resources. As we will see, it also affects how the foundations approach PPI. Patient associations, in particular, expressed an increasing pressure from their members and by looking towards what international organisations does, to work with PPI in order to better accommodate the needs and priorities of their members. Other private foundations had initiated a few progressive practices in their efforts to support the development of legitimate PPI, along with one regional public foundations shared similar aim. But these were exceptions compared to rest of the funders, as we will show later.

In the vain of authoritative, national guidance on PPI, senior managers at the research funders looked beyond Denmark and used international networks to learn about PPI – such practice occurred mostly among patient organisations, but also stated among public and private foundations. Through international enquiries, funders recognised the importance of PPI both in their own organisations and in the assessments and reviews of research applications: Two senior managers at two different patient organisations explained:

> We look a lot towards England. I visited seven years ago seeing how they did it. We were first concerned with user involvement in healthcare, where they had different ways of involving patients, such as user panels. We started that up here in collaboration with two hospitals in Denmark. We had a director who was very interested in that. (#1Senior manager, patient organisation)

> The (UK) Heart Association held a seminar some three years ago. And there we saw that we were a bit behind on PPI in research. Afterwards, we invited them to talk about how we could approach this. We also invited a UK person from our sister organisation (in England) who was the head of research and has done a lot of work on this (PPI). (#4 Senior manager, patient organisation)

As these quotes demonstrate, the healthcare field can be envisaged as a transnational field, given that research funders search for and exchange ideas internationally, along with their use of articles they either explicitly cite or enact upon, showing a legitimation of the knowledge that is being exchanged (Grineski, 2011). In some of the documents retrieved, research funders also cited international guidelines on PPI, predominantly from INVOLVE in the UK, as providing helpful information for researchers (#1, #4, #6). Funders motive to acquire knowledge about PPI demonstrates that the knowledge is applicable in other countries. This shows outward orientations from within the healthcare field. Even though funders has diverse characteristics and Denmark do not have a state definition of PPI that funders could lean towards, funders looked outside of Denmark for PPI experience to inform their theory and practice.

6.2. Funders' rationales for encouraging PPI?

Funders use different terminology about PPI, often interchangeably. Such conflation tends to disregard differences in collaborative traditions (Williams et al., 2020; Williams et al., 2020b). Yet what is key is whether the PPI is output-oriented (technocratic outcomes) or democratic-oriented. As mentioned above, they can coexist but the lack of the other is problematic. None of the funders engaged with the notion of patient- or user-led research or more transformative forms of collaborative work, so researchers would more consult patients and citizens at certain stages in the research process. While all seven research funders had an explicit policy for PPI in research, they differed. Some of the funder's documents about involvement were publicly accessible and cited mostly INVOLVE in the UK as providing helpful information for researchers. Yet, as depicted in Table 3, the majority (#1, #2, #4, #5, #6) used technocratic rationales to promote PPI.

Four research funders (#1, #2, #4) incorporated patient representatives in their research commissioning panels and these patient representatives were expected to help with reviewing funding application. Yet, only three of these (#1, #2 #4) had established specific PPI criteria for the review process that outlines different PPI activities. These funders (#1, #2 & #4) had their own research unit, where one had worked with PPI.

6.2.1. Technocratic rationales dominate values

As Table 3 shows, the majority of the research funders used predominantly technocratic rationales to promote PPI. This was reflected in statements that conveyed an idea of PPI as a means of improving the relevance and value of health research for *user*.

> "The objectives of user involvement in health research include increasing the relevance and value of research results for users" (#1 Funder policy, patient associations)

> "The purpose of user involvement in health research is (…) to increase the relevance and value of research results for users" (#4 Funder policy, patient association)

> "Research projects (…) must be perceived as relevant by end-users (…) We involve end-users in research and ensure that real user involvement is worked towards in relevant parts of each research project's processes. (#2Funder policy, public foundation)

> "Researchers and clinicians in hospitals should invite patients and relatives into dialogue on the development of research projects, thereby ensuring that the project has a relevant patient focus with patient-centred outcomes" (#7 Funder policy, public foundation)

Both senior managers and strategic documents on PPI expressed the view that users with lived experience" can say where the problem is" in contrast to the research priorities of researchers' and what they believe may be most relevant. Users were also seen as having an important role in the review of funding applications based on the idea that the sheer presence of patients would lead other panel members to think more about a given projects' relevance for end-users. It is worth noticing that slightly different conceptions of users are expressed in the above quotes. While some explicitly defines users as "patients and relatives" (#7ID), others leave it to the researchers to define who constitutes (end-)users (#2ID). Reflecting what we call a *technocratic* rationale for PPI, the main purpose of involving users is expressed in terms of increased "relevance" and "value" of research for the users; that is to increase the *usability* and thereby the *impact* of research in health service delivery and/or the everyday life of patients and caregivers. Accordingly, PPI is not seen as an end in itself but as a means of obtaining better research.

Table 3
Overview of research funders' approach to PPI.

Participant ID	User panels	Type of funder	Explicit criteria for patient or citizen participation in research evaluation	Citizens or patient participation in research evaluation	Explicit guidance on PPI in research	Explicit PPI research policy	Rationales
1#	Yes	Patient organisation	Yes	Yes	Research	Yes	Predominantly technocratic, lesser extent democratic
2#	Yes	Public	no	Yes	Yes	Yes	Predominantly technocratic
3#	No	Private	No	No	No	Yes	Predominantly technocratic
4#	Yes	Patient organisation	Yes	Yes	Yes	Yes	Predominantly technocratic, lesser extent democratic
5#	No	Public	Yes	No	no	Yes	Predominantly technocratic
#6	no	Private institution	no	Yes, but differ across funding programs	Yes	Yes	Predominantly technocratic
7#	Yes	Public	Yes	no	yes	Yes	Dominating technocratic, lesser extent democratic

6.2.2. PPI as a means of retaining organisational legitimacy

All research funders were aware of external expectations of PPI and expressed a need to develop explicit policies on PPI to maintain organisational legitimacy. Even when the managers were well aware of the difficulties in doing PPI, they saw it as a necessary endeavour along with ambitions to do "proper" PPI. Along with a reciprocity towards the communities they serve, these external expectations drove organisational efforts of meaningful user involvement at several levels, including the review of research applications, feedback to researchers, and formulation of research policies. As two senior managers in a patient association stated:

> SM1: A lot of involvement turns into … (short pause) a show trial, right? That's the whole danger of this. Something like 'tokenism'.
>
> SM2. Pseudo-involvement (laughs)
>
> SM1: Pseudo involvement. Because we must involve as a patient association. And we must do it properly. But it can also be that we just do involvement processes to show that we do it. But where the result might not be as visible as the processes. That's the danger of it. (#4 Senior managers, patient association)

When noting that involvement as PPI is a "must" for patient associations, the senior managers expressed a view of PPI as a necessary and progressive path for being recognised as a legitimate patient association that serves the needs of its members. Although senior managers as well as leader were concerned explicitly with public legitimacy of their organisations, they did not mention any democratic rationales for PPI. As the senior manager explained:

> "It's difficult for us to obtain legitimacy because we do not have a board with elected members (because of their founding principles). So, involvement becomes a short-cut to legitimacy. When we say we want involvement in research, we remove some of the boards decision-making competencies and put in their hands, to gather legitimacy. I say to them (researchers), if you tell me that this (topic) is something the users want and need, then I would like to grant it. Instead of me saying, "I think this is beautiful and I want to fund it". (#3 Research director, public foundation)

Likewise, a senior manager at #7 (public foundation) described involvement as a way of obtaining organisational legitimacy, as their board cannot be elected directly by the citizens because of the founding principles, which requires board members to be appointed politically. Such justifications of PPI as a "short-cut" to organisational legitimacy can be understood as a response from research funders conforming to the international shift towards the participatory turn (Beresford, 2013; Robert et al., 2022), while also expressing a genuine interest in knowing and adhering to the research priorities of patients and/or citizens.

Whilst two funders (#1#4) obtained legitimacy by functioning as patient associations for the benefit of their members, others described using involvement performatively to enhance public perception. Among several interviews, there was a sense of involvement as a 'trendy' mark. In line with DiMaggio and Powell's seminal work on institutional isomorphism (DiMaggio & Powell, 1983) the participatory turn in health research seems to spread from the UK to Denmark through bilateral networks and organisational mimicry, inducing an aspect of organisational isomorphism (DiMaggio & Powell, 1983) That is, the structuring of organisations to deliberately mirror those of others. The discourse surrounding PPI was often one of enthusiasm, evident in both statements from senior managers and in documents. Telling a story of promise and change towards improved services, more effective organisations, and better research:

> "We do it a lot (PPI). But we need to have paperwork on it and describe it. My assessment is that we are very good, compared to other patient associations. I don't know if the Heart Association have patients on their committee yet, because we did that quite quickly. (…) The employee who was allocated to work on involvement has resigned. So, we need to boost it a bit again (…) what the research team with [patient contributors] is doing is really good." (#1 Senior manager, patient association)

6.2.3. Summing up research funders' approach to PPI in Danish health research

UK discourses on PPI concerning more efficient, impactful research feed into arguments used by Danish funders to explain their approach to PPI. In the Danish context, however, funders mainly justify PPI through a technocratic focus on more relevant research outcomes and greater impact through user involvement. At the same time, the research funders used the concepts of PPI to justify themselves as legitimate organisations. By referencing the work of other agencies on PPI and comparing their relative progress the funders sought to derive legitimacy and enhance their status within the research infrastructure. Although funders mostly envisage PPI through a technocratic rationale, they also use PPI to signal progressiveness and thereby positioning themselves closer to the participatory turn. Importantly, research funders have variable resources in terms of staff to support patient and/or citizen involvement, conduct evaluations of ongoing initiatives, explore the adequacy of research policies to obtain the stated goals of PPI, and follow-up upon researchers' previous experiences of patient and/or citizens involvement. As such, they have a diverse set of possibilities and prerequisites to shape PPI as a concept with multiple practices that are being translated into a Danish context.

Addressing Collyer's questions about motivations, we see that the rationales for involvement were often explicitly presented in documents and statements from senior managers at the funders. Our findings indicate that funders justify involvement with a mixture of democratic but mainly we find the prevalence of the technocratic rationale to be dominant with an emphasis on efficiency and relevance of research funding decisions, suggesting that these justifications are not commonly considered as mutually exclusive within the Danish context. However, we also find that funders perceive involvement as a strategic means to attain organisational status and legitimacy, achieved both through the research they fund and by positioning themselves closer to participatory policies that arise in the wider research infrastructure. Funders risk to produce legitimacy towards vague ideals of involvement with only underpinned technocratic values, which have been critiqued internationally (Brandsen et al., 2018; Cluley et al., 2021; Green, 2016; Ocloo & Matthews, 2016; Williams et al., 2020a). The positioning of research funders suggests that PPI constitutes a 'trendy' mark to some extent in Denmark that reflect an aspect of organisational isomorphism (DiMaggio & Powell, 1983), shaping how theory and practice of involvement becomes endorsed between funders in the research landscape to maintain organisational legitimacy.

6.3. How research funders may shape PPI in Danish health research

6.3.1. Testing the waters – assessing readiness for collaborative work

All research funders sought to encourage the involvement of patients (and other members of the public) in health research by explicitly promoting or requiring this in the guidelines for applicants. However, only private funder #4 raised the risks of such actions leading to tokenistic involvement:

> We talk a lot about how you describe involvement in an application so that we think it's a *real* collaboration. It's easy to just use the right words. Some research institutions have a user panel that they talk with about what's important. Then, applications start from a completely different place. In our program, we test the waters of collaborations, so if you get to submit a full application, then we invite you and your partners to a meeting about the application and what it takes. That means we get them all around the table. (…) We ask them, how are you going to collaborate on this project? How did

this idea come about? So, we test if their collaboration exists. (…) and we can empower their partner if the project is a bit immature and give advice based on previous collaborative projects (Senior manager #4, private foundation)

This funders' strategy of 'testing the waters' in the sense of actively evaluating the readiness of researchers and patients/citizens to collaborate before the outset of research projects was done to avoid tokenistic practices and actively support the development of a 'mature' collaboration. While this assessment strategy was unique to funder #4, several funders, especially patient associations, did express during interviews a call in their organisation for action to assess involvement in research applications and projects.

Another way of research funders' to influence the practice of PPI was to 'socialise' applicants into their interpretation of PPI, as expressed by a research director:

… all the senior doctors had written "well, we're studying patients, so that's why we have users in our research project". And I just thought, I've written instructions, about what we mean by involvement in research (…) and yet they don't even bother to read it. So, they did not receive a grant. Maybe their project had super scientific merit, but they had misunderstood the task … we (members of the panel) all agreed on that. We also asked about science communication to the end user. They just wanted to write a scientific article in an English journal, which also dragged down the evaluation of their applications" (Research director, #2, public foundation)

By giving much weight to PPI in the evaluation of applications, and even letting this criterium overrule scientific merits, some research funders sought to reduce the risk of tokenistic practices and legitimate what they saw as 'real' collaboration. This example demonstrates a very active positioning of the funder in implementing their policy on involvement – if applications did not meet the PPI criteria, the funder would not use all the allocated funds for that call.

The examples underscore the power of funders to shape the practice of PPI in health research through the formulation of explicit criteria on PPI and active enforcement of these criteria in research reviews; in one case, by interviewing both researchers and their partners about the collaboration. Through these efforts of making tokenistic practices illegitimate, the research funders also sought to enhance their own legitimacy.

7. Discussion and conclusion

Building on Collyer's (2017) conception of field theory, this study investigated the role of research funders in shaping PPI in Danish health research. We undertook this study because the development of involvement in healthcare research is still in its infancy in Denmark compared to other countries. In this early development the role of funders in shaping PPI is a particularly important and interesting point of inquiry because unlike in other countries Denmark does not have a national organisation responsible for promoting involvement in health (care) research which put significant influence and power in the hands of funders.

Employing Collyer's questions as a way to engage with field theory has proven instrumental to comprehend the implications of funders theories and practices of PPI. Relationality, consistent with field theory, is the recognition of the relationship between central actors in diverse positions in the field, which also sees the transfer of and legitimisation of knowledge as central to those relationships. We therefore note through our material reconfigurations of knowledge production within the healthcare field with the case of participatory approaches such as PPI that uphold democratic and technocratic rationales. Although technocratic rationales are currently the more widely embraced claim for working with PPI. Thus, there is a contest over what rationales define involvement within the healthcare field Previously, the use of Collyer's questions and envisaging of the healthcare sector as a field have been underutilized in relation to the participatory agenda in the healthcare sector. This approach holds potential in exploring broader configurations of knowledge within the healthcare sector in relation to exploring the pivotal role of central actors within the academic infrastructure and how ideas from outside Denmark influence PPI in health research.

International critiques of PPI has raised awareness of significant gaps between the potential value of PPI and exiting policies and practices of PPI. (e.g. addressing issues of equality, diversity, and inclusion has been fundamental to the theory underlying the PPI agenda in different nations, though much of the critique directed towards PPI has centered on failures to achieve these aims in practice (Ocloo & Matthews, 2016; Smith et al., 2022). Without greater attention to democratic rationales and funders allocating seed funds to enable early involvement in development of health research projects, the value that could otherwise by generated through involvement practices will fail to be realised. This can lead sub-optimal or even detrimental PPI approaches, such as extractive practices, mismatch between what patients, clinicians and local communities identify as important topics of research and the actual research conducted. This reflects, PPI initiatives that are not fit for purpose (Beresford, 2013; Boaz et al., 2021; den Oudendammer et al., 2019; Elberse, 2012; Filipe et al., 2017; Patrick, 2016; Rai et al., 2022; Teunissen et al., 2013). These forms of critiques are indisputably relevant for a Danish context, not least because of the relative recency of the 'participatory turn' in Denmark compared to other countries. This presents a unique opportunity and useful position for Denmark as research funders and other centrally placated actors in Denmark can learn from the mistakes and errors made elsewhere. This delay allows for a deliberate approach in the development of participatory initiatives, leveraging the valuable lessons learned from the hard-earned critique of contemporary PPI by international scholars (Beresford, 2020, 2021; Boylan et al., 2019; Brett, 2014; Brett et al., 2014; Ives et al., 2013; Louise & Annette, 2019; Martin, 2008, 2009, 2011; Ocloo et al., 2021; Ocloo & Matthews, 2016; O'Shea et al., 2019; Robert et al., 2022; M. Williams et al., 2019; Williams et al., 2020). Unless this learning opportunity is seized, there is a genuine risk of perpetuating ineffective and potentially harmful methods of PPI. Still, as this study demonstrates, local translation of international conceptions and practices of PPI are likely to occur. In the Danish case, Ideas of PPI have been particularly influential, with central ideas crossing national borders (Grineski, 2011). However, while definitions and practices of PPI in the UK tend to be influenced by the perspectives of deliberative democracy, PPI is predominantly understood through a technocratic lens by Danish research funders. It may be considered if it would be useful to have one definitive policy of PPI in Denmark to support research innovation and meaningful approaches to PPI. The pros of such an approach would be to improve the literacy about PPI, creating legitimacy towards the value of producing research such way and carving the way for better development of support systems. However, a highly centralised approach might also overlook that there is not a 'one-size-fit-all' PPI solution for every situation. Consequently, a reflexive approach is warranted where constraints to PPI initiatives are considered on a running basis and addressed collectively by those involved.

In Denmark, research funders are centrally position to legitimising such a reflexive approach to PPI. In addition to the measures already taken by Danish research funders, they may encourage health researchers to actively address the critiques and challenges associated with their involvement initiatives before, during and after. In line with earlier work of Irwin and colleagues (2013) and Steffensen and colleagues (2022), we advocate against a predetermined bias concerning what constitutes 'good' or 'bad' forms of patient and public involvement (Irwin et al., 2013; Steffensen et al., 2022). Such judgement should not rely on hierarchical classifications, where increased citizen control is automatically assumed to be better (Gauvin, 2010; van de Bovenkamp & Zuiderent-Jerak, 2015). Instead, we suggest a need for critical reflection on the purposes of PPI in particular initiatives, the methods best suited

to meeting these purposes, the risks of these methods and ways of addressing such risks to secure equitable involvement. This amounts to thinking with a so-called "dark logic model" (Williams et al., 2020). Such a dark logic model invites critical reflections on the issues that can potentially impede researchers and patients/citizens from working collaboratively.

Danish funders do not currently have the same extent and depth of resources available and accumulated over time as others has. To accommodate equitable involvement there is a lack of guidance and training on how PPI members can contribute meaningfully through ongoing collaborations with funders and other stakeholders, along with better development of resources for internal reviewers of funding application and guideless for researchers who are applying for grants. As Denmark is at early stage of its 'PPI journal' the presents an opportunity to learn from success and challenges elsewhere; how the former are sustained and the latter mitigated through for example the type of best practice guidance developed by NIHR on research inclusion, which brings new dimension to the participatory turn considering equity, diversity and inclusion in PPI, thereby recognising the relationship between inclusion in research and equitable outcomes. This call for more attention to the democratic rational in Danish research policies as emphasis in for example UK research policies.

In conclusion, to facilitate a change in health research towards more inclusive ways of producing knowledge, funders play a central role. Research funders hold power to shift the balance of rational affiliated with PPI by increasingly starting to address existing inequalities and injustices as central to their wish of maintaining their own legitimacy as research funders. Future studies can fruitfully explore how application of 'dark logics' of PPI may shape the practices of PPI in different contexts.

CRediT authorship contribution statement

Jonas Stage: Writing – review & editing, Writing – original draft, Visualization, Validation, Software, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation. **Oli Williams:** Writing – review & editing, Validation, Supervision, Formal analysis, Data curation, Conceptualization. **Maria Kristiansen:** Writing – review & editing, Validation, Conceptualization. **Sarah Wadmann:** Writing – review & editing, Validation. **Mary Jarden:** Writing – review & editing, Validation. **Glenn Robert:** Writing – review & editing, Writing – original draft, Methodology, Data curation, Conceptualization.

Consent for publication

Not applicable.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgements

The authors wish to thank all the participants who contributed to the study as well as participants from the Medical Sociology (MedSoc) conference in 2023 for their thoughtful comments. Likewise, we would like to thank Graham Martin, Annick Prieur and Nete Schwennesen for their constructive feedback on the manuscript. The study has been co-financed by Region Zealand and Roskilde University. Lastly, we want to honour Mogens Hørder who passed away. He had a special role in the project and paper, being inspiring, kind and supportive in many ways, while being a key figure in a Danish context for leading the change towards more PPI.

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