

Conversing with theory in context: frameworking patient involvement in health research agenda setting

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Patient involvement in health research is increasingly supported by frameworks to design and evaluate meaningful practices and policies. However, designers of patient involvement can face tensions between protecting a framework's principles and fostering local co-design. Sensitized by the concepts of 'technologies of democracy' and 'situated intervention,' this study untangled how a framework (the Dialogue Model) was used in the design of a patient involvement initiative that aimed to co-create an agenda for the Huntington Knowledge Network Netherlands. We argue that designing patient involvement could benefit from 'frameworking': the explicit navigation between different scenarios (i.e. design options and their consequences), while diffracting their competing rationales, to politically establish hierarchies in the doing and negotiate the direction for action. By proposing this definition for frameworking, we aim to articulate an ideal practice of conversing with theory in context, thereby inspiring reflexive patient involvement in health research.

Keywords patient involvement, research agenda setting, health research policy, co-creation, patient engagement

1. Introduction

In the last three decades, many organizations in the health research domain have introduced principles of patient involvement in their policy discourse and collaborating with patients in health research is starting to become an accepted practice (Elberse et al. 2017). With this development, a supporting infrastructure emerged, including patient involvement experts, whose expertise materialized in the publication of frameworks in the academic and grey literature (Greenhalgh et al. 2019). Frameworks are theory-based tools (e.g. models, guidelines, and checklists etc.) which conceptualize patient involvement for designing and evaluating meaningful involvement practices and policies (Greenhalgh et al. 2019; Chudyk et al. 2022). These frameworks come in different shapes and forms: Some are more abstract and principled, whereas others suggest more concrete processes and actions, and some are suggested to be used for design, whereas others are more evaluative. However,

despite the increasing experience with patient involvement and the proliferation of frameworks, confusion and disappointing experiences seem to persist (Solomon et al. 2016; Richards et al. 2023). The literature on patient involvement appears to remain divided about what involvement is, and what it should do, as the existing frameworks regularly conflict and contradict each other (Martin 2008; Tritter 2009; Greenhalgh et al. 2019). It seems as if patient involvement in health research is suffering from what Williams et al. (2020) describe as 'cobiquity'—'an apparent appetite for participatory research practice and increased emphasis on partnership working, in combination with the related emergence of a plethora of "co" words, promoting a conflation of meanings and practices from different collaborative traditions' (p. 2). Consequently, those involved may have varying expectations, which do not always coincide. The diversity in frameworks and accompanying practices and policies suggest that the concept of patient involvement is diffuse and illusive, while in the meantime tokenistic practices can persist.

Scholars reflecting on frameworks for patient involvement describe these conceptual contradictions and argue that their use can result in tensions between protecting their principles and fostering local co-design (Knaapen and Lehoux 2016; Greenhalgh et al. 2019). On the one hand, frameworks could help to protect certain principles of good involvement, such as inclusivity or representation, and thereby prevent powerful actors from shaping involvement to their needs (Knaapen and Lehoux 2016; Zvonareva 2023). Moreover, frameworks could reduce the confusion experienced around patient involvement practices (Martin 2008). On the other hand, the use of frameworks can be impractical as they could become standardized recipes that do not align with situated relational endeavours (de Graaff et al. 2021; Dedding et al. 2022). The many frameworks that have been developed are heterogeneous and seem to be hardly used beyond their context of development, suggesting their usefulness is limited to local settings (Greenhalgh et al. 2019). Additionally, using a framework may result in expert norms being imposed over local ones, which seems to conflict with the participatory ideal (van Oudheusden 2011).

To navigate such tensions, Knaapen and Lehoux (2016) aimed to clarify the contradictions in the abstract norms underlying patient involvement and argue to use frameworks as ‘methods for purification’ that can be incorporated in relation to local expertise and norms in practice (p. 258). Along a similar line, Greenhalgh et al. (2019) pragmatically propose that designers should go through a ‘frameworking process’ (p. 796), using published theory-based frameworks to inform the co-design of a locally relevant framework with the actors involved. Vat et al. (2021) adopted this suggestion and developed an evaluation framework that is explicitly flexible, giving designers the task to tailor it to a local initiative in co-creation with the actors involved (Fruytier et al. 2022). However, while the growth and institutionalization of patient involvement in health research has been well studied (Vat 2021; Harmsen 2023), the entanglement of underlying rationales and how these manifest in the dynamics of the design process has received less attention. Some scholars suggest that designers seem to miss the opportunity for deeper reflection on norms and principles and their relation to contextual needs and considerations for patient involvement practices (Martin 2012; McCoy et al. 2018; Harmsen 2023). Therefore, we identify a need to empirically study and provide thick descriptions of how patient involvement practices are constructed in their specific contexts.

Building on Greenhalgh et al. (2019) and Knaapen and Lehoux (2016), this article aims to draw learnings from the dilemmas encountered in an involvement initiative, to advance our understanding of how a framework can meaningfully inform the design of patient involvement practice. In the field of Science & Technology Studies (STS), and specifically public engagement in science, the relationship between its theories and practices has been studied broadly (Gad and Ribes 2014). Therefore, we first turn to this body of literature to be inspired by the notions of ‘technologies of democracy’ and ‘situated intervention.’ Weaving these scholarly works together, we propose a definition for ‘frameworking’ to articulate an ideal practice of conversing with theory in context. Second, we describe how a framework (the Dialogue Model) was used in a patient involvement initiative and study how frameworking manifested in the design dynamics of this initiative that aimed to co-create an agenda for the Huntington Knowledge Network Netherlands (HKNN). This Dialogue Model, developed by Abma

and Broerse (2010), is a priority-setting framework for collaborative agenda setting in health research. By this means, we aim to contribute to patient involvement theory and policy to inspire collective and reflexive patient involvement design.

2. Frameworking technologies of democracy for situated intervention

Scholars from the STS ‘critical public engagement’ stream approached public engagement in science as ‘a legitimate object of study in itself’ (Irwin 2006 p. 310) and looked more closely how those engagement processes are shaped (e.g. Irwin 2006; Felt and Fochler 2008; Chilvers 2012). These scholars view public engagement initiatives as mediation activities that are context-dependent and exclusionary and framed through the practice of constructing issues, publics, and procedures (Chilvers and Kearnes 2020; Kelty 2020). Adopting this constructivist view helps us to advance our understanding of how patient involvement initiatives are designed and deal with the tension around theory-based frameworks. Starting from this view, the relationship between theory and context is not characterized by tensions, but by opportunities for creativity (Gad and Ribes 2014). Laurent (2011) argues that frameworks for public engagement initiatives can be labelled as ‘technologies of democracy’: ‘The instruments that organize the conduct of democratic life, that is, the participation of various publics in the definition and treatment of public problems, and the oppositions among them’ (p. 650). Providing this lens, Laurent proposes to abandon the question of what meaningful engagement in the abstract is, and instead ‘make explicit the political constructions they enact’ (p. 650). He shows how experiments with technologies of democracy perform a diverse range of interventions of political philosophies and emphasizes the multiplicity of their forms and effects. Each technology of democracy enacts its own normative political frame through its use. When the use of such a technology, or what we call a framework, stabilizes and travels across contexts, its normative underpinnings often fade from view, thereby closing alternative frames (Voß 2014).

More experimental STS work in healthcare contexts follows on this perspective by challenging the universal application of standardized frameworks (Zuiderent-Jerak 2015). Zuiderent-Jerak argues to explore issues and solutions through local standardization together with healthcare professionals, patients, caregivers, and other actors, which he refers to as ‘situated intervention.’ Following this approach, it is assumed that patient involvement initiatives do not lack normative guidance, but are actually implicitly and explicitly shaped by various norms and values, creating a normative surfeit (Zuiderent-Jerak 2015; Knaapen and Lehoux 2016). Consequently, the decisions and actions of patient involvement designers are justified by varying rationales—the constructions of moral reasoning that guide their behaviour—which need to be elucidated to understand what is meaningful in the initiative’s context. Zuiderent-Jerak proposes we can only understand this normative surfeit through intervention. So choosing to work and experiment with a framework as intervention in a patient involvement initiative can help to understand the variety of rationales that shape the approach (Knaapen and Lehoux 2016). Through such interventions, the

designers engage with the complexity of patient involvement and learn about the effects of their interventions to inform new actions (Zuiderent-Jerak 2015). Rather than rigidly imposing a framework, designers could use a framework as a tool for discussion and reflection, opening the design of the patient involvement initiative to diffract underlying rationales, and their norms and values (Zuiderent-Jerak 2015). Importantly, the normativity of working with such a framework should neither be banned for the sake of objectivity or local specificity nor translated into general beliefs, but instead should be welcomed to come to an *'ethics of specificity'* (Zuiderent-Jerak 2015 p. 190).

In this study, these concepts were used to reflect on the practices and consequences of working with a framework to inform more reflexive patient involvement design (Voß 2014). Viewing frameworks for patient involvement as 'technologies of democracy' (Laurent 2011), we build on the suggestion of Greenhalgh et al. (2019) to locally co-create such a framework and approach such co-creation as 'situated intervention' (Zuiderent-Jerak 2015). Building on these notions, we propose a definition for 'frameworking' as explicit navigation between different scenarios (i.e. design options and their consequences), while diffracting their competing rationales, to politically establish hierarchies in the doing and negotiate the direction for action. Through frameworking, hidden rationales can be exposed, diffracted, and contested, which can help to meaningfully challenge different types of power imbalances inherent to collaborations between professionals and patients (Laurent 2011; Zuiderent-Jerak 2015). Sensitized by these concepts and the notion of frameworking as an ideal for patient involvement design, we analysed an example of how a framework was used in the design of an initiative: the agenda-setting trajectory for the Huntington Knowledge Network Netherlands. Particularly, we analysed how the designers of this initiative navigated the multitude of rationales that guided their decision-making. Therefore, the aim of this analysis is not to evaluate the framework that was used, but draw learnings from the initiative to advance our understanding of how a framework can meaningfully inform the design of patient involvement practice.

3. The case: the Huntington knowledge network Netherlands

3.1 The background

Huntington's Disease (HD) is a rare genetic neurodegenerative disorder, characterized by motor, behavioural, psychiatric, and cognitive symptoms (Roos 2010). There is large diversity in how the disease manifests and progresses over time, with an average duration of 17 to 20 years (Roos 2010). Currently, there is no curative therapy for HD (Roos 2010). In 2019, The Dutch ministry of Health, Welfare and Sports started a program to strengthen the knowledge infrastructure for people receiving care with low prevalence rates and high complexity rates for whom there is a need to improve knowledge development, implementation, and sharing (Koopmans et al. 2022). One of the target populations for this program is people with HD and therefore the Huntington Knowledge Network Netherlands (HKNN) was established. The network consists of seven long-term healthcare centres and a central knowledge centre. One of the tasks that the government required from the knowledge centre was to develop an

agenda—designated by the network as 'knowledge agenda'—to create awareness of the knowledge gaps and to encourage the network to continue knowledge development and dissemination in a focused manner. Requirements for this agenda are that it should be developed with all relevant stakeholders, including patients, and that it should be developed with a 'proven methodology.' Research agenda setting knows a relatively long tradition of co-production with patients. Several models and frameworks that aim to provide theoretical and methodological guidance exist (e.g. Mullen 1999; Abma and Broerse 2010; Madden and Morley 2016; Goold et al. 2019). The network chose the Dialogue Model (Abma and Broerse 2010) because of its principles, practical applicability, concrete methodological steps, and capacity to involve patients.

3.2 The dialogue model

The Dialogue Model is a principled process model, developed for collaborative agenda setting in the domain of health research (Abma and Broerse 2010). The model has been used in around 20 agenda-setting trajectories (Pittens et al. 2014; Abma et al. 2015). The model is derived from the philosophy of participatory action research and views patient involvement as a 'relational, deliberative and dialogical process' (Abma and Broerse 2010 p. 161). Its normative frame is based on the Habermasian notion of the 'ideal speech situation' (Habermas 1984), aiming for democratic justice in health research (Baart and Abma 2011). Epistemologically, the model embraces pluralism and is based on the idea that 'experiential knowledge—knowledge gained via reflection on experiences—is necessary in addition to technical or expert knowledge to reach solutions that acknowledge context, value, and meaning' (Abma 2019 p. 432). It is grounded in constructivism and embraces epistemological quality criteria of credibility and fairness, requiring careful listening, probing, and member-checking to gain an understanding of the experiences, questions, and concerns of patients (Abma and Broerse 2010). The model prescribes a trajectory of six phases to come to a shared construct. The first two phases are divergent (identification, exploration, consultation), the third and fourth phases are convergent (prioritization, integration, negotiation), the fifth and sixth phases are action-oriented (programming, co-developing, implementation, stimulation). Ultimately, the model strives towards harmonized integration of needs through mutual learning and temporary fixture of perspectives in a shared agenda which provides direction for action. The methodology is grounded in six principles: active engagement of stakeholders, good social conditions, respect for experiential knowledge, dialogue between stakeholders, emergent and flexible design, and process facilitation (Abma and Broerse 2010). Although the dialogical ground pattern and the separate phases are suggested to be taken as preset, the model encourages a tailormade approach in terms of, for example, the consultation methods. The model suggests that facilitation should be done by an independent facilitator, acting as Socratic guide and mediator, while also including stakeholders in the design process early on.

4. Methods

4.1 Study design

In this study, the agenda-setting initiative for the HKNN is studied as a case of patient involvement in health research. We

conducted participatory action research, adopting a researcher-as-instrument approach, whereby the researchers are both participants and sense makers (Bell and Willmott 2020). In 2021, the HKNN collaborated with the Athena Institute, to set up a multi-phased agenda-setting trajectory for the co-creation of their knowledge agenda and the establishment of the knowledge council (Fig. 1). For a detailed description of the agenda setting process see appendix 1. The design of phases 1–4 of the trajectory was steered by a project group, also referred to as the designers, who used the Dialogue Model (Abma and Broerse 2010) as framework. The work of the project group forms the unit of analysis for this study. The project group consisted of three academic facilitators, one representative of the Dutch patient organization, and six representatives from different healthcare centres across the Netherlands. These six representatives practiced different occupations in the care for people with HD. One of them was also HKNN policy advisor. The project group met online, for 1–2.5 hours per meeting, six times in total: once after each phase, as well as mid-way during the consultation phase and just before the distribution of the prioritization questionnaire. The academic facilitators and HKNN policy advisor met approximately once per two weeks to prepare for the project group meetings and discuss follow-up actions. In phase 5, the HKNN established a knowledge council and drafted an implementation plan for programming and implementation of the agenda. The establishment was guided and advised by an academic facilitator (until November 2022). The execution of the plan is still ongoing at the time this article is written. When the council had started, the trajectory finished. One year later the seven authors of this article, who were all members of the project group, examined the design process. Drawing on the notions of technology of democracy and situated intervention, they aimed to answer the questions:

1. How was the collaborative process designed?
2. What were the underlying rationales for design choices? And how were these stemming from and shaped by either a framework or the local and institutional context?
3. What were the consequences of these design choices, in relation to their underlying rationales?

4.2 Data collection

The following process data were collected:

- Five of the six project group meetings were audio-recorded and observational notes were taken during and after discussions of all meetings.
- Notes were taken during the meetings between the academic facilitators and the HKNN policy advisor in phases 1–4 of the trajectory.
- Documents related to the trajectory were gathered. These include the project plan, a description of the history of the knowledge network, the formal requirements for formalization of the HKNN, a plan for the transition towards a formal knowledge network, notes from a network meeting prior to the start of the trajectory, facilitator guides for interviews, focus group discussions, the questionnaire and the dialogue meeting, the final knowledge agenda, the

implementation plan of the knowledge agenda, and the profile and task description and year plan of the knowledge council.

- In phase 1, six exploratory interviews were conducted to understand the aims and interests of stakeholders and the context and social conditions of the network. These interviews were conducted with a person with HD, the director of HKNN, a representative of a national funding agency, and three members of the project group (including two healthcare professionals and one representative of the patient organization). The interviews were audio-recorded, and notes were taken.
- In phase 3, a prioritization questionnaire was conducted. This questionnaire included an open question on missing topics, from which the answers were included for analysis.
- Notes were taken by four facilitators during the plenary and parallel sessions at the dialogue meeting. These notes included their own reflections on the dynamics of the discussion.
- Notes were taken during the first meeting of the knowledge council. In this meeting the implementation plan was discussed and a more concrete plan for the first year was drafted.

4.3 Data analysis

All audio-taped recordings have been transcribed. The notes of the project group meetings had been distributed to the project group for member check. After the trajectory had finished, the process data were analysed for the purpose of understanding the design process and the role of the Dialogue Model in it through two-step framework analysis, ‘a content analysis method which involves summarising and classifying data within a thematic framework’ inspired by the research questions (Green and Thorogood 2004 p. 184). The documents were taken together with the notes, questionnaire responses, and transcriptions of the interviews and the meetings and were analysed through a material-semiotic lens: viewing documents as ‘modifiers’ of patient involvement initiatives (Asdal 2015). First, to understand how and why design choices were made and what their consequences were, the process data were open coded by SF in Atlas.ti, according to a coding scheme consisting of *design choice* (DC), *rationale*, or *consequence*. Each coded data-segment was also given an open inductive code. Through axial coding, the design choices were abstracted into 10 general themes, and related rationales and consequences were charted to the design choices using the network function in Atlas.ti. The codes describing a rationale were abstracted in five themes. Second, to understand the role of the Dialogue Model, tensions occurring between the rationales and the mechanisms through which these tensions were navigated were interpreted and described. These navigation mechanisms were clustered in three themes. This process evolved iteratively in a small research team (author 1, author 2, and author 7), who went back and forth between the data, literature, and their own reflections on the process. Author 1 performed detailed coding and analysis of the full dataset. Author 2 and author 7 coded a smaller section, interpreted design choices, and checked the overall analysis for consistency. Codes and interpretations were compared, differences were discussed, and consensus was negotiated on an ongoing basis to develop a deep shared

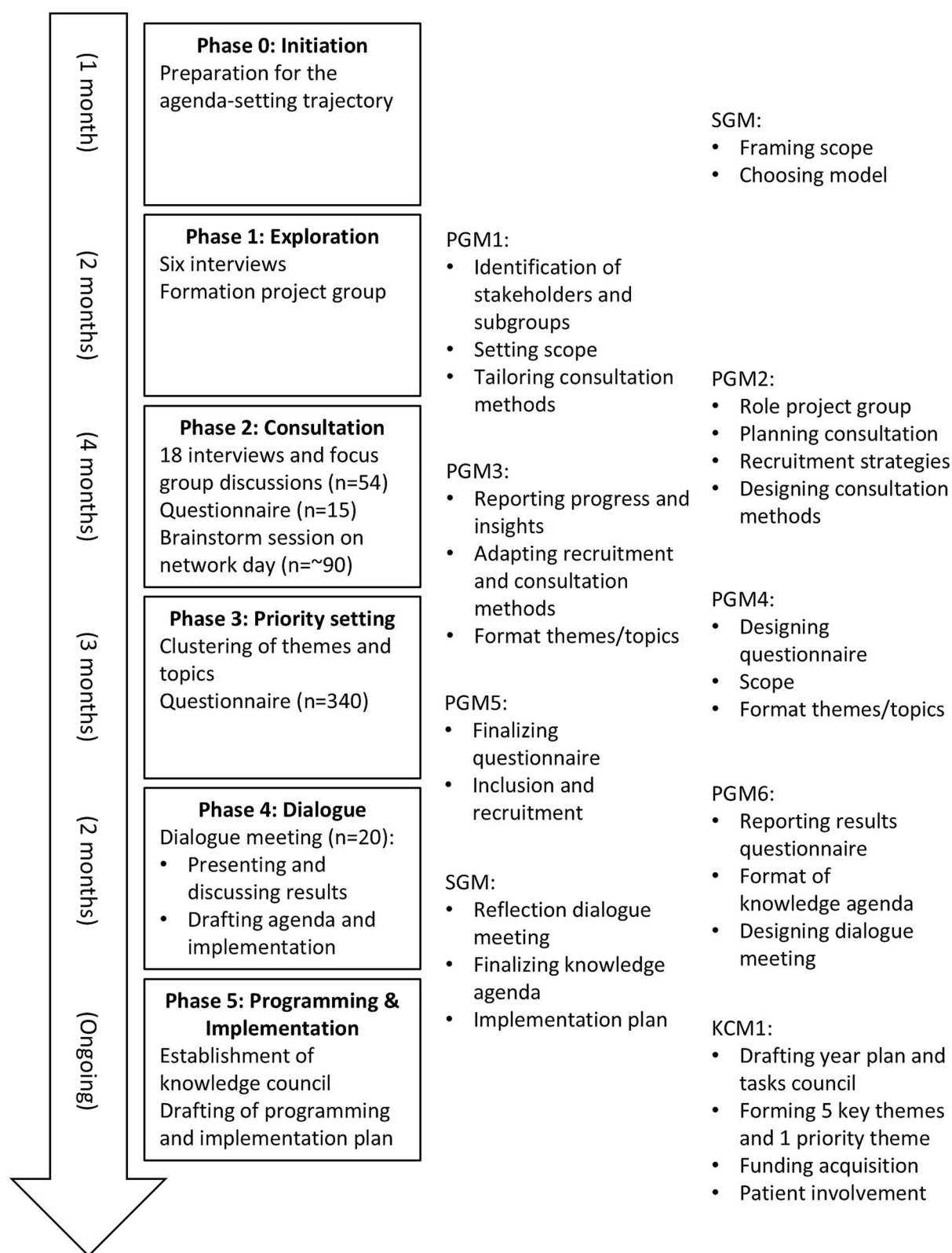


Figure 1 Co-creation trajectory to set the knowledge agenda for people with HD (July 2021–Nov 2022). PGM = project group meeting, SGM = sub-group meeting; academic facilitator and policy advisor HKNN, KCM = knowledge council meeting.

understanding of the case. These findings were presented to the full co-author team and refined based on their reflections and feedback. The quotes that illustrate the themes in the results section are translated from Dutch.

4.4 Ethical considerations

The Research Ethics Review Committee (BETHCIE) of the Faculty of Sciences, Vrije Universiteit Amsterdam, has declared that the

study complies with the Code of Ethics of the faculty (2021.027). All participants in this study were informed about the goals and scope of the project and provided written and/or verbal informed consent. Specific care was taken for the informed consent of people with HD, through careful verbal explanation by a familiar healthcare profession before engagement with the researcher. Privacy and confidentiality of the participants were assured through careful data management. All data were pseudonymized before analysis and procedures were followed to assure findings could not be traced back to individuals apart from the authors of this article.

5. Results

When working with a framework, designers of patient involvement may face tensions, consciously or subconsciously, between protecting principles and stimulating local co-design. In our analysis, the rationales and navigation dynamics of such decision-making processes were untangled, aiming to advance our understanding of how frameworks can meaningfully inform patient involvement design. To present our findings, we first give a description of the process of co-creating the knowledge agenda, including the design choices. Figure 1 illustrates the agenda-setting trajectory in chronological order. It depicts the evolution of the process that led to the shared construct of the knowledge agenda. Second, we describe the five rationales that were used by the designers to support their decisions. Third, we show how these rationales at times were at tension with each other and how the designers navigated the Dialogue Model through three mechanisms: 1) Following the framework as director, 2) Dismissing the framework as meddler, and 3) Welcoming the framework as mentor. The design choices (DC 1–10), the phases in which these were discussed, rationales, tensions, consequences, and navigation mechanisms are summarized in Table 1.

5.1 Process and design choices

Prior to the start of the project, the HKNN director and policy advisor were given the task to develop the knowledge agenda for the network. They tentatively decided to align the scope of the topics on the agenda to aspects that are relevant for long-term care, because this aligned with the expertise in the network (DC 1). They left the precise delineation of the boundaries of this scope up to the project group. They also decided to work with the Dialogue Model (DC 2) and invited the Athena Institute to support the trajectory.

In phase 1 of the trajectory, the social context of this initiative was explored. The project group was formed through purposive selection by the initiators of this initiative, informed by six exploratory interviews and their own prior knowledge of the network (DC 3). The project group started with the identification of the relevant stakeholder groups and drawing boundaries between them (DC 4 and DC 5). The group decided to include three groups: People with HD, relatives, and healthcare professionals. In the three groups, homogeneous sub-groups were formed for the focus group discussions.

In phase 2, the project group decided to conduct interviews, focus group discussions and a questionnaire to understand the daily life challenges and identify knowledge needs experienced by people with HD, their relatives and healthcare professionals (DC 6). Tailored strategies were defined to recruit the different

stakeholder groups (DC 7). Through qualitative thematic analysis, the problems and needs were clustered in eight themes, each including six or seven topics for knowledge development and use for the prioritization questionnaire (DC 8). The project group decided to cluster and categorize the experiences inductively, staying close to the wording in which the participants had expressed the experiences (DC 9).

In the third phase, a questionnaire was developed to prioritize the topics (DC 8). Respondents were asked to indicate their first and second priority topics within each theme, to rank across all the themes, and to indicate any missing topics. The questionnaire was distributed via the healthcare centres and the patient organization (DC 7). When descriptively analysing the results of the questionnaire, a distinction was made between the perspective of people with HD, relatives, and healthcare professionals (DC 5). The designers decided to exclude one theme from the top 14 and to mention these topics separately (DC 1).

In the fourth phase, a dialogue meeting was organized (DC 2) to share and discuss the results of the prioritization questionnaire, finalize the agenda, and discuss its implementation. The meeting was attended by 20 people, of which four people with HD and three relatives (DC 4 and DC 5). In four parallel sessions, the participants were asked to select three topics of the prioritized 20 they found most important, and two topics they found least important and discuss their selection (DC 8). After the dialogue meeting, the prioritizations were analysed by the designers and a final agenda was drafted (Box 1). In the final agenda, a distinction was made between topics for knowledge development and implementation (the top 14) and for other means (mentioned separately) (DC 1).

In the fifth phase, a programming and implementation plan was drafted, and a knowledge council was established (DC 10). It was decided that the knowledge council members should represent all the following stakeholder groups: the seven healthcare centres, patients, and external researchers. During their first meeting, the knowledge council decided to simplify the 14 topics of the agenda to five key themes, to keep the agenda clear and manageable. These five topics are: Loss of autonomy, Physical deterioration, Cognitive and behavioural decline, Application of care, and Support offered for relatives and children of people with HD. This last theme was selected as the primary focus for the first year (DC 1).

5.2 Normative surfeit

Analysing *why* the designers made certain design choices, we can distinguish various rationales that build on different norms and values for developing a ‘good’ knowledge agenda, creating a situation of normative surfeit. In this section, we describe the five different rationales that the project group drew on to support their decisions while co-creating the knowledge agenda (Table 1). Based on our dataset, we could only identify rationales that were explicitly stated by project group members in the meetings, interviews, or documents. We identified two rationales that aligned with theoretical underpinnings of the Dialogue Model. The first was a *deliberative democratic rationale*, arguing for authentic deliberation with people with Huntington as equals to ensure just decision-making. For example, the designers mentioned several times that they desired the agenda ‘to do justice to what has been shared’ by people and relatives that are suffering from HD in their family, ‘and that we can find the patient voice in it [the agenda], even of those who are the sickest.’ The second rationale was *epistemic*

Table 1 Design choices in the design of the knowledge agenda.

Design choice (DC) (Phases of dialogue model)	Rationales	Tensions	Consequences	Navigation mechanisms
1. Determining the scope of the knowledge agenda (Phase 0, 1, 3, 4, & 5)	• Strengthening the network between HCs • Efficient use of resources • Epistemic pluralism • Accountability and positioning	Staying close to what is fundable and what is possible for the network to execute <i>versus</i> staying close to the needs of patients and their relatives.	Non-HD-specific topics are considered in scope.	Following the framework as director
2. Determining the process model (incl. The phases of the process and level of influence of participants in these phases) (Phase 0, 1, 4, & 5)	• Deliberative democratic decision-making • Epistemic pluralism • Strengthening the network between HCs • Accountability and positioning • Efficient use of resources	There was no tension experienced. The different rationales aligned.	Fundamental research is considered out of scope, though this was repeatedly voiced as a priority by patients. Knowledge implementation and care policy is considered in scope. The process consisted of four phases wherein participants were gradually given more influence.	Dismissing the framework as meddler Welcoming the framework as mentor Following the framework as director
3. Determining the roles and composition of the project group (Phase 0 & 1)	• Strengthening the network between HCs • Efficient use of resources • Epistemic pluralism • Accountability and positioning	Ownership within the network and designing appropriate involvement <i>versus</i> managing the burden of participants and offering patient involvement expertise.	A larger more influential role was attributed to the academic facilitators.	Welcoming the framework as mentor
4. In- and excluding groups and individuals (Phase 1, 2, 3, 4, & 5)	• Epistemic pluralism • Deliberative democratic decision-making • Accountability and positioning	All relevant perspectives should be included <i>versus</i> integration of knowledge through dialogue and mutual learning	Most HCs were represented.	Welcoming the framework as mentor
5. Setting boundaries between perspectives (Phase 1, 2, 3, 4, & 5)	• Strengthening the network between HCs • Epistemic pluralism • Deliberative democratic decision-making • Efficient use of resources	Stimulating connections between healthcare staff <i>versus</i> groups/professions/organizations may have diverse needs <i>versus</i> manageable size and number of focus group discussions	There was a disbalance between patient and professional representatives. People with HD with severe speaking and/or cognitive impairment were excluded from deliberation.	Dismissing the framework as meddler Following the framework as director
6. Shaping consultation (Phase 2)	• Deliberative democratic decision-making • Epistemic pluralism • Strengthening the network between HCs	Making knowledge explicit <i>versus</i> including all relevant perspectives	Organizations were mixed.	Welcoming the framework as mentor
7. Recruiting participants (Phase 1, 2, 3, & 4)	• Epistemic pluralism • Deliberative democratic decision-making • Strengthening the network between HCs • Efficient use of resources	Including all relevant perspectives <i>versus</i> creating sufficient internal support for the agenda <i>versus</i> manageable size and number of focus group discussions	Professionals were split in external, outpatient, and inpatient care. Patients were split into risk- and gene carrier, outpatient, and inpatient care. Focus group discussions were shortened, simplified, slowed down, decreased in size, and supported for people with HD. Extra session was organized on a network day and an extra questionnaire distributed <i>via</i> Facebook.	Welcoming the framework as mentor Welcoming the framework as mentor Welcoming the framework as mentor Welcoming the framework as mentor

(Continued)

Table 1 Continued

Design choice (DC) (Phases of dialogue model)	Rationales	Tensions	Consequences	Navigation mechanisms
8. Shaping prioritization (Phase 3)	- Epistemic pluralism - Deliberative democratic decision-making - Accountability and positioning	Including all relevant perspectives and the topics that were brought up versus fitting a manageable format for a questionnaire Just and responsive knowledge agenda versus action-oriented expertise and research infrastructures	The questionnaire included eight themes, with each six or seven topics.	Following the framework as director
9. Shaping (experiential) knowledge to format of the agenda (Phases 3 & 4)	- Epistemic pluralism - Deliberative democratic decision-making - Accountability and positioning	Staying close to expressed experiences versus Executable agenda	The agenda has broad inductive topics.	Welcoming the framework as mentor
10. Determining the roles and tasks of the knowledge council (Phase 5)	- Deliberative democratic decision-making - Strengthening the network between HCs - Accountability and positioning		Simplification of the 14 topics of the agenda to five key themes	Dismissing the framework as meddler

pluralism, welcoming a plurality of knowledges, including experiential knowledge, and integrating them for mutual learning to develop a responsive knowledge agenda. For example, the designers often referred to agenda-setting trajectory as a way of '*making the knowledge gaps visible, the topics that are currently underexposed but that are interesting to do more research on.*'

In addition, the designers followed three alternative rationales that emerged from the local and institutional context. The third rationale the designers drew on was a *network rationale*, aspiring to strengthen and formalize internal connections between actors in the HKNN. This also included aligning with existing structures and expertise within the network to build support and make the agenda actionable. For example, the knowledge agenda was often referred to as a binder, to bring the different centres, their professionals, and research efforts together: '*so that we are no longer working past each other but work with each other.*' The fourth rationale the designers drew on was more outward-looking and labelled *accountability and positioning rationale*. Here, the designers aimed to fulfil the requirements set by the ministry and to align to existing research (funding) infrastructures to be able to execute and enforce the agenda. For example, the HKNN wanted to use the agenda to develop collaborations within the international research field and to engage with the government: '*so that we have this status for the government, of speaking on behalf of the HKNN, that would give us sufficient body to be taken seriously, instead of all working on our own island.*' Last, the designers drew on an *efficiency rationale*, arguing that resources for a rare disease as HD are scarce and collaborative agenda setting would result in their efficient distribution and use. For example, several times the high financial pressure on complex long-term care was emphasized, including the desire to minimize waste: '*so that you don't spend unnecessary money on research that is not relevant anyway to anyone, making efficient use of finite resources.*' In some design choices, these rationales were compatible with each other and could co-exist. In other design choices, tensions were experienced and designers needed to establish a hierarchy between them to come to a decision (Table 1).

5.3 Navigation mechanisms

In the next sections, we describe how the designers dealt with tensions between rationales and worked with the Dialogue Model. We identified three mechanisms of navigation between rationales to come to a decision. The navigation mechanisms are explained with narratives of design choices that were chosen to be most illustrative of this mechanism.

5.3.1 Following the framework as director. During several design choices, the designers followed the Dialogue Model relatively strictly as if it took the shape of a director. This means that the model's notions were accepted as valid and its suggested process steps were adopted without questioning their applicability to the situation through explicit discussion or negotiation of underlying rationales and their tensions. We have identified this mechanism in relation to four design choices (Table 1). An example of such a design choice was the inclusion of relevant stakeholder groups, particularly people with HD, in the phases of the trajectory (DC 4). The Dialogue Model urges the facilitators to give specific attention to the inclusion of patients as equals in a dialogue (Abma and Broerse 2010). Consultation methods

Box 1 Themes on the HKNN knowledge agenda.

The agenda contains 14 ‘knowledge themes’ for which there is a need for new knowledge or implementation of existing knowledge. In the knowledge agenda, the themes are illustrated with examples and quotes and connections between the themes are described (Appendix 1). There is no hierarchical order in the themes.

Knowledge-top 14:

- Dealing with behavioural change
- Supporting family members, including children
- Dealing with choking
- Better matching care offer between diagnosis and symptoms
- Dealing with reduced awareness of the disease
- Dealing with self-determination and safety
- Work, hobbies and daytime activities
- Application of technology and innovations
- Coping with changing roles between people with HD and their families
- Dealing with forgetfulness and concentration problems
- Dealing with/strengthening (physical) balance (mobility)
- (further) Development of shared decision-making
- (further) Development of customized care, treatment and guidance
- Coping with uncertainty, anxiety, loss and dependence

In addition, the agenda includes four topics that were highly prioritized, but which will be addressed by the HKNN through other activities than knowledge development and implementation, varying from developing new policies to organizing an awareness campaign. These topics are:

- Making the disease as subject of discussion
- Familiarity and understanding
- Knowledge and understanding among local healthcare providers & Collaboration of healthcare organizations
- Attracting and retaining healthcare personnel

More information can be found on the website of the HKNN: <https://www.hknn.nl/>

would need to be tailored to specific groups and care should be taken ‘to stimulate fair inclusion and to empower patients’ (p. 170) (*deliberative democratic rationale*). The underlying notion is that ‘all stakeholders have a unique and relevant perspective and that dialogical exchanges will result in mutual understanding and shared action agendas supported by the different stakeholders’ (p. 168) (*epistemic pluralism rationale*). From the exploration phase on, the project group agreed that a great effort would be made to involve individuals with HD in the last stages of the disease. This group is often marginalized due to their cognitive and speaking impairments and a reduced awareness of their condition.

However, when trying to operationalize this in the various phases of the trajectory, the project group experienced a tension. They believed that severely affected individuals would need support from healthcare professionals to participate in the focus groups or questionnaire. But this could increase the risk of interpretation bias. For example, when a person with HD would not be able to provide a coherent answer to the question ‘how are you doing?’ it was thought to be difficult, even with support, to complete a long textual questionnaire with so many topics. Therefore, adaptations and inclusion criteria for the focus group discussions and questionnaire were discussed. For the focus group discussions, the size of the groups was decreased to 4–5 people, the length of the sessions was shortened, the language was adapted, and extra time was taken to let people think and write when answering a question. In addition, a healthcare professional who knew the participants well joined to help during the conversations. For the questionnaire, the designers took care to not make the questionnaire too long and complex. Still, this would not make the questionnaire accessible for everyone. The project group could not agree on pre-set exclusion criteria and

decided to place the responsibility for inclusion in the hands of others:

“The EVV-er [first responsible caretaker who would be instructed to assist] just decides [if someone is able to participate], and we give the tip of just be careful not to fill in the blanks. And if you think someone just can’t make a good choice [regarding the topics they would prioritize] right now, then don’t include him.” – Project group member

This example shows the complex relational circumstances in which the project group needed to navigate.

For the next phase in the trajectory, the dialogue meeting, patients were selected based on their openness towards such activities and their ability to express themselves (*deliberative democratic rationale*). Disease awareness and cognitive ability were not considered as inclusion criteria. Healthcare professionals and relatives were asked to support individuals with HD if they needed help during the dialogue. In this example, one of the designers describes a moment during a discussion about the highly prioritized topic ‘Dealing with behavioural change’:

“The patient indicated not being bothered/not noticing behavioural change in themselves. For this reason, it is also not perceived as a problem. The nurse [...] says that behavioural change is often perceived as very problematic by the environment, but it is not the problem first mentioned by patients themselves. Then it is more about the physical challenges experienced, and less about behavioural change. Patients find it difficult to interpret it that way.” – Facilitator notes, session two, dialogue meeting

In this case, the nurse seemed to be wanting to help by articulating and interpreting the patient's perspective. She tried to navigate a perceived unclarity by drawing on her own experience with individuals with HD and their reduced awareness of their condition. However, the complexity of HD makes it extra challenging to understand patients' needs. Potentially, this led to a biased interpretation that unintentionally devalued the patient's perspective. Nonetheless, the facilitators noted that the atmosphere in the sessions was highly respectful, with strong mutual interest in each other's perspectives, and such assistance was accepted.

These examples show how the project group followed the rationale of the Dialogue Model as director. The decision to try to also include people in late stages of the disease drew on the model's democratic and epistemic pluralism rationale, emphasizing that all experiential knowledge should be respected and that everyone 'should be able to have a 'say'' (p. 169). The project group members strongly resonated with this principled rationale, as they desired to centralize patient perspectives. The prescriptions of the model also draw on deliberative and direct democratic rationale, arguing for the integrating of views through 'mutual learning between stakeholders by means of ongoing dialogues' (p. 168). This is practiced through the focus group discussions and dialogue meeting. In this involvement initiative, these two rationales conflicted. The speaking and cognitive impairments and reduced disease awareness that are associated with later stages of HD complicated such discursive politics of deliberative dialogue and learning, thus presenting a risk of interpretation bias. Because of the specific symptoms of this condition, the project group experienced tensions between rationales within the model, which needed to be navigated. They could have reflected more on the conflicting norms and values underlying these rationales. For example, by weighing whether they attached greater importance to creating opportunities for all people with HD to participate in one or another, or to the benefits of the discursive and deliberative methods and scope as proposed by the Dialogue Model. Although alternative approaches to involve people in later stages of the disease were extensively discussed and adopted, the project group did not question the basis of the model's deliberative direct democratic rationale and its dialogue-based methods. Instead, they went for more pragmatic solutions within the model's boundaries, thereby excluding a group of people with later stages of HD from participating. Therefore, the project group missed the opportunity to discuss alternative rationales. For example, they could have considered the representational democratic rationale (Zuiderent-Jerak 2015), whereby the sickest people with HD could have elected a representative, or the liberal egalitarianism rationale (Durant 2011), whereby the project group could have restricted the scope of decision-making or they could have appointed an experiential expert to speak on behalf of those who are not able to speak. Though all rationales and accompanying strategies may have their own limitations, more careful consideration of these limitations and the specific norms and values they harm could have situated the approach to the specifics of HD, thereby improving the quality of decision-making regarding the knowledge agenda. The limitations of the chosen dialogue approach might have been accepted, since all facilitators noted a feeling of mutual respect and interest during the discussions. Nonetheless, we see that, when the model's rationales are readily followed, this implicitly narrowed the strategy of the patient

involvement initiative and concealed alternative rationales that could have been meaningful in this situation.

5.3.2 Dismissing the framework as meddler. In other design choices, the Dialogue Model was dismissed as if it took the shape of a meddler. This means that the model's notions were considered unapplicable in the context of this initiative and the designers deviated from its suggested practices without explicit discussion or negotiation of underlying rationales and their tensions. We have identified this mechanism in relation to three design choices (Table 1). An example of such a design choice was the decision to exclude fundamental biomedical and clinical research, including medicine development, from the scope of the knowledge agenda (DC 1). The model of Abma and Broerse (2010) suggests that 'since stakeholder issues are not known beforehand, the design emerges in conversation with the stakeholders' (p. 168) (*deliberative democratic rationale*). In the second phase, 'initially a broad overview of experiences needs to be obtained' (p. 164) to ultimately in phase 4 come to an 'integral research agenda' (p. 167) (*epistemic pluralism rationale*). However, this created a tension: the network did not include (bio)medical scientists so not all topics that could be mentioned by participants would align with the activities and expertise of the HKNN (*network rationale*). Moreover, the designers felt that cure-focused research already dominated the research field and was not in line with the mandate given by the Dutch Ministry of Health, Welfare and Sports (*accountability and positioning rationale*). Therefore, the HKNN had tentatively focused the scope on long-term care before the start of the trajectory.

During the exploration phase, the precise boundaries of the scope were discussed. It became clear that the proposed scope might not align with the priorities of people with HD:

"It [HD] is a very small [i.e. rare] disease but there is a very large field of research possible. I suppose we will limit ourselves to long-term care. But . . . because I think when we start asking patients, they will always first say 'research for cure is our biggest goal'." – Project group member

However, the designers decided to limit the scope to all research that would not be considered by the Dutch Huntington's Disease Research Network (DHDRN), a neighbouring research network focused on fundamental and clinical research. To enforce this limitation, the facilitation guide for the focus group discussion of phase 2 stated in its introduction that 'on the knowledge agenda topics related to curing HD will not be included' (p. 2, emphasis in original) and 'solutions/improvements [brought in by participants] that [. . .] are not within the scope of the HKNN are parked on the parking flap' (p. 4). Similar restrictions were included in the prioritization questionnaire. Regardless of these measures, the topic of medicine development was still brought up in multiple focus group discussions with people with HD and relatives and mentioned by eight participants as missing topic on the questionnaire. The facilitators parked these needs on the parking flap, excluding them from the agenda. During the dialogue meeting, the topic was brought up in one of the four parallel sessions. This group concluded that it would be good to explore how the HKNN could connect with medicine development research. In the final agenda, the boundaries of the scope have been described, but the 'bycatch' was not mentioned.

This example shows how the project group dismissed the rationale of the Dialogue Model as meddler. The decision to exclude types of research that are associated with the DHDRN from the knowledge agenda followed from the network rationale and accountability and positioning rationale. The designers argued the knowledge agenda should align with expertise in the network, should help to position the network in relation to others, and should be executable and enforceable by the HKNN. Though most project group members were aware that people with HD and relatives have high hopes for medicine development, they did not see this need fitting within the scope of activities of the HKNN. This rationale conflicted with the rationale from the Dialogue Model. The democratic deliberative rationale and epistemic pluralism rationale of the model would translate in this example in respecting and including all topics that are brought up by the consulted actors. Even more so when these topics had been mentioned several times by people with HD and relatives. Though the precise boundaries of the scope were extensively deliberated, the question whether such boundaries are actually desirable remained undiscussed. When the rationales of the Dialogue Model would have been more carefully considered, the project group may have considered alternative strategies. For example, the project group could have broadened the boundaries to understand and acknowledge the importance of these topics by including them in the consultation and prioritization phase. As such, they could have referred to their relative importance in the agenda, while still reasonably excluding these topics from their own activities since they would not fit the scope of the HKNN. Additionally, the HKNN could have explored the potential of collaboration with the DHDRN. However, the project group did not consider alternative routes to bring excluded topics to attention, even when the importance of these topics became increasingly apparent. Thus, this example shows how the rationale of the Dialogue Model appears to have been dismissed without much explicit consideration because the decision to limit the scope made sense in the context of this initiative.

5.3.3 Welcoming the framework as mentor. In most design choices, the Dialogue Model was neither strictly followed nor dismissed but welcomed as a mentor. In such situations, the model's notions were respected for their principles or expertise but considered and compared to other values and rationales, to explicitly negotiate the direction for action with those involved. We have identified this mechanism in relation to nine design choices (Table 1). An example of such a design choice was the clustering and organizing of the experiences gathered in the consultation phase into a list of themes and topics (DC 9). The experiences and needs shared in the consultation phase were highly diverse, differing not only between stakeholder groups but also within stakeholder groups. The Dialogue Model suggests that the experiences gathered would need to be moulded to fit into the format of the prioritization questionnaire, while ensuring that 'stakeholder issues emerge in the process, and are grounded in experiences' (Abma and Broerse 2010 p. 168) (*epistemic pluralism rationale*). Though Abma & Broerse deliberately do not recommend a specific structure or formulation of the themes and topics, they warn that 'communication between patients and researchers gets complicated by diverging expectations and scopes, language barriers and the low status of experiential knowledge' (p. 169) and argue facilitators must 'prevent ways

of exclusion' (p. 169) when 'information gets redefined and deliberated during the process' (p. 169) (*deliberative democratic rationale*). Following this argumentation of the model, broad practical topics, closely resembling the formulation of the people with HD, relatives, and care professionals, were thought to be most recognizable and responsive. However, the project group felt that more scientific topics that resembled structure and formulation of researchers and the national funding agency ZonMw were more directional, more easily implemented in ways of working, and less prone to a researcher's own interpretations (*accountability and positioning rationale*).

Therefore, the project group experienced a tension. They could inductively linger to the literal wording by which the experiences had been expressed, particularly by people with HD, relatives, and care professionals, or they could more deductively interpret and abstract the experiences, lingering to the language of researchers. For example, they doubted between the more practical 'trouble with stimuli' versus the more scientific 'irritability.' After extensive deliberation, a project group member suggested:

"Should we perhaps also split this discussion? That on the one hand we have the discussion of: Suppose we say together that we feel ourselves responsible to do research on the themes that will come out later, how are we going to do that well together? And on the other hand, also the question that [project group member] started with: How do we do it smartly and strategically, to things like ZonMw and so on? That we're not just being too idealistic but that we're also a bit smart and strategic about that. I think these are two different questions." – Project group member

Eventually, the project group decided to go for broad inductive topics, placing most value on what a project group member explained as: 'fitting the club we are doing this for.' In the final agenda, the rationale for this choice is explained. This included the addition that the translation of these broad inductive topics to concrete (research) activities would be deliberated with all relevant stakeholder groups, to ensure implementation remains in alignment with their needs.

In this example, we see that the use of the Dialogue Model seemed to align all actors to the same rationales of developing a just and responsive knowledge agenda. However, its local employment caused tension with situated rationales of developing an action-oriented agenda that would align with existing expertise and research infrastructures. The project group welcomes the notions of the Dialogue Model to the conversation as mentor. They acknowledge the politics of these notions and weigh their importance and value against situated rationales. They theorized about different possibilities and their consequences and weighed pros and cons of each of these different approaches. The quote above shows how a project group member made the tension explicit, helping the group to understand which values are at stake. Through deliberation, the group ordered the rationales hierarchically for this specific situation and developed consensus.

6. Discussion

Prompts, recommendations, and requirements for patient involvement are increasingly embedded in health research policies and the number of frameworks to guide such initiatives

has grown exponentially. There is a need to advance our understanding of how frameworks can meaningfully inform the design of patient involvement initiatives. Sensitized by the concepts of ‘technologies of democracy’ and ‘situated intervention,’ this study dived into the navigation dynamics of a specific initiative, the co-creation of a knowledge agenda using the framework of the Dialogue Model, and unravelled its decision-making processes, to draw learnings for patient involvement designers.

6.1 Frameworking

The designers in this patient involvement initiative were faced with the challenge of dealing with various rationales for developing a ‘good’ knowledge agenda, aligning with the applied framework as well as the local and institutional context of the initiative. At several moments in the design process these rationales clashed and the development of the knowledge agenda faced a normative surfeit. Our findings illustrate how the designers navigated this normative surfeit, using the framework in three ways: *Following*, *dismissing*, or *welcoming* its guidance in the design process. These findings suggest that navigation between various rationales is inevitable when designing patient involvement. For most design choices, the project group proposed and carefully considered different scenarios. However, explicating and negotiating underlying rationales is complex and can simply evade the designers’ attention while they are caught up in the routine and hustle of the process. In the moments that the framework was followed as director or dismissed as meddler, the rationales of design choices were less visible and the conversations of the project group turned more towards the practicalities of boundary work and methods. However, when the framework was welcomed to the design work as mentor, the designers embraced its expertise while the limits of the framework were acknowledged. We argue that this navigation mechanism aligns most closely with the notion of ‘frameworking’: explicit navigation between different scenarios (i.e. design options and their consequences), while diffracting their competing rationales, to politically establish hierarchies in the doing and negotiate the direction for action (Laurent 2011; Zuiderent-Jerak 2015; Greenhalgh et al. 2019). We conclude that, like a good mentor, frameworks for patient involvement could function as fingerposts: they guide their pupils in choosing between different directions while at the same time appreciate being challenged and allow for their pupil to find their own path (Zuiderent-Jerak 2015). By proposing this ideal and connecting it to our empirical findings, we hope that we can create a language to articulate a practice of conversing with theory in context that can inspire more reflexive patient involvement design.

6.2 The risks of foregrounding a framework as method

The normative surfeit in this case reflects a broader problem in patient involvement in health research. Principled frameworks and local expectations can arise from contradicting and unattainable ideals (Martin 2008; Madden and Speed 2017; Greenhalgh et al. 2019; Chudyk et al. 2022). For example, while some argue patient involvement is primarily a political matter of redistributing power across a broader collective, others frame it as a means of incorporating personal preference and individual experience

(Madden and Speed 2017). These arguments are accompanied by different and often incompatible approaches. Patient involvement scholars have argued that keeping such contradictions implicit can fuel the confusion around patient involvement and suggest that frameworks could usefully inform local co-design (Knaapen and Lehoux 2016; Greenhalgh et al. 2019; Fruytier et al. 2022). However, others have shown that local co-design of practices also presents the risk that the ideals of patient involvement are co-opted by dominant actors with vested interests, who are able to close involvement down to particular configurations (Chilvers and Kearnes 2020; Gunn et al. 2023; Zvonareva 2023). Our findings add to these studies by illustrating the politics of contestation between different rationales and the powerful position of designers. They point particularly to the importance of making such contestation visible by reflexively diffracting the rationales underlying a framework and local or institutional expectations.

One way to help designers in navigating the contestation of rationales is to embed flexibility into frameworks. The Dialogue Model promotes an emergent and flexible approach as one of its core principles (Abma and Broerse 2010). Among the most well-known frameworks for agenda setting with patients, the Dialogue Model seems to be the only one that encourages such tailoring of process design (Manafò et al. 2018). Another well-known and often-used framework, developed by the James Lind Alliance, does not have such flexibility explicitly embedded in its structure and other scholars reflected on its constraining and performative effects (Madden and Morley 2016; Nygaard et al. 2019; Werner et al. 2024). In this agenda-setting case, the Dialogue Model’s flexibility seemed to contribute to more reflexive consideration of certain design choices. For example, regarding the framing of relevant stakeholder groups and the consultation methods. However, for other aspects, the framework seemed to direct the designers more rigidly, for example regarding the importance of a dialogue (as exemplified in section Following the framework as director) and the broad scope of topics (as exemplified in section Dismissing the framework as meddler). Consequently, at times the designers still missed the opportunity to explicitly discuss its normativity and consider alternative rationales and scenarios. In these moments, the framework appeared to have been foregrounded as a method.

Other scholars have also noted the increasing endorsement of patient involvement by policymakers and funders and criticize the tendency to foreground patient involvement as a method (McCoy et al. 2018; Dedding and Aussems 2024). Requirements, quality criteria, or methodological standards for patient involvement are integrated in policy structures, trying to safeguard the meaningfulness of such collaborations (e.g. Staniszevska et al. 2011; Cavaller-Bellaubi et al. 2021). This initiative was no exception to this, as the ministry requested from the HKNN to involve patients using a ‘proven methodology,’ seemingly implying that a framework should be followed rigidly. This requirement seems to be based on a positivist epistemology, striving for an objective representation of reality from which the evidence-based medicine movement derived (Bensing 2000). Imposing such requirements and subsequent rigidity of frameworks can manifest as a form of ‘validity policing’: ‘excluding or suppressing what does not comply with, and thereby affirm, the approved procedures’ (Bell and Willmott 2020 p. 1371). This clashes with democratic and epistemic patient involvement ideals (Bensing 2000; Dedding and Aussems 2024). When patient involvement is designed through a positivist lens, we may reduce a framework for involvement to a method, risking

that we end up ‘fighting a struggle against technocracy by establishing a new technocracy’ (Voß 2014 p. 14). As for science itself, a positivist view may distract us from the messiness that is inherent to the collaborative work of involving patients in health research, desensitizing us to its politics (Knaapen and Lehoux 2016; Bell and Willmott 2020).

6.3 Abandoning proven methodologies for co-creation

Reflecting on frameworks for patient involvement, Greenhalgh et al. (2019) point us to the domain of co-creation. Here, scholars adopt more pragmatist conceptions of knowledge and aspire contextual usefulness. Our findings align with others in showing the tinkering and contestation of translating a theory-based patient involvement framework to a particular initiative, in which navigation and reconciliation between rationales seems unavoidable (Madden and Speed 2017; Heerings et al. 2022). Adopting a pragmatist perspective helps us to see the situated emerging relations of patient involvement, shifting our focus to productive interactions (Marres 2007; Zuiderent-Jerak 2015). Several scholars have argued for a recognition of patient involvement as *work*, to help designers appreciate ambiguity and unanticipated consequences and urge them to situate the initiative (de Graaff et al. 2021; Dedding et al. 2022). As infrastructures for supporting patient involvement in health research expand and standards and requirements stabilize, there is a risk of moulding practices according to traditional epistemic hierarchies (Braun and Könninger 2018; Schölvinc Anne Floor et al. 2019; Egger and Zvonareva 2025). This could undermine the transformative work that can actually make patient involvement meaningful. In the HKNN case, the requirement for a proven methodology and a certain rigidity in the Dialogue Model seemed to contribute to a strong sense of trust in the framework and the expertise of the academic facilitators. This may have hindered collective reflection on what *works* within the context and blinded the designers for alternative strategies for meaningful involvement of people with HD. Drawing on situated intervention as an appreciation for normative work, we echo that the notion of work provides an attractive alternative lens. Not only could it support the call to policymakers and funders to provide space and resources for patient involvement, but it also encourages designers to resist against imposed use of a proven methodology and rigidity in frameworks and strive for a frameworking approach instead.

6.4 Limitations and recommendations

This study aimed to address a knowledge gap by providing empirical insight in the navigation between rationales when using a framework to design a patient involvement initiative. Our study is confined to the data of the agenda-setting trajectory, which had not been gathered with the specific aim of this study in mind. Moreover, the data provided limited insight in the designers’ implicit rationales as well as in how the agenda was received, used, and further constructed within the network beyond the involvement of the academic facilitators. As writers of this article, we performed a dual role: first as designers of the initiative and second as researchers analysing the design dynamics. This dual

role could be considered as a limitation since it may have limited our ability to critically assess the initiative and propose alternative views. However, we also consider this as strength, as it provides an embedded view ‘from the trenches’, helping us to better interpret how various rationales framed the design of this initiative (Verwoerd et al. 2022). The different levels of familiarity with the academic literature on patient involvement and STS within the author group required us to take extra time for developing a shared understanding in the analysis process. All co-authors were engaged through reflective exercises and sessions, contributing to a multi-sided view of the trajectory. The variation in background knowledge also proved valuable as this prompted new reflections and reconsideration of assumptions, enriching and nuancing our findings. Moreover, we feel that our dual role could strengthen our call to other designers of patient involvement initiatives to implicate themselves and their own norms and values in the design process. This means they would abandon the idea that their role is or should be either neutral or practiced from a position of authority and reflexively consider their own positionality in dialogue with others involved. By diffracting and contesting the rationales of frameworks and those emerging in the local and institutional context, we could attend to the multiplicity of alternative rationales of concerned actors in the broader ecology of a patient involvement initiative to come to an ethics of specificity. Therefore, we encourage designers, policymakers, and funders to attend to the contingency, ambiguity, and mediating consequences of patient involvement. Moreover, we encourage scholars to experiment with the notion of frameworking, to understand how it could intervene in initiatives and structures.

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Conflict of interest

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Data availability

The data underlying this article cannot be shared publicly due to protection of the privacy of individuals that participated in the study. The data will be shared on reasonable request to the corresponding author.

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