Health service provider views on measuring patient involvement in healthcare: an interview study with researchers, clinicians, managers, and policymakers

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Research Article

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Abstract

Background Strategies aimed at promoting patient involvement vary in purpose across different healthcare settings and are assessed using a wide range of outcomes. However, there is no consensus on the most appropriate measurement tools or ways to evaluate patient involvement initiatives.

This qualitative study aimed to explore the perspectives of stakeholders from micro, meso, and macro levels within the Danish healthcare system on patient involvement and its measurement.

MethodsThis descriptive, explorative study employed semi-structured interviews with open-ended questions to elicit participants' views and experiences of patient involvement and measurement tools. A purposeful sample of participants was identified, to include decision makers, researchers, and health professionals (n=20) with experiences of patient involvement in healthcare at micro, meso, and macro levels across Danish organizations. Data underwent reflexive thematic analysis.

Results Three main themes were identified: 1) Determining the purpose of patient involvement and measurement alignment; 2) Reflecting on the qualities, fit, and usefulness of measures; 3) Recognizing conflicting stakeholder paradigms. Despite the interest in and positive attitudes toward patient involvement, views on the meaning and value of evaluating involvement and innovating varied; in part, this was attributable to challenges in selecting criteria, methods, and measures for evaluation.

Conclusion The findings indicate the need to integrate the perspectives of all key stakeholders in designing the evaluation of patient involvement initiatives. The application of a multiple stakeholder approach and co-production of a multidimensional evaluation may provide some common ground for selecting evaluation criteria and measurement tools in the healthcare setting.

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Background

Patient involvement is a key goal of policy, research, and practice innovation in healthcare [1]. Patient involvement in healthcare is described as the active participation and collaboration of patients, healthcare providers, and caregivers in decision-making processes, as well as the empowerment of patients to take an active role in their care through goal-setting and care planning [2]. In Denmark, several interventions have been introduced to improve patient involvement in healthcare, service delivery, and research, such as a legal requirement to include patient perspectives when designing health policy, research, and service improvement [3, 4] setting national goals for health services that require practitioners to respect patient autonomy and preferences in all aspects of care [5]; health regions and organizations setting up infrastructure to support research; and quality improvement projects to enhance patient involvement practices within services [6, 7]. However, there are variations in how patient involvement interventions are conceptualized and integrated within healthcare infrastructure at the macro (political health system), meso (organizations and teams within the healthcare setting), and micro (clinical setting related to individuals and their interactions and practices) levels [2, 8].

A recent review classified measures assessing patient involvement interventions within Danish healthcare. No single measure was used across all patient involvement intervention evaluations, and there was a lack of common ground in conceptualizing patient involvement or intervention success. Few measures captured explicitly patient perception of involvement in healthcare; rather, they assessed associated outcomes such as practitioner communication, increased self-management, or satisfaction with care [9]. A key barrier to the integration of patient involvement interventions in Denmark is the lack of a shared understanding of patient involvement, and agreement on how to measure meaningful improvement when evaluating interventions designed to improve service outcomes and patient benefit [1, 6, 10].

Drawing on the multiple-stakeholder framework Making Informed Decisions Individually and Together (MIND-IT) [9], it is likely that different health service delivery stakeholders have different goals, needs, knowledge, experience, skills, and values that impact on judgements and decisions about patient involvement intervention type and methods of evaluation. For this study, patient involvement refers to a range of activities or practices within healthcare to support the active engagement of patients in the process of securing appropriate, effective, safe, and responsive healthcare [9]. Acknowledging the different views of health service providers (Fig. 1) on the meaning, definition, and purpose of patient involvement is a necessary step towards identifying whether there is a shared approach to how researchers, practitioners, managers, and policy leads can think about patient involvement and its measurement [11, 12].

(Insert Fig. 1 around here, please)

Limited research [13, 14] has investigated directly what different health service providers consider to be meaningful patient involvement, how it is created and justified, and if there is a common understanding of indicators that can be measured. Politicians, researchers, and clinicians seem to be moving at different paces and in different directions with regard to the implementation of patient involvement interventions [15]. This study aimed to explore the perspectives of stakeholders from the micro, meso, and macro levels within the Danish healthcare system on patient involvement and its measurement. Our findings aim to support the establishment of a way to share understanding between health services researchers, practitioners, managers, and policymakers about methods to assess patient involvement and find common ground when innovating practice.

Methods

Study design

This study used an explorative study design employing qualitative methods. Semi-structured interviews were conducted to elicit data, and thematic analysis was conducted to generate themes [16]. It is the second of three studies on the assessment of patient involvement in the Danish healthcare system. The first study was a rapid review identifying measures used to evaluate patient involvement interventions in Danish healthcare [9]. This study explores professional perspectives on patient involvement and its measurement. A third study will explore patient perspectives on patient involvement and its measurement.

Organizational framework

We applied an organizational framework to divide the hospital environment into three analytical levels representing health service providers at macro, meso, and micro levels [8]. This approach is used across and within healthcare systems to study perspectives on patient participation, shared decision making, and person-centred care in policy, research, and implementation [8, 17–20]. At the macro level, health services aim to ensure an optimal result for their patients by letting them influence policymaking and clinical guidelines. At the meso level, managers aim to organize care to enhance patient engagement by facilitating service delivery that enables patient involvement. At the micro level, individuals aim to enhance their practice and support effective patient-professional interactions [17, 20].

Participants and setting

A purposeful sample size sufficient to meet the aims of this exploratory study and attain variation in participant characteristics was sought [21]. Participants were invited to participate based on the following criteria: working actively with patient involvement in healthcare (practitioner, researcher, or service improvement) in hospital-related service delivery (micro, meso, or macro system level) in Denmark (Capital Region of Denmark, Zealand Region, Southern Denmark Region, North Denmark Region, and Central Denmark Region). Researchers affiliated to the Research Centre for Patient Involvement [22] helped identify eligible participants directly or through staff leaders. The first author contacted people interested in participating, sending a study information sheet with a consent form and participation schedule via email.

Data collection

Individual semi-structured interviews were conducted with participants employed in the Danish healthcare system (see Table 1). The participants chose the location for the interview. Nine face-to-face interviews were conducted in a hospital or office, ten online, and one via telephone. An interview guide was developed by the first author with reference to qualitative guidelines [23], literature on patient involvement interventions and measurement [9, 10], and frameworks for healthcare organizational structures [7]. The guide was reviewed by the interdisciplinary research team. The interview guide comprised three domains: 1) views on or experiences with patient involvement, 2) contextual factors significant for patient involvement, and 3) evaluation and measurement of patient involvement. It contained an initial open-ended question for each domain and three to four sub-question prompts, which differed slightly for the macro, meso, and micro organizational levels. The interview guide was pilot tested in the first interview, and modified to enhance the clarity of the questions. Interviews were conducted by the first author between May and August 2022, and audio recorded; they lasted on average 38 minutes (range: 21–52 minutes). The first author is a health services researcher and health professional with experience in qualitative methods, and trained in conducting interviews.

Table 1
Characteristics of participants at the macro, meso, and micro levels of the Danish healthcare system

	Macro	**Meso**	**Micro**	**Total**
Number of participants	4	8	8	20
Average duration of interview (min.)	39	38	37	38
Range (min.)	29–45	30–44	21–52	21–52
Gender				
% Women	50	88	62	70
Job title (n=)				
Healthcare professional	0	0	4	4
Clinical specialist/researcher	0	0	4	4
Research lead	0	6	0	6
Clinical manager	0	2	0	2
Organisational, policy, or strategic lead	4	0	0	4
Region of Denmark (n=)				
Central Denmark Region	3	3	7	13
Capital Region	0	3	0	3
North Denmark Region	0	0	0	0
Zealand Region	1	0	0	0
Southern Denmark Region	0	2	1	3

Data analysis

A thematic analysis approach, guided by Braun and Clarke's six-phase method, was used to classify the data [24–26]. The first and second phases of the analysis were conducted by the first author, and phases three to six involved the entire research team. The analysis process was iterative, with several rounds of discussions to finalize the themes and results. The NVivo software package was used to organize codes from the second phase. In brief, the phases were:

- Phase one – interviews were transcribed verbatim and read multiple times to gain a comprehensive understanding of the data and identify both latent and manifest content. Summaries were written after each interview, and across all interviews.
- Phase two – initial codes were generated systematically for interesting features of the data. The coding process focused on specific topics from the interview guide, such as patient involvement, views on contextual factors, and purposes of using evaluation instruments.

- Phase three – an open and reflexive approach was taken to collate the codes and identify patterns of shared meaning [21]. This process was carried out by four authors (LØR, TE, CBR, and BST), who gathered all data relevant to each potential theme. Central sub-themes and themes were identified based on the collated codes and reviewed by the research team to ensure they accurately reflected the data [27].
- Phase four – a thematic map was generated to visually represent the codes and their relationship to the findings.
- Phase five – definitions and names for each theme were refined in a workshop involving all authors, with any discrepancies resolved before the themes were further developed.
- Phase six – extract examples were selected based on their relevance to the research question [24, 28].

As this is an explorative study, we set out to present a range of views, and did not strive for data saturation. No feedback was sought from the participants as this approach is not congruent with the methodology of thematic analysis [16].

Results

In total, 36 people were invited to participate; eight people declined to participate, and eight people did not respond. A total of 20 people at the macro level (n = 4), meso level (n = 8), and micro level (n = 8) participated. The majority were women (70%) and from the Central Denmark Region (65%) The characteristics of the participants are shown in Table 1. To maintain anonymity, we refrained from describing further characteristics of the participants.

(Insert Table 1 around here, please)

Interview findings

Three themes were constructed from the data: theme one – Determining the purpose of patient involvement and measurement alignment; theme two – Reflecting on the qualities, fit, and usefulness of measures; theme three – Recognizing conflicting stakeholder paradigms (see Table 2). The themes and sub-themes demonstrated that different challenges for fundamental issues related to patient involvement and its measurement were evident within and between the macro, meso, and micro levels. The overall findings across levels are presented, and the individuals quoted are assigned an identification number (#) and tagged according to their organizational level. More illustrations of the themes and sub-themes are presented in Additional file 1.

Table 2
Overview of the themes and sub-themes

Themes	1) Determining the purpose of patient involvement and measurement alignment.	2) Reflecting on the qualities, fit, and usefulness of measures.	3) Recognizing conflicting stakeholder paradigms.
Sub-themes	1a) Negotiating the meaning and definition of patient involvement.	2a) Choosing a tool that makes sense.	3a) Defending qualitative or quantitative inquiries.
	1b) Deciding if patient involvement is a means or an end.	2b) Questioning the use of outcome measures.	3b) Adapting to the specific setting.
	1c) Identifying the coherence between indicators and measurement tools.	2c) Reflecting on the qualities of generic and disease-specific measurement tools.	3c) Ensuring implementation of measurement in clinical practice.

(Insert Table 2 here, please)

Theme 1 – Determining the purpose of patient involvement and measurement alignment

Sub-theme 1a) Negotiating the meaning and definition of patient involvement

This section describes the nature and significance of patient involvement, and what patient involvement means to the participants. Participants recognized that there was no single definition or simple intervention that could encompass the full complexity of patient involvement in healthcare. Patient involvement was described as either a necessity, a political trend, or something ‘taken for granted’, with a range of views about what might constitute an ideal level of involvement. There was recognition that effort is needed to reach a shared understanding among colleagues and teams of what patient involvement means and how it can be promoted and maintained in clinical practice, and throughout an organization.

“We had to talk our way into what it [patient involvement] is all about. Well, it actually took some time to find out: how do we view it and what do we think is important? (…) When we ask, ‘what is patient involvement?’ then you mean something, I mean something, everyone means something different.” [#16-macro]

In clinical practice, patient involvement was described as both an independent and delineated part of an intervention, as well as a part of the process of communicating with patients. Notably, in psychiatry, it was referred to as a therapeutic approach, with participants making explicit the contradiction in a service wanting to promote patient involvement but also needing to endorse the use of restraints on patients against their wishes. Agreement existed among the participants on the need to give an explicit definition and a stated purpose for patient involvement before evaluation and innovation.

Sub-theme 1b) Deciding if patient involvement is a means or an end

This section captures perspectives describing patient involvement as an activity, method, or instrument used to obtain a goal of care (means) or as an outcome (an end in itself).

“Should we measure patient involvement or should we measure it as a means to achieve it [another outcome]? We actually aim for increased health literacy, increased self-efficacy, increased self-management, and so on. So, patient involvement measures are means to get there.” [#10-meso]

Patient involvement was considered to be a means to reduce patient outcomes such as the use of hospital services and to ease pressure on hospital systems that lacked resources. At the macro level, a national patient feedback survey item measuring patients’ perceived involvement (engagement) with the healthcare provided was used as a way a hospital could benchmark itself against other hospitals, assess the impact of service improvement initiatives, or make judgements about the quality of care provided. This discrepancy in the meanings and definitions of patient involvement as a means or an end has implications for which innovations are implemented or evaluated, and which measurement tools are used to gather evidence of improvement.

Sub-theme 1c) Identifying the coherence between indicators and measurement tools

This theme classifies perspectives about indicators associated with patient involvement and measures of patient involvement, and their alignment. These discussions referred to different types of interventions that can be implemented and evaluated to enhance patient involvement in practice, and implications for the selection of measures to assess change. Participants highlighted the challenges of finding coherence between an intervention, a measurement tool, and an indicator associated with patient involvement. Inconsistency in the ability to distinguish between indicators and measures, and their interrelatedness, was a concern for the participants.

“Have you ever used a tool that can change the parameter you are measuring? If the hypothesis is that it should improve people’s quality of life, well, then it is important first to have determined what defines quality of life, and which parameters can improve quality of life.” [#17-meso level]

Participants at the meso level were the ones most concerned with these aspects of assessing patient involvement. They found it necessary to establish consensus on indicators for assessment and coherence with structure, process, or outcome measures. Concerns were expressed about a lack of clarity concerning the selection of indicators, measures, and measurement tools as this would lead to poorly structured evaluation design. Some researchers requested more comprehensive evaluation design with a stated programme theory; for example, reporting the goal of the interventions such as increasing health literacy, self-management, or shared decision making. The programme theory should explain how the intervention is understood (theoretical framework), the treatment components that impact on health outcomes (active ingredients), how the intervention produces change (mechanisms of change), and the context affecting implementation and outcomes. Such an evaluation design was perceived as a way to ensure that patient involvement was explicitly included as a success criterion and measured appropriately.

Theme 2 – Reflecting on the qualities, fit, and usefulness of measures

Sub-theme 2a) Choosing a tool that makes sense

This theme classifies perspectives on selecting measures to collect quantifiable data. The measurement tools the participants referred to are questionnaires, interviews, or observational instruments used by researchers and practitioners to assess, evaluate, or collect data related to patient involvement from different stakeholder perspectives.

All participants agreed about the importance of ensuring meaningful and useful measurement. However, there was little agreement on the role of measurement and which measures made sense. At the meso and macro levels, it made sense to prevent the overtreatment of patients to obtain economic savings for the benefit of society as a whole. In this case, choosing measures that could assess cost-effectiveness was meaningful. At the micro level, the value of assessing patient involvement was linked to delivering the most beneficial treatment for the individual patient. A trade-off was made between direct measures assessing clinical outcomes to test the efficacy of an intervention and indirect measures assessing patients' self-reported experiences of improvement in care.

Notably, participants reported a need for a pragmatic measure to integrate within current practice to ensure sustained measurement. Without a reasonable measure, services would continue to rely on routinely collected ‘proxy’ data, such as survival rate, waiting times, or length of stay, which had already been collected. Integrating new measures within systems was seen as desirable and necessary to allow assessment of the mechanisms of change including meaningful and important aspects of a good life for the patient. There was some reflection on potentially different priorities among researchers and clinicians.

“There could be a difference between whether a specific tool makes sense when you are in a research setting (…) what you use in terms of research and what is used in clinical practice.” [#5-micro]

Researchers emphasized that measurement tools should be chosen to evaluate phenomena and interventions because of their relevance to what they were intended to measure. They stated that measures were sometimes chosen because of their ease of use or common use by others. Clinicians emphasized that measurement tools should be chosen well and used sensibly to be suitable and feasible in clinical practice. Moreover, they found it important that measures were meaningful to both the patient and the clinician.

Sub-theme 2b) Questioning the use of outcome measures

Some participants drew on their experiences of using patient-reported outcome measures (PROMs) to articulate their views on using self-report measures of patient involvement and interventions to facilitate patient involvement. Other participants referred to routinely collected clinical data as outcome measures.

At the macro level, participants expressed a need to use outcome measures systematically for the systematic assessment of patient involvement. Outcome measures combined with PROMs were needed to inform decision making and priorities across health systems. At the meso and micro levels, some scepticism was expressed about using outcome measures as evidence to evaluate patient involvement. These participants perceived the use of outcome measures to assess patient involvement to be driven by top-down goals, and viewed these measures as inappropriate and reductionist.

Two conflicting narratives arose from micro-level clinical participants around the use of patient self-report questionnaires to capture patient involvement. One view was that integrating patient-reported measures such as PROMs within routine practice was a waste of time and resulted in less time to spend on more traditional aspects of service delivery such as caring and conversations with the patient about what mattered to them. There was a perception that the extensive use of questionnaires would result in patients being viewed as data sources rather than individuals with unique issues. The opposing view was that self-report questionnaires such as those concerned with PROMs should actively be used with patients to prepare them for consultations and inform dialogue during these meetings. These issues underpinned discussions about measures of patient involvement.

"We are also in a time when one must be able to measure everything, but some of these soft values are just very hard to measure…then you go back to something that you are used to measuring in years of life and re-admissions – those hardcore outcomes (…) but why do we have to measure everything?" [#14-meso]

Views on the role of measurement differed among the participants, and there was no clear distinction between process and outcome measures. Notably, only one researcher addressed the potential of using patient-reported experience measures (PREMs) as a measurement of patient-centredness.

Sub-theme 2c) Reflecting on the qualities of generic and disease-specific measurement tools

Issues concerning generic or disease-specific measures were raised by participants when talking through PROMs. Generic measures were perceived to have the potential to compare outcomes across different populations and interventions. Disease-specific PROMs were perceived as having greater sensitivity in measuring the efficacy of interventions and treatments. Micro-level researcher decisions were associated with using measures employed by others to elicit data, which made it easy to compare findings across settings and views on good practice for research.

"Well, we have been kind of raised with that when you do this [research] then you make both a generic questionnaire and a little more disease-specific questionnaire." [#12-micro level]

Both micro-level researchers and clinicians talked about the quality of measures and the decision to use questionnaires. Discussions illustrated a trade-off between choosing to have a psychometrically robust measure, having a measure that was translated into Danish, the lack of a 'better' measure, or one that was too time-consuming to use in everyday clinical practice. An example given was the five generic questions developed in Denmark for assessing patient involvement in the clinical setting [29]. This questionnaire is easy to administer but may not capture the relevant components of patient involvement or those associated with clinically noticeable differences.

Participants commented that many measures generated responses with high ceiling effects. Measures with high ceiling effects were perceived as being less useful or losing their value as scores as they may not be able to identify patients experiencing different levels of involvement. Participants identified ways to increase the utility of measures including developing PROMs for relatives, a greater use of measures across sectors evaluating patient pathways and processes, integration of measurement into clinical practice as a learning opportunity for clinical teams, and greater support at the macro level to use patient-reported outcomes in an evidence-based and meaningful way.

Theme 3 – Recognizing conflicting stakeholder paradigms

Sub-theme 3a) Defending qualitative or quantitative inquiries

This theme classified perspectives reflecting conflicting paradigms of patient involvement as either a qualitative or quantitative concept, which in turn impacted on decisions about evaluation method. Having two competing paradigms was perceived to add to the complexity of measuring patient involvement. Qualitative methods were acceptable at all levels. The prevailing goal of each individual determined the kind of measures favoured and valued and vice versa. The preferences of the participants were not related to whether their position is at the macro, meso or micro level, but rather determined by their professional role, setting, and specialty. All participants agreed that a combination of clinical outcome measures and person-centred measures would be appropriate to be able to generalize and attain depth. Participants perceived the beginning of a cultural shift towards a more person-centred and qualitative mind-set in the healthcare system, mentioning that more attention should be paid to patients' perspectives. However, at the meso level, a ‘paradigm battle’ was going on, with little value placed on self-report measures such as PROMs.

“They say that it’s just such a questionnaire nonsense, and that is not the same quality as those biomarkers…implicitly meaning that it is inferior research. I get so angry.” [#1-micro]

At the meso and micro levels, researchers and clinicians did collaborate, but their reasoning for the choice of measure differed. The healthcare system was seen as being more concerned with effect rather than quality. Partly as a result of historical practices, systems have been set up to measure clinical indicators associated with the treatment of illness rather than health service indicators associated with the experience of care. Nor were the role of the active patient and partnership with health professionals discussed as aspects that might impact on traditional clinical outcomes. Measures and actions taken were viewed as interrelated and an expression of the direction of a healthcare system.

“You see and react to what you are measuring.” [#19-macro]

Sub-theme 3b) Adapting to the specific setting

Measurement was perceived as being contextually grounded. The context was perceived to be most important in the assessment of patient involvement in healthcare. There was concern about using measures incompatible with the differing needs across clinical specialties, sectors, research areas, or clinical practices. Furthermore, the relevance and usefulness of outcomes and measurement tools developed in the hospital setting were not seen as transferable to primary care settings and vice versa.

“Measures are not just such a context-free thing, where we can just find a tool and then it is perfect. We have to think about what we want to achieve with it and what it is the measurements should inform (…) there is a huge tendency to use measurement tools which are developed in the hospital setting.” [#13-meso]

Though research and practice were closely related and dependent on each other, there were slightly different priorities. Researchers were interested in measures across populations, whereas clinicians argued against a population-centred ‘one-size-fits-all’ approach, wanting something meaningful on a patient level. Measures developed for research purposes were not always seen as acceptable for implementation in clinical practice, especially if they were adapted from another clinical context. At the micro level, clinicians and researchers talked about needing more collaboration between health service and research personnel to develop a mutual understanding about measures, and provide a chance to identify solutions for implementation in practice together.

Sub-theme 3c) Ensuring implementation of measurement in clinical practice

This theme synthesized perspectives about the implementation of patient involvement measurement and differences in goals. Discrepancies existed in views on how the measurement of patient involvement should be implemented and who was responsible. Macro-level participants acknowledged their responsibility to provide good terms and conditions for patient involvement, but views differed on whether implementation should be based on bottom-up processes run by individuals familiar with meso- and micro-level systems or top-down to ensure sustainability in organizational-level systems. Micro-level participants reported little support from organizations for research and evaluation to help properly implement innovation. There was a tension between meso-level goals to prioritize and implement an intervention and micro-meso-level goals to develop rigorous methods and resources to evaluate the implementation of interventions and find evidence of impact on service and patient benefit.

“The hospital owners and the administrators expect it to be implemented immediately. That is not how it works (…) if you take it seriously, you have to set aside resources to implement it properly.” [#17-meso level]

Discussion

This study investigated views about patient involvement and its measurement among participants with responsibility for delivering healthcare, investigating healthcare outcomes and patient benefit, and implementing and evaluating health service improvement in Denmark. We found that measurement alignment is essential for assessment, and that stakeholders should reflect on the qualities, fit, and usefulness of measures to be able to justify their choice of evaluation design, which requires recognition of conflicting stakeholder paradigms.

Patient involvement in healthcare was described as being an intrinsic part of a) the patient and their active engagement with their health problem and management, b) the professional and their actions to involve patients with their diagnosis and care plans, and c) the organization and its actions to manage the quality of healthcare services.

There was recognition that professionals have different definitions of patient involvement, opinions about measurement, and approaches to innovating patient involvement practices. It was also acknowledged that effort is required to develop a shared understanding between stakeholders about a working definition of patient involvement, its measurement, and interventions before projects or innovations in practice can be implemented. However, there was little consensus on how to measure patient involvement, what approach to measurement was meaningful, useful, or valid, and why measurement of patient involvement was needed. The indicators, measures, and measurement tools used only reflected whether the user viewed patient involvement as desirable in its own right or as a means to achieve other specific outcomes. It has been suggested that achieving acceptable assessment requires distinguishing between these two views and assessing patient involvement discretely using indicators and measurement tools that are compatible with only one view per project [30]. Some of the challenges perceived by the participants in our study were related to distinguishing between two conflicting types of evaluation strategies, i.e. generic and specific measures with different benefits and limitations. The choice of measure may become a trade-off between the two types [31], taking into consideration the risk of ending up with evaluations that are fragmented or siloed within an isolated intervention or a specific disease [32]. The indicators for measurement are usually defined by professionals working in a bio-medically oriented healthcare system with an emphasis on outcome measures [33]. It has been argued that greater emphasis should be placed on integrating patient stakeholders' perspectives to ensure measurement has meaning and relevance for them, and to capture variations in views. Acknowledging the complexity of evaluation methods may bridge the gap between healthcare professionals at different organizational levels and allow interests in research and practice to converge. A shift towards person-centred ‘cultures’ in healthcare settings should be reflected in the evaluation of processes and outcomes [34] by the increased use of qualitative or mixed method evaluations. This will foster sensitivity to the complexities of patient involvement, implementation processes, context, and system fit, and enable the evaluation of more than just effectiveness [35, 36]. This may meet the needs of participants who desired an increased focus on the meaningful implementation of measures in existing evaluation strategies, ensure successful implementation of measurement tools in clinical practice, and fulfil the request for open-source methods, tools, and guidelines on how to systematically implement patient involvement initiatives in a clinical setting [37].

This study may facilitate a debate on how to establish the criteria, outcomes, and measurement tools needed to complete successful evaluations [35]. It has been argued that evaluation of complex interventions needs to be multidimensional and contextual [38]. The complexity of the multiple constructs involved requires the interventions to be broken down into smaller components to make measurement feasible [11].

As with previous research, our findings illustrate that participants want a coherent approach to assessing patient involvement that is meaningful for those delivering services, and useful to those using and innovating healthcare, as well as those evaluating healthcare quality [36, 39, 40]. These processes should be conducted collaboratively by stakeholders so they can develop a shared understanding and generate a mutually acceptable evaluation [10]. One challenge to achieving a coherent approach to patient involvement measurement is the complexity of unpacking the core elements underpinning people’s use(s) of the term ‘patient involvement’. Although our findings illustrate that patient involvement is recognized as an important part of healthcare, this umbrella term is used to refer to a range of components (actions, perceptions, and experiences) attributable to different people engaging with healthcare (patients, professionals, and service providers), with different goals (health literacy, self-management, shared decision making, and quality improvement), explanations for its impact on healthcare delivery and experience (structural, process, and outcome measures) [9, 10, 41, 42], and opinions about interventions to innovate practice (staff, patient, and infrastructure resources).

It is likely to be helpful if the field moves away from rhetoric implying that patient involvement is a unified or simple concept, and explicitly discusses patient involvement practice, interventions, and measurement within a framework of complex interventions impacting on multiple stakeholders with different goals. Drawing on frameworks for structuring research to develop, implement, and evaluate complex interventions in healthcare, and implementing health service quality improvement initiatives are necessary steps towards developing a meaningful approach to patient involvement measurement that meets the needs of multiple stakeholders [35, 36, 43–48].

Of benefit to our study was inviting steering group members from our previous project [9] to be active collaborators on this study’s methods and analysis, and interpretation of its findings. Their experiences of patient involvement interventions and measurement varied across healthcare settings, and were informed by different disciplinary, professional, and methodological perspectives, ensuring findings are relevant to professional, researcher, and policymaker goals. Identifying the discrepancies in respective understandings of the purpose of patient involvement and measurement was seen as significant. This highlights the need for critical debate to enable researchers, healthcare professionals, and improvement managers to find common ground about measures that can show which practices, and interventions, enhance or hinder patient involvement. Furthermore, it will be important to be explicit about how and why measures are meaningful for different stakeholders at the micro, meso, and macro levels within the delivery and experience of healthcare. Many measures that have been developed and psychometrically tested for use within patient involvement interventions, and to evaluate their impact, can be integrated within healthcare to tailor care, enhance practice, and act as indicators of service quality. Our findings suggest understanding more about the active ingredients of patient involvement interventions is important to the selection and use of measures at different organizational levels. Having a theoretical framework to underpin these discussions is likely to help different stakeholders unpack what is meaningful about a measure [9, 40], what is good to use when screening for variations in quality, and how a measure complements other measures of service outcomes, patient benefit, and healthcare quality.

Future directions

It must be recognized that patient involvement is multifaceted and involves multiple stakeholders to reach consensus on how to approach and process it in an organization. The MIND-IT framework [49], in combination with the Medical Research Council’s framework [35], may be helpful in designing the evaluation of complex interventions by providing an overview of different stakeholders at the macro, meso, and micro levels and measures targeting different aspects of patient involvement. A valuable asset when co-producing multiple-stakeholder evaluation designs is knowledge of patients' and relatives’ understanding and experiences of patient involvement and use of PROMs in healthcare, and establishing a matrix may be a way to take into account the perspectives of all stakeholder groups.

Future research should focus on where and when patient involvement is happening and how patients experience involvement. Routine use of a generic measure at the micro level, e.g. the SHARED questionnaire [50] in Danish, may be appropriate when investigating within healthcare settings whether common ground can be reached between patients, health professionals delivering care, health service managers, researchers, and quality improvement leaders [9]. However, it is important to recognize that one generic measurement tool or one core set of evaluation tools is unlikely to meet the goals of all stakeholders all of the time and across all interventions [51].

Strengths and limitations

The strength of this study is its methodological rigor in illustrating differences between perspectives on patient involvement and its measurement, which is likely to impact on the implementation of measures within the Danish healthcare setting and innovate practice informed by evidence [9]. It provides in-depth data and new insights on measuring patient involvement from multiple healthcare professional stakeholder perspectives. However, the members of our sample were self-selecting, representing professionals with a specific interest in patient involvement. The main limitation was the focus on the views of professionals about patient involvement and measurement; patient perspectives were not included in this study [40]. It was noteworthy that when talking about patient involvement, participants did not discuss topics identified as being relevant to patient stakeholders, such as burden [52], disempowerment, tokenism, manipulation, or forced responsibilization [11]. This concurs with a recent study which revealed that healthcare professionals do not see patient involvement through the lens of the care they are offering, but rather as a means to improve healthcare quality [53]. However, our findings indicate a willingness to integrate patient perspectives into healthcare delivery and evaluation design, and to prioritize person-centred measures, which are the ones that matter to patients [51].

Conclusions

This study provides descriptions of how stakeholders at the macro, meso, and micro levels of the Danish healthcare system understand patient involvement interventions and what constitutes patient involvement, and how measurement tools are justified and used. Stakeholders’ views of the success criteria were unclear and they had little shared understanding of patient involvement and how it is measured.

Applying a multiple-stakeholder approach may be a way to integrate different perspectives when measuring patient involvement through collaboration on the selection of evaluation criteria and measurement tools. The co-production of evaluation designs may bridge the gaps that exist between stakeholders at different organizational levels, where everyone makes their own decisions about how measurement tools are justified and used.

Abbreviations

PREMs: patient-reported experience measures; PROMs: patient-reported outcome measures

Declarations

Supplementary information

Additional file 1

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Authors' contributions

HLB, LØR, and BST conceptualized the study and the methodology. BST was the principal investigator for the study. TE, BKN, LØR, and BST created the information material for the participants, and BKN, TE, LØR, and BST recruited them. BST, LØR, HLB, JHT, TE, and MSL developed the interview guide. BST conducted, transcribed, and coded the interviews. TE, CBR, LØR, and BST completed the initial analysis of the large data set. TE, LØR, BST, MSL, BKN, and JTH interpreted the findings relevant to the research question and generated the themes. BST, LØR, and HLB drafted the manuscript. All authors critically read and approved the final manuscript.

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Availability of data and materials

The data sets used during the current study are available from the corresponding author on reasonable request.

Ethics approval and consent to participate

The study was registered with the Danish Data Protection Agency, Central Denmark Region (1-16-02-400-21) on 15 October 2021. The Research Ethics Committee waivered approval of the study as interview studies according to Danish law (Denmark Committees on Health Research Ethics, §14, 2) are exempted from registration. The principles of the Declaration of Helsinki were followed [54], and written informed consent was obtained from all participants.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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Figures

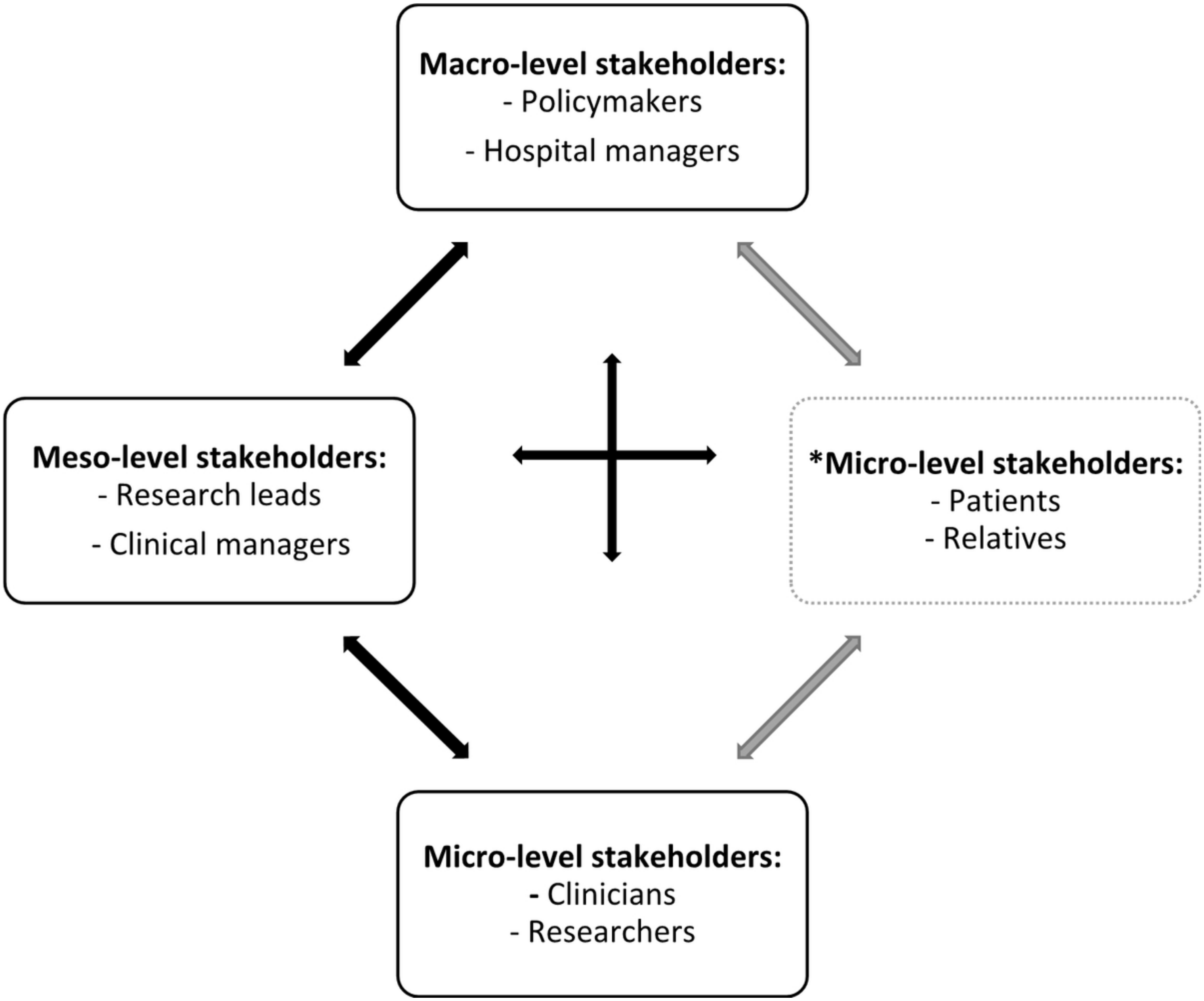

Figure 1

Macro-, meso-, and micro-level stakeholders in the healthcare system

*Patients' and relatives' perspectives are not part of this study.

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