Primary healthcare professionals' experience with patient participation in healthcare service development: A qualitative study

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A B S T R A C T

Objective: How healthcare professionals experience patient participation in health service development impacts its use. This participatory study explores primary healthcare professionals' perceptions of developing health services with patient representatives.

Methods: Four focus group interviews with primary healthcare professionals ($n = 26$) were conducted. We analyzed data by applying Braun and Clarke's reflexive thematic analysis.

Results: The healthcare professionals perceived having a complementary interprofessional relationship with the patient representatives and regarded them as colleagues. However, the professionals navigated between a position of authority and collaboration, reconciling the need for participation with its challenges, e.g., to identify the representatives' collective representation among their personal experience, to ensure a more evidence-informed result that they and their colleagues would endorse.

Conclusions: Regarding patient representatives as colleagues can blur the line between professionals and representatives' positions and functions and further complicate health service development. Our results indicate a need for skilled facilitators to lead the process.

Innovation: This study identifies issues that professionals are uncertain about when collaborating with representatives to develop primary healthcare services; difficulties that professionals must overcome to collaborate constructively with representatives. Our findings can inform healthcare professionals' education about patient participation on all levels. We have suggested topics to address.

1. Introduction

Patient participation, or user involvement, in health service development and quality improvement represents a widely acknowledged practice of developing health services to suit the public's needs [1,2]. Primary healthcare worldwide is under great pressure to meet the needs of persons with mental health conditions and chronic illnesses. Therefore, the World Health Organization (WHO) [3] and the Organisation for Economic Co-operation and Development (OECD) [4] call on primary healthcare professionals to establish well-functioning and sustainable health services by involving individuals, families, communities, and society at large in their health policy making and planning [3].

Patient participation in health service development in this study is understood as "the active participation in planning, monitoring, and development of health-services of patients, patient representatives, and the wider public as potential patients" [5,p. 1]. The term "patient representatives" (hereafter called representatives) refers to persons with experiential knowledge about living with a health challenge and its consequences, and who either represent a patient organization or themselves.

Studies indicate that the professionals' conduct is crucial in facilitating patient and public involvement [6]. Their ability to foster knowledge sharing determines the success of patient participation in health service development [7,8], and their experiences with patient involvement impact how they facilitate involvement [9,10]. However, professionals say they are uncertain as to how to involve representatives in health service development [9,11].

Stakeholder involvement represents a complex intervention [12]. If professionals are uncertain about aspects of patient participation, they may be

less likely to practice it. Recent studies have uncovered barriers and enablers to patient participation, e.g., time and resources, training of professionals, and representatives' engagement [13-15]. Still, little has been written concerning the collaboration process [16].

In order to inform a more comprehensive approach and strengthen patient participation in health service development, there is a need to investigate professionals' perceptions of collaboration with representatives. The call for research aligns with several reviews emphasizing the need to investigate approaches to health service development with patient participation [17-20]. Therefore, this study aims to contribute to the discourse about patient participation by generating new knowledge concerning the challenges that professionals may encounter [21]. Our objective is to explore the professionals' perceptions of collaborating with representatives when developing primary healthcare services under the leadership of a healthcare professional acting as the facilitator.

2. Methods

This study has an exploratory qualitative research design. It is positioned within an interpretivist/constructivist paradigm, focused on "understanding `the world of human experience´, suggesting that knowledge is socially constructed" [22,p. 4]. The reporting of this study was guided by 'Standards for Reporting Qualitative Research: A Synthesis of Recommendations' [23].

2.1. Involvement in research

This study is part of a qualitative Ph.D. project exploring patient participation in primary healthcare service development from the perspective of the involved professionals, the representatives, and the healthcare professionals leading the processes. The authors constitute the Ph.D. project's research team. The first, third, and last authors have extensive experience conducting health service development with patient participation, and all the authors, except the first, have extensive experience with involvement in research.

The Ph.D. project includes a co-researcher (hereafter called the second author), a person with knowledge from being a patient who is a fully included member of the research team [24]. The Ph.D. project also has an advisory panel. Ontologically, involvement in research emphasizes the integration of multiple perspectives in the research process [25]. Epistemologically, this implies opening the research process to knowledge being socially produced, in line with Mackenzie and Knipe's [22] interpretivist/constructivist paradigm.

The involvement is based on a substantive value system to enhance the quality, relevance, and credibility of the research [26]. The second author has patient experience from primary and specialized healthcare, user organization activities, and education about involvement in research. The panel constitutes three patient representatives and three healthcare professionals, all experienced with patient participation in health service development. They offered their advice and perspective during this study's research process and impacted the interview guide's content and the analysis.

2.2. Setting

Norwegian municipal Healthy Life and Coping Centers promote health and prevent non-communicable diseases by offering low threshold activities that support the participants' efforts to live a healthier lifestyle or to better cope with health challenges. The centers are encouraged to develop their services with patient participation [27,28] in response to international societal democratization trends and the desire to make the healthcare system more efficient and less costly [29].

The centers rely on professionals and representatives' active involvement under the leadership of a healthcare professional acting as a facilitator when developing health services [30]. We thus contacted the administrative offices of four municipalities about joining our study; each municipality has a Healthy Life and Coping Center. They all agreed to participate and

appointed a contact from their local center. The municipalities were different in terms of population, the extent of their experience with patient participation in health service development, and localization characteristics.

2.3. Sampling strategy

The participants were purposively sampled to best represent the research topic and help generate rich data [31,32]. We used the concept of information power to plan the number of participants and to decide when we would reach data saturation and a satisfactory level of information power [32]. We strived to include participants with different health- or social care professions in each focus group; these professionals had developed health services with representatives at least once, more than three times, or more than ten times. Most of the participants had been involved more than ten times. After the fourth focus group interview, we found that we could adequately answer the research questions.

The contacts in the four municipalities recruited the 26 primary healthcare professionals participating in the focus groups. All invited agreed to participate. The participants included 24 women and two men, with five, six, seven, and eight, respectively from each of the four municipalities. The professional titles of the participants included: nine nurses, five physical therapists, three occupational therapists, three psychologists, two healthcare administrative managers, one deacon, one nurse trained in learning disabilities, one teacher, and one theologist. Their age range was 30–64, with an average age of 49.

2.4. Data generation

To familiarize ourselves with the place, culture, and people, the first and second authors participated in a health service development meeting in each municipality [33,34]. We kept reflexive journals, recorded our preconceived notions concerning the research sites, discussed what our researcher roles meant for the research process, contradictory interpretations, and what was significant to explore in the focus group interviews [33]. The meetings also enabled establishing a good relationship with the contacts and safeguarding the purposive sampling of participants [32].

The first author wrote the interview guide based on the participation in health service development, discussions with the second author concerning the first municipality, and the results of our scoping review [18]. Based on suggestions from the panel and the authors, questions were added to the guide. The questions were altered slightly between the focus group interviews to ensure for clarity and that they would generate data that would answer the research questions adequately [32].

Through discussions, focus group interviews can facilitate the participants' social meaning-making [35]. We conducted and audio-taped a 90-min focus group interview in each of the four municipalities to generate data. The first author moderated the focus groups, supported by the second author. The participants were encouraged to express their views and experience concerning the interview guide's topics and were given multiple opportunities to speak. The topics included the participants' professional background, characteristics and context of primary healthcare service development, perceived functions, and expectations of those involved, actions taken to include the representatives in the team, and the potential impact of patient participation. After each focus group interview, we added reflections about the interviews and the participants to our reflexive journals [36]. We then compared our interpretations. Together with the other authors, we evaluated the data we had generated and whether to continue or close further data generation.

2.5. Analysis

The focus group interviews were transcribed verbatim; pauses were marked, and participants anonymized. Quotations included were tidied up as suggested by Braun and Clarke [36]. We removed repeated words and phrases while staying true to their meaning. The quotations were

then translated and back-translated in collaboration with a professional language consultant. The data were sorted using NVivo [38].

We applied thematic analysis "for systematically identifying, organizing, and offering insights into patterns of meaning (themes) across data sets" [39,p. 57] as it "allows the researcher to see and make sense of collective or shared meaning or experiences" [39,p. 57]. The six-phase process for reflexive thematic analysis was used: familiarization with the data, coding, generating themes, reviewing themes, defining and naming themes, and writing up the study [40].

In the initial phase of familiarizing ourselves with the data, the first, second, and last authors read and recorded our "noticings", as suggested by Braun and Clarke [37,p. 204]. The noticings included first impressions, ideas, and associations concerning the data. Aware that the noticings would reflect what we brought into the reading, we used them to clarify our different perspectives and presuppositions when interpreting the data. The first author then coded the data transcripts of each focus group, making new codes, applying previous ones, and renaming the codes more precisely during the process. When all relevant focus group data were adequately coded, the first, second, and last authors discussed the codes until a consensus was reached. In line with Braun and Clarke [40], we then looked for patterns of shared meaning across the focus groups that were underpinned by a central meaning concept. The first author developed the initial themes and discussed them with the second author and the panel before they underwent further analysis with the authors. The clustering of themes evolved by repeatedly going through the six sequential phases. The discussions between the authors and the panel enabled the integration of reflections representing many perspectives and contributed to a rich analysis. The analysis was highly iterative until the final manuscript was in place.

2.6. Techniques to enhance trustworthiness

Lincoln and Guba [41] suggest trustworthiness relies on a study's credibility, transferability, dependability, confirmability, and the researchers' reflexivity.

To enhance credibility, the first and second authors spent time getting to know each research site and identifying what would be of interest to explore in the focus group interviews. We developed a semi-structured interview guide with open-ended questions to describe the participants´ experience and attitudes. The participants were encouraged to discuss the topics freely and openly. The codes and themes were developed based on the data content. To safeguard against research bias, we kept reflexive journals and discussed our preconceptions, respective roles, and interpretations of observations and findings.

Investigator triangulation was strived for by the first, second, and last authors scrutinizing the codes until consensus was reached, involving the panel in initial interpretations of findings and the other authors in further analysis.

To enhance transferability, the study's setting, sampling strategy, the participants' characteristics, and data generation have been carefully documented. Addressing dependability, we have described the applied research method and method of analysis. To strengthen confirmability, we have supported the result section with quotations to substantiate our interpretations of the participants´ experience. Informed by Braun and Clarke's [42] guidelines for assessing the quality of thematic analysis research and by following the stages in reflexive thematic analysis [40], we argue that we have further strengthened the study's transferability and transparency.

2.7. Ethical issues

The Ph.D. project was approved by [name of institution and reference number] and the four municipalities' Personal Protection Officers. The research has been conducted in line with the Declaration of Helsinki [43] and [name of institution] guidelines for research [44].

3. Results

Based on the analysis, the four overarching themes developed by the authors were:

  I. Valuing a complementary interprofessional relationship
 II. Navigating between a position of authority and collaboration
III. Reconciling the need for patient participation with its challenges
IV. Identifying collective representation to ensure a more evidence-informed result

3.1. Valuing a complementary interprofessional relationship

The primary healthcare professionals regarded the collaboration with the patient representatives as collaborating with their colleagues.

The professionals pointed to how the patient representative input had complemented theirs and that working with them was meaningful and reassuring. The meaning was derived from learning about living with significant health challenges. The insights had value in their professional lives and when meeting with patients. The reassurance was derived from the belief that the representatives' input would enhance the service development's relevance to the service users.

> It has worked well when we have received input where we lacked the necessary knowledge and experience. For instance, we have been caught up in our expertise and thoughts about how things should be with the limited resources within the municipality. And then, we have received input that has made the service suit a specific need. So, it has worked very well.
>
> [(Professional, focus group 3)]

As the patient experience and knowledge complemented the professional knowledge, the professionals thought of participatory service development as interprofessional collaboration.

> It is like interprofessional collaboration. A nurse knows something, a social worker, something else, a physical therapist other things. If we can get all that, we can gain a lot of knowledge. In addition, we get the patient's knowledge, and then the service is based on even more knowledge.
>
> [(Professional, focus group 2)]

The professionals talked about the representatives as "colleagues" contributing to their shared knowledge field. Perceiving them as colleagues was also apparent in the manner the professionals dealt with the representatives' fluctuating health challenges. Assuming the representatives would probably need help, the professionals would check how they were doing and take precautions to cover for them if they could not participate as planned. They compared this to helping colleagues get their job done.

3.2. Navigating between a position of authority and collaboration

The professionals found it difficult to manage their authoritative position in regard to the patient representatives they considered colleagues.

The professionals recognized their authoritative position regarding the representatives. Their authority was founded on their professional expertise and knowledge, and because the representatives had to meet in the professionals' arena in connection with service development. The professionals understood that their authority was expressed through their interaction with the representatives.

> I feel that I always have a lot of authority as a healthcare professional. To compensate for this, I am very gentle, attentive, and agreeable when working with patient representatives.
>
> [(Professional, focus group 3)]

The professionals' also thought their authority caused the representatives to have difficulties speaking up and pointed to the need to ensure all voices were heard. At the same time, professionals, especially those new to participatory service development, felt they had to struggle in order for the representatives to hear and understand their point of view. Professionals familiar with participatory service development did not share this view and reasoned that being established in one's professional position helped in being open toward the representatives' concerns and suggestions.

The more secure we feel as healthcare professionals, the more open we are to patient participation. The less confident we are, the less we dare to confront and take on board the patient representatives' competencies.
[(Professional, focus group 1)]

Still, they acknowledged that they sometimes refrained from expressing their professional opinion. They also reiterated that they must dare to speak their minds when involved with health service development with patient participation.

3.3. Reconciling the need for patient participation with its challenges

The professionals had to adjust to their pace and communication of experienced-based knowledge when working closely with patient representatives.

The professionals often felt impatient and compelled to interrupt or rush what they felt were the representatives' unnecessary discussions during service development. This was specifically relevant in situations where the professionals were clear and decided about an issue due to their professional background or training, but the representatives still felt the need for discussion. The professionals also said that they sometimes interrupted or ignored patient representatives they perceived to convey input that did not align with their professional knowledge. They tried not to offend the patient representative but worried afterward that they had.

The professionals found one specific type of situation especially difficult to manage; representatives sharing very private experiences in service development discussions.

Our meeting became an arena for him to share his personal experiences instead of discussing how his experience could benefit the participants of a self-management program. (…) It just made me feel bad on his behalf.
[(Professional, focus group 1)]

The professionals considered the representatives to be vulnerable when sharing their negative experiences. However, it was perceived to be out of place and time-consuming. The professionals described struggling to find a way to interrupt representatives, due to fear of hurting their feelings. Often no one knew how to, the representatives finished their stories, and the professionals felt uncomfortable.

The professionals acknowledged these as challenging aspects of working closely with representatives. While reflecting on what could prevent such situations, the professionals stressed the importance of having enough time to develop a shared understanding and starting point, despite different backgrounds.

3.4. Identifying collective representation to ensure a more evidence-informed result

The primary healthcare professionals were skeptical toward the meaning content and origin of the patient representatives' input in terms of its relevance when developing evidence-based results.

To develop an evidence-based health service, the professionals needed the representatives' input, in addition to professional knowledge and research evidence. The professionals thus wanted the representatives to provide relevant experience that was true for several patients or users, not just themselves. At the same time, there was an underlying assumption that representatives might only share their personal illness experience. The

professionals explained that they felt they had to make sure this did not happen.

Many patient representatives become very subjective and concerned with their own experience and illness. So, it is all about getting them to look at the *bigger* picture. (…) Not to only think about what's in it for *me*, but about what's best for all *service users*.
[(Professional, focus group 2)]

The professionals' assumption that the representatives' ideas and contributions would be based solely on their personal experience raised a general concern that the health service development result would not be evidence-based. Although there was an awareness that their professional views were also personal, the professionals said they thus preferred working with representatives who have been educated or trained to better represent the opinions of their respective patient organizations.

In general, receiving input from the representatives that focused on their personal experience seemed to challenge the professionals' idea of what professional healthcare service development should be. Discussions revealed that the professionals placed more value on representative input when the representatives had talked it over within their organizations or networks and shared a common perspective. To deal with the challenge of the input possibly being founded only on personal experience or opinion, it appeared that the professionals assumed a skeptical position toward what the representatives shared: If a patient representative's input was perceived to represent only private interests, the professionals said that they would disregard it. The professionals also described that sometimes representatives, who did not have a healthcare professional background, provided medical advice or knowledge. They found that such situations could cause friction, as they did not trust the representatives´ input to be supported by medical evidence.

It is challenging when the patient representatives, in addition to their personal experience, give medical advice; as healthcare professionals, we need to base our recommendations on well-supported evidence.
[(Professional, focus group 1)]

They acknowledged disregarding the representatives' input at times because it was their responsibility to ensure an evidence-based service development result. They explained that their skepticism, and need to ensure an evidence-based result, sometimes caused the professionals to adjust and translate the representatives' input within their professional context.

We need to be clear that we work in the health services, and while the patient representatives' personal experiences are good, they represent personal experience. Therefore, we must be careful about implementing this into primary healthcare for the public's good. Our task is to address this and ensure that the service is evidence-based.
[(Professional, focus group 2)]

The professionals problematized interpreting and translating patient experiences within a professional context. They suggested that while the representatives shared their experience of being ill as narratives of lived experience, the professionals must place these narratives into a professional context and terminology, i.e., diagnosis and symptoms. The professionals emphasized this as essential for ensuring an evidence-based result that they and their colleagues would endorse.

4. Discussion and conclusion

4.1. Discussion

This study sheds light on primary healthcare professionals' experience regarding collaboration with patient representatives when developing primary healthcare services. The four overarching themes identified from the data imply that (I) the professionals valued a complementary interprofessional relationship with the representatives. However, (II) they

navigated between their authoritative position and collaboration, and (III) reconciled the need for patient participation with its challenges. Lastly, (IV) the professionals found it challenging to identify the representatives' collective representation to create a more evidence-informed result.

Our results suggest that the professionals' relationship with the representatives is complex and contradictory, and it is critical to understand what does not work well in order to strengthen patient participation [21]. Therefore, we first address the complementary characteristics of the representatives' contributions before turning to the three main challenges that the professionals described concerning collaborating with representatives. The discussion is informed by existing research and Andreassen's [1] framework for examining the implications of different forms of involvement.

Several studies have described professionals and representatives as partners in health service development [45-47]. In our study, the professionals considered the representatives their colleagues and associated the collaboration with interprofessional collaboration (IPC). While we have not found empirical studies with similar findings, the comparison is not farfetched. IPC is described as "two or more healthcare professionals who have specific roles, perform interdependent tasks, and share a common goal" [48, p. 148]. We suspect the professionals' wording is not semantics but describes the function that professionals expect, or want, from `a colleague patient representative´.

To work with colleagues may be understood as the involved parties are equals [49]. In the professionals' collaboration with the representatives, however, their authoritative position appeared to disturb their perception of being colleagues. Implications of this can be seen in the professionals' descriptions of behaving in a "gentle" and "agreeable" manner towards the representatives. Studies emphasize that professionals' supportive behaviors can enable involvement [19,20]. Still, the professionals' behaviors can be understood as describing how healthcare providers act around their patients. It seems to imply that professionals can sometimes confuse their colleague and healthcare provider roles when collaborating with representatives, and this illustrates that the `patient or partner´ relationship is complex [50].

Andreassen's [1] framework for examining implications of involvement when developing or enhancing health services is inspired by work by Tritter [51], Dent and Pahor [52], and Vrangbæk [53], among others. The framework suggests that when professionals collaborate with representatives, their traditional functions are repositioned and diversified. Furthermore, health service development with patient participation changes the professionals' function to that of colleagues with the representatives. Andreassen [1]calls for research on what this positioning means to the professionals in practice. The framework [1] manifests a theoretical understanding of the professionals' repositioned function in health service development. However, the change may not be apparent in practice. Our results imply that while thinking of the representatives as colleagues, the professionals found it challenging to treat the representatives as equals in practice.

Studies have shown that professionals find patient participation helpful [54-56], especially since involvement makes the health services more relevant for the public [55,57,58]. Researchers have also found that professionals appreciate the process of reflecting and discussing with representatives [59]. Our results support these findings, but they also contribute to a more nuanced perspective. While the professionals in our study appreciated the participation of representatives, they also felt impatient about having to adjust to the representatives' pace and communication of their experienced-based knowledge.

Professionals play a crucial role in enabling involvement [19,20], and the professionals' impatience may negatively impact their collaboration with the representatives and its result. For example, the representatives may interpret the professionals' impatience as an indication that their contribution is considered unimportant or not useful. Bergerum and colleagues [45] have found that while professionals realized the value of incorporating patient knowledge into quality improvement, experiential knowledge was not recognized as equally important to professional knowledge. Our results are more ambiguous.

The position of experiential knowledge compared to professional knowledge in health service development has been explored in previous studies [45,56,60]. Renedo and colleagues describe that professionals navigate "from scientific `facts´ and clinical guidelines, to their own personal experience and institutional discourses" [56 ,p. 781]. Also, patients build their experiential knowledge on a mix of illness and medical-related experiences, including values and common sense [56]. Therefore, when professionals and representatives collaborate, the result depends on how the professional and experiential knowledge types "communicate with each other, and on whether they are asymmetrical with respect to the legitimacy granted to each of them" [56 ,p. 782]. These findings resonate with our results and the professionals' impatience when trying to adjust to the representatives' pace and experience-based knowledge.

In addition, the professionals struggled to incorporate the representatives' input to develop an evidence-based service. Other studies have identified the same challenge [11,45,56]. It appears the professionals are sometimes skeptical and judgmental about whether the representatives' input suffices. Previous studies [45,56,61] have also identified professionals' concerns about the representativeness of the representatives' input. These concerns may be interpreted as negativity toward patient knowledge. However, they can also be understood as patient participation challenges professionalism as a value, as the profession theorist Evetts [62] has described.

In clinical work, professionals earn respect and authority by being professional when meeting with patients, users, and informal caregivers, and professionalism "requires professionals to be worthy of that trust" [62 , p. 780]. When involved with health service development, the professionals must also be able to put to use the representatives' input. However, it is not a clear-cut task. It entails interweaving "knowledge based on lived/embodied illness experiences and scientific biomedical knowledge" [56,p. 791]. Andreassen's framework [1] identifies the professionals involved with health service development with patient participation as "recipients, interpreters and translators of feedback" [1,p. 10]. Our results imply that the professionals fulfill all these functions when involved with health service development with patient participation, empirically supporting the framework's implications.

The framework [1] further suggests that patient participation in health service development causes the professionals to become objects of evaluation to be held accountable for the quality of the developed service. Professionalism may be applied to establish suitable work identities, conducts, and practices [62]. The professionals in our study can be understood to have used their professionalism to ensure an evidence-based result for which they would feel comfortable being held accountable for. This may partly explain why the professionals reported disregarding input that did not fit their standards and adjusting other useful input to fit their professional context and the service development result. Some studies [45,60] describe the collaboration process between the professionals and the representatives as `a tug of war´ or a competition. We partly agree, acknowledging that the professionals seem to have the last say.

Supporting previous studies [11,14,45], we found that the professionals needed experience with patient participation and collaboration skills to put the representatives' contributions to use. Still, the collaboration can create uncomfortable situations for the professionals, for example, when representatives spend too much time sharing very personal information in service development meetings. The implications of the professionals' struggles were expressed through their preference for working with representatives who are trained in representing their organization or patient group.

Our results suggest that health service development with patient participation requires professionals to handle complex relationships and emotions. Furthermore, if the professionals regard representatives as colleagues, this can confuse or blur the line between the professionals' and the representatives' positions and functions, and further complicate their collaboration. Our results support previous studies [11,14,45,56], emphasizing a need for professionals' patient participation and collaboration competence to contribute constructively to health service development. We want to emphasize that professionals should be given opportunities to

discuss and reflect on the significance of the similarities and differences between themselves and the representatives, in terms of their status or position, and the types of knowledge they can contribute. Our results further suggest the need for skilled facilitators to lead such complex processes and to ensure a meaningful experience for those involved.

The limitations of this study relate to social desirability and reporting bias about the participants' self-presentation in the focus groups [63]. The first author may have been regarded as a special advisor from [name of institution] and not an independent researcher. It may have caused the participants not to reveal negative information [63]. However, the participants were actively involved in the discussions, addressing positive and negative aspects of health service development. As such, the four focus group contexts comprise four sites that "provide a different window on social interaction" [63 ,p. 629]. A strength of this study is the credibility of its interpretations which were made with the involvement of a panel constituting healthcare professionals and patient representatives, in addition to the authors. Another strength stems from its use of reflexive thematic analysis, which enabled staying close to the empirical data and a comprehensive iterative analytical process [42].

4.2. Innovation

This study adds to the current field of research a more nuanced and profound understanding of difficulties and uncertainties that healthcare professionals must overcome to collaborate constructively with patient representatives.

The World Health Organization [3] and the OECD [4] assert the need for patient participation in primary healthcare service development. We believe addressing the challenges that professionals experience when collaborating with representatives is necessary for strengthening patient participation in health service development. Our findings may be applied to educational programs of all levels that aim to support professionals to contribute to involvement. We further encourage professionals experienced with, as well as new to patient participation, to discuss potential challenges and how to handle them before getting involved. Topics for such discussions are suggested in Table 1.

The Norwegian National Advisory Unit for Learning and Mastery in Health is planning to revise the manual "The Standard Working Method for the Learning and Coping Centers – the 2011Version" [30]. The Ph.D. project to which this study belongs was initiated as a first step. The next step is to involve representatives and professionals in the revision. This study's results will be applied in the process.

Table 1
Topics to discuss among healthcare professionals before developing health services with patient representatives.

Complementary roles	Healthcare professionals find that patient representatives' experiential knowledge and insights complement their own knowledge and expertise when developing healthcare services.
	- How can representatives´ knowledge complement professionals´ knowledge and expertise? - What are suggestions for further improving this?
Positions and power	Healthcare professionals describe that they sometimes do not dare to speak their minds when collaborating with patient representatives.
	- How can this be interpreted from the perspective of professionals? - How can this be interpreted from the perspective of the representatives? - What are suggestions for improving this?
Knowledge application	Healthcare professionals can experience skepticism in applying the input that patient representatives contribute while trying to ensure an evidence-based result.
	- How can this influence their collaboration? - What are suggestions for improving this?

4.3. Conclusion

This study's results call for opening a broad discussion about the complexity of health service development with patient participation in primary health care, including which competencies and what knowledge can benefit the involved healthcare professionals. How to contribute constructively, as well as how to value and use the patient representatives' input, seems not to be fully understood or integrated into the professionals' collaboration practice.

Our study indicates that if professionals position themselves as colleagues of the representatives, this can complicate the collaboration. To advance patient participation in health service development, we suggest acknowledging the differences in the professionals' and representatives' functions and types of knowledge, while also emphasizing the strengths of building on multiple perspectives.

To inform a more comprehensive approach and strengthen the knowledge base about health service development with patient participation, it is necessary to investigate different approaches to patient participation in a primary healthcare context. Given the complexity of the collaboration process, there is also a need for research regarding what structural resources are needed for the facilitators to be able to conduct constructive primary healthcare service development with patient participation. Finally, further exploration of how representatives perceive the collaboration with professionals in health service development, and which competencies they may need to contribute constructively, would help to inform future approaches to patient participation.

Data availability statement

The data are not publicly available due to ethical restrictions. All relevant data are available on reasonable request from the corresponding author.

Declaration of Competing Interest

The authors declare that there are no competing interests.

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