

MARJAANA JONES

Patient and public involvement in healthcare

Potentials and challenges of lay expertise and
experiential knowledge

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ACADEMIC DISSERTATION

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The topic of this thesis has been slowly simmering somewhere at the back of my brain since the autumn of 2010 when I started my job as a staff nurse at Bethlem Royal in South London. During the hospital trust's induction day, I attended a session facilitated by two experts by experience, who had themselves been service users. Their first-hand experiences of receiving care at the hospital shed light on the power structures within mental health care, forced me reflect upon my own practice and provided a viewpoint that had not been strongly present during my studies. Although I left the UK in 2013 and slowly moved into a new field of work, this and other involvement related experiences stayed with me and resurfaced as I began to ponder my PhD topic. Luckily my supervisor encouraged me to continue exploring these interests, which eventually developed into this thesis.

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Tampere 12 May 2021

Marjaana Jones

ABSTRACT

Patient and public involvement (PPI) has become an established part of the health policy agenda in several countries, including Finland. It is founded upon various rationales ranging from democratisation of decision-making to increased healthcare consumerism. Although, involving patients and the public has the potential to strengthen the acceptability of healthcare decision-making and improve service accessibility, its practical implementations can also be tokenistic and inconsequential. In practical terms, involvement refers to the inclusion of patients and members of the public – i.e. lay participants – in all aspects of healthcare related planning, development, delivery, and research. Involvement can be implemented through various direct and indirect methods that occur on societal/political, service, and individual/treatment levels. Whilst this study touches upon the political and individual levels, the main focus will be on the more recent developments in Finnish health policies and services, which bring brand new expertise into healthcare development and delivery in the form of lay expertise and experiential knowledge.

In this study, I delve deeper into the potentials and pitfalls of patient and public involvement by exploring it from the policy, lay participant and third sector organisation perspectives, with examples drawn from involvement occurring within cancer and mental health services. The materials consist of national health policy documents (n=7) and interviews with experts by experience, peer support workers and organisational representatives (n=27). The materials are analysed using a variety of qualitative methods to gain insights into the positions constructed for and by lay participants; to identify tensions, barriers, and benefits

of service level involvement; and to explore the construction and applications of experiential knowledge.

The results indicate that although involvement is supported by the policy rhetoric, it is often narrowly interpreted. People with lived experiences and the organisations representing them have new channels through which they can influence service development and delivery. However, they also face significant barriers that relate to ambivalent policy guidance, lack of role clarity, dismissive attitudes and structures that make involvement much easier of groups and individuals that do not require much facilitation. In practice, involvement is made easier for active and ‘participation ready’ individuals, which can limit the diversity of the experiences that get through to health services.

Lay participants attempt to establish themselves as experts, positioned between health professionals and patients. Although their experiential knowledge is rarely afforded equal value to that of clinical/professional knowledge, it is being used in involvement activities to relate and support patients, educate professionals and provide a more complex and rounded view of what it is like to live with a condition, receive treatment and navigate care services. The results suggest that experiential knowledge has transformative potential, although certain restrictions and filters are imposed upon it during its use and communication through involvement activities. In order to overcome some of the barriers outlined in this study, there needs to be more institutional commitment towards involvement, willingness to adapt and clarity over the aims and rationales. Additionally, it is important for policy makers and health services to think of ways to engage the public as well as those who are not able to engage without facilitation. Health services and professionals should attempt to understand both the limitations and potentials of experiential knowledge within healthcare and the wider society.

Keywords: experiential knowledge, healthcare, health policy, lay expertise, patient and public involvement.

TIIVISTELMÄ

Potilaiden ja kansalaisten osallisuus on noussut terveystaloudelliseen agendalle useassa maassa, Suomi mukaan lukien. Terveystalouden markkinointumisen on vahvistanut ajatus palvelujen käyttäjistä asiakkaista, joilla on oikeus tehdä valintoja ja esittää näkemyksiään terveyspalveluista. Osallisuutta kuvataan myös tapana demokratisoida yhteiskunnallista päätöksentekoa sekä parantaa palvelujen laatua ja saatavuutta. Vaarana on kuitenkin se, että käytännön tasolla osallistuminen jää pinnalliseksi ja merkityksettömäksi. Osallisuudesta puhuttaessa viitataan potilaiden ja kansalaisten – eli maallikoiden – mahdollisuuksiin vaikuttaa terveyspalvelujen suunnitteluun, kehittämiseen, tuottamiseen ja niitä koskevaan tutkimukseen. Osallisuutta voidaan toteuttaa suorien ja epäsuorien menetelmien kautta sekä yhteiskunnallisella/poliittisella, palvelujärjestelmän että hoitosuhteen tasoilla. Tässä tutkimuksessa sivutaan politiikan ja hoitosuhteen tasoilla tapahtuvaa osallisuutta, mutta pääpaino on suomalaisessa terveystaloudessa ja terveydenhuoltojärjestelmässä tapahtuneissa muutoksissa, joiden myötä maallikkoasiantuntijoista ja heidän kokemuksesta tiedostaan on tullut osa palvelujen kehittämistä ja tuotantoa.

Tarkastelen osallisuuden mahdollisuuksia ja haasteita terveystalouden, maallikko-osallistujien sekä kolmannen sektorin organisaatioiden näkökulmista käyttämällä esimerkkejä syövänhoidossa sekä mielenterveyspalveluissa tapahtuvasta osallisuudesta. Tutkimusmateriaalit koostuvat kansallisista politiikkadokumenteista (n=7) sekä yksilöhaastatteluista (n=27) kokemusasiantuntijoiden, vertaistukihenkilöiden ja järjestöjen edustajien kanssa. Analysoin materiaaleja useiden laadullisten menetelmien avulla, keskittyen erityisesti maallikko-osallistujien asemaintiin; palvelutason osallisuuteen liittyviin

jännitteisiin, esteisiin ja hyötyihin; sekä kokemustiedon rakentumiseen ja käyttötapoihin.

Tutkimustulokset osoittavat, kuinka myönteisestä poliittisesta retoriikasta huolimatta, osallisuutta tulkitaan usein kapea-alaisesti. Elettyjä sairaus- ja palvelunkäyttökokemuksia omaaville maallikoille on toki luotu uusia mahdollisuuksia vaikuttaa terveydenhuollon kehittämiseen ja tuotantoon. He joutuvat kuitenkin kohtaamaan monia esteitä, joihin lukeutuvat ambivalentti poliittinen ohjaus, epäselvät rooliodotukset, vähättelevät asenteet ja tuen puute. Osallistumisesta on tehty helpompaa aktiivisille ja 'osallistumisvalmiille' yksilöille, mikä voi osaltaan rajoittaa terveydenhuollon kehittämisessä käytettävien kokemusten moninaisuutta.

Maallikko-osallistajat pyrkivät legitimoimaan omaa asiantuntijuuttaan terveydenhuollossa ja asemoimaan itsensä terveydenhuollon ammattilaisten ja potilaiden välimaastoon. Heidän omaamansa kokemustietoa ei usein arvoteta samalle tasolle klinisen/ammattillisen tiedon kanssa. Sitä kuitenkin käytetään niin potilaiden tukemiseen kuin osana ammattilaisten koulutusta. Lisäksi sen avulla pyritään luomaan moniulotteisempi kuva sairausarjesta ja hoitokokemuksista. Kokemustiedon integroiminen osaksi palvelujen kehittämistä ja tuotantoa voi johtaa laajamittaisiin muutoksiin, mutta ainakin tällä hetkellä terveydenhuollossa käytettävä kokemustieto käy läpi eräänlaisen suodatusprosessin. Osallisuuteen liittyvien esteiden purkaminen vaatii vahvempaa institutionaalista sitoutumista, muutosvalmiutta ja tavoitteiden selkeyttämistä. Poliittisten toimijoiden ja terveyspalveluiden tulisi pohtia kuinka kansalaisten sekä haavoittuvammassa asemassa olevien yksilöiden ja ryhmien osallisuutta voisi vahvistaa. Terveydenhuollon ja terveyspalveluissa työskentelevien ammattilaisten tulisi pyrkiä ymmärtämään kokemustiedon rajoituksia ja käyttömahdollisuuksia sekä palvelu- että yhteiskunnallisella tasolla.

Avainsanat: kokemustieto, terveydenhuolto, terveyspolitiikka, osallisuus, maallikkoasiantuntijuus

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ABBREVIATIONS

MCA	Membership Categorisation Analysis
NMP	New Public Management
PPI	Patient and Public Involvement

ORIGINAL PUBLICATIONS

- Publication I Jones, M. & Pietilä, I. (2018) “The citizen is stepping into a new role” – Policy interpretations of patient and public involvement in Finland. *Health and Social Care in the Community* 26(2): e304–e311.
- Publication II Jones, M. & Pietilä, I. (2020) Alignments and differentiations: People with illness experiences seeking legitimate positions as health service developers and producers. *Health* 24(3): 223–240.
- Publication III Jones, M. & Pietilä, I. (2020) Personal perspectives on patient and public involvement – stories about becoming and being an expert by experience. *Sociology of Health & Illness* 42(4): 809–824.
- Publication IV Jones, M., Jallinoja, P. & Pietilä, I. (2021) Representing the ‘voice’ of patients – how third sector organisations conceptualise and communicate experiential knowledge in health service planning and development. *VOLUNTAS: International Journal of Voluntary and Nonprofit Organizations*. doi:10.1007/s11266-020-00296-5.

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1 INTRODUCTION

This study explores patient and public involvement (PPI) in Finnish health services. I focus specifically on the more recent developments, which enable lay experts with lived experience of illness and care to engage with healthcare as service developers and deliverers. The terms involvement and participation are often used interchangeably, but in this study, involvement does not merely refer to taking part in something, but contains the idea that participants are able to create change and influence decision-making. Patient and public involvement can occur through participation in treatment decisions, engagement in service development and evaluation, provision of education and training to healthcare professionals, engagement in research (Tritter 2009) and involvement in service delivery. Indeed, Britten and Maguire (2016) have argued that lived experiences are being considered as legitimate resources and the expert patient has become a stakeholder in health policy and services. In many countries this has also led to developments where people with lived illness experiences are employed by health services as peer support workers or experts by experience (Thompson et al. 2012; Gillard et al. 2013; Pomey et al. 2021). This has effectively given rise to an evolving occupation (Rebeiro Gruhl et al. 2016) that is attempting to find its place and establish its position within an environment controlled by more established professional groups.

Patient and public involvement can both reveal and alter the position of people who use and (through taxation) fund health services. Members of the public are considered to possess attitudes, values and local perspectives that are based on experiential rather than expert knowledge (Hendriks 2011). Through involvement activities, they are able to contribute to service design and the

determination of priorities (Coulter 2006). From this perspective, people with lived experience of illness are no longer positioned as passive recipients of healthcare, but as active participants and joint collaborators, or even as experts (Armstrong 2014; Niskala et al. 2017). Although involvement can be viewed as empowering, Dent and Pahor (2015) have also drawn attention to responsibilisation, which they describe as the ‘hidden component of patient involvement’ (p. 549). Another longstanding problem related to all forms of public participation is tokenism, which Romsland et al. (2019) have described as ‘a false appearance of inclusiveness, indicating a gap between policy aims and actual practice’ (p. 2). It can occur in situations where the participants abilities are undervalued or when they find it challenging to contribute experiential knowledge to the issues at stake (Morrison & Dearden 2013).

Thus far, research on involvement has been particularly focused on involvement in individual care planning (e.g. Dy & Purnell 2012; Alanko & Hellman 2017) and involvement in health policy and research (e.g. Bingham et al. 2005; Brett et al. 2012; Conklin et al. 2015; Madden & Speed 2017). Frameworks have been developed to conceptualise PPI and to provide better understanding of the different approaches used and the demands and expectations associated with involvement (e.g. Tritter 2009; Dent & Pahor 2015). In this study, I focus on involvement in service development and delivery and thus offer new perspectives into the implementation of patient and public involvement in Finnish healthcare. During a period when Finnish health and social services are due to undergo a major reform, involvement is also a timely and relevant topic, as it addresses questions on who should be able to make decisions and set agendas regarding the future development of healthcare.

Although it is gaining prominence, patient and public involvement in health services has thus far received limited research attention in the Finnish context. Until the 2000s, such involvement was mainly implemented through participation in personal treatment decisions and the provision of feedback through

questionnaires and surveys. The public could, and is still able to, voice their opinions in indirect ways through national and municipal elections, or by making choices regarding their healthcare providers. In this study, I touch upon various implementations of patient and public involvement in Finnish health services. However, the main emphasis is on involvement that takes place at the service level and aims to influence health service planning and delivery. I focus especially on the most recent developments that have enabled people to take part in the development and delivery of health services as lay experts whose experiential knowledge is increasingly recognised as a resource. These developments provide an interesting point of departure for this study, as the position and legitimacy of lay experts is highly contested (Brosnan & Kirby 2016).

Indeed, prior studies have highlighted the need to address the consequences of involvement and the various challenges associated with it (e.g. Mockford et al. 2012; Brett et al. 2012; O'Shea 2019). Moreover, whilst lived experiences are viewed as valuable resources to the development of healthcare services, there are concerns about the legitimacy of the type of knowledge that patients and members of the public possess and are therefore able to contribute to healthcare (Daykin et al. 2007; Boivin et al. 2010). This study addresses these questions and provides an added perspective to the patient and public involvement literature by delving deeper into the questions regarding the legitimacy of experiential expertise and knowledge. Additionally, this study provides an insight into the tensions related to the practical implementation of involvement by exploring the challenges, which individuals and collectives face as they attempt to integrate experiential expertise into health service development and delivery.

I take a multifaceted look at patient and public involvement in service development and delivery from different perspectives that include national health policy, lay participants, and third sector organisations. I examine how health policies categorise people who use health services and seek to demonstrate how these categorisations can both enable and restrict involvement opportunities. By

analysing involvement from the perspective of lay participants, I contribute to the discussions regarding the position, legitimacy and contributions of lay expertise and experiential knowledge in healthcare. The inclusion of the third sector organisations into this study widens the scope further, offering a more nuanced understanding of experiential knowledge. The potentials and challenges identified in this study in relation to lay expertise and experiential knowledge can be utilised by various stakeholders in the future development of patient and public involvement.

The thesis comprises four peer-reviewed, published articles and this summary, which is structured as follows. In Chapter 2, I define in more detail what patient and public involvement is and the rationalisations that have been offered to justify the need for increased involvement. Secondly, I discuss conceptualisations of involvement with particular attention to the models developed by Dent and Pahor (2015) and Tritter (2009). Thirdly, I outline some of the literature that addresses the changing role of healthcare service users and the concept of lay beliefs and experiential knowledge. Lastly, I summarise prior studies regarding the benefits and barriers to involvement and describe the development of patient and public involvement in Finland. In Chapter 3, I present the aims and research questions of this study and in Chapter 4, I introduce the study materials and the analysis methods used in the four articles. The thesis continues with a synthesis of the articles' results (Chapter 5), which is followed by a discussion (Chapter 6) that focuses on the consequences and barriers of involvement and explores the tensions related to the content, form and applications of experiential knowledge. Additionally, the limitations of this thesis and future research avenues are covered. The thesis concludes with Chapter 7, which summarises the main conclusions of this study. The original articles (I–IV) can be found in Chapter 10 (Publications).

2 BACKGROUND

2.1 Patient and public involvement (PPI)

2.1.1 Rationales and aims of involvement

The idea of involving people in the modernisation and development of public services is not new. Indeed, it has been growing in prominence in several Western countries since the 1960s, and can be connected to a wider phenomenon referred to as the *participatory turn* (Bherer et al. 2016). Participatory mechanisms were initially developed to harness citizens' perspectives that could be used to influence the otherwise bureaucratic and political decision-making processes (Bherer et al. 2016). It was also imagined that the implementation of these tools would empower citizens and hold elected political decision-makers accountable (Fung & Wright 2003). From the governance perspective, participatory practices were understood as ways to make governments more transparent, responsive and efficient, as well as making their decisions socially and politically acceptable (Tendler 1998). Participatory practices appear to attract all types of organisations operating in the public, private and third sectors. The reasons for the widespread adoption of these practices include a push from external funding agencies and international organisations. Additionally, organisations may view such practices as tools to enhance social acceptability or gain political legitimacy. Participatory arrangements create spaces where agreements and consensus can be reached through deliberation in a collaborative and mutually respectful atmosphere. Additionally, they are portrayed as a way to move beyond the old style of conflictual partisan politics (Bherer et al. 2016). From a more cynical perspective,

the popularity of ideas such as patient and public involvement (henceforth referred to as PPI) may lie in their easy usage as empty signifiers that can be used to fit with whatever policy idea about citizen engagement happens to be in vogue (Stewart 2012; Madden & Speed 2017).

Over time and across different contexts, PPI has been implemented through a multitude of varied involvement activities (Bherer & Breux 2012; Bherer et al. 2016). In this study, the primary focus is on involvement activities that take place within public sector health services. People's right to participate in healthcare has been recognised for decades (e.g. the Alma-Ata Declaration, WHO 1978) and it has become so deeply rooted that participation is no longer described simply as a right but a duty (Petersen & Lupton 1996). Nowadays, involvement opportunities are being developed in several countries (Dent & Pahor 2015), and they range from collaboration in individual care-planning to the development of services and policies. However, PPI's ascent onto health policy and service delivery agendas is based on varied rationales. In this section, I will outline these multiple rationales in order to highlight the diversity of purposes, the disputes around who should be included, and the conflicting expectations regarding the substance of people's contributions.

Democratic rationales are based upon the idea that the 'voice' of citizens can be articulated in the planning, evaluation and delivery of health services through involvement (Greener 2008). Indeed, in many countries service user groups and patient organisations have campaigned for increased involvement as a means of increasing social inclusion and democratising decision-making processes (Brown et al. 2004; Beresford 2010). The democratisation discourse claims that people should have the right to be part of the decision-making that influences their lives. Hence, demands for power-sharing and autonomy are at the core of involvement. Madden and Speed (2017) have suggested that at its best PPI can strengthen democratic accountability and improve health outcomes. However, there is also the risk that it can be 'insignificant, tokenistic and overly managerialist' (Madden

& Speed 2017:1). Additionally, the democratic rationales entail dilemmas relating to representation, as the voice of patients is often conceptualised as a form of representation. This dilemma has produced tensions within PPI policies and activities, where lay participants are expected to simultaneously be professional and ordinary (Martin 2008; El Enany et al. 2013). Additionally, problems relating to the selection of participants and the over-reliance on those who are 'participation ready' can create barriers to PPI activities based upon democratic rationales (Barnes et al. 2003; Cowden & Singh 2007). Democratic rationales can also be blurred with *technocratic rationales* (Martin 2008), which suggest that PPI participants are able to provide access to specialised knowledge. Nevertheless, the content and legitimacy of this knowledge remains contested (Barnes et al. 2003; Ives et al. 2013; Kerr et al. 2007; Prior 2003; Renedo & Marston 2011).

Involvement has also been called as *emancipatory*, which connects it with health-related social movements demanding for autonomy and challenging medical paternalism. For example, Gibson et al. (2012) have emphasised the emancipatory potential of involvement, which could enable new 'knowledge spaces' to be constructed where different stakeholders could engage with each other in more equal terms. Rose (2014) has argued for PPI to be conceptualised in more political terms in order to gain a better understanding and to highlight the distinctive form of knowledge that people with lived experiences possess. However, there is no consensus regarding the status of PPI and whether it truly constitutes a social movement (Baggott and Forster 2008).

On the other hand, involvement also reflects the strengthening *consumerist ethos*, which both encourages increased self-sufficiency (Newman & Kuhlmann 2007) and positions people that use services as customers who have the right to make choices and voice their opinions (Sturgeon 2014). Healthcare takes on an increasingly commodified form, where service products are traded on a market; health professionals are positioned as service providers reacting to patients' wishes; and patients are positioned as (empowered) consumers making

individualised choices (Lupton 1997; Fotaki 2009; Timmermans & Oh 2010). Indeed, according to Dent and Pahor (2015) patient choice has become one of the most widely implemented variants of PPI. Perhaps it has been widely embraced as it fits well with broader approaches that aim to commodify and marketise health services, such as new public management (NPM), which has contributed to the reconfiguration of the relationship between users and providers of healthcare services. Some of the distinctive features of NPM include greater competition, private-sector-style management practices, a stress on cost improvements, and an emphasis on the public as customers (Hunter 2006). NPM has thus turned the old bureaucratic form of administration on its head and rebranded service users as consumers exercising choice by, for example, switching providers if they are dissatisfied with the service (Sorrentino et al. 2018). Hence, involvement based on consumerist rationales can be added to the repertoire of public managers attempting to increase efficiency (Alford 2009).

More recently, the new public governance model has shifted the focus away from hierarchical forms of organisation, towards collaborative partnerships and participatory governance (Howler & Ramesh 2016). The inclusion of a plurality of stakeholders and public engagement are seen as practical and useful ways to address problems that are increasingly complex (Sorrentino et al. 2018). In combination, these various developments have paved the way for PPI, which in its current form can broadly be described as ‘consumerist’, ‘deliberative’ and ‘participative’ (Fotaki 2010; Tonkens 2016). Being a mixture of different rationales creates some inherent tensions for PPI activities. Additionally, all these rationales include aspects of responsabilisation that makes lay participants increasingly accountable regarding health and healthcare related decisions.

2.1.2 Conceptualisations of PPI

The ladder of participation, developed by the urban development specialist Arnstein (1969), was one of the first theoretical frameworks to describe citizen involvement in planning processes. Arnstein's ladder depicts the user-professional relationship, with the level of user involvement increasing at each step. When the ladder is applied to healthcare, the lower end describes forms such as manipulation and therapy, which do not enable involvement. The middle section consists of tokenistic forms such as informing and consulting people and placation (e.g. people can plan or advice but hold no power over final decision-making). At the top is citizen control, which consists of partnership, delegation, and citizens' ability to make decisions on agendas they can set and control. This framework has been adjusted to several contexts. Charles and DeMaio (1993) have applied it to describe patient involvement in healthcare decision-making.

However, the model has also faced criticism for being too normative, idealistic and narrowly focused (Contandriopoulos et al. 2004). Thompson (2007) has argued that it reflects professional rather than patient perspectives. Additionally, the framework fails to capture the complex, dynamic and evolutionary nature of involvement processes (Tritter & McCallum 2006; Carpentier 2016). After all, PPI does not comprise a homogenous set of activities, but can take multiple shapes, and enables people to take on different roles. Hence, it has been argued that rather than understanding certain levels of PPI as good or bad (Contandriopoulos et al. 2004), researchers should pay attention to the roles and tools that are provided and how the process can empower or disempower participants (Dent & Pahor 2015). A more recent model by Carman et al. (2013) proposes for PPI to be viewed as a continuum: at the higher end of the continuum involvement is characterised by the sharing of power and responsibility, with patients playing an active role in defining agendas and making decisions. However, the authors emphasise that reaching the higher end is not the main goal, as such and intensive form of involvement is not necessarily better

in every setting or for all patients. Carman et al. (2013) highlight the multiple factors that influence engagement, such as patients' motivation, willingness, knowledge, attitudes, functional capacity; organisational factors such as policies and practices; and the socio-political environment, influenced by norms, policies and regulations. As a framework, the idea of a continuum is less restrictive than that of a ladder, since the latter suggests that only certain methods in PPI are correct. The continuum is mainly focused on patients, which can be seen as a limitation as public engagement or the involvement of those with infrequent contact with health services goes largely unaddressed. However, due to its focus on patient involvement, the framework is highly relevant to this study.

Grasping and conceptualising PPI can be challenging, due to problems with its definition, its purpose, and its varying practice across countries with different histories and funding arrangements. I will introduce the conceptual frameworks that have offered me the necessary vocabulary and structure to approach, explore and discuss PPI in policy and practice. Nevertheless, I also wish to highlight that I see PPI as complex and dynamic by nature. Due to its overlapping and at times conflicting rationales and goals, it is often difficult to pin down. One of the more consistent themes running through the different conceptualisations has been the idea that people who are affected by certain decisions or who use certain services should be given opportunities to get involved. However, what this involvement means, what it looks like, who can or should participate in it, and what its overall aims should be are all constantly being renegotiated. In this study, I explore some of the ways in which PPI is currently implemented, shaped and constructed in Finnish health services. In doing to, I use a model developed by Dent and Pahor (2015), which makes it easier to assess and compare the wide range of involvement methods different countries are using. The model consists of three approaches to involvement: *choice*, *voice* and *co-production*, which can take place at the individual or collective level.

Choice is well-known and possibly the most widely implemented method of involvement in healthcare across Europe (Coulter & Magee 2003). Choice represents a consumerist form of involvement that provides people with the opportunity of exit, i.e. it enables them to vote with their feet. However, depending on its application, choice can be understood as the freedom to choose between service providers, health professionals or treatment modes. This form of involvement ‘contrasts with voice that transforms individuals and groups from consumers to citizens with a right to engage in decision-making processes’ (Fredriksson & Tritter 2020: 329). Voice can therefore be seen as a more deliberative and participatory form of involvement. It highlights the social rights of the public to participate both as potential user of health services and as taxpayers (Knaapen & Lehoux 2016). Fredriksson (2013) has noted that the dominance of choice can negatively impact upon voice. However, it can also be argued that the complete absence of choice – i.e. ability to walk away – health services would lack sufficient incentive to listen to service users and implement other forms of involvement.

Lastly, as Baim-Lance et al. (2019) have noted, the concept of co-production has gained popularity in health policy and management circles, which has led to the inclusion of co-production in health policy frameworks. Co-production is a process where services are developed and delivered in partnerships between health professionals and patients (Dent & Pahor 2015). Hence, it allows patients to influence their own care and the delivery of services on a wider scale as they can shape the processes and outcomes of healthcare (Dunston et al. 2009). Through co-production, health services attempt to enhance efficiency and achieve a better fit between patient needs and care delivered (Baim-Lance et al. 2019).

Knaapen and Lehoux (2016) have also produced three conceptual models of PPI, which are very similar to those suggested by Dent and Pahor (2015). They are the consumer choice model, the democratic voice model and the lay expertise

model. The first two closely resemble the choice and voice conceptualisations outlined earlier. The third refers to co-production, but it also highlights the ideas that patient expertise has become more prominent and that the integration of experiential knowledge into healthcare decision-making can be a central aspect of PPI. I therefore include Knaapen and Lehoux (2016) in this section because I feel that the lay expertise model further expands the idea of co-production. By emphasising patients' knowledge and expertise, lay involvement can be justified in even in the highly professional and technical areas of medicine, such as training and research (Martin 2008).

In addition to these models, which aim to capture the different responses to PPI, I use a framework devised by Tritter (2009), which differentiates between aims, types and methods. It offers a clear way of outlining and differentiating different types of involvement activity: involvement in treatment decisions, service assessment and development, training health professionals, and engaging various aspects of research. The framework also considers that involvement can occur in individual and collective forms, both directly and indirectly. Hence, this framework provides a unified vocabulary, since I describe different levels of practical involvement activity in the articles.

Table 1. Model of involvement (from Tritter 2009: 277)

	Direct	Indirect
Individual	Proactive/reactive	Proactive/reactive
Collective	Proactive/reactive	Proactive/reactive

Firstly, according to Tritter (2009), involvement can happen directly or indirectly. The latter is the most common form and includes activities such as gathering information from patients to inform service delivery. However, indirect forms allow professionals to make the final decisions and gives them the power to ignore the information gathered. In contrast, direct involvement means that patients and the public are included in the actual decision-making. Additionally,

certain involvement activities can be directed towards individuals (e.g. a patient making a personal treatment decision) or collectives (e.g. a group of patients engaging in the redesign of a clinic). Finally, Tritter (2009) distinguishes between proactive and reactive involvement. This refers to the ways in which organisations choose to engage with users. In other words, are their views only sought for a specific purpose, or are participants able to engage in agenda-setting and raise new issues?

In this study, I explore PPI in Finnish health services from multiple perspectives, some of which offer a more macro-level policy view on patients and the public and their opportunities to influence healthcare. Other perspectives focus on lay participants' experiences of attempts at involvement, both as individuals and through collective groups. These two frameworks have proven to be functional, as they provide a structure and a vocabulary to use when describing the aims, methods and types of involvement. I use Dent and Pahor's (2015) framework, in conjunction with the model suggested by Knaapen and Lehoux (2016), to illustrate the different methods of involvement that have been implemented in Finland, i.e. choice, voice and co-production, where the latter also includes the strengthened ideas of lay expertise and experiential knowledge. Additionally, I apply Tritter's (2009) framework when providing more detailed information about the varied forms that involvement can take under the three headings. His framework (shown in Table 1) allows me to differentiate between direct and indirect, collective and individual methods of involvement in more detail, and to outline the numerous activities in which people are able to engage. Both models are used when I discuss the results of this thesis, as this may help to make some of the findings comparable with other countries and more easily accessible for readers who are less familiar with the Finnish system. Nevertheless, these models are ideal types, and in practice the distinctions between them may not have such clear boundaries. Indeed, different PPI rationales and activities may overlap or be used in combination.

2.1.3 Patients, experts and consumers

The relationships and dynamics between service providers and the people who use and fund public services are constantly shifting and changing. These changes are also demonstrated in PPI, which often positions people as active participants, joint collaborators or even experts. Coulter (2002:6) has suggested that the 21st-century health service user is at once ‘a decision-maker, a care manager, a co-producer of health, an evaluator, a potential change agent, a taxpayer and an active citizen whose voice must be heard by decision-makers’. This reflects a significant change within both the doctor-patient relationship – traditionally described as a relationship between ‘the one who knows’ and ‘the one who does not know’ (Berg 1996) – and the relationship health services have with their (potential) users, i.e. the public. It also signals that the citizen is expected to have huge amounts of knowledge, and to be willing and able to contribute at different levels of decision-making.

However, as Fredriksson and Tritter (2017) have highlighted, patients and the public should not automatically be viewed as having the same roles, rights, responsibilities and aims. Their knowledge bases may also differ, as only patients have lived illness experiences and can legitimately claim to possess experiential knowledge. Patients are of course also members of the public, but as Coulter (2006) highlights, the needs and interests of patients using health services may differ from those of citizens and taxpayers. Hence, patients with first-hand experience of illness and service use may wish to challenge paternalism and their limited ability to manage their own health (Fredriksson & Tritter 2017). In this section, I will focus in more depth on previous literature on the changing role of the patient, as this study concentrates specifically on a recent shift that has allowed people with personal illness experiences to reposition themselves as experts and even establish themselves as a group working in collaboration with health professionals.

In clinical settings, doctors have traditionally been presented as experts, and patients have been expected to trust them to act in their best interest (Coulter 2005). Initially, studies on laypeople's relationship with health services focused heavily on different forms of illness behaviour, lay referral, and the reasons behind compliance or non-compliance with medical advice (Williams 2013). However, Armstrong (2014) has argued that since the middle of the 20th century, patients have been encouraged to exercise increasingly autonomous behaviour. Indeed, there has been a considerable shift from the sick role (Parsons 1951), characterised by acceptance of the medical professional as a source of knowledge and authority, to the more recent roles of the *expert patient* or the *resisting consumer* (Fox & Ward 2006).

From the 1970s onwards, the literature on non-compliance, and later non-concordance, promoted the idea that patients had their own views on medical advice and should be encouraged to engage with health professionals with regard to their own treatment (Armstrong 2014). Active social movements such as the gay rights, disability and mental health movements also acted as strong campaigners, not only changing healthcare practices but also creating a shift in the role of patients. The AIDS epidemic of the 1980s was a major turning point that not only challenged the doctor-patient relationship but also shook trust in medicine as an institution. In this climate, AIDS activists were able to position themselves as experts attempting to find cures and answers together with health professionals and researchers (Epstein 1996).

Indeed, such moments – when medicine seems unable to cope with a new threat (e.g. AIDS), when cases of serious malpractice surface, or when medical practices appear to lead to harm rather than good – have often provided openings for individuals and collective groups both to challenge medicine and medical expertise, and to promote experiential perspectives. For example, Brown et al. (2004) have suggested that embodied health movements have been able 'to address disease, disability or illness experience by challenging science on etiology,

diagnosis, treatment and prevention' (p. 50) and by drawing attention to weak science and scientific oversights. The participants in such movements 'have arrived at their activism through a direct, felt experience of illness' and their identities are shaped by the biological disease process happening within their body (Brown et al. 2004: 55). Additionally, movements centred on health and healthcare-related issues have been driving forces for change, as they have been able to change medical research practices, expand funding, increase the recognition of alternative treatments, and broaden awareness of laypeople's capacity to manage their own health problems (e.g. Epstein 1996; Osuch et al. 2012). They have also been able to enhance the civil rights of patient groups, challenge stigma, and counter discriminatory practices (Goldstein 1999; Rashed 2019). Hence, the potential power of laypeople and people with lived experience to make changes regarding issues related to health, illness and care is substantial. These movements have also paved the way for patients and the public to become actively involved in decision-making regarding care, treatment decisions and service delivery.

However, there are also individuals and groups that hold strong views regarding health services, treatments and illnesses but which operate completely independently of health services, choosing not to collaborate or engage with them through established channels such as the various PPI opportunities. Instead, they operate through loose networks or tightly knit communities that share their beliefs regarding treatment and health-related choices. These are often groups, whose views and opinions do not align with those of health professionals. Two examples are online pro-ana groups and the anti-vaccination movement, which actively promote alternative views on health and the need for medical intervention, and which often draw knowledge from personal experiences (Fox et al. 2005; Blume 2006). Although these groups are not the focus of this study, it is important to recognise their role and their use of experiential knowledge, and to highlight that PPI activities do not attract everyone.

The language of consumerism has become commonplace in health policies in many Western countries (Harris et al. 2010), and the consumerist ethos has strongly influenced the position of health service users. The origins of the term *consumer* are in the world of business and it emphasises the need for producers to recognise the preferences of those purchasing goods and services. Since, the 1970s and 1980s, the term has been more widely adopted and applied to users of various public services, such as healthcare (Gabe 2013a). As consumers, people using services are positioned as customers who can make choices between service providers and available treatments (Sturgeon 2014). Despite also being promoted by health consumer organisations, this position has attracted criticism, as the consumption of health services differs from other forms of consumption. Additionally, scholars have voiced the concern that positioning patients as consumers conceals the limited extent to which they can control their own health, fails to take into account that the restricted amount of choice available to patients and overlooks the fact that many are either unable or unwilling make choices (Victoor et al. 2012).

Technological developments and increasing levels of education have meant that information is now more readily available than ever, providing people with access to research studies, medical guidance and public discussion forums. This also allows people to network and share personal experiences of illness and treatment (Ziebland & Wyke 2012; Foster 2016) on a much wider scale. In addition to providing access to information and an opportunity to create networks, technological advances have also produced a multitude of different self-monitoring devices that can be used to track bodily functions, maintain health and manage illness (Lupton 2017). However, although patients have become more autonomous actors, they have concurrently been saddled with increasing amounts of responsibility over illness prevention and managing their own conditions. One example of this is the Expert Patient Programme developed in the UK (Department of Health 2001). On one hand, it acknowledges that

patients with long-term chronic illnesses in particular accumulate a great deal of knowledge about their condition and its management. The programme aims to harness and support this knowledge, but it has been criticised for shifting responsibility from health services onto individuals, and for failing to contest the assumptions that professionals' continue to hold regarding people with chronic illness (e.g. Wilson et al. 2007).

The Expert Patient Programme is also a sign of another shift in the patient role that has been reflected in healthcare and health policy in several countries, including Finland. This shift is the portrayal of the patient as an expert on their own life and condition. With PPI this idea has expanded, as patients can also be regarded as having experiential knowledge that can inform healthcare and health policy on a wider scale. Thus, PPI and the discourse around lay knowledge and patient expertise are closely intertwined. Perhaps it is no surprise that patients need to be dubbed 'experts' in order to become participants in health services. After all, this is a hierarchical field dominated by established professionals with specialist knowledge and skills. In order to voice their views and ideas in this expert environment, patients may also feel the need to adopt new roles that provide them with legitimacy.

It is also important to acknowledge that patients' motivations, abilities, levels of health literacy and eagerness to participate can vary. It is likely that the duration and nature and impact of different health conditions and the amount of contact people have with the health services all influence how they feel about involvement. Someone living with and managing a chronic long-term condition may view involvement differently from a person with a fractured arm visiting a hospital casualty department. Some may wish to maintain a more traditional doctor-patient relationship where the doctor clearly holds the expert role; others may have very limited interest in PPI altogether. People's ability to gather and evaluate health and health service-related information varies and may exclude them from involvement activities (Peat et al. 2010). Additionally, some will

require proactive facilitation to get involved. For example, people whose capacity may be lowered or who communicate through different means may require support for involvement.

As Miettinen et al. (2017) have highlighted, historical baggage and the ways in which people have been treated in the health services may also influence their involvement and the roles they are able to adopt. It may be challenging for people to adopt more autonomous roles or reshape their relationship with health professionals in service settings where paternalistic and even oppressive practices have been commonplace in the past. Additionally, people with illnesses such as mental health problems have had to endure stigmatising attitudes and stereotypes, which they may also have internalised (Laitila 2010). These burdens should be recognised and addressed in order for people with lived experiences to become an influencing force within healthcare (Noorani 2013). Hence, when PPI is planned and implemented, it is necessary to consider issues such as the different stakeholders' attitudes and beliefs regarding lay participation and lay knowledge, the participants past experiences with the healthcare system, their current health status and self-efficacy (Dy & Purnell 2012).

In this study, I have chosen to focus on people and collective groups that want to build collaborative relationships with health professionals. However, it is important to recognise that patients and the general public do not form homogenous groups with unified opinions or perspectives. Instead, there are numerous views, opinions and stances, which can shift and change, differ and align, depending on the issue at hand. Although the participants in this study wanted to engage in PPI, expressing many similar opinions and aims, they nonetheless had differing ideas among themselves regarding their relationship with health services. These will be explored in more detail in the results section, but before that I wish to bring a closely connected issue into the discussion: experiential knowledge and its potential contribution to health services.

2.1.4 From lay beliefs to experiential knowledge

Adolf and Stehr (2014) have written about knowledge societies, referring to the way in which knowledge and expertise have come to govern politics, work and everyday life. In an increasingly ambiguous world, knowledge can be produced within and outside of expert organisations (Beck 1994; Gibbons et al. 1994), and people with lived experience can take part in this by turning their illness experiences into a special form of expertise and knowledge (Coulter 2011). Nevertheless, the integration of experiential knowledge into health service development and delivery continues to be a source of contention and adds to the growing challenge directed at more traditional forms of expert knowledge (Williams & Calnan 1996). Despite these tensions, experience-based knowledge and information have been actively promoted by patients and the collective groups that represent them, as well as through health policy in several countries (Conklin et al. 2015; Brosnan & Kirby 2016; Niskala et al. 2017; Alanko & Hellman 2017).

In this section, I will discuss how over the decades lived experiences have come to be known as experiential knowledge. Lay experiences and perspectives have received a lot of interest among social and health scientists, as researchers have approached them in different ways and suggested various terms to describe laypeople's understandings and the information they gather and possess. Initially, these were referred to as *lay beliefs* or views that people develop about health, illness or service use, and they were studied in order to make sense of health-related behaviours (Williams & Popay 2006). However, the term lay beliefs has a paternalistic tone, often connoting the ideas that experts know better and that laypeople should be educated to think and act in the 'correct' manner.

As technological advances have made information more accessible and allowed people with illness experiences to create wider communication networks, there has also been a shift in the research literature. Instead of speaking about

beliefs, research now describes lay perspectives in terms of knowledge or even expertise (Prior 2003). Indeed, the idea that lived experiences could constitute knowledge and expertise was first addressed in the 1970s, with the interest towards lived experiences increasing over the following decades (Prior 2003). Concurrently, patient activists and health social movements have been more direct at questioning and challenging traditional forms of knowledge and expertise. They have been instrumental in establishing the epistemic dimensions of lived experience and they have managed to influence health policy and medical research, using experience-based knowledge alongside scientific expertise (Epstein 1996; Rabeharisoa et al. 2014).

Lived experiences provide the foundation for what can be termed experiential knowledge. The concept is not clear-cut or universally recognised by all, but it is gaining both academic interest and influence within healthcare through PPI. One of the earliest definitions of experiential knowledge was provided by Borkman (1976), who described it as ‘truth learned from personal experience with a phenomenon rather than truth acquired by discursive reasoning, observation, or reflection on information provided by others’ (p. 446). Since the 1970s, the concept has been developed further. Borkman (1990) has continued to conceptualise experiential knowledge by comparing it with concepts such as folk/lay knowledge, described as piecemeal and professional knowledge, which in turn is highly specialised. In contrast Borkman (1990) portrayed experiential knowledge as complex, layered and holistic. It entails social, emotional and embodied experiences of living with and managing an illness as well as experiences of stigma and vulnerability (Rowland et al. 2017; Noorani et al. 2019). Faulkner (2017) has suggested that experiential knowledge can create a much more nuanced understanding of the illness experience. On a personal level, it has the potential to support coping and deal with the more practical aspects of living with an illness, or another type of problem (Vennik et al. 2005; Noorani et al. 2019). On a societal level and within health services, experiential knowledge can

also be used to challenge medicine and healthcare practices, and to create alternative imagery of ill health (Eriksson 2013).

Caron-Flinterman et al. (2005) have suggested that experiential knowledge is not merely based on personal experiences as it is constructed through a collective process, which involves sharing and distilling various perspectives together. People who have taken part in expert by experience training, have also highlighted the importance of distancing oneself from past experiences, reflecting upon them and gaining new perspective through feedback from peers (Jones 2018). Hence, the construction of experiential knowledge can be seen as both personal and collective in nature. For decades, third-sector organisations have provided a basis for the formation and development of this knowledge through peer support groups and other activities that bring patients together. Additionally, the expansion of internet use over the past decades and the creation of numerous social media platforms has made it increasingly possible for people with lived experiences to connect, share and compare stories.

These days experiential knowledge is not only shared and used within patient organisations and networks. It is also emphasised in top-down initiatives led by healthcare institutions and policy makers (Martin 2012), which has led to an ever-growing interest in collecting, understanding and using experiential perspectives in the development of health services and policy (Coulter et al. 2014; Locock et al. 2020). Nowadays, experiential knowledge is more widely recognised and viewed as the basis for experiential expertise, as indicated by the usage of terms such as *expert patient*, *experiential knowledge* and *expert by experience* in involvement initiatives, national and local level policies (Noorani 2013; Toikko 2016; Castro et al. 2019). Despite these developments, there is no consensus on what experience(s) should be considered knowledge (Pols 2014; Blume 2017). Additionally, Blume (2017) has suggested there are various constraints, which act as ‘filters’ and control the experiences that come to function as experiential knowledge. Knowledge and power hierarchies play an important role in

determining whose experiences get included in health-related decision-making and participants with recognised qualifications and credentials often play a key role in involvement activities (O'Shea et al. 2019). This means that although experiential knowledge may be a wider pool of understanding, certain experiences can easily be excluded or deemed of lesser value. In relation to PPI initiatives, it is important to question whose lived experiences are being represented, how experiential perspectives are communicated and by whom (Horner 2016). This study addresses these questions by exploring some of the definitions and applications of experiential knowledge as well as the 'filters' associated with its use in involvement activities. Thus far, experiential knowledge has been primarily studied from the perspectives of individuals with lived experiences. In this study, I also explore experiential knowledge from the perspectives of organisations that represent collective groups of patients.

2.2 Lay involvement and experiential knowledge in health services

Before describing the Finnish health service context and developments in relation to involvement, I will outline previous literature on the benefits of involvement and the factors that can support its implementation, as well as highlighting some of the tensions and barriers related to involvement.

2.2.1 Benefits

Previous studies have shown that involving people with lived experiences in the planning, assessment, development and production of healthcare can benefit the participating individuals (whether lay or professional) and the services. Thompson et al. (2012) have argued that PPI 'can provide opportunities for those involved to reconstruct reflexively positive subject positions based on their

involvement and the acquisition of skills, knowledge and experience' (p. 617). Indeed, on an individual level, involvement has been associated with improvements in confidence, self-esteem and social interaction (Nicholls 2003). Involvement in a developmental role can also improve the knowledge lay participants have of specific subject areas (e.g. care pathways) and decision-making processes (Conklin et al. 2015). Additionally, participation in involvement activities can provide a steppingstone to new opportunities, such as a new line of work (Rissanen 2015), which suggests that participation can be especially meaningful for groups and individuals whose opportunities have been limited due to their illness.

In Farr's (2018) study of co-design and co-production processes, participants sought to find issues of mutual concern that they could all identify with, and to generate consensus based on the understanding of different perspectives. Both staff and service users taking part in the process expressed that it had been emancipatory and had a positive impact on them. Studies have also suggested that working in collaboration can positively affect lay and professional participants' attitudes, values and beliefs about involvement (Mockford et al. 2012) and increase service providers' and decision makers' awareness of different ways of operating in the healthcare sector (Conklin et al. 2015). Furthermore, in a survey conducted by Omeni et al. (2014), health professionals reported a high level of satisfaction with training provided by people with lived experience.

On a service level, involvement has been credited with improving information about and accessibility of services (Crawford et al. 2002). According to a review conducted by Mockford et al. (2012), involving people with lived experience in the development and planning of the service environments made a difference to how the physical environments and their surroundings were developed. Involvement also led to practical changes in relation to the accessibility, location and provision of additional services. Additionally, studies included in the review reported revisions to the information provided to patients, and the initiation of

awareness-raising campaigns directed at patients and professionals. According to Farr (2018), involvement activities can facilitate different stakeholder groups to work collaboratively across and within institutional structures, and the acknowledgement of the emotional aspects of experience can facilitate connections between diverse groups of people, enabling them to connect on an emotional and relational level.

Despite these findings, the tangible and measurable evidence concerning the effects of involvement on public services remains scarce (Conklin et al. 2015). However, Thurston et al. (2005) have suggested that the success of involvement should perhaps be measured more in terms of the establishment of a formal partnership that is capable of informing the development of health policy by challenging the status quo and adding priorities to the agenda. Additionally, Staniszevska et al. (2012) have argued that successful involvement relies on many factors, including thorough planning, inclusivity, and adequate time and budget, as well as skills, resources and motivation. Indeed, the problems associated with involvement are often related to the lack of consideration of these factors.

2.2.2 Tensions and barriers

In previous literature, the barriers associated with involvement have been linked to differing aims and justifications; power imbalances; knowledge and claims to expertise; representation; and on a more practical level, attitudes and lack of clear guidance. Earlier, I discussed the different rationales and sociocultural changes that have led to the implementation of involvement in health services. These rationales also lead to different aims. Hence, if the aim is to reduce costs, involvement will look different from how it looks when the aim is to better integrate people into decision-making processes. Tensions and potential clashes can be expected if aims are not clearly communicated, as participating individuals and groups may have very different expectations in mind (Rise et al. 2011).

Involvement has the potential to shake up and create change in health service decision-making by turning patients and the public into collaborators whose experience-based knowledge can improve services. For example, Petsoulas et al. (2014) have argued that the traditional patient category should be reconceptualised into one that acknowledges peoples' ability to contribute to care planning and service development. However, this change is unlikely to happen if existing power imbalances remain unaddressed. O'Shea et al. (2019) have highlighted the hierarchies of power in involvement, which are reflected in the ways that different forms of knowledge are used and how the holders of that knowledge are viewed. Experience-based knowledge or claims to expertise based on personal experience of illness are not ranked as highly within health service settings as professional or biomedical knowledge and expertise (Daykin et al. 2007; Boivin et al. 2010; Greenhalgh et al. 2015). Professionals possess qualifications, knowledge and expertise that enable them to establish a greater level of power than patients or members of the public (O'Shea et al. 2019). Hence, even though the experiences and voices of patients have become increasingly integrated as a core dimension of healthcare development, people with lived experience still need to justify their participation and find ways to enhance the legitimacy of their knowledge base. Additionally, lay participants may not have opportunities to influence agenda-setting; or their views may be gathered and noted, but they may lack access to the spaces where actual decisions are made (Jones & Pietilä 2019). If involvement is seen mainly as a necessity, an image booster for the health service organisation, or a mere consultation process, this may lead to involvement becoming tokenistic (Ocloo & Matthews 2016) and leave lay participants feeling disappointed and dissatisfied (Mockford et al. 2009).

On a more practical level, ambivalent or negative professional attitudes towards involvement and experiential knowledge can hinder implementation (Brett et al. 2012) and make participants feel that their contribution is not valued. Additionally, members of the public and patients who participate in involvement

activities do not always have a clear position within health services (Jacobson et al. 2012), which may be down to a lack of guidelines and effective communication. This situation can offer participants opportunities to provide their own role interpretations (Jones & Pietilä 2020). However, it can also lead to frustration and what Broer et al. (2014) have termed *mutual powerlessness*, which refers to professionals and patients struggling to understand the functions they should fulfil. Involvement can also feel pressurising, as service users may be expected to adapt to existing organisational ways of doing things, and to possess technical insights into and understandings of complex processes. Hence, individuals may be left feeling isolated, particularly if they are unfamiliar with structures and policies (Robert et al. 2003). This leads us to another barrier. There are multiple factors that affect peoples' health beliefs, their ability to use services and their capacity to be successfully involved, including income, level of education, cultural differences and cognitive skills (Peat et al. 2010). Ocloo and Matthews (2016) have suggested that consequently, the narrow PPI selection processes can lead to a situation where 'those with the most to gain are the most excluded from healthcare decision-making' (p. 629).

Related to the above arguments regarding exclusion and capability is the idea that involvement is becoming increasingly professionalised. The drive to involve people has led to a situation where an ever-growing participatory workforce is developing around the world, including public participation professionals who work in the private, public and third sectors and are paid to plan and facilitate involvement (Bherer et al. 2017). Concurrently, laypeople with lived experience who are invited to participate may also adopt increasingly professionalised traits. The need to be seen as a credible participant in a health service setting can lead lay participants to highlight specific forms of expertise, above and beyond experiential expertise (Thompson et al. 2012). Various levels of professionalisation have been noted within peer support work (Aiken & Thomson 2013) as well as among people who engage more directly with

healthcare development and delivery tasks, such as experts by experience (Jones 2018). These professionalised lay participants may also ‘pursue their own professional status by delineating a distinctive body of ‘expert’ management knowledge that bounds their jurisdiction, and from which they can exclude those they perceive as ‘less expert’ users’ (El Enany et al. 2013: 24).

From health professionals’ perspective, involvement may appear to be an additional strain, and it may not be viewed as a priority (Peck et al. 2002; South 2004; National Centre for Involvement 2009). Additionally, involvement can be associated with emotional labour, and can leave professionals feeling drained by the effort to push it forwards (Staniszewska et al. 2012). However, it has been suggested that some of these problems can be mitigated by the proper facilitation and understanding of involvement, and the preparedness to experiment, give up some control and allow genuine dialogue to develop (Staniszewska et al. 2012). Adding to these recommendations, Ocloo and Matthews (2016) have recommended that involvement should build on people’s existing strengths and be based upon reciprocity, mutual respect, clear expectations and responsibilities between participants. Additionally, they advocate for the removal of tight boundaries between different stakeholders to enable shared control (Ocloo & Matthews 2016).

Finally, it is also important to acknowledge that the broader social and political environment influences the implementation of PPI. These factors include social norms that influence whether people view themselves as able to contribute to the improvement of their care or services more generally (Carman et al. 2013). Policymakers can create spaces for patients and the public to deliberate, provide input and participate in shaping services and policies, and they have the means to ensure that the third sector has the resources to support involvement (Carman et al. 2013). Additionally, professional groups working within healthcare play an important part in facilitating involvement. Hence, it is important to consider the incentives they have for accepting and supporting PPI within service settings.

2.3 PPI in the Finnish context

In this study, I focus on the involvement that occurs within the public sector. However, I acknowledge that this is not the only sector producing and providing services. Hence, I will provide some general information regarding the rather complex and decentralised Finnish healthcare service system. Firstly, health services have multiple funding sources, and first contact care is distributed through three channels: public, private or occupational health (Keskimäki et al. 2019). At the primary-care level, public health services consist of municipal health centres, funded by local authorities, with service users making co-payments. Additionally, primary services can be accessed through occupational health, funded by the employers and employees, or by using the private sector, where services are mainly funded by out-of-pocket payments. However, some of the cost of using private services is reimbursed by the National Health Insurance and private health insurance (Tynkkynen et al. 2016). Both private and occupational care providers are also likely to implement involvement activities, but these are outside of the scope of this study.

The articles of this study explore involvement specifically within two large service sectors – mental health and cancer services – where PPI was actively implemented during the 2000s and 2010s. In both service sectors, acute treatment is provided through specialist services that can be accessed through referral from primary care. Follow-up care and rehabilitative services are organised through either primary care, community-based specialist services, or services provided by private practitioners and third-sector organisations. Additionally, this study addresses the role of Finland's extensive voluntary sector, which comprises third-sector organisations that provide rehabilitative services and peer support, and increasingly engage in informing and lobbying (Toivainen et al. 2010).

2.3.1 Voice, choice and co-production in health policy and services

In Finland, patients' rights, agency and decision-making powers regarding their own care have slowly strengthened over the latter part of the 20th century. In the early 1990s, the Act on the Status and Rights of Patients (785/1992) was passed to reinforce people's rights to make treatment decisions in collaboration with health professionals (Ministry of Social Affairs and Health 1992). Additionally, it introduced an ombudsman system, enabling patients and relatives to make complaints to the authorities responsible for healthcare supervision (Torjesen et al. 2017). Despite these legislative changes, PPI, particularly in terms of voice and co-production, did not become a policy priority until recently. The choice element, however, has been a central feature of health policies for much longer, although it should be noted that in comparison with the private sector, choice has been much more limited in the public sector. Since the 1990s, economic and business interests have played a central role in health policy (Ollila & Koivusalo 2009). Healthcare reform initiatives have also encouraged different applications of market governance, and have introduced practices such as contracting out, purchaser-provider splits, choice and competition in public service delivery (Tritter et al. 2010; Tynkkynen et al. 2016). These changes have also pushed patients' right to choose higher up the agenda (Leppo & Perälä 2009). People using health services have also been increasingly pressured to act as critical choice makers (Julkunen 2008). The Act on Service Vouchers in Social and Healthcare (2004) and later the Healthcare Act (2011) allowed people to make choices regarding their care providers.

Alongside the choice element, voice and co-production have slowly entered the policy rhetoric. The biggest steps were taken in the latter part of the 2000s and early 2010s with the National Mental Health and Substance Abuse Plan (2009) and the National Development Programme for Social and Healthcare Services (2012). These programmes began to promote direct involvement and

experiential expertise in service development, claiming that ‘involvement and customer-orientation are the central principles’ (p. 19). Traditionally, the main methods for exercising one’s voice in relation to healthcare services had been indirect, such as by voting in national and municipal elections and thus guiding the development of health services through the democratic process. Additionally, health services have introduced methods such as patient satisfaction questionnaires and feedback forms in order to gather information from service users, which have enabled individuals to express their views and make suggestions for improvements.

The policy emphasis on PPI remained and even intensified during the 2010s. Following the parliamentary elections in the spring of 2015, Sipilä’s newly appointed centre-right coalition government included involvement in its Strategic programme (Prime Minister’s Office 2015) for health and welfare. The government also introduced their plan for a large health and social care reform that placed choice and competition at the centre of healthcare, in connection with the transfer of responsibility for the organisation of health services from municipal and local authorities to autonomous regions. The government was not able to carry out the planned reform prior to the elections in spring 2019, when Marin’s centre-left government took office. The new government then released its own Strategic programme (2019), which highlighted a commitment to enhance client satisfaction and continue collaboration in service development (Prime Minister’s Office 2019). Hence, in terms of involvement, the current Strategic programme appears to follow a similar rhetoric to the previous one. However, the choice and competition elements have reduced in the government’s health and social care reform plan, but the aim continues to be to shift organisational power to autonomous regions.

Involvement has continued to be strengthened, particularly within mental health services. Indeed, Alanko and Hellman (2017) have argued that within mental health policy, the dismantling of the professionals’ exclusive expertise role

began in the 1990s and continued during the next decade with the service users being positioned as experts. The newly published National Mental Health Strategy and Suicide Prevention Agenda 2020–2030 (Vorma et al. 2020) outlines that people should have the right to influence decision-making as citizens, peer supporters and experts by experience. Hence, the strategy strongly ties involvement to the voice discourse, and further cements the position of people with lived experience, who participate as peer supporters and experts by experience. Additionally, in 2018 plans were put in place to make involvement a legal requirement in mental health services (Ministry of Social Affairs and Health 2018). The legislation has not yet been passed, but if and when it is, it will likely place pressure on other service areas to implement involvement too.

Other collective involvement opportunities (such as participation in municipal residents' forums) and direct individual opportunities (such as including service users in decision-making bodies, and planning and developing services together with service users) were included in the Local Government Act (410/2015, §22). In 2012, a new state-level Citizens' initiative was introduced to promote civic involvement; in practice, it means that citizens are collectively entitled to submit initiatives to parliament (Ministry of Justice 2012). Indeed, there has been a surge of different types of collective groups organised by municipal authorities and health service providers, such as patient forums and service user panels (Lindfors et al. 2017). Nevertheless, neither giving individual feedback nor participating in collective groups offers people direct influence over decision-making. Some groups may have more resources and influence, but unless they are integrated into the decision-making processes, their role remains mostly consultative, and in some cases merely tokenistic (Jones & Pietilä 2019).

In Finland, patient organisations have traditionally provided collective channels for involvement. They engage in awareness-raising and lobbying (Toiviainen 2005), with many harbouring close relationships with political decision makers. Indeed, as patient advocates, organisations have been able to

push for changes such as reforms to drug reimbursements and insurance legislation (Torjesen et al. 2017). Organisations have always been the main source of peer support services and trained people to act as peer support workers. However, more recently they have begun to train people with lived experiences to become experts by experience, whose main aim is to get involved in the development of health services. In the 1990s, some of the mental health organisations had begun to use the term *expert by experience*. Since then, it has significantly widened in scope and the training of experts by experience has become more systematic (Niskala & Savilahti 2014). As regional health authorities and vocational colleges have also begun to provide training, the number of experts by experience has further increased, enabling people from different illness groups to get involved. Hence, a term that was once used mainly within mental health and substance abuse services has become more commonly applied with reference to people who have lived experience of illness or caring. Currently, there are no unified guidelines for training, and different programmes can vary significantly in length and content (Hirschovits-Gerz et al. 2019). One common feature of the training programmes is that they are group-based. Additionally, a central part of the training is to provide the participants with the opportunity to construct a personal story based on lived experiences (Toikko 2016; Hirschovits-Gerz et al. 2019). The training programmes can include information about the service system and legislation and well as information about the work done by experts by experience. There can also be sessions about (mental) illnesses from the clinical perspective, and practical support on media management, marketing and presentation skills.

The growing group of lay experts also relates to co-production, as people with lived experience are increasingly included in the planning and delivery of services. Traditionally, co-production has related to individuals making joint decisions with health professionals regarding their own care as outlined in the Act on the Status and Rights of Patients (Ministry of Social Affairs and Health 1992). Nowadays,

co-production can also mean the processes through which individuals and groups are included in service production and delivery (Weiste et al. 2020). Co-production has been implemented in the third sector for decades as people with experience of illness have delivered services, for example by providing peer support as well as working and volunteering at all organisational levels. Within healthcare, mental health and substance abuse services have been the forerunners in this area, where the most recent developments include hiring experts by experience as team members in municipal health centres, hospitals and community teams (e.g. City of Vantaa 2019; Finnish Institute for Health and Welfare 2018; Seppänen 2018). Thus, it could be argued that through PPI, health services are now increasingly adopting some of the working methods and service innovations that the third sector has developed over the past decades. However, as Tuurnas (2016) suggests, the anchoring of co-production in organisational practices in a sustainable way is still in its infancy.

Overall, the market-driven ethos has made it possible for people to act as health consumers and to influence services through feedback and choice-making. Concurrently, there has also been an increase in other types of service-level involvement opportunities, enabling people to act as developers, planners and evaluators (Filppa & Hietanen 2013). This has strengthened the idea that experience-based knowledge can improve services (Niskala et al. 2017). There has also been a considerable push towards recognising people with lived experience as experts. In 2020, it was announced that the Funding Centre for Social Welfare and Health Organisations would fund a three-year project to find new ways to involve patients and organisations in the development of the *Current care guidelines* (Duodecim 2020). The *Current care guidelines* (*Käypä hoito -suositukset*) are national, independent, evidence-based clinical practice guidelines developed by the Finnish Medical Society Duodecim. Thus far, patients and organisations have been consulted during the guidelines' development, and for some illnesses – such as diabetes and cardiovascular disease – patient representatives have been included

in the group that develops the guidelines (Komulainen 2020). This particularly strengthens the voice and co-production aspects, producing more opportunities for direct and indirect involvement. In articles about this project, patients are also referred to as experts by experience (Komulainen 2020), showing that the positioning of people with lived experience as experts appears to be widening in scope.

Table 2. Examples of choice, voice and co-production in Finnish public sector health services (adapted from Dent and Pahor 2015)

Choice	Voice	Co-production
Opportunity to choose between service providers. Voucher schemes for purchasing services.	Patient organisations consulted during or included in policymaking processes. Lived experience used in the training of health professionals and to inform service development.	Patients' rights to plan their own treatment in collaboration with health professionals. Experts by experience involved in health service delivery.

2.3.2 Lay involvement in service development and delivery

I have thus far outlined developments in relation to PPI in Finnish healthcare. The emphasis has been on policy and legislative frameworks, which can be considered significant driving forces of involvement. They have been accompanied by several projects initiated by third-sector organisations and municipalities, which have encouraged people to get involved (Meriluoto 2016). Service-level involvement is currently implemented in several different health service settings, from primary care to specialist services. These developments have been most active in mental health services, but somatic services, such as cancer care services, are beginning to follow a similar path. This study focuses particularly on the newer developments – the inclusion of experiential knowledge and people with lived experience in service development and delivery. By focusing on service level involvement, this study offers a valuable addition to Finnish involvement research, which has thus far focused on involvement in

municipal decision making (e.g. Tuurnas 2017) and service user involvement in social care (e.g. Meriluoto 2016, 2018; Matthies et al. 2018). Additionally, third sector organisations have been largely overlooked in studies regarding involvement. Although service level involvement opportunities are expanding, we know very little about the complexities of integrating lay participants and experiential knowledge into health service settings. Prior to introducing the research questions, I will briefly 1) describe who the lay participants and organisations engaged in service development and delivery are, 2) explain in practical terms what service development and delivery entail, and 3) outline the service settings chosen for this study.

'Lay' participants and third sector organisations: In Finland, the terminology surrounding involvement and people with lived experience is manifold and at times confusing. Different organisations and even individuals use different terms in reference to themselves and the work they do. Two of the more established terms are *peer support worker* (*vertaistukihenkilö*) and *expert by experience* (*kokemusasiantuntija*). The former is mainly used in reference to people who provide support to patients and run support groups, whereas the latter refers to people who use their personal experiences and the knowledge derived from them to inform health services through involvement. However, there is quite a bit of overlap between these roles in relation to PPI, as the work done by peer support workers and experts by experience is often very similar. For example, experts by experience can also provide peer support and peer support workers can act in service development roles. The term expert by experience is also relatively new and was initially used in reference to people with lived experiences of mental health and substance abuse issues. Its' scope only began to widen during the 2010s as various patient groups and organisations began to adopt it. Currently, it is used in reference to people with a range of lived experiences such as being a carer, living with autism or having illnesses such as cancer or dementia.

In this study, all the participants identified as either peer support workers or experts by experience and I have decided to refer to them with the terms they chose to use. When discussing them collectively, I have chosen to refer to the participants with lived experiences as 'lay' participants or experts. In relation to involvement, the term 'lay' differentiates them from health professional, who have recognised qualifications and hold legitimate positions within healthcare settings. Hence, the term is mainly used to describe the relationship these participants have with health services and to emphasise that they are included in PPI due to their lived perspectives. However, I recognise the problems associated with the term 'lay', as people with lived experiences can also hold professional qualifications. I will address these issues related to the chosen terminology later in the results section.

Overall, the study participants represent a growing group of people with lived experience of illness and caring. A working paper on expertise by experience, published by the National Institute of Health and Welfare, found that the 55 organisations that replied to its survey had trained over 2000 experts by experience (Hirschovits-Gerz et al. 2019). These lay participants are increasingly involved in health service development and delivery, presenting experience-based knowledge as a tool to improve healthcare.

Third sector organisations have traditionally been consulted during policymaking and healthcare development processes (Ministry of Social Affairs and Health 2011a; Finnish Institute for Health and Welfare 2014; Ministry of Social Affairs and Health 2019). Many organisations hold established positions and have connections with policymakers (Toivanen et al. 2010). However, the number of organisations has increased exponentially since the 1990s (Baggott & Foster 2008), which may mean more competition to be heard and gain a seat at the policymaking table. The organisations also collaborate with health service providers and have an important role in gathering patients' views and experiences. Additionally, organisations train experts by experience and peer support workers.

This study focuses specifically on the role of these organisations in communicating the voice of lived experience to health services.

Involvement in service development and delivery: I focus in detail on involvement in service development and delivery that occurs through individual and collective means. Development refers to the opportunities for individuals and groups to participate in the planning, development and evaluation of services as members of planning and management groups, or by participating in patient forums. I have also chosen to include education under the development category, although I recognise that it is a much more indirect way of influencing services. Education refers to the training provided by people with lived experiences to frontline staff and to nursing students and student doctors. People with lived experiences also give talks at information events aimed at newly diagnosed patients and their family members. I decided to include this aspect of involvement as the participants of this study portrayed it as an important means through which they are trying to improve health services by influencing attitudes and widening perspectives.

Delivery refers to service-level co-production activities. I acknowledge that co-production can encompass individual-level activities such as joint care planning (Baim-Lance et al. 2019). However, my focus is specifically on service-level activities where lay participants themselves become care providers by delivering support to patients attending a service. Over the past few years there has been a gradual change that has enabled people with lived experiences to enter and provide support in hospital settings. Some community-based teams have employed experts by experience to work as members of multidisciplinary groups, and a small number of municipal health centres employ experts by experience whom patients can meet by appointment. Despite increased PPI opportunities, lay participants are not yet a common feature in any healthcare setting. They occupy a grey area between patients and health professionals. This makes it particularly interesting to study how people with experiences of illness can

become directly involved, how they attempt to forge a space for themselves, and what benefits and barriers are associated with their involvement.

Health service settings: In this study, I draw examples from both mental health and cancer services. In Finland, service level PPI has been most prominent in the mental health sector, where it has also been promoted by national policies (Ministry of Social Affairs and Health 2009; 2018). Hence, the study participants from mental health settings have a range of experiences and views regarding the past, present and future of PPI. From an international perspective, cancer services have been another setting where PPI has been implemented actively. In Finland, this process has not been as prominent and involvement opportunities have mostly been indirect. With the recent establishment of the National Cancer Centre (Ministry of Social Affairs and Health 2019), more emphasis has been placed on involvement. However, direct involvement in cancer service development and delivery is a fairly recent and not fully established. Hence, in the Finnish healthcare context, cancer services provide an example of an area where service level involvement is currently emerging and expanding.

3 AIMS AND RESEARCH QUESTIONS OF THE STUDY

The aim of this study is to explore the involvement of patients and the public in the development and delivery of health services from the perspectives of Finnish national health policy, lay participants and third-sector organisations, and the definitions and uses of experiential knowledge, by asking:

- 1) What roles and positions become available to lay participants through PPI?
- 2) How is lived experience constructed into experiential knowledge, how is this knowledge positioned in relation to other forms of knowledge used in health services, and how do different stakeholders claim it might be applied in health service development and delivery?
- 3) What benefits, tensions and barriers do different stakeholders identify in relation to PPI?

4 MATERIALS AND METHODS

This chapter outlines the study design and data collection process, and expands on the methodologies used in the articles. Additionally, I will discuss ethical issues related to the study.

4.1 Materials and the study's methodological approach

The materials analysed in this study consist of national-level health policy documents (n=7) and individual interviews with experts by experience, peer support workers and representatives (n=27). These sets of materials were gathered in order to provide the study with meso, macro and micro perspectives on PPI. The analysis of the policy documents offers a national policy-level perspective, while the analysis of the interviews enables me to explore involvement within health service settings from the perspective of third-sector organisations and also from the personal perspectives of people with lived experiences. Together the health policy documents and interview materials offer a more nuanced look at PPI in Finnish healthcare. The variety of materials also enables me to capture different dimensions related to lay expertise and experiential knowledge, and how different stakeholder perceive the benefits, tensions and barriers associated with service level involvement.

Article I focuses entirely on the policy perspective, and therefore all the policy documents are included as materials. For the other three articles, I made choices regarding which interviews to include in the analysis. Article II explores the positions of lay participants within different health service settings, and therefore includes all the expert by experience and peer support worker interviews (n=17).

Article III looks at service-level involvement and the construction of experiential knowledge. For this I included the expert by experience interviews (n=13), as they provide the most in-depth discussions of the issues in question. For Article IV, I included all the interviews with organisational representatives (n=11), which also meant the inclusion of four interviews with experts by experience that involved people acting in dual roles.

The aims and materials chosen for each article informed the choice of methodologies. The materials were analysed using different qualitative methodologies: membership categorisation analysis, discourse analysis and narrative analysis. The variety of analytical tools provided by these methodologies enabled me to approach involvement from several viewpoints. Nevertheless, there is also a thread, which runs through all the individual articles and places particular emphasis on language. Potter (1996) has argued that words are never simply neutral reflections of reality and should be understood as influential choices that represent reality in selective ways. In other words, language allows us to say, do and be things (Gee 2014).

In this study, the interviews and policy documents socially construct and define PPI, experiential knowledge and the position of lay expertise in healthcare. I explore how the study materials: categorise people who use health services (Article I), provide justifications for involvement and construct positions for lay experts (Article II), describe the construction of new social identities and personal stories (Article III) and define the content and potential uses of experiential knowledge in healthcare (Article IV). Studying how involvement and the positions of lay experts and experiential knowledge are constructed also enables me to explore the hierarchies of power within PPI activities, which can lead to some professionals and lay participants gaining more influence in service development and delivery than others.

Table 3. Summary of the four articles (title, research questions, materials, methods and main findings)

Research questions of the study		1) What roles and positions become available to lay participants through PPI? 2) How is lived experience constructed into experiential knowledge, how is this knowledge positioned in relation to other forms of knowledge used in health services, and how do different stakeholders claim it might be applied in health service development and delivery? 3) What benefits, tensions and barriers do different stakeholders identify in relation to PPI?	
Articles	Research questions of the article	Materials and methods of analysis	Main findings
I 'The citizen is stepping into a new role' – Policy interpretations of patient and public involvement in Finland Answers study questions: 1, 3	1) What categories do policies construct for patients and the public in relation to involvement? 2) How do these different categorisations orientate involvement activities?	National health policy documents (n=7); membership categorisation analysis	The policies categorise people as customers and service users, linking involvement activities with choice-making. However, they also recognise lay expertise and lived experience as resources for service improvement. However, involvement relies strongly on capable, active, and knowledgeable individuals and policies do not address groups that require facilitation to participate.
	1) What justifications do people with experiences of illness provide for their involvement? 2) What strategies do they adopt in order to establish a position within healthcare services?	Individual interviews with experts by experience and peer support workers (n=17); discourse analysis	Lay participants argue that experiential views can help to create more responsive services. To gain legitimacy, they position themselves between patients and professionals, aligning with and differentiating from both groups. To patients, they are peers with similar experiences, providing information and support. Yet, to work in a professionally dominated environment they need to adopt professional traits and highlight their skills, training, and expertise.
III Personal perspectives on patient and public involvement – stories about becoming and being an expert by experience Answers study questions: 1, 2	1) How do people with lived experiences describe the process of becoming an expert by experience? 2) What kinds of identities do they construct for themselves through their stories? 3) What kinds of narratives do their stories draw from?	Individual interviews with experts by experience (n=13); narrative analysis	Becoming an expert by experience helps to recontextualise past experiences and turn them into structured stories. Through this process, and by working in healthcare, people can adopt more professionalised and politicised identities, and aim to influence health services, challenge stigma and campaign for increased involvement. However, the process can also entail exclusionary elements, and it can reinforce the narrative that an illness must lead to self-recovery and act as a motivator for change.
	1) How do representatives of third-sector organisations describe experiential knowledge, and what arguments do they provide for its use in health services? 2) What restrictions are placed on experiential knowledge as it is communicated to health professionals?	Interviews with organisational representatives (n=11); discourse analysis	Experiential knowledge is contrasted with clinical/professional knowledge, which is seen as distant from the everyday experience of living with illness. Experiential knowledge offers practical insights, but at its core it is all-encompassing and seeks to transform practices and challenge medical understanding. Yet, when used in healthcare, adjustments are required.
IV Representing the 'voice' of patients – How third sector organisations conceptualise and communicate experiential knowledge in health service planning and development Answers study questions: 1, 2, 3			

4.1.1 Policy documents

The policy documents used as materials in Article I provide a national policy-level perspective for this study. They are also included because documents such as policies and strategies can be used to transmit ideas and influence the course and nature of activity (Prior 2004). The data-gathering process with the policy documents began in the latter part of 2015. During the initial stage, I went through the online archives where national-level policy documents published by previous governments and the Ministry of Social Affairs and Health are publicly available. I first read through a number of policy documents published over a period of two decades, and I noticed that PPI was barely addressed within the documents until the latter part of the 2000s. Prior to this point, involvement was related to patients' rights to make choices about their personal care. Hence, I made the choice to focus on the documentation that had been published within the past decade. This also enabled me to see how new and varied forms of involvement had been included in the policies.

After narrowing down the materials to national-level documents that directly referred to or addressed involvement in health services, I chose seven documents that had guided service developments in several health service sectors. The documents were: *National mental health and substance abuse plan* (2009); *Finland's disability policy programme* (2010); *Socially sustainable Finland 2020: The social and health policy strategy* (2011b); *National development programme for social and healthcare services* (2012); *Quality recommendation to ensure good ageing and improve services* (2013); *Well-being is functional capacity and participation: The future review of the Ministry of Social Affairs and Health* (2014); and *Finland, a land of solutions: Strategic programme of Prime Minister Juha Sipilä's government* (2015). These documents provided accounts of health service development and the strategies set for the future. Additionally, they described the users of health services and their positions, while also attaching certain rights, expectations and responsibilities to those descriptions. I chose to study involvement from this perspective firstly since these types of national-level

documents can be considered strong guiding forces in the development of PPI. Secondly, by focusing on the policy language and underlying rationales, I wanted to delve more deeply into the seemingly neutral and descriptive rhetoric of these documents, which were written using the passive voice throughout. Potter (1996) has described this rhetoric as *out-there-ness*, which draws ‘attention away from concerns with the producer’s stake in the description – what they might gain or lose – and their accountability, or responsibility for it’ (p. 150). Through the analysis of policy documents, I wanted to highlight that choices are constantly made during the production of documents and that there are always several alternative ways in which issues could be presented (Prior 2004).

4.1.2 Individual interviews

Qualitative interviewing refers to interviewing techniques that provide textually rich data, which offers insights into how the participants view, experience and conceptualise aspects of social life (Kelly 2010). For this study, I conducted individual interviews with laypeople who engaged in involvement activities, and with representatives from third-sector organisations acting for people with lived experience of illness (see Table 4). Individual interviews were chosen as they can offer deep insight and detail regarding the participants thoughts, feelings and perspectives (Stokes & Bergin 2006) regarding PPI. As the interview participants lived and worked around Southern and Western parts of Finland, individual interviews also served a pragmatic purpose. They allowed me to organise meetings according to each participants’ schedule and at their preferred location. The interviews took place between 2016 and 2018, and they are used as materials in Articles II, III and IV in different combinations. All the interviews were recorded and transcribed verbatim. The duration of the interviews ranged from 30 minutes to 2,5 hours, but on average they lasted approximately an hour.

Initially, I set out to interview people with personal experience of illness who were participating in PPI activities (health service development or delivery, or the training of health professionals) either as experts by experience or as peer support workers. I chose to recruit participants from both of these groups because I had discovered that although experts by experience more actively participating in PPI activities, peer support workers may also be involved in very similar ways. Additionally, recent international studies indicate that peer workers are increasingly being employed by health services as team members (e.g. Burr et al. 2020; Pomey et al. 2021). I also wanted to have perspectives from different health service areas that serve wide patient populations. I chose mental health services because they were the forerunners in implementing PPI in Finland. Cancer services were chosen in order to include a service area where the implementation of PPI had only begun more recently. In order to recruit participants, I contacted patient organisations, which forwarded the call for interviews to their members who were either experts by experience or peer support workers. Those who were willing to participate then contacted me directly to organise the interviews.

The interview participants with lived experience of mental illness (e.g. depression, bipolar disorder, psychosis) were aged between 23 and 62. One of the participants had experienced mental illness and cared for family members and one of them had been a carer for their spouse. The participants in their twenties were students and the rest had been working in fields such as sales and administration. Interestingly, four participants held professional healthcare qualifications, and had worked in health or social services prior to their illness. However, the vast majority of the participants had not been able to continue in their previous line of work due to their illness. They all identified as experts by experience and had participated in service development and production activities, including being members of managerial or development groups, working as team-members in service settings, training front-line staff and running support groups in hospitals.

The interview participants with lived experience of cancer were overall slightly older (aged 52-71). They were or had been working in fields such as education, sales and law. The older participants in their late 60s and early 70s had already retired. Unlike the participants with lived experiences of mental health problems, this group of interview participants had been able to continue in their previous line of work despite their illness. This group of interview participants identified themselves as peer support workers, which as a term is much more commonly used within cancer organisations and services. However, the content of their work did not radically differ from those who identified themselves as experts by experience. Nevertheless, I acknowledge that the differences in age and occupational status between interview participants are likely to influence how they perceive involvement activities and the position of lay participants in healthcare.

In addition to conducting interviews with people who had lived experience of illness, I also interviewed people who worked in third-sector organisations that represented collective patient groups and experiential perspectives. My aim was to gather a variety of perspectives by interviewing the managers and key staff engaged in involvement activities. Thus, I approached the managers of large and small-scale organisations that operate on regional and national levels. The interview participants were from seven different organisations, three of which represented people with mental health problems and four of which were cancer organisations. The cancer organisations represented breast and prostate cancer patients, patients with rare cancers and one was a large regional cancer organisation. All of them acted either as the managers of the organisation or as staff members responsible for facilitating involvement activities. Throughout this study, I have used the term *organisational representative* in reference to this group of interview participants. Each of the organisations had been instrumental in developing expert by experience training and had been advocating for

involvement activities in the healthcare sector. All the interview participants have been listed in the table below.

Table 4. List of interview participants

Interview number	Year interview conducted	Participant's role (C=cancer organisation, MH= mental health organisation)	Analysed in article
1	2016	Peer support worker (C)	II
2	2016	Peer support worker (C)	II
3	2016	Peer support worker (C)	II
4	2016	Peer support worker (C)	II
5	2016	Peer support worker (C)	II
6	2016	Peer support worker (C)	II
7	2017	Expert by experience (MH)	II and III
8	2017	Expert by experience (MH)	II and III
9	2017	Expert by experience (MH)	II and III
10	2017	Expert by experience (MH)	II and III
11	2017	Expert by experience (MH)	II and III
12	2017	Expert by experience (MH)	II and III
13	2017	Expert by experience (MH)	II and III
14	2017	Expert by experience (MH)	II and III
15	2017	Expert by experience (MH)	II and III
16	2017	Expert by experience (carer)	II and III
17	2017	Expert by experience/organisation manager (MH)	II, III and IV
18	2018	Expert by experience/organisation manager (MH)	III and IV
19	2018	Expert by experience/organisation employee (MH)	III and IV
20	2018	Organisation manager (MH)	IV
21	2018	Organisation employee (MH)	IV
22	2018	Organisation manager (C)	IV
23	2018	Organisation employee (C)	IV
24	2017	Organisation manager (C)	IV
25	2017	Organisation manager (C)	IV
26	2017	Organisation employee (C)	IV
27	2017	Organisation manager (C) with lived experience	IV

These organisations that took part in this study represented wide and common illness groups, whose involvement has actively been promoted in Finnish health policies and strategies. Hence, the representatives of these organisations had first-hand experience of involvement in health service planning and development. Although the organisations varied on size and structure and represented different patient/illness groups, there were also similarities between them. Their core functions included the provision of information and support. The organisations

gathered experiential views through a variety of methods that included facilitating online platforms, organising peer groups, conducting surveys and posting questions in chat forums. Additionally, the organisations provided training for people, who wanted to become peer support workers and experts by experience.

As mentioned earlier, some of the experts by experience, peer support workers and organisational representatives occupied a dual role. They were either experts by experience, who also possessed professional healthcare qualifications, or they worked for a third sector organisation and had lived illness experiences. Those with prior healthcare qualifications had a better understanding of health service, which could make participation in involvement activities easier for them. This is also likely to influence how they view and experience involvement and the opportunities available to them. The latter dual role is potentially a reflection of a wider trend within third sector organisations. Prior to the 1960s and 1970s, physicians later had a significant role in establishing patient organisations (Toivanen et al. 2010). However, since then people with illness and caring experiences have become more active and thus these organisations are more likely to be managed or include staff members with lived experiences. Additionally, organisations that train experts by experiences usually have more experiential representation within the organisations.

The interviews analysed in this study were semi-structured and a topic guide was used that included themes and questions to prompt discussion of specific issues (see Attachment 2). For people with lived experience, these themes included motivation, training, and experiences of working in health services. For patient organisation representatives, the themes were more related to their views on involvement and the functions of the organisation. However, the purpose of the guide was simply to provide a general basis for each interview; the interviews were loosely structured to allow new questions to emerge as relevant avenues of enquiry were suggested by the participants. This also meant that the sequencing of the topics covered during the interviews flowed differently during each

encounter. The interviews generally began with questions related to the participant or their organisation. The experts by experience and peer support workers were asked a question either about their personal journey (e.g. can you tell me how you became an expert by experience/peer support worker?) or about the organisation (e.g. can you tell me about the organisation and what it does?). Later during the interviews, the issues raised could be explored further through more specific questions. Even though the main emphasis of the interviews was on involvement and not on personal experiences of illness, it soon became evident that these issues could not be separated. The experts by experience and peer support workers provided accounts of becoming ill and receiving treatment, as well as accounts of participating in involvement activities. This initially unplanned occurrence made the interview materials even richer, and enabled me to widen to scope and methods of analysis used in the articles. After the interviews, the participants were given the opportunity to read through the interview transcripts and remove parts or make additions if they wished. However, there were no requests to remove parts from any of the transcripts. One of the participants wanted to make a short addition regarding their experiences as an expert by experience. They send this addition to me by email and I added it to their interview transcript.

Both the interviews and the process of initial analysis were completed in Finnish, because in studies that focus on how participants use language it is more appropriate to conduct data analysis in the original language rather than in translation (Squires 2009). Following the analysis, the interview extracts included in the final versions of the articles were translated into English. As all the authors involved in the writing of the articles spoke Finnish and English fluently, the translations could also be discussed and checked for accuracy. The aim was to find a balance where the translations were as literal as possible while also retaining the original meanings and ideas expressed by the participants. I recognise that interviews are both interpersonal and revealing, which places a requirement on the researcher to be sensitive to aspects such as the location of the interview, the

visibility of participation and the reporting of data (Kelly 2010). I will address these issues and the choices I made regarding them in the section on ethical considerations. Prior to this, I will discuss the materials and methods used in the study in more detail by going through each of the articles.

4.2 Membership categorisation analysis (Article I)

We constantly classify and categorise people, things and activities as part of daily life. However, the commonality of this activity does not mean that categorisations are mundane. Indeed, they are very important, because without them the planning and coordination of activities becomes difficult. Douglas (2000) has suggested that culture is based upon people trying to organise their experiences and the complexities of life. By assigning meaning to things and dividing them into categories, we are able to structure and organise these complex issues (Juhila 2004).

The first article focused on policy categorisations of people who used health services. The aims were to explore the varied categorisations and the rights and responsibilities attached to them, particularly in relation to involvement. The materials consisted of national-level health policy documents published over the last decade by the Ministry of Social Affairs and Health, and the analysis method chosen for the article was Membership Categorisation Analysis (MCA). It provided tools to explore how people that used health services were described and grouped or categorised in the documents. Categories are both culturally and contextually bound and various competencies, qualities, rights, responsibilities, qualities and expectations are attached to them (Jokinen et al. 2012). In their empirical use, ‘categories short cut and package common-sense knowledge about category members and their actions’ (Stokoe 2012:300). Although they may appear to be descriptive, categories also carry moral connotations (Jayyusi 1991). Hence, through the use of MCA, it was possible to dive beneath the seemingly

neutral and declaratory policy language, and to explore the opportunities and expectations connected to different categories in relation to involvement. Baker (2004) has suggested that ‘when speakers “do describing”, they assemble a social world in which their categories have a central place... these are powerful statements about what could be the case, how the social order might be arranged, whether or not it really is’ (p. 175). Through the analysis process, I attempted to reveal the power of these different categorisations in guiding who could get involved and through what means.

In practice, the analysis process began by collecting purposive data – i.e. national policies that discussed PPI in relation to healthcare – and followed the stages suggested by Stokoe (2012). Within the data, I gathered explicit mentions of categories (e.g. customer, patient, expert) and focused on the descriptions attached to them. Following this, I focused in locating the position of categorial instances within the text and analysed how actions were orientated in relation to different categories. The analysis process provided insights into how certain expectations, responsibilities and opportunities were attached to the categories constructed in policy documents. The categorisations also carried moral connotations relating to individual responsibility for health and well-being. The documents placed an emphasis on specific categories (e.g. customer, expert), which also highlighted the rationales that these policies offered for involvement.

4.3 Discourse analysis (Articles II and IV)

Article II explored everyday experiences of involvement from the perspective of lay participants who had been involved in health service development and production. The aims were to study the ways in which these active lay participants justified their involvement and attempted to establish legitimate positions for themselves in health services. A focus on these aspects also made it possible to address some of the lay participants’ underlying rationales for involvement, and

the benefits and barriers they encountered as they tried to collaborate with health professionals. The materials consisted of individual interviews with people who dubbed themselves experts by experience or peer support workers (n=17).

The analysis was conducted using discourse analysis, which can be described as an approach rather than a fixed method (Cheek 2004). In Article II, I focused specifically on the justifications provided by the interview participants and how they attempted to position themselves and others discursively during the interviews. Moghaddam and Harré (2010) have stated that positioning is about 'how people use words (and discourse of all types) to locate themselves and others' (p. 2). This concept rests on a constructionist approach (Slocum & Van Lagenhove 2003) that can facilitate the thinking behind linguistically oriented social analysis, and may prove to be more dynamic as an analytical concept than role (Davies & Harré 1990; Harré & Slocum 2003). Harré (2012) has described a *position* as a 'cluster of short-term disputable rights, obligations and duties' (p. 193). Positioning also has moral implications; for example, a person may be 'trusted' or 'distrusted' (Moghaddam & Harré 2010). The participants in this study were interestingly positioned as *lay* people, i.e. non-experts. This could enhance their legitimacy, as they could claim to offer a new perspective; but it could also diminish their credibility within a health service environment. Hence, they attempted to navigate this terrain by aligning with and differentiating themselves from professionals and patients, as well as by negotiating their own position as a new kind of expert.

During the analysis process I looked at the parts of the interviews where participants spoke about the involvement activities in which they had engaged, and I studied how they described themselves and their relationships with others (e.g. health professionals, patients). In these accounts, they positioned themselves as active and capable participants who possessed specialist knowledge founded upon personal experience. Their unique knowledge base, and their ability to use experience as a supportive and informative tool, enabled them to strengthen their

position as legitimate participants and collaborators in relation to health professionals. In relation to patients, they were peers who had processed their experiences and distanced themselves sufficiently to provide information and support. However, by positioning themselves in this manner, they also positioned others in the process. For example, health professionals were positioned as specialists with learned knowledge who nevertheless lacked personal experience and the ability to fully relate to patients. Hence, the participants were able to claim that their involvement was necessary to fill this gap. They described their own skill sets and abilities, which gave legitimacy to their involvement. Using positioning as the basis of the analysis also allowed me to highlight the subtle tensions that the participants described in relation to involvement and their attempts to collaborate with health professionals on equal terms.

In Article IV, I used the methods of discourse analysis slightly differently, as I focused on organisational representatives' (n=11) descriptions of experiential knowledge and its use in health services. Again, the underlying idea was to explore how participants constructed a specific phenomenon within their interview accounts. However, as Wetherell and Edley (1999) have suggested, 'when people speak, their talk reflects not only the local pragmatics of that particular conversational context, but also much broader or more global patterns in collective sense-making and understanding' (p. 338). Thus, the analysis in Article IV is much more focused on the wider sociocultural discourses that people use to make sense of or describe an issue. In this case, the participants discussed the meanings and uses of experiential knowledge, as well as the wider role of third-sector organisations in development and decision-making regarding healthcare. The descriptions that the interview participants provided regarding experiential knowledge were also attempts to make sense of what people's lived experiences of illness consisted of, how they could be turned into knowledge, and what benefits that knowledge could provide for health services. Indeed, the participants' accounts had many similarities with previous studies that attempted

to describe and conceptualise experiential knowledge. Additionally, their accounts reflected the wishes and concerns that third-sector organisations experience as they seek a stronger voice on health-related issues and in health service development. Despite wanting to strengthen involvement and be seen as collaborators, these organisations want to retain an autonomous stance (Martin 2012).

4.4 Narrative analysis (Article III)

The third article gave more depth to the micro-level perspective on PPI by focusing on the process through which people with experience of illness could turn difficult life events into resources and become involved in health services as experts. The aim was to study the narratives of becoming an expert by experience and the identities people were able to construct for themselves through this process. The materials consisted of individual interviews (n=13) with people who had illness and/or caring experiences. Eleven of them had experiences of living with a mental illness (e.g. depression, psychosis, bipolar disorder), one of the participants had cared for their spouse and one had lived experienced of mental illness and caring for a family member. They had a variety of involvement experiences ranging from the development and assessment of health services and care pathways to working as co-producers in multi-professional teams and providing training for health professionals. Four of the participants had also worked in health or social care in the past and held professional healthcare qualifications.

The interview accounts were approached as small stories (Bamberg 2006) about the processes of becoming and being an expert by experience. This approach was chosen because as I read through the transcribed materials, I realised that the accounts contained several stories about living with an illness, using health services and working as an expert by experience. Due to the nature

of the interview accounts, I decided to explore these stories further, and I focused specifically on the stories that related to involvement. Initially, I wanted to explore the process of laypeople becoming experts. Crossley (2000) has suggested that ‘through narrative we define who we are, who we were and where we may be in the future’ (p. 67). This idea inspired me to see what narrative forms these small individual stories created and how the participants actively constructed identities for themselves through their accounts (Bamberg 1997; de Fina 2013).

Therefore, I selected interview accounts where the participants talked about the process of becoming and later working as an expert by experience, and I approached them as stories constructed by participants in a specific temporal and interactional context (Bamberg 2011). The stories were viewed as performed verbal acts where the participants positioned themselves and others in varied ways (Bamberg 1997, 2006; De Fina 2013). I also considered that these verbal acts were produced within a specific social context, shaped by dominant cultural narratives of health and illness. Although the article explored life after illness and not during it, the two could not be fully separated. The experience of illness was a strong motivator and source of knowledge that allowed the participants to construct new identities for themselves. However, the main emphasis was on the opportunities or alternative futures that opened up for the participants as they became experts by experience. Additionally, I approached the stories from a more critical perspective, suggesting that despite positive aspects, the training and professionalisation processes may also have contained elements that might lead to the exclusion of some, and which might impose requirements on the stories communicated to health services

4.5 Ethical considerations

A statement from the Ethics Committee of the Tampere Region was obtained for this study in the spring of 2016, and the guidance published by the Finnish National

Board on Research Integrity (2019) was followed. Throughout the research process, I also reflected on my situatedness within the research in order to identify the potential impact of my own beliefs, biases and experiences, and to understand my own role within the process of knowledge creation. Stronach et al (2007) have described reflexivity continuous internal dialogue that enables the researcher to critically evaluate their own positionality and its influence on both the process and outcome. This challenges the idea that knowledge production is independent of the researcher producing it (Berger 2015). Reflexivity is a deliberate and conscious effort from the part of the researcher to monitor one's own reactions, identify the effects of personal, contextual and circumstantial factors and to maintain awareness of themselves within the world they are studying (Berger 2015). This enables the researcher to think about the ways in which they can contribute to and hinder the process of co-constructing meaning (Lietz et al. 2006). Hence, reflexivity can enhance the quality of research as it can help the researcher to manage and present their data better, and to recognise the complexity of social phenomena. In contrast, the absence of reflexivity may lead to the acceptance of 'apparent linearity, thereby obscuring all sorts of unexpected possibilities' (Russel & Kelly 2002: paragraph 37).

I am aware that my own experience of working in mental health services strongly influenced my choice of topic. I had observed a disparity between the policy rhetoric of engaged and active service users and the everyday encounters that people with experience of illness had with services. I had also attended training sessions conducted by people with lived experience of mental illness, which impacted on my own outlook as a health professional. Yet I also noticed that my colleagues expressed mixed feelings about patient involvement when it was directed towards professional practice or service enhancement. After moving back to Finland from the UK in 2013, I continued to observe how involvement was implemented at different levels of health and social services. I attended events hosted by experts by experience, whose position appeared to be consistently strengthened by policies and strategies. I chose to explore this phenomenon in more depth, and I wanted experiential perspectives to be represented in the study. However, I also felt that it was important to have a

critical view that recognised the multifaceted nature of PPI. My position as a doctoral researcher enabled me to access the field, but my explicit and tacit knowledge supported me throughout the study, as I had an understanding of the healthcare system and related practices. De Tona (2006) has suggested that participants could be more willing to share personal experiences during interviews if they perceive the researcher to be understanding and sympathetic of their situation. Indeed, many of my participants were interested in what had led me to this research topic, and we often discussed it prior to or following the interview. Although I did not express opinions regarding different forms of involvement, I feel that my strong interest in the topic and in their views and stories enhanced rapport during the interviews.

I greatly value the interview participants' contribution and fully recognise that their input and willingness to take part is what made this study possible. Although I highlight critical aspects in relation to PPI, I wanted to ensure that the criticism was directed towards involvement as a phenomenon or institutional practices, and not towards individuals. Many of the participants emphasised the difference involvement had made to them personally. Valentine (2007) reminds us that during analysis and reporting, it is helpful to alert oneself to 'unconscious editing', which can occur due to our own sensitivities. By recognising this, the researcher may be able to engage with the data in more depth. Hence, throughout the study I attempt to strike balance, being critical of the phenomenon while also respecting and valuing individuals and their contribution, and acknowledging the positive impacts of involvement on their lives.

Overall, I found that the process of gathering and analysing policy documents did not include as many dilemmas and considerations as the use of interview data. The documents had been produced by public institutions, and they had been made publicly available. In Article I, the data-gathering and analysis processes are clearly outlined, and during the analysis I spent a considerable amount of time going back to the original documents and making sure that my interpretations and claims had a strong foundation in the data. I also feel that it should always be possible to subject policy documents to critical analysis and scrutiny.

Prior to the interviews, the participants were provided with written information about the topic and aims of the study. These issues, as well as the use and storage of the interview materials, were also discussed with all the participants. Most of the interviews were conducted in private meeting rooms located in libraries around the cities where the participants lived. Some of them preferred to hold the interview in their workplace or in a space belonging to a patient organisation. As the interviewer, I aimed to accommodate the participants' wishes regarding the place and timing of the interviews. Both before and after the interview itself, I ensured that participants had time to ask questions. They also provided informed consent, both verbally and in writing.

Kelly (2010) has highlighted the interpersonal and revealing nature of interviews. Indeed, many of the interviews touched upon personal issues. Although they also share these experiences and perspectives with others as part of their work, I wanted to ensure that these materials were used sensitively. Additionally, as the Finnish involvement scene is still quite small, there was a chance that the participants would be easily recognisable. Hence, for the purposes of this study, I wanted to ensure that the materials were effectively anonymised by not attaching too many recognisable attributes to interview extracts, and by ensuring that the descriptions of the participants were informative but not overly specific regarding individuals. Therefore, in order to ensure their anonymity, the participants were given pseudonyms (Article III), or were only referred to in general terms as experts by experience, peer support workers (Article II) or patient organisation representatives (Article IV).

I plan to deposit the interview materials in the Finnish Social Science Data Archive after the PhD study is completed and when it has been ensured that all the materials are fully anonymised. As the guidance published by the Finnish National Board on Research Integrity (2019) suggests, the research participants were informed about this prior to the interviews, and all of them provided verbal and written consent. This means that the materials will be available to other researchers upon request and can be studied and analysed by others, which may provide new

perspectives and insights. Making these materials available may also ease the pressure on active experts by experience, who are still a small group but who receive a great deal of interest from both researchers and journalists.

5 RESULTS

I have divided the results section under four subheadings that provide a synthesis of the main results from Articles I, II, III and IV, and which relate these findings to the research questions set for the study. In the articles, I have addressed questions regarding the positioning of patients and the public, the legitimacy of experiential knowledge and expertise and the benefits and challenges associated with involvement in service development and delivery.

5.1 Positioning patients, overlooking the public(s)

The health policy documents analysed in Article I provide a national policy-level perspective on involvement activities and the rationales that underpin them. As national-level guidance, these documents can influence how involvement is shaped, and thus they have the potential to both enhance and limit involvement opportunities for different participant groups. Overall, involvement is depicted in rather narrow and ambivalent terms. The passive voice used in the documents makes it unclear who makes decisions, facilitates or provides guidance. The only people who are clearly addressed as active doers are health service users making informed choices. Apart from a few references to customer- or service user-centred care, it is unclear what involvement is expected to provide. This offers health professionals very little incentive to implement involvement. Additionally, no attention is paid to the barriers to involvement.

The policies construct an ideal participant who is active, responsible and knowledgeable. The assumption is that providing people with information will result in their making rational choices about health and between service

providers. The idea that people are knowledgeable, active and rational may overshadow the fact that many who require services may have limited capacities, use different methods to express themselves, or experience other difficulties due to their illness and treatment. They may require additional assistance and facilitation in order to be heard. Not addressing any of these issues implies a lack of commitment, and does not suggest that the policy aim is to truly listen to the wide plethora of voices of people who use health services.

The language of the documents is influenced by economic and marketisation discourses that highlight individual responsibility, which means that involvement is often framed as a choice-making activity available to people who engage with services as customers. However, alongside the consumerist rhetoric, people with lived experiences are also positioned as *experts*. Initially, expertise was used in reference to people with lived experience of mental health and substance abuse problems. More recently, it has also been used in reference to anyone with lived illness and service use experiences. These references to expertise suggest that people with lived experience have specialist knowledge that can offer new perspectives for health services. Those who are able to adopt an expert role have direct involvement opportunities increasingly available to them (e.g. lay experts can become members of managerial and developmental groups), as expertise is more aligned with the voice and co-production aspects of involvement. Hence, the policy discourse that connects PPI and expertise represents a major shift for Finnish services, where direct involvement opportunities have traditionally been very limited.

Positioning people as consumers and experts raises questions and may have unexpected consequences. Firstly, people's enthusiasm for continuous choice-making can be questioned and in some situations people are not able to make choices about their service use (e.g. if treated under the Mental Health Act). Additionally, in many areas of healthcare, opportunities to make choices are limited, and the information provided regarding different service providers may

not offer a substantial basis for making comparisons. Currently, people have the opportunity to change e.g. primary care providers, but they have not been very active in doing so (Valentine et al. 2008; Tynkkynen et al. 2016). Additionally, the meaning of choice can be interpreted in several ways: as choices between professionals, available treatments or service providers. When people do adopt positions as consumers and experts, their participation is not always welcomed with open arms. For example, studies focusing on cancer peer support suggest that shopping around for a second opinion is an activity that is used by people with cancer and recommended to others as a way to bolster individuals' demands for certain treatments or medications (Oliffe et al. 2010; Jones & Pietilä 2020). This shows that people with experience of illness can also make more consumerist interpretations of involvement, which can lead to behaviours that were not originally intended or hoped for by policymakers or health professionals. Additionally, offering people involvement opportunities as customers and experts also does not erase the problem that the expectations placed on active citizen-consumers can become extra burdens for those with lowered capacities, or for people with multiple health conditions that require treatment/monitoring.

The policies do very little to address public involvement. I acknowledge that patients are equally citizens and taxpayers, i.e. members of the public. However, policy documents clearly construct more direct involvement opportunities for people who have lived experience, i.e. who are or have been patients. It should be acknowledged that the perspective of a healthy person who uses services occasionally is likely to be different from that of someone with personal experience of severe long-term illness. As Fredriksson and Tritter (2017) have argued, patients should not be used as proxies for the public in healthcare decision-making, as patients may have very different views and aims. They suggest that people's perspectives on and justifications for involvement may vary depending on their relationships with health services. Those with care needs and

experience of illness have an interest in ensuring access to the most recent treatments, and in challenging medical paternalism and patients' limited capacity to manage their own illness. In contrast, members of the general public with few or no care needs may provide justifications based on equality of access, cost-efficiency, democratisation, and declining trust in public institutions (Fredriksson & Tritter 2017).

According to the policies, the main involvement option available to the public is choice-making, in addition to other, already established forms of indirect involvement such as voting and providing feedback. Nevertheless, the involvement options for the general public have not expanded in range in the same way as those of patients. These findings raise interesting questions about the public's ability to exert an influence. After all, there are issues related to health services, healthcare provision and related ethical issues (e.g. regarding biobanking, uses of health data, healthcare prioritisation) that have far-reaching consequences and may impact upon people who do not themselves regularly use health services. Indeed, the public may have strong interests related to community issues: civic engagement and even loud protest are likely to ensue when local services such as obstetric units or casualty departments are under threat of closure. Numerous people care for family members and have concerns regarding service provision for their loved ones. Lubi et al. (2020) have argued that policymakers and decision makers should take civic activism more seriously into account, and that local community members should be increasingly consulted and involved. One of the more recent innovations aiming to address the decline in public trust in the democratic process has been the introduction of deliberative mini-publics, which involve citizens more directly into policy making. A recent study conducted in Finland showed that citizens indeed report high levels of trust in their capacity to be involved, whereas policy makers were much more sceptical about their value (Koskimaa & Rapeli 2020).

Additionally, it is important to recognise that neither patients nor the public constitute internally homogeneous entities, but rather splinter into smaller groups with varied perspectives on the aims, levels and intensity of involvement. Hence, it needs to be accepted that some people have little or no interest in participating in involvement activities or as Kivinen et al. (2020) have highlighted, willingness to be involved can be situational and context bound. At the same time, there are groups that campaign for involvement at all levels of healthcare decision-making, some as paid employees, others as volunteers or activists. Hence, reaching out to different groups for PPI is likely to require different approaches.

5.2 Constructing a position between patients and professionals

Whereas the policy documents frame involvement mainly in terms of *choice*, the lay participants and organisational representatives placed much stronger emphasis on the *voice* and *co-production* elements of involvement. They used the policy rhetoric tactically to their advantage by including these rationales to justify their involvement and strengthen their position. However, the findings from Articles II, III and IV suggest that lay participants who were or had been patients repeatedly highlighted improvements to service quality and the need to democratise decision-making by involving people with lived experience and the organisations that represent them. The expert position – which is also made available through the policy documents – was advocated by lay participants and organisational representatives. By adopting an expert position, lay participants could gain more authority in settings dominated by professional groups. One way to gain legitimacy was to position oneself in the grey area between professional and patient, highlighting both similarities to and differences from these two groups. Paradoxically, these similarities and differences could concurrently be

both the main sources of legitimacy and the main reasons why lay participants' role might be undermined and dismissed.

In relation to patients, lay participants positioned themselves as relatable peers and forerunners who were paving the way for other people with lived experience to follow. Lived experiences also provided them with authenticity, which was used to legitimise involvement and to highlight their uniqueness. However, the findings also suggest that lay participants did not wish to fully align themselves with patients. Indeed, at times they could gain legitimacy by differentiating themselves from patients and highlighting their expertise. This meant closer alignment and collaboration with health professionals, as well as placing an emphasis on the knowledge, skills and training they possessed.

Thus, in relation to health services and health professionals, lay participants tried to establish themselves as knowledgeable, reliable but critical collaborators, and to position themselves as experts with specialisms and qualifications. Prior education, training and work experience were emphasised, as these could differentiate lay experts from other patients and integrate them into health services. There was also a small but extremely interesting subgroup of study participants who had worked as health professionals but been unable to return to their profession due to their illness. Thus, they were not actually *lay* at all, as they had the same skills and qualifications as other health professionals, as well as lived experience. It is possible that this group found it easier to negotiate their return to health services, perhaps because they could draw on their past training and work experience for extra legitimacy. They knew the correct terminology, and they understood the practices and daily routines of the service setting. Yet despite having this dual qualification, they faced many of the same challenges as participants without professional qualifications.

Some of the lay participants and organisational representatives argued that people with lived experiences who participated in service delivery and development should become an occupational group of trained experts. However,

taking the lay participant role this far was not supported unanimously. The arguments against integrating lay participants into health services as employees included fears that the relationship between lay participants and patients would somehow suffer, or lose its pureness and authenticity, if lay participants were to be paid. Third-sector organisations also expressed worries that public health services would begin to shift responsibility onto the third sector, expecting laypeople in precarious situations to do the work health professionals were unable to do due to lack of resources.

Generally, the creation of a new occupational group was advocated more by people with lived experience of mental health problems and the organisations representing them. There was some support for the idea from people with lived experience of cancer, but they mainly described lay participants as volunteers who provided an experiential perspective and offered peer support to patients on a voluntary basis. Historical baggage may partially explain this variation. Perhaps in relation to mental health, the drive to make services responsive, accessible, equal and fair was thought to be particularly pressing. After all, the history of cancer care does not carry such oppressive baggage. Finding new legitimate and respected 'proto-professional' roles may feel more important for those trying to tackle stigma. In Finland, individuals with mental health problems and collectives that represent them were also the forerunners in adopting terminology such as *expert by experience*, and in training people to take part in PPI activities. The variation in perspectives can also be related to the motivations and characteristics of the study participants, such as age and occupational status. For example, a more professionalised form of involvement may appear more appealing to someone in their twenties wanting to return to employment than for someone in their late sixties, who approaches involvement as a voluntary activity.

In Chapter 2 of this study, I mentioned that I had chosen to refer to the participants as *lay*. However, I fully recognise the problems and contradictions associated with the term. After all, I am arguing that some of the participants

were trying to construct a more professionalised position and possessed professional qualifications. Hence, when searching for a term that I could use to collectively describe the participants, I thought about experts by experience, patient or service users. The problem was that all the participants did not identify as experts by experience, although they all expressed possessing expertise based on lived experience. Additionally, many of them were currently not receiving any treatment and could at best be referred to as ex-patients or ex-service users. I also wanted to emphasise that their legitimacy was not merely founded upon service use but on the more all-encompassing experience of living with an illness. Eventually I decided to refer to them collectively as *people with lived experiences* and *lay participants/lay experts*. Lay expert is an oxymoron, but the term lay is used to highlight the participants' relationship with healthcare and health professionals. It also reflects how they themselves describe their position as outsiders who strongly identify with other patients, whilst also possessing knowledge and skills that health professionals lack.

Additionally, the lay participants took on roles that were not addressed in the policy documents. For them, involvement in health services was only one aspect of wider civic engagement. Their aims were not simply to make service-level changes, but to influence attitudes, share information, and campaign for others on a far wider scale. Many of the participants chose to speak about their experiences at public events and in the media. They talked about becoming the 'face of illness', allowing the general public to gain an insight, and enabling patients to see someone they could relate to or whose experiences could offer a point of reflection. One of the study participants described their organisation's peer support workers as 'beacons' who could be approached by anyone in the community that needed information or support. Indeed, there were many examples of people approaching the study participants, in a variety of social situations, to ask for information about an illness or how they could help a loved one with a similar condition, or to tell them about their own condition. Thus,

they became easily approachable points of contact for other patients, their family members, and people in the community.

Being involved was also a political act, even though participants seldom described themselves as overtly political. On a personal level, they were constructing new identities, not as patients or people in recovery, but as experts, advocates and supporters of others. Lay participants were connected to local, national and even international networks (e.g. the European Patients' Forum), and chose to make their own experiences public by openly sharing their stories with wider audiences. They were engaged in activities that aimed to shape a range of issues, from medication/treatment availability to challenging stigmas and misperceptions about certain conditions. Even though the lay participants and organisations tried to find consensus and act collaboratively, their goals were rather radical as they attempted to change how healthcare institutions operated, and widen the knowledge basis upon which decisions were made and policies drafted.

Thus far, PPI has not been as strongly advocated by user groups, patient organisations or lived experience activists in Finland as in other countries such as the UK or France (e.g. Rabearisoa et al. 2014). In Finland, involvement has been implemented in a more top-down fashion. However, there appears to be a shift, as lay experts are coming together to form new organisations that drive involvement forwards and campaign for the increased use of experiential knowledge (e.g. KoKoA ry 2019). The politicised positions adopted by my participants suggest that lay participants might become a stronger stakeholder group that will influence how involvement takes shape in the future. As the findings in Article IV suggest, third-sector organisations can support these developments, as many already hold established positions in decision-making processes. However, it should be noted that organisations and collectives representing lived perspectives are numerous, have various aims and advocate for certain segments of patients/ex-service users.

5.3 The potential and limits of experiential knowledge

Currently, there is no clear or shared understanding of what experiential knowledge is and how it can be used in health services. Much like PPI, the content and uses of experiential knowledge are under ongoing negotiation. The study participants highlighted that anyone with lived experience of illness, caring or service use could be regarded as an expert in their own right. Hence, they could all possess valuable information and understanding that would enable them to contribute to their own care. Organisational representatives argued that one of the great strengths of organisations was their ability to gather and combine these experiences and use them to gain new insights to inform the organisation's agenda. The basis of experiential knowledge lies in these varied and multifaceted experiences, which comprise embodied, affective and social aspects of being ill, caring for a loved one, and trying to navigate services. In their descriptions, embodied experiences were used in reference to the biological illness processes, which had occurred within their bodies. Embodied experiences also related to the subjective impact that symptoms and treatment side-effects have on people. According to McCann and Clark (2004) these can change the appearance or functioning of the body, which no longer acts in a familiar way. Embodied experiences are also linked to the emotional and social aspects of being ill, as changes in the body can lead to feelings of loss, embarrassment, shame and withdrawal (McCann & Clark 2004). The participants in this study clearly emphasised that experiential knowledge was constructed through individual and collective processes that included reflection and structuring. These processes made experiential knowledge more than ad hoc tales or individual accounts.

There is a long history of constructing and telling personal stories within peer support groups. This tradition is also strongly present in the training of experts by experience and peer support workers, who are encouraged to construct personal accounts of their experiences. The participants in this study described

the process of constructing their own stories, gaining feedback, and discovering new angles or perspectives on their own experiences. This supports findings from other studies that highlight the importance of self-reflection and interaction with peers in the construction of experiential knowledge (e.g. Toikko 2016; Meriluoto 2018). The participants expressed that their training – facilitated by third-sector organisations, and more recently by health authorities and educational institutions – provided them with a foundation to work with patients and health professionals, providing support and enhancing services. They also emphasised that the process of self-reflection and the verbalisation and structuring of experiences had supported their personal recovery and enabled them to reframe difficult life events. Baillergeau and Duyvendak (2016) have reported similar findings, suggesting that experiential knowledge can help individuals to cope with uncertain futures, and offer health services new insights for dealing with complex problems and uncertain situations.

According to both lay participants and organisational representatives, experiential knowledge provides a glimpse into the everyday of living with an illness, the emotions and bodily sensations that people go through during treatment, the fears and insecurities they experience, and social ramifications such as experiences of stigma or changes in social relationships. When describing experiential knowledge, the study participants often compared it to other forms of knowledge used to understand illness (e.g. biomedical knowledge). They did not suggest that experiential knowledge should replace other forms of knowing, but they felt strongly that it should be recognised as another important source of information.

A common argument expressed by the participants was that healthcare and professional groups had become so highly specialised that the wider perspective had been lost. Professionals focused on symptoms and specific body parts, instead of engaging with the person and trying to understand what it was like to live with a condition. Clinical knowledge was described as cold and distant. In

contrast to this, experiential knowledge was defined as *all-encompassing*. It combined the social, embodied and emotional aspects of living with an illness, providing an authentic lived perspective for decision-making. It could provide health professionals with new insights and widen their perspective on health, illness and treatment, or challenge their assumptions about certain illnesses. Herein also lies the *transformative* potential of experiential knowledge, as it can both challenge and expand notions about illness and care. The participants in this study argued that people with lived experience and the organisations representing patient groups should be regarded as equal stakeholders in these processes, and that the experiential knowledge they brought to the table was not mere lay belief but knowledge and expertise that would be difficult or even impossible for outsiders to attain.

By using experiential knowledge, lay participants and organisations could challenge (bio)medical authority and the paternalism that still exists within health services (Fredriksson & Tritter 2017), as well as contesting its impartiality and its potential to properly understand health problems in the new modernity (Beck 1992). Hence, the transformative potential of experiential knowledge is made apparent when lay participants use it to challenge professional authority, making lay participation a political challenge to the institutional power of expert knowledge in general and medical knowledge in particular (Williams & Popay 2006). Additionally, insights stemming from everyday experience can reveal how the practices and priorities of institutions and policies diverge from the needs of people living with an illness (Holmberg 2020).

Experiential knowledge contained information about service use, and could provide an understanding of what people might need from health professionals when they or their loved ones were unwell. This *practical* information could be used to make practical improvements by answering questions such as: how do they want to be cared for? What information do they need? How can service settings be made accessible? However, lay participants and organisational

representatives alike argued that experiential knowledge should not only be used to make practical or cosmetic changes. Both argued that this pool of knowledge should be integrated into all levels of decision-making, which would ensure that its transformative potential could be fully reached. The findings also highlighted ways in which experiential knowledge could be used in service delivery. The participants who engaged in co-production suggested that experiential knowledge provided patients or service users with practical tips, relatable examples, hope and emotional support. Indeed, the study participants provided practical examples of the varied uses of experiential knowledge, e.g. in the planning of new care pathways, or in providing practical tips on how to manage auditory hallucinations.

Although the process of constructing experiential knowledge from personal experiences was described as empowering, various filters and limitations are placed upon experiential knowledge when it is being used in PPI activities. Based on the findings from Articles III and IV, I also argue that the process of turning individual experiences into experiential knowledge involves both distancing and choice-making. The participants described the need to structure their experiences and make conscious decisions about what they wanted to keep in and leave out. They tried to find varied, engaging perspectives, and they often combined experiential knowledge with other forms of learned information about e.g. health services or different illnesses. Although leaving things out is a form of filtering, it also serves an important purpose. It gives people the option to be in charge of their story, and in some case to protect the privacy of themselves and others. The participants emphasised that they needed to take a step back from their personal experience in order to contribute effectively to PPI activities.

Additionally, both lay participants and organisational representatives talked about neutrality and the need to communicate effectively and engagingly with health professionals. Nevertheless, distancing was a double-edged sword, as lay participants could easily be regarded as being ‘too well’, leading them to lose some of their authenticity and legitimacy. One of the participants explained that they

had not been booked to do a training job because the health professionals booking them worried that other patients would not believe their story or would doubt that they had ever been unwell at all. Similarly, excessive neutrality could be interpreted as being ‘too professional’ and pose a similar threat to authenticity. Overall, this suggests that in order to engage in PPI, lay participants are expected to voice emotional and affective issues, and yet to show sufficient restraint to portray themselves as credible collaborators.

In addition to filters, the participants talked about the limits of experiential knowledge. On a personal level, each lay participant sets their own limits and boundaries. They construct their own expertise and specialism, which is connected to their own experience. Hence, they may have expertise related to prostate cancer, depression, chronic pain, or caring for parents with substance abuse problems. These specialisms can be further extended through additional training or work experience, and by viewing personal experience from a new perspective to include issues such as bullying, male sexuality or female empowerment. Nevertheless, the lay participants also made it clear that they did not want to overextend their expertise. For example, a lay expert with lived experience of psychosis did not claim to have expert knowledge about eating disorders. Although the emotional and physical experiences of living with an illness are likely to remain relevant and relatable, there may be an expiration date on the applicability of experiences related to service use. For example, experiences of cancer treatment a decade or two ago may no longer be used as a basis for service development now.

To move away from individual participants and the boundaries of their expertise, the limits of experiential expertise also need to be negotiated between different institutions. One of the main limits relates to the right to have a say on issues related to treatments and professional care practices. Traditionally, these issues have clearly fallen into the professional realm, and experiential views have not been consulted. Health-related social movements have been challenging this

division for decades, and it seems that third-sector organisations and lay participants involved in PPI activities are willing to cross this boundary. People with lived experience are directly involved in delivering care to patients; as collective advocacy groups, organisations are willing to take a stand regarding treatment availability. These developments extend the influence of experiential knowledge into areas where it has previously been very limited.

5.4 The benefits and barriers to involvement

As the results from Article I show, the *benefits* of involvement outlined in health policies are varied and general in nature. They contain the suggestion that involvement could enhance services by making them more patient-centred. Some of the documents also claim that patient-centred services could be more cost-effective because they are better at responding to actual needs. Additionally, involvement provides people with more choice-making opportunities. Outside these claims, the policies provide little concrete information. They also fail to address the changes that would need to happen within health services and among health professionals, especially for direct forms of involvement to be fully integrated into the development and delivery processes.

The participants with lived experience provided several examples of how the involvement of lay participants and the use of experiential knowledge could benefit patients, health professionals, and service development and delivery. On an individual level, becoming involved as a lay participant was described as a meaningful process. People with experience of illness were able to turn their difficulties into positive resources, strengthen their self-esteem, and gain a valued new role as an expert. Some of the study participants had not been able to work due to their illness, and through involvement activities they had been able to discover a new line of work. Those who had worked as health professionals prior to becoming ill could return to a working environment that was familiar to them.

Additionally, the participants argued that health providers should employ people with lived experience, as they were able to relate to patients' experiences, support them and guide them. For patients who had reservations about accessing health services, they could be a safe, easily approachable access point. The study participants described how speaking to someone with similar experiences enabled people to *dive in at the deep end*: they did not need to explain their situation in detail, but were able to start talking about personal and difficult issues more quickly.

The benefits of involvement for health professionals and health services were also addressed. These related particularly to service development and delivery, and the education and training of health professionals. Health services were described as hectic environments where professionals may lack the time to engage with patients. Someone with lived experience could ease the pressure by meeting with patients and providing them with time and opportunities to speak. Having people with lived experience working in health services could also allow professionals to ask questions and gain a deeper understanding and new perspective on illnesses and treatments, thereby providing professionals with a chance to learn and reflect on their own work. Some also suggested that including people with lived experience in health services as co-producers might encourage professionals to discuss their own experiences and think of ways in which these could inform their practice more openly. There were also suggestions that contained stronger critical elements, as the participants suggested that the skills and knowledge possessed by health professionals had their limitations. The lay participants attempted to position themselves as an expert group who could fill the knowledge gaps by providing experience-based information and support. Thus, they could claim that involvement had the potential to enhance the quality and scope of services.

Many of the participants had been involved in the training of health professionals, for example by giving lectures and telling their stories to students. They said that lived experience should be used as learning resources, to give

future health professionals a more in-depth and rounded understanding of the illness experience and how, for example, different treatments can impact on individuals' daily lives. Additionally, it was suggested that experiential knowledge could be used to enhance the practical aspects of service delivery – for example, by improving the service environment, accessibility and communication.

The participants faced material, attitude and language *barriers* as they attempted to collaborate with health professionals and access health service settings. The material barriers related to the spatial restrictions imposed upon lay participants and organisational representatives within health services. They had access to meeting rooms and were allocated spaces in hospital lobbies. Any further steps away from these points needed to be negotiated on a case-by-case basis. Some had successfully negotiated access to wards at allocated times to hold support group meetings, and those working as paid team members could usually operate freely within the buildings, although their access to any electronic systems was restricted. Hence, up to a point, lay participants and organisational representatives are always outsiders, invited to join certain spaces while being excluded from others. Renedo and Marston (2015) talk about lay participants as 'guests', because the participatory locations are often chosen by professionals, and the participants lack control over physical access to these spaces. Overall, access to and exclusion from spaces was determined by health professionals.

Nevertheless, this did not mean that lay participants accepted the current situation. Although many doors remained closed to the participants in this study, negotiations are ongoing. Lay participants who are currently working in healthcare have played an important role in opening doors for others. One boardroom and corridor at a time, they have subtly paved the way. For example, peer support workers have walked down corridors to ward reception areas to deliver information leaflets and negotiate times when they can visit patients. Experts by experience have established ongoing support groups for patients on wards, and have suggested that they might be present in casualty departments to

support patients experiencing acute mental health problems. They have set their sights on new areas, and slowly but surely, they have been able to gain access and create new paths for lay participants. Additionally, spaces can be viewed in a more abstract, temporal manner, with lay participants trying to ensure continuity and lay the foundations for participatory spaces to exist in the future too (Jones & Pietilä 2019).

Professionals' attitudes towards involvement and experiential knowledge were often cited as the reason why lay participants and organisations needed to make adjustments. The people communicating experiential knowledge needed to be clear and engaging, and during PPI activities, the participants were expected to understand professional jargon and organisational practices. All of these expectations were placed upon the laypeople, yet at the same time it was all too easy for professionals to exert their dominance by disengaging or dismissing experiential views. Resisting these adjustments was risky, as lay participants and organisations could be excluded from involvement activities. There appears to be a need to adapt, learn professional terminology, and become fluent in health service jargon. Choosing not to fully adapt to the neutral, professional communication style might therefore be a gamble, as one may not be taken seriously; but it can also be viewed as a form of quiet resistance.

However, the study participants also provided examples of encouraging professionals who collaborated with them and championed their involvement. Nevertheless, lack of guidance or understanding regarding the position of lay participants can lead to frustration. As Broer et al. (2014) have described, lay participants and professionals can experience mutual powerlessness as they attempt to figure out what lay professionals' contribution and role can be. For professionals, direct service-level involvement may also raise questions about responsibility. Will the lay participants be similarly accountable, or will professionals need to shoulder responsibility for their practice? Similarly, the lay participants working in healthcare settings described occasions when the

professionals were unsure how to interact, work with or position them within the service setting.

Additionally, the potentially burdensome effects of disclosing and using personal experience for PPI may be overlooked. Those working as experts by experience particularly indicated that they needed time to recuperate, because every time they told their story they expressed deeply personal and emotional issues. Open disclosure meant that lay participants had to give up some of their privacy, which caused the worry that they might be pressurised into sharing too many personal issues, including because certain illnesses continue to carry stigma and social connotations. There were also worries that openly disclosing experiences of illness might cause adverse reactions, for example when applying for work outside health services. Experiences could also include references to family members or friends, who were not necessarily happy about being included in openly disclosed stories. Hence, in order to retain control, the lay participants made strategic choices on what to include and what to leave out (Moll et al. 2013). For health professionals, the open disclosure of personal experiences may be interpreted as crossing a boundary (Oates et al. 2017), making such disclosures a rare event (Moll et al. 2013). For lay participants, the revelation of aspects of their personal history is expected, and offers them a chance to connect with other patients/service users. The use of experience and experiential knowledge is likely to continue as a forte and specialism of experts by experience. However, this does not mean that professionals are not able to learn from hearing about lived experiences and being exposed to experiential knowledge. Indeed, Slomic et al. (2016) have suggested that in some health service settings, experiential knowledge has already been integrated more firmly into the professional knowledge base.

Engagement in service-level PPI tends to involve some trade-offs, but it is important to acknowledge that currently it is often the lay participants who need to adjust, not the service or the professionals. It is possible to challenge the current situation by enabling people to discover and search for their own voice

during training, and to choose how they wish to convey their experiences. However, excessive pressure appears to be placed on individual participants, who are expected both to adjust to services and to maintain a critical stance. Health services implementing PPI need to address these issues and reflect upon their own practices. Additionally, organisations are perhaps better positioned to support and campaign for experiential knowledge and its integration.

6 DISCUSSION

6.1 Looking ahead: consequences and future paths

I will now discuss some of the potential changes that PPI in general, and the involvement of lay experts in particular, may bring to Finnish health services. I will also explore the paths that involvement may take and provide some recommendations for the future. My aim is to draw attention to the structures and practices that can encourage, motivate or exclude participants. Additionally, I wish to further explore the expectations and requirements placed on participants, and the tensions related to the content, form and uses of experiential knowledge within and outside health services.

6.1.1 The reactive nature of service level involvement

The results of this study portray service level involvement of lay participants as periodic and largely dependent on professional discretion. This suggests that the voice and co-production elements of PPI (Dent & Pahor 2015), currently implemented in Finnish healthcare services, require appraisal. These findings can also be interpreted as reflections of the hierarchies of power that afford some actors much more influence over agenda setting and decision-making (O'Shea et al. 2019). Lay participants and health professional have different knowledges, qualifications and experiences, which are reflected in different levels of power in decision-making and agenda setting and usually lead to professionals holding a position of authority. Finn et al. (2010) have shown that multidisciplinary work does not necessarily remove existing professional boundaries or help staff outside of the clinical profession to gain an equal footing. Indeed, attempts to create more

egalitarian working practices and facilitate integration may result in the reproduction of existing power hierarchies (Finn 2008). The results from this study partially support these findings, as the lay participants experienced the need to continuously legitimate their involvement, educate themselves further and create networks. They also felt that they were expected to adjust to existing practices, and in order to become part of the institution and its decision-making processes, they were expected to familiarise themselves with the 'correct' (i.e. medical and professional) terminology. Similarly, the organisational representatives spoke about the pressure to adjust the ways in which experiential knowledge was communicated in an engaging and articulate manner.

These imposed and self-imposed requirements reflect how subtle exclusions operate within involvement activities. The issues are exacerbated by the current situation, where most lay participants are only included on a temporary basis. After their contract or a specific project ends, there is no guarantee of future work, and it might be assumed that they are satisfied with an arrangement where their only gain is a new experience or support for their recovery (Matthies 2017). Thus, there is pressure on lay participants to prove that they are flexible and able to adjust to the existing culture. From the perspective of Tritter's (2009) model of involvement, this episodic way of involving lay participants provides them with very limited opportunities to shape the healthcare development agenda. In other words, service level involvement can be seen as *reactive* rather than *proactive*. In order to move towards proactive forms of involvement, services would need to be prepared to change their operating logics. This requires a shift from ad hoc co-production experiments towards more sustainable solutions (Tuurnas 2016).

These requirements can also fuel stratification among people with lived experience. Those who are able to engage with health services in the desired manner are more likely to be involved and have their voices heard, which means that experiences that are less cohesive, more highly critical, or less articulately communicated may be lost or excluded all together. Although the participants

emphasised that things had ‘got better over time’, medical and professional dominance was still visible. Involvement in service development and delivery was largely reliant on professional discretion and lay participants’ ability to network and create collaborative relationships. This suggests that even though health services organise involvement activities, they are not prepared to adapt to or accommodate participants who are not familiar with professional terminology or ways of working.

Overall, these findings are an indication that unequal power relations in terms of influence continue to be central issues in service level involvement. However, exclusionary practices are often subtle – for example health professionals not speaking to lay participants, showing a lack of interest in experiential perspectives, walking out of talks given by lay participants, questioning people’s understanding, or scheduling the lay participant as the last speaker of the day, every time. These are small but meaningful actions, which may not always be done purposefully. Nevertheless, they can undermine involvement efforts and influence people’s motivation, as it requires determination and commitment to engage in involvement activities.

Matthies (2017) argues, involvement requires much more than small-scale changes within organisations. After all, health services are expected to respond to complex needs and to deliver timely and appropriate forms of care to individuals. Involvement can potentially be a step towards a more tolerant, more skilful and less authoritarian service system. Participants with lived experiences can also provide fresh ideas and solutions. However, for involvement to be worth implementing, all stakeholders must be open to new suggestions and practices (Matthies 2017).

6.1.2 The professionalisation and stratification of involvement

As Bherer et al. (2017) and Saurugger (2010) have highlighted, the trend to involve the public or sections of the public is occurring across societies and

institutions. They have also claimed that involvement is consequently becoming more professionalised, with new professional groups and even industries emerging. Alanko and Hellman (2017) have suggested that promoting people with lived experiences into experts has fuelled a de-professionalisation or de-expertisation trend within healthcare. However, I would argue that although the door has been opened for lay people to participate in health service development and delivery in new ways, it does not directly lead to de-expertisation as the involvement process appears to turn this new group of selected participants into experts with specialist skills, knowledge and training. Indeed, a distinct subgroup seems to be forming in Finland of lay participants and organisational representatives striving to form a new occupational group. Their goals mirror developments that have gone much further in countries such as Canada, the UK or other Nordic nations, where peer support workers and experts by experience have more established positions within health services (Gillard et al. 2013; Rebeiro Gruhl et al. 2016; Burr et al. 2020). Their attempts to establish themselves within health services follow similar trends to occupational groups such as nurses and midwives, who in their early attempts to professionalise began to regulate training and created registration processes to enable occupational closure (Hyde 2013).

Although the position of lay participants is not directly comparable to that of nurses, the calls to unify training content, make training compulsory, establish a pay structure, and construct job roles that only people with experiential knowledge can fill suggests that there are strong efforts to professionalise at least some aspects of involvement. El Enany et al. (2013) have argued that professionalisation occurs through a combination of self-selection and selection controlled by professionals, who choose which participants to choose and educate. Additionally, lay participants themselves attempt to strengthen their 'professional' status by constructing their own distinctive body of knowledge and by excluding those regarded as 'less-expert' (El Enany et al. 2013). In this study,

the participants emphasised the importance of training and the process of structuring experiences into a clear story. The participants who sought an established occupational role also highlighted their other qualifications, prior skills, and wide national and international networks. The strong emphasis on training may be due to the national context, as Finland has a strong cultural tradition of valuing education. However, the enthusiasm towards establishing a new occupational group was not equally championed by all study participants.

The requirement to adopt professional traits may restrict entry into involvement activities, and may lead lay participation to become more stratified. By positioning themselves as experts, and their knowledge base as another form of expert knowledge, lay participants in many ways simulate health professionals. Indeed, the term *lay participant* may not be the most appropriate for those that seek more professionalised roles. Some even hold or are studying for healthcare qualifications themselves, further blurring the line between lay and professional. Lakeman et al. (2007) have argued that this can lead to new hierarchies of authority developing among people who use services. They propose that the bottom of this hierarchy is made up of the vast majority of people who use services voluntarily or involuntarily. They may try to seek collaborative relationships or influence, but their authority is weak. Slightly further up the hierarchy are people who belong to collective groups and organisations; above these are 'professional service users', who invest considerable amounts of time and effort in service user groups but may also be directly employed or contracted by institutions. At the top of the hierarchy, the authors place 'celebrity or corporate service users', described as articulate and charismatic people able to claim legitimacy through prior involvement or lived experiences.

Drawing boundaries around more professionalised forms of involvement can also be interpreted as a response to the developments occurring in the wider socio-cultural environment. Anyone can potentially claim experiential expertise and for example, in the media terms such as expert by experience or experiential

knowledge are sometimes used mockingly in reference to people who lack ‘real’ or more authoritative forms of knowledge about a topic. Additionally, the same terminology is used by individuals and collectives promoting ‘alternative’ perspectives to illness and care. Hence, it may be important for people with lived experiences who want to be regarded as equal collaborators in healthcare development and delivery to differentiate themselves from those who are untrained, have not processed their experiences or those who represent more ‘alternative’ forms of expertise. Creating boundaries and more professionalised roles can be an attempt to clarify and claim the terminology surrounding experiential expertise. In an environment where traditional forms of knowledge and expertise are being challenged or even dismissed (Newman & Clarke 2018) the participants of this study argued that despite being critical, they appreciated scientific and clinical expertise and wanted to improve healthcare together with health professionals.

Although the potential for stratification is reflected in the results of this study, the participants who reach higher levels within health services are not necessarily cut off from collective groups or required to disregard any critical views. Indeed, the participants in this study were often trying to balance an activist position with their professionalised healthcare developer or provider position. This was not always easy and often required certain adjustments, but the positions were not mutually exclusive, as the study participants were often involved in a variety of activities. They could be members of collective groups running peer support meetings, and also members of health service management or planning groups. This kind of wide-ranging interest in a multitude of activities and through a variety of national and international networks is not exclusive to the participants in this study, but seems to be a wider trend among those who engage in PPI and third-sector activities (e.g. Jones & Pietilä 2019; 2020). In relation to Tritter (2009), these findings suggest that although service level PPI was often an

individual activity, the study participants portray collective involvement as equally important and attempt to influence services through both means.

There is a possibility that involvement opportunities are mainly offered to a narrow selection of people who are eager and willing to participate, but this is an issue that should also be acknowledged and addressed by the health service providers and professionals who make these choices. It is also important to take into consideration factors such as educational level, income, cognitive skills and functional capacity, which can enable or prevent people from getting involved (Peat et al. 2010). El Enany et al. (2013) claim that those selected for involvement activities tend to be more articulate and have existing skills that enable them to work with professionals. However, a narrow selection process can lead to a situation where those who might have much to gain and much to contribute are excluded from healthcare decision-making (Ocloo & Matthews 2016). Current practices appear to rely strongly on the capability and proactivity of individuals. Hence, more attention should be paid to the formal and informal rules that have formed around service-level involvement and who is considered a legitimate participant. Issues around inclusion and exclusion need to be reflected upon if the aim is to engage with a more diverse group of patients, and not merely with those that are participation ready.

6.1.3 Practical considerations for service level PPI

On a more practical note, if health services choose to employ people with lived experience as employees, certain issues need to be considered. Some of these issues are more abstract, such as considering the rationales and aims behind involvement, and considering whether involvement overall should be as strongly focused on individual participation. It is also important to define more clearly the work content and responsibilities of employees with lived experience. Additionally, staff should be made aware of the role of their new team members,

which may alleviate some of the difficulties related to role confusion and unclear expectations described by both Otte et al. (2020) and Broer et al. (2015). A more comprehensive solution would be to integrate these issues as part of the training of health professionals. Based on the findings of this study, experts by experience appear to be well aware of the scope and limitations of their own knowledge and skills. They also actively educate themselves, which enables them to work with highly complex issues such as the planning of care pathways.

A small number of individuals are already employed in Finnish health services as experts by experience. If this trend is to continue and widen, it is important to address issues related to pay, job security and supervision. Third-sector organisations have published general guidelines on fees (Ilomäki 2019), but the level of payments and fees can vary widely, which means that some institutions may expect people to do work (e.g. give lectures) for free. Those working as team members are often employed on a temporary basis, with no guarantee that the work will continue afterwards. This paints a rather precarious picture of the working life of experts by experience. Additionally, the nature of experiential work and the workers engaged in it needs to be considered.

Rissanen and Jurvansuu (2019) have highlighted the impact that working as an expert by experience can have on well-being, and how it can support people to return to the workforce. This line of work means sharing personal experience openly and listening to other people's problems on a daily basis, which can be emotionally taxing. Hence, if health services employ people with lived experience, those people need to be provided with supervision (just like other professionals working in healthcare), and there should be some flexibility depending on the expert by experience's personal situation. Nevertheless, taking these things into consideration should not lead to a situation where excessive attention is focused on the well-being and behaviour of the expert by experience. For example, Otte et al. (2020) describe an example where a worker with lived experience hesitated to call in sick because they were scared that any absence would be interpreted as

a symptom of their illness. After all, people who become experts by experience are usually at a stage in their lives where they feel sufficiently strong and capable to return to work and provide support for others.

Tritter's (2009) framework distinguishes between individual and collective involvement. This is an important distinction and relates the findings of this study as the lay participants often described service level involvement as an individual activity. They were included in development and delivery work as sole agents rather than groups, which can place pressure on the participating individuals. One way to reduce pressure and facilitate integration is for services to hire more than just one person with lived experience (Chinman et al. 2008; Burr et al. 2020).

6.1.4 Integrating experiential knowledge: transformation or colonisation?

As highlighted by this study and many others, the narration of personal experiences and the construction of a personal story can be supportive, beneficial and empowering for people with experience of illness (e.g. Charmaz 2000; Kirkpatrick & Byrne 2009; Grant et al. 2015). Turning lived experience into experiential knowledge can also boost self-esteem and help people with (chronic) illnesses to deal with uncertainties (Baillergeau & Duyvendak 2016; Jones 2018), which may be particularly important for people who have experienced marginalisation and stigma due to their illness. Experiential knowledge can mobilise individual and collective action and be a driving force for change. PPI widens the scope of experiential knowledge even further, making it possible to influence service development and delivery directly. However, as the results of this study have illustrated, integrating experiential knowledge into health services may bring with it new expectations and requirements that can filter and erode the transformative potential.

Despite the discourse of 'putting the patient in the driver's seat' (Tynkkynen et al. 2016), patient-centred care (Storm & Coulter 2017) and interest in narrative

medicine (Zaharias 2018; Charon 2009), experiential knowledge is still finding its place in healthcare, and can all too easily be discarded by health professionals. This ability to dismiss experiential knowledge suggests that even when lay participants are included in service development activities, their involvement can still be interpreted as *reactive* and *indirect* (Tritter 2009) as health professionals can choose whether their views are included in decision-making. The closer integration of experiential knowledge into health services also raises the fear that experiential knowledge and lay participants might lose their authenticity, critical stance and autonomy. Previous studies have suggested that mainstream services can colonise experiential work, creating a workforce in their own image (Daniels et al. 2010; Rebeiro Gruhl et al. 2016) and even limiting the sharing of personal experiences (Gillard et al. 2013). So, will the integration of experiential knowledge into health services depoliticise involvement?

Traditionally, experiential knowledge has been portrayed as a challenge to medical/expert knowledge, as it contests the latter's impartiality (Beck 1992), objectivity and authority to determine how problems are defined in policy and healthcare arenas (Williams & Popay 2006). Although these aspects remain, the participants in this study did not approach health services in a confrontational way. They wanted to voice criticisms but to do so in a constructive manner, and they presented experiential knowledge as an additional, compensative form of knowledge. Recent studies (Näslund et al. 2019a; Näslund 2020) focusing on Swedish service user entrepreneurs and mental health service user organisations have yielded very similar findings. When dealing with public services, lay participants and organisations choose to take a consensus-oriented approach. The participants in this study indicated that they wanted to engage with health services and health professionals individually and collectively. They created wide networks, educated themselves, gathered experiences from large groups of people, processed them, structured them, and offered them as resources for health services. Their strategy was to position themselves as knowledgeable

collaborators who could provide important new perspectives. Within this process, experiential knowledge was constructed as a necessary addition to the existing knowledge base, not a replacement or a threat.

The findings of this study also draw attention to the complexities related to authenticity and representation of the voice of lived experience. When third sector organisations communicate experiential views to health services, their involvement can potentially be interpreted as either direct or indirect, depending on the composition of the organisation. Some organisations gather patient views, which are communicated forward by organisational employees, who do not themselves have lived illness experiences. Concurrently, there are organisations that consist of people with lived experiences who themselves communicate experiential views to health services and policy makers. In both cases, one could argue that the voice of patients is being represented. However, using Tritter's (2009) terminology, the former can be viewed as indirect involvement, whereas the latter could be interpreted as a more direct forms of involvement. In this study, I have not addressed whether one form could or should be regarded as more 'authentic', but this would be an interesting to explore further. Particularly in the Finnish context, where third sector organisations are widely included in health service and policy development.

From a wider perspective, a variety of experiential knowledge and experiences that clearly challenge current biomedical understandings of diagnosis, illness and treatment are being circulated, particularly online. However, the knowledge that is being shared with health services through PPI activities is less likely to be openly challenging. Indeed, this study's findings indicate that health services can be dismissive of those who want to form collaborative alliances with them but approach issues from an experiential perspective. Other studies have also noted that only people with particular diagnoses are frequently included, and the narratives shared are expected to be neatly structured and to focus on positive outcomes (Eriksson 2013; Näslund 2020). The experiential knowledge that filters

through to services is likely to be based on the experiences of those who have recovered from an illness and who possess the skills and abilities required to create structured, cohesive accounts.

Hydén (2018) has suggested that stories about illness are strongly influenced by narrative norms – i.e. notions of how well the story is organised – and this may have a detrimental effect upon those who have communicative, speech or cognitive problems, as their inability to comply with the established norms can position them as unreliable narrators. This is directly relevant to PPI, as one of the main resources used by lay participants is their own personal stories constructed during training. Hence, in order to capture more chaotic experiences or stories that may lack temporal coherence, health services and health professionals should be more proactive and open to accounts that are less coherent and neatly packaged.

Although this study has strongly focused on the restrictions imposed on experiential knowledge, it is also interesting to explore why it continues to be dismissed or disvalued. One explanation stems from the transformative potential of experiential knowledge. After all, medical dominance in society – i.e. ‘the profession’s cultural authority to determine, for example, what is to be counted as sickness’ (Elston & Gabe 2013: 152) – and medical dominance over patients might be profoundly altered. Experiential knowledge can challenge the ways in which we classify and treat illnesses, whereas PPI activities aim to shape the doctor-patient relationship into a more collaborative form. Hence, even the more consensus-driven approaches may have wide-ranging consequences. In the long run, the integration of experiential knowledge may have a significant impact on medical dominance, and as Gabe (2013b) has suggested, it will be interesting to see whether a new form of professionalism based on active trust and partnership will emerge.

6.1.5 The power of stories and the importance of narrative competency

The narrative turn in society has shifted attention onto reflexive, subjective and culturally engaged first-person stories (Grant et al. 2015). The wider cultural interest in personal stories can provide additional support for the lay participants and organisations within and outside of health services as experiential perspectives are often conveyed in narrative form. As discussed earlier, engagement in PPI places several filters and expectations of experiential accounts and can enforce certain narrative structures such as the quest narrative described by Frank (1995), which presents the illness as a motivator for social action or change. Although the participatory turn has encouraged public institutions to engage with citizens, not everyone is equally keen to get involved through the channels created for PPI and involvement activities are by no means the only environments where experiential knowledge and different forms of illness/caring narratives are used.

Firstly, the participants in this study demonstrated that they used experiential knowledge outside the realm of health services. They wanted to change attitudes and perceptions and be involved in creating policy changes, both as individuals and as collectives. In addition to influencing attitudes and policy processes, experiential knowledge can also have other applications. As shown by Näslund et al. (2019b), people with lived experience can also become entrepreneurs who establish companies and base their career on their lived illness experiences. Drawing on their individual narratives, they express themselves in the media, give lectures and write books. There were some indications that this avenue was also being followed by some of the participants in this study, as some spoke of e.g. offering training and lectures on female empowerment.

Lived experiences can also be harnessed by citizen scientists and they can be collected and used outside of health services or established research institutions. One example of this is the private enterprise called PatientsLikeMe, which

operates online and encourages people to ‘take charge’ of their condition and ‘heal together’. The site collects large amounts of user-generated data on thousands of conditions, produces research findings based on the data, provides people with tracking applications and enables people with illness experiences to connect with each other (PatientsLikeMe 2020). Additionally, experiences of illness and caring are actively shared nowadays through magazine articles and social media outlets by a variety of people, indicating that there is a general interest in lived perspectives. These publicly shared accounts have become increasingly popular (Järvi 2014; Mäkelä & Karttunen 2020) and can also be used for self-promotion and marketing purposes, and for spreading unfounded information (Raipola 2020). Although personal stories can provide information, hope and a reflection point to those reading them, their strong representation in the media can also draw attention away from structural issues and factual information and enforce culturally dominant narratives (Mäkelä & Karttunen 2020; Raipola 2020).

The lay participants and organisational representatives at the centre of this study are not the only ones to benefit from the cultural interest in personal stories and the rise of experience-based expertise. This climate also provides a platform for individuals, networks and groups who want to use experiential knowledge for very different purposes. Brown et al. (2004) have written about embodied health movements that seek to address ‘disease, disability or illness experience by challenging science on aetiology, diagnosis, treatment and prevention’ (p. 50). Although these movements draw from lived experience, they may also include people who are not ill but perceive themselves as vulnerable to the disease (e.g. breast cancer). Additionally, there are many individuals and groups suffering from undiagnosed conditions (e.g. chronic fatigue syndrome) who are seeking recognition and care, as well as people whose understanding of health and illness is in direct conflict with current medical views (e.g. pro-ana groups, the neurodiversity movement).

Experiential knowledge, shared through powerful narratives, provides a source of legitimacy for groups that want to engage with health services, and for those that want to pose a challenge from the outside by confronting and criticising existing practices, authorities and expertise. Hence, experiential knowledge can also be an effective and very importantly affective tool in a climate where people have access to huge amounts of information and are encouraged to act as critical consumers, and where trust in authorities is wavering. Experiential knowledge can be highly emotive, although within health services, a level of neutrality is imposed upon it. However, outside that context there is much more narrative freedom, and these affective aspects can be used to their full extent. One example of this is the anti-vaccination movement, which actively uses stories told by parents as a source of legitimacy for its cause (Blume 2006). It uses much more chaotic, exciting and dynamic narratives, free from strict adherence to evidence (Shwetz 2019). Indeed, Shelby and Ernst (2013) have argued that effective storytelling has become one of the most powerful tools in the arsenal of groups that want to challenge existing medical practices. In the current climate, instabilities related to expertise and knowledge (Newman & Clarke 2018) can grant further influence to these stories.

Although the groups and networks that use first-person narratives and experiential knowledge may be very different, they also pose a wider challenge to health services and policymakers. They are often talented at building networks, and they actively gather and interpret research information, combining it with experiential views and producing their own knowledge bases. Additionally, their experiential knowledge and alternative views are not merely due to knowledge deficits (Dubé et al. 2015). Hence, public institutions and professionals need to learn how to navigate this terrain, engage with the groups that wish to collaborate with them, and deal with the challenges arising from varied and splintered outsider groups. Ambivalence or the dismissal of all forms of experiential knowledge is unlikely to be an effective solution, and at worst may lead to

disappointment and discontent among patients and publics that want to contribute. Hence, I join Shwetz (2019) in calling for increased *narrative competency* in healthcare, which may help decision makers, organisations and professionals to better understand where different and at times challenging views are coming from and how they might better respond to them. This requires at least a basic understanding of concepts such as experiential knowledge and lay epidemiology in order to comprehend the varied and complex ways in which people attempt to make sense of issues such as health, illness and care. Nevertheless, it is also important to acknowledge the cultural pervasiveness of stories, which some critics fear have become a replacement for facts and reasoned argument (Salmon 2017:5). Thus, the role and impact stories should have in health-related decision-making should also be critically considered and addressed.

6.2 Study limitations and further research directions

The main focus of this study has been on the growing involvement of individuals and groups who are expected to provide an experience-based perspective for health service development and delivers. The study's participants represent two service areas (mental health and cancer services) and I recognise that within other sectors PPI may be taking forms, which I have been unable to explore. Additionally, the participants in this study were people who chose to answer my call for interviews, and they are likely to be a selective group who have managed to establish themselves as participants. Although this meant that they had a variety of PPI experiences, this recruitment method was likely to leave out those who had disengaged from PPI, and of course those who had never engaged in PPI activities to begin with.

In the future, it would be interesting to explore lay participants who have engaged in service-level PPI activities but have stopped or been quietly replaced by others more 'suited' to the job. The individuals and networks who openly

challenge medicine and healthcare practices from the outside have received both media and research attention. However, little is known about those who get involved through PPI but are either excluded or decide to drop out. In Finland more and more experts by experience are being trained, while at the same time involvement opportunities are limited and employment opportunities scarce. Hence, it is important to also study what happens to participants whose perspectives do not align with those of healthcare/health professionals, and what happens to the trained experts by experience who have been prepared for PPI but lack opportunities to participate. This study has touched upon public involvement and the results indicate that it is a somewhat neglected area within Finnish health policy. Hence, forms of public participation related to healthcare decision-making ought to be explored further. Additionally, it is vital to study the perspectives of professional groups that play an integral role in the implementation and future developments of PPI. More research is also required into the experiences, perspectives and needs of those who use services provided by experts by experience.

7 CONCLUSIONS

In this thesis, I set out to examine 1) the positioning and legitimacy of lay experts in healthcare development and delivery; 2) the construction and applications of experiential knowledge; and 3) the benefits and barriers related to service level involvement. Prior research literature on PPI had highlighted the need to address the various consequences of involvement; challenges associated with its implementation; and the legitimacy of the knowledge that patients and members of the public possess and are able to contribute to healthcare (Daykin et al. 2007; Boivin et al. 2010; Mockford et al. 2012; Brett et al. 2012; O'Shea 2019). Additionally, Dent & Pahor (2015) have encouraged researchers to pay attention how involvement processes can empower or disempower participants. This study has explored these issues from the perspectives of national health policies, lay participants and third sector organisations. The results provide a nuanced view of involvement in Finnish health services and offer insights into the tensions related to the practical implementation of involvement in service development and delivery.

The national health policies analysed in this study, portrayed PPI in rather narrow and ambivalent terms. Although *voice* and *co-production* were mentioned, involvement was mainly depicted as a *choice-making* activity. The policies construct ideal PPI participants as active, responsible and knowledgeable individuals, who are able to engage with health services as consumers (making informed choices and providing feedback to improve services) or experts (knowledgeable collaborators engaged in the planning of personal care and in the development of services). Overall, the policies do very little to address public involvement and direct involvement opportunities are aimed at people with lived

experiences. The results suggest an over-reliance on individuals who are active and already possess the qualities needed for involvement – such as high levels of health literacy, self-efficacy, specialist knowledge and skills – and find it easier to position themselves as experts. However, attention needs to be paid also to those whose capacity may fluctuate, who are not as familiar with the functioning of the health system, or who otherwise need support to find the suitable engagement level for them. More *proactive* forms of involvement are required for their perspectives to be included and for lay experts to be able to take part in setting agendas.

Although the national health policies analysed in this study offer a rather narrow view on involvement, they also provide new opportunities for lay participants and organisations to contribute and influence health services. The lay experts, who were engaged in the development and delivery of services, constructed involvement as an empowering yet challenging process. Lay participants wanted to turn their experiences into positive resources that could improve care delivery. Involvement could support recovery, strengthen self-esteem and provide new work opportunities. However, the main emphasis was on service improvement and ensuring patients get adequate support. Lay participants argued that they could enhance the accessibility and quality of services by ‘bridging a gap’ between health professionals and patients. They portrayed themselves as both collaborative and critical, highlighting their ability to recognise good practice, areas of further development and deepen health professionals understanding of illness and service use experiences. Involvement was also described as an ongoing negotiation. Lay participants were attempting to negotiate entry into new service areas one corridor, hospital ward and boardroom at a time, pave the way for others and establish their presence as equal partners in service development and delivery.

The main barriers and tensions identified in relation to service level involvement related to attitudes, subtle exclusionary practices and various

requirements placed upon lay participants. Involvement can be burdensome on lay experts, who continuously share their personal experiences and whose work is often irregular and episodic. Both lay participants and organisations also felt that they were expected to adjust and adapt to existing ways of operating. The power of professional groups and the dominance of biomedical knowledge in healthcare was made visible in the daily practices of PPI. Additionally, the professionalisation of experiential work can lead to the exclusion of people deemed 'less expert'. Despite these barriers, this study observed that lay participants also found ways to resist the expectation to adapt to existing culture and did their best to retain their autonomy.

The legitimacy of lay experts stemmed partly from their training, prior work experience and their ability to learn and adjust to health service settings. Nevertheless, the main source of legitimacy was based on lived experiences and the experiential knowledge they claimed to possess. Experiential knowledge was portrayed as *all-encompassing*, *practical* and *transformative* and the participants argued that it should be integrated into all levels of health-related decision-making. The lay participants and organisational representatives taking part in this study portrayed themselves as willing collaborators, attempting to find common ground and bring their experiential knowledge to the table as an additional resource that could be used in conjunction with other knowledge bases. Based on the findings, I argue that experiential knowledge should not be regarded merely as a coping resource for people with lived experiences, but as a carefully constructed tool used to create change in healthcare. Nevertheless, there are also filters that can regulate how and by whom experiential knowledge is communicated to health professionals.

Ultimately, if policymakers and health services are committed to service level PPI and want to move towards collaborative partnerships and proactive modes of involvements, they need to recognise the legitimacy of lay expertise as well as the scope and limitations of experiential knowledge. In order to for a wider variety

of voices and experiences to be heard in health service delivery and development, there needs to be more tolerance for listening to, and accepting experiences that are not neatly structured, neutral, or communicated in an audience-friendly manner.

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9 ATTACHMENTS

Attachment 1

TUTKIMUSTIEDOTE

Tutkimus

Pyydän teitä osallistumaan väitöskirjatutkimukseeni, jonka yleistema on osallisuus terveyspalveluissa. Yhtenä osana tutkimusta tarkastelen vertais- ja kokemustoimijoina työskentelevien henkilöiden kokemuksia sekä järjestötoimijoiden näkemyksiä osallisuudesta.

Tutkimuksen kulku

Haastattelut tehdään yksilöhaastatteluina. Jokaista tutkimukseen osallistuvaa haastatellaan kerran. Haastattelu on muodoltaan vapaamuotoinen keskustelu, jossa seurataan tutkijan etukäteen suunnittelemaa keskusteluteemoja (mm. näkemyksiä kokemustoiminnasta ja sen kehittämisestä sekä sairauskokemuksia omaavien henkilöiden osallistumisesta erityisesti terveyspalveluissa).

Tutkimukseen osallistumisesta ei makseta palkkiota. Tutkimustulokset voivat kuitenkin tuottaa myös hyödyllistä tietoa terveydenhuollon toimijoille ja suunnittelijoille sekä järjestöille.

Luottamuksellisuus, tietojen käsittely ja säilyttäminen

Haastattelu kestää noin tunnin verran ja se nauhoitetaan ääninauhalle, jonka jälkeen haastattelu kirjoitetaan tekstitiedostoksi. Tässä yhteydessä haastateltavien ja haastatteluissa esille tulevien muiden henkilöiden nimet poistetaan ja muutetaan peitenimiksi. Tarvittaessa muutetaan tai poistetaan myös paikkatietoja ja muita erisnimiä, jotta tutkimukseen osallistuneiden henkilöiden tunnistaminen ei enää ole mahdollista.

Väitöskirjatutkimuksen keston ajan haastateltavien yhteystiedot ja äänitallenteet ovat vastaavan tutkijan (Marjaana Jones, Terveystieteiden yksikkö, Tampereen yliopisto) hallussa. Tekstitiedostoiksi kirjoitettuun aineistoon pääsevät käsiksi vain suoraan tutkimuksessa mukana olevat henkilöt (tutkija itse sekä ohjaajat).

Haastatteluissa esille tulleet asiat raportoidaan tutkimusjulkaisuihin tavalla, jossa tutkittavia tai muita haastattelussa mainittuja yksittäisiä henkilöitä ei voida tunnistaa. Tutkimusjulkaisuihin tullaan sisällyttämään suoria otteita haastatteluista. Niiden yhteydessä saatetaan tarvittaessa mainita haastateltavan sukupuoli ja ikä.

Vapaaehtoisuus

Haastatteluun osallistuminen on täysin vapaaehtoista ja osallistuja voi milloin tahansa keskeyttää osallistumisen tutkimukseen tai kieltäytyä vastaamasta hänelle esitettyyn kysymykseen.

Tutkimustuloksista tiedottaminen

Halutessaan tutkimukseen osallistuvilla on oikeus saada nähtäväkseen oma purettu haastattelunsa sekä saada tietoa tieteellisistä julkaisuista, joissa haastattelua on käytetty aineistona.

Tutkijan yhteystiedot

Jos olette halukas ottamaan osaa haastatteluun, voitte ottaa yhteyttä suoraan tutkijaan: TtM, väitöskirjatutkija Marjaana Jones, [sähköpostiosoite ja puhelinnumero].

Vastaan mielelläni lisäkysymyksiin ja tiedusteluihin tutkimusta sekä haastatteluja koskien.

Attachment 2

TOPIC GUIDES FOR INTERVIEWS

Topics discussed in interviews with experts by experience and peer support workers:

First question for everyone: Could you tell me how you became an expert by experience/a peer support worker?

Themes covered in each interview:

- Personal experiences of working as an expert by experience/peer support worker: e.g. what has been rewarding, what has been difficult, where have you worked, what has your work entailed, what could be improved/developed in relation to work
- Training and support: e.g. have you attended training, could you tell me about the training (content, duration, motivation for attending), do you receive any supervision/support, what kind of support do experts by experience/peer support workers require
- Skills and knowledge: e.g. what kinds of skills are beneficial/needed, what kinds of information/knowledge is needed
- Views on involvement: e.g. how should involvement be developed, should experiential workers receive pay
- Future prospects: e.g. how would you like the role of expert by experience/peer support worker to evolve within the next five to ten years, what are your own prospects/aims/hopes

Topics discussed with representatives of third sector organisations:

First question for everyone: Could you tell me about your organisation, its activities and aims?

Themes covered in each interview:

- Views on involvement: e.g. what is the organisation's perspective on involvement, does the organisation support/facilitate/advocate for involvement and for whom, have methods of involvement changed, on what levels should involvement take place
- Training, knowledge and skills: e.g. what kind of training is provided, how do various forms of training differ, who is training aimed at, what opportunities are there for trained experts by experience/peer support workers, what opportunities should there be, what kind of knowledge/skills should experts by experience/peer support workers have
- Position of experiential work: e.g. should experiential workers receive pay, how should experiential work be developed, which issues should be addressed by experiential workers
- Future prospects: e.g. how should involvement be developed, what kinds of opportunities should be provided

10 PUBLICATIONS

PUBLICATION I

**“The citizen is stepping into a new role” – Policy interpretations of patient
and public involvement in Finland**

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“The citizen is stepping into a new role”—Policy interpretations of patient and public involvement in Finland

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Abstract

Involving patients and the public in healthcare decision-making is on the policy agenda in several countries. The aim of our study was to describe and analyse the development of patient and public involvement from a policy perspective. We argue that the language of health policies can influence both the aims and the development of involvement methods. In this study health policy documents, which have guided the development of patient and public involvement in Finland have been analysed using methods of Membership Categorisation Analysis. This has enabled us to explore how health policy documents categorise patients and the wider public in relation to involvement and orientate the involvement activities in which people are able to participate. Different set of abilities, expectations, responsibilities and opportunities is attached to the categories of *patient*, *risk group*, *service user*, *customer* and *expert*. Health policy documents often equate involvement with choice making by service users and customers; or as involvement in service development by experts. In both of these cases, involvement is depicted as an individual activity that requires personal responsibility and specialist knowledge. Although involvement opportunities have overall increased, they are primarily available to people that are “participation ready” and able to adopt roles promoted in policies. Health policy documents produce one interpretation of involvement, nevertheless it is important that diverse groups of patients, the public and health professionals participate in the discussion and express their views, which may differ from those of policy makers.

KEYWORDS

health policy, patient participation/role, qualitative research, user involvement

1 | INTRODUCTION

Patient and public involvement has established its position on the policy agenda (Martin, 2008). In Finland, similar to numerous other western countries, policy makers have been promising to put people utilising health services “in the driver's seat” (Tynkkynen, Chydenius, Saloranta, & Keskimäki, 2016). This rhetoric has been particularly common in relation to health services, which are the focus of this study. Despite becoming widespread, prior studies have demonstrated the complexities and variations of involvement as it has been adopted into health and social care policy and practice around Europe (e.g. Leppo

& Perälä, 2009; Lichon, Kavcic, & Masterson, 2015; Pavolini & Spina, 2015; Vrangbaek, 2015).

Patient and public involvement in healthcare has historical roots ranging back decades with patient organisations and user groups promoting of patients' rights to participate in decision-making (Beresford, 2010). Hence, at its core involvement entails demands for power sharing and self-determination. However, when translated into policy, these concepts can be turned into something much less progressive or even counterproductive by policy makers (Stratigaki, 2004). Cowan, Banks, Crawshaw, and Clifton (2011) have argued that this has happened to concepts such as “social inclusion” and “recovery,” which

have been transformed to fit a quasi-market agenda. Indeed, the once passive and helpless patient has been reconstructed as active, self-reliant and demanding critical consumers (Armstrong, 2014; Newman & Kuhlmann, 2007). Both increased access to health information and the growing influence of consumerism in healthcare have been contributing to this change and it is in this setting that involvement has risen onto the policy agenda. Hui and Stickley (2007) have highlighted the role of policy rhetoric in defining and guiding involvement.

In practical terms, involvement can take a variety of forms including participation in *treatment decisions*; involvement in *service development*; *evaluation of services*; participation in *education and training* of health professionals; and engagement in all aspects of the *research cycle* (Tritter, 2009). Additionally, there are opportunities for people to participate in the *co-production* of some services, which can offer a transformative way of developing services, presuming it is not merely based on compliance or cost-cutting (Needham & Carr, 2009). Arnstein's (1969) ladder of participation has been central in shaping the theoretical framework for involvement, describing a continuum of participation ranging from being informed to complete control. Nevertheless, it is also a hierarchical model, placing a great emphasis on power while failing to capture the complex, dynamic and evolutionary nature of involvement processes (Carpentier, 2016; Tritter & McCallum, 2006). Tritter (2009) suggested an alternative way of conceptualising patient and public involvement in order to differentiate between the aims, types and methods of involvement activities. This conceptualisation divides involvement into indirect and direct forms, where the former entails gathering information from service users and the latter entails that people have the opportunity to take part in actual decision-making. Involvement can occur on an individual level, such as deciding on a specific treatment, or a collective level, e.g. when a patient group takes part in the planning of a new service. Additionally, involvement can have both proactive and reactive dimensions, depending whether participants are able to participate in setting the agenda or respond to an existing one.

In this study, we will focus on the development of patient and public involvement in Finnish healthcare, from a health policy perspective. Over the past decade, there has been a policy shift towards implementing more involvement opportunities into healthcare. Nevertheless, we argue that these new opportunities are not evenly distributed and health policy language plays a part in orientating involvement activities. Indeed, the ways in which policies position patients and the public can orientate involvement by enhancing options for some while limiting them for others. Hence, through the analysis process, we are able to both challenge policy terminology and discuss the development and guiding principles of involvement among different groups. Prior to the policy analysis, we will briefly outline the development of involvement in Finnish health policies.

1.1 | Development of patient and public involvement in Finland

Finland is a Nordic welfare state, based on ideas of universal rights to health and social care. However, patients' right to choose has risen

What is known about this topic

- Patient and public involvement is a common trend in health policy and policy makers claim to be putting people in the driver's seat.
- Involvement is a complex, dynamic process which can take different forms.

What this paper adds

- Policy categorisations of patients and the public can both enhance and limit involvement opportunities.
- Political agenda for increasing choice can be a powerful driving force in shaping involvement.
- Categorising people as customers and experts makes involvement a specialist and demanding task.

high on the policy agenda, bringing to the fore the needs and agency of the service user (Leppo & Perälä, 2009). It has also been argued that business and economic interests have taken a guiding role in health policy (Ollila & Koivusalo, 2009). The Finnish healthcare system is complex with a highly decentralised administration, multiple funding sources, and three distribution channels in first contact care (Tynkkynen et al., 2016). On a primary care level, services can be accessed through municipal health centres, occupational health services or private services. Local authorities are responsible for providing care through municipal health centres, with service users paying a co-payment for accessing services. Additionally, primary care is organised through occupational health services, funded by the employers and employees, or people can choose to pay for services organised by the private sector.

Compared to countries such as the UK, the Netherlands or other Nordic countries, Finland is a relative newcomer to developing patient and public involvement in healthcare. During the 1990s, patient rights were strengthened by passing the Act on the Status and Rights of Patients (785/1992). This legislation enforced a direct, individual form of involvement by highlighting the rights to be involved in decisions about individual treatment and care. Additionally, people have been able to voice their opinions through indirect, collective ways such as voting in national and local elections. It has also been possible to engage collectively through patient organisations.

On a policy level, involvement received little attention until the latter part of the 2000s, when The *National Mental Health and Substance Abuse Plan* began to promote direct involvement and experiential expertise in service development. Following, involvement and particularly direct forms of involvement filtered into the general national-level policies with the *National Development Programme for Social and Health Care Services* (2012) claiming that "involvement and customer-orientation are the central principles" (p. 19). These programmes were instrumental in linking involvement with health service development. Indirect, collective involvement opportunities such as participation in municipal residents' forum; and direct,

individual opportunities such as “including service users in decision-making bodies” and “planning and developing services together with service users” were also included in the Local Government Act (410/2015, 22§). Following the parliamentary elections in the spring of 2015, the newly appointed centre-right coalition government continued to include involvement into their Strategic Programme (2015) for health and welfare. They also embarked on a large-scale reform process of health and social care services coinciding and connected to a reform, which includes transferring responsibility for organising health services from municipal and local authorities to autonomous regions. These reforms are likely to impact on the forms involvement will take in the upcoming years.

2 | METHODS

In this study, the emphasis is on the policies and strategies, which have described and extended the idea of involvement in Finnish healthcare. In order to distinguish between different forms and varied aims of involvement, the terms (direct-indirect, individual-collective) suggested by Tritter (2009) will be applied throughout. The questions we pose in this study are (1) what categories do policies construct for patients and the public in relation to involvement and (2) how do these different categorisations orientate involvement activities? The materials consist of key national health policy documents ($n = 7$) which have discussed and described involvement: the *National Mental Health and Substance Abuse Plan* (2009); *Finland's Disability Policy Programme* (2010); *Socially Sustainable Finland 2020 – Social and health policy strategy* (2011); the *National Development Programme for Social and Health Care Services* (2012); *Quality Recommendation to Ensure Good Aging and Improve Services* (2013); *Wellbeing is functional capacity and participation – The Future Review of the Ministry of Social Affairs and Health* (2014); and *Finland, a land of solutions – Strategic Programme of Prime Minister Juha Sipilä's Government* (2015). The first six documents have been the main national level publications mapping out the policy aims and developments in health services, covering a range of different health sectors. The last document presents the current government's national policy goals in relation to health services. Additionally, all these documents describe and discuss the introduction and development of involvement in healthcare settings. All the documents are freely available online and have been published by the Ministry of Social Affairs and Health (MSAH), apart from the latter, which was published by the Prime Minister's Office.

We analysed the documents using methods of Membership Categorisation Analysis (MCA). In this study, categories are understood as being both cultural and context bound with particular qualities, expectations, responsibilities, rights and competencies attached to them (Juhila, Jokinen, & Suoninen, 2012). Although categories may appear descriptive, in social interaction they also carry moral connotations (Jayyusi, 1991). While conducting the analysis, we have applied the principles suggested by Stokoe (2012). We began by *collecting* purposive data, i.e. national policies that discuss patient and public involvement in relation to healthcare. Following this, we *built* explicit

mentions of categories (e.g. patient, customer, expert) and descriptions attached to them; *located* the position of categorial instances within the text; and *analysed* how the actions are orientated in relation to different categories. In other words, we focused on the involvement activities and opportunities were connected to different categorisations within the documents. Through this process, we were able to explore how certain categories were bound with certain activities, expectations, responsibilities and opportunities, as well as including moral connotations regarding individual responsibility over health and well-being. In the results section, the focus is specifically on the categories applied to people in relation to involvement in different aspects of healthcare.

3 | FINDINGS

“The citizen is stepping into a new role” announced the Future Review published by the MSAH (2014, p. 15). This section explores these roles by focusing on policy documents that claim to enhance involvement opportunities and champion customer-oriented care. Involvement has been developing within a policy context, which emphasises individual choice making and economic necessities to reform and reorganise health services. Involvement is championed as means to decrease social inequalities; enhance customer-orientation; increase efficiency and reduce costs. Over the past decade, there has also been a shift towards introducing a greater mix of involvement methods including indirect, direct, individual and collective forms of engagement. We have arranged the categorisations under three headings: (1) Categories which imply passivity and offer limited involvement options; (2) categories linked to activity, offering involvement through individual choice making; and (3) the expert category, which demands specialist knowledge but offers a wider variety of direct involvement opportunities.

3.1 | The limited involvement options of patients and risk groups

There are no references to patients in parts of the documents where involvement is discussed, implying that active participation is neither expected nor encouraged from people categorised as patients. This creates a contrast between the category of patient, which the documents associate with increased need for care, and other categorisations associated with active agency. Categorising someone as a patient does not inherently imply passivity; however, it is only applied in reference to people who require intensive long-term care in a hospital or care home setting. This implies dependence on services and potentially high costs, which are not viewed positively in policies that aim to reduce expenditure. It is also notable that, apart from these exceptions, the word patient in direct reference to people has almost disappeared from the documents and it is mainly used when referring to patient records or patient safety. The phasing out of the term patient can be seen as surprising as prior research has suggested that people still prefer to be referred to as patients rather than clients, customers

or consumers (Deber, Kraetschmer, Urowitz, & Sharpe, 2005). On the other hand, the disappearance of the term is likely to reflect the wider policy aim to reduce care dependency and construct people as active self-sufficient participants, which is perhaps easier to accomplish with alternative terminology.

Although the patient category has almost vanished, another potentially marginalising category titled risk groups is applied to people who are long-term unemployed, prisoners, homeless, immigrants, ethnic minorities, poor, people with mental health or substance abuse problems and minority language groups. In relation to risk groups, involvement is promoted as a way to reduce social inequalities. However, the personal agency, capacity to make decisions or take part in development tasks are not supported by the policy language used to describe the risk groups.

Targeted and encouraging methods which promote the health and well-being of risk groups are being developed and implemented together with the public sector, organisations and companies.

(MSAH, 2012, p. 21)

Although the involvement of risk groups is promoted as an important policy aim, people belonging to risk groups are not described in terms that would emphasise collaboration or highlight them as valued sources of information and knowledge. On the contrary, the above extract positions public services, companies and organisations as the active agents attempting to promote the health of risk groups. This category exists within policy discourses of cost-cutting, increased effectiveness and the requirement to take personal responsibility over one's well-being and lifestyle choices, making it challenging to interpret the categorisation as value free. It is also notable that although involvement is expected, the policies do not take into consideration the potentially varied requirements, which enable involvement among those who utilise health services. Overall, the policy stance towards involvement from people placed in these categories appears ambivalent, particularly in comparison to the other categories such as customers and experts.

3.2 | Service users and customers—Involvement through choice

Customer is the most common category applied throughout the documents. In contrast to patients and risk groups, customers are depicted as active, knowledgeable and driving forces of change. Despite this, involvement options for customers appear limited to individual choice making and the customer category links involvement with the agenda of opening healthcare provision to private providers.

The customer's expertise is increasingly made use of in the development of social and healthcare services, in order for services to be customer-oriented. (...) Currently customers have the opportunity to choose their place of treatment only from the public sector. It is necessary to clarify how

the right to choose has been implemented and assess whether this right should be extended.

(MSAH, 2014, p. 15)

Nevertheless, there are subtle differences in this category relating to age groups. Discussion on children's ability to participate is almost entirely absent from the documents. However, elderly people, despite also being referred to as customers, are provided with more involvement opportunities than working age adults. Policies balance between describing older adults on the one hand as active participants and on the other hand as people requiring protection and care. Those who are active and capable can get involved through collective means such as Elderly Councils and Citizens' Juries. Hence, the older adults capable of participating in these activities are more closely tied with the democratic process, but are mostly in a position to offer feedback, voice opinions and issue statements rather than set agendas. Additionally, branding healthcare users as self-sufficient customers raises several challenges, particularly in relation people who may lack capacity or require facilitation to participate.

Another category connected to involvement is that of a service user, which can be seen as less value-laden than categories such as customer or consumer. Nevertheless, it has been criticised for providing a simplistic view of people merely as users of health services and fails to acknowledge the complex identities and multiple roles people inhabit (McLaughlin, 2009). The policy documents engage service users as developers and assessors. This presents new opportunities and also shared responsibility for service development.

People's roles are transforming into more active ones. The service user is also an evaluator and developer. People are placing new aims for customer relationships, service availability and mobility.

(MSAH, 2014, p. 11)

Similarly, to customers, service users are described as demanding driving forces for change and willing participant in evaluation and development activities. Despite this, there is a lack of further elaboration on means through which evaluation or development could be undertaken. Although customers and service users are given increased opportunities, the categories are also bound with responsibility.

Services are reformed as a whole in a way which involves users actively in their development. Service users need to be offered up to date and impartial information regarding treatment options and service providers. In this manner, users' ability to bear responsibility over their health and well-being increases.

(MSAH, 2011, p. 11)

This extract does not only introduce the commodified view these policies draw of healthcare services, but there is also an attempt to renegotiate the division of responsibilities between the service users, service providers and the state. The emphasis is on personal responsibility that is connected to both customer and service user categories and can be

viewed as examples "of neoliberal methods of governing late modern societies through inculcating self-management and individualisation of responsibility" (Crawshaw, 2012, p. 200). Health is depicted as a matter of choice and the individual is expected to shoulder the responsibility for their well-being. Service users appear subservient and are expected to accept both "impartial information" and responsibility. There are also references to expertise, which is a new category in Finnish policies, but it can play a significant role in orientating the future development of involvement.

3.3 | Experts by experience and peer support workers—Involvement in service development

The idea of people possessing unique knowledge due to personal experiences is not new, however, it has not featured in health policies prominently until 2009 when the National Mental Health and Substance Abuse Plan included the involvement of experts by experience and peer support workers in service planning and development as one of its main aims.

The involvement of experts by experience and peer support workers should be increased in the planning, implementation and evaluation of mental health and substance abuse services in order for the services to take customer/client requirements into more consideration. Peer support workers are people, who relying on their own experience, as volunteers provide for example long-term support for customers/clients within the service system, operate in peer support groups, or as individual peer supporters. (...) Experts by experience are those people who have personal experiences of a mental health or a substance abuse problem either having suffered from it personally, having recovered from it or accessed services due to it or being a family member or a close relation. Experts by experience should be used in municipal strategy work, service evaluation and rehabilitative groups. They can be invited as experts into the governing bodies of service units. (...) Expert by experience activities and the associated reward systems should be developed jointly with organisations and municipalities. (MSAH, 2009, p. 20)

The National Mental Health and Substance Abuse Plan differs in many ways from the other policies as it included clinical professionals and patient organisation representatives in its production. The follow-up reports have even included experts by experience as co-writers. In contrast to the other documents, the plan placed a stronger emphasis on the democratising potential of involvement and downplayed the economic arguments. Central to the categories of peer support worker and expert by experience is the usage of personal experience, but although peer support workers are expected to do this on a voluntary basis, experts by experience could be receiving pay for their work, which has potential to enhance the creation of hierarchies between involved patient groups. However, these categories also provide opportunities to engage directly

with service providers, clinical professionals, and political decision-makers and make co-production of services a possibility. However, taking part in meetings and management groups is often undertaken on an individual basis, making this form of involvement individual rather than collective. Involvement at this level can also require a wide range of skills and knowledge, extending beyond personal illness experience.

In recent years, the idea of patient expertise and particularly the expert by experience role has been broadened beyond the field of mental health and substance abuse. In Finland, being able to adopt these roles generally requires training provided by patient organisations and hospital districts, ranging from a few days (for peer support workers) to several months (for experts by experience). Becoming an expert by experience or a peer support worker can offer a less stigmatising category for those branded as risk groups in other national policies. However, questions can be raised about the capacity of those from disadvantaged groups to adopt these roles and about the potential professionalisation of patients, as involvement is channelled through roles that require substantial training and long-term commitment. These are some of the practical issues, which health bodies will need to consider if they wish to support effective involvement from a diverse group of participants.

3.4 | Indications of future developments

The current government was appointed in the spring of 2015 and shortly afterwards they outlined their strategic priorities. Under the health and welfare section, involvement is linked with the aim of making services more customer-centred (Prime Minister's Office, 2015). Concurrently, the Ministry of Social Affairs and Health has begun a project that aims to produce clearer definitions for involvement and enable experiential knowledge to filter more effectively to civil servants and policy makers (MSAH, 2017). Overall, the key strategy document continues the trend of referring to people as customers, which is in line with the government's vision to extend the right to choose service providers and increase the use of service vouchers in the coming years.

Notably, the expert by experience categorisation continues to be utilised, signalling that the position of experts by experience may be strengthened in the future. Currently, experts by experience lack a clear position within healthcare and it has been left on to active health professionals and the voluntary sector to pilot new forms of involvement and create opportunities for experts by experience. At present, experts by experience are, e.g. working in some municipal health centres and community mental health services and participating in hospital and municipal executive meetings. Indeed, experts by experience currently have the most direct opportunities accessible to them. However, most of these opportunities are open to individual experts, with collective forms of involvement being less common.

4 | DISCUSSION

Despite policy documents claiming to champion patient and public involvement, the policy language describing involvement can be

ambiguous. In this study, we have explored the use of categories, which national-level health policies apply to people in relation to involvement. Through the analysis, we found that policies attach varied opportunities, abilities and expectations to different categories. However, there appeared to be an underlying assumption that within categories, healthcare users would have homogenous views and requirements. In most cases, involvement still occurs through indirect means, although during the past decade, there has been an increase in direct opportunities. Indirect, collective forms of involvement include voting, or providing feedback by participating in citizen juries, councils or panels. Direct, but mostly individual ways of engaging include becoming a member of managerial/planning/steering group. The opportunities for proactive involvement, where patients or the wider public are a part of agenda setting remain limited. Hence, for most people, involvement is mainly about responding to pre-existing agendas.

During the latter part of the 20th century and early parts of the 21st century, the role of the patient and their relationship to health professionals has undergone numerous changes, with patients being reconstructed as having active agency, skills and technical competence (Armstrong, 2014). In our analysis, the passive patient had not completely vanished, manifesting itself partly in the risk group category, which existed in contrast to the customer and expert categories, where agency, skills and competence were emphasised.

The "demanding and sceptical citizen consumer" described by Clarke, Newman, Smith, Vidler, and Westmarland (2007) is strongly present in Finnish health policies, following a similar trend to other countries (Newman & Kuhlmann, 2007; Sturgeon, 2014). Addressing people as customers and service users enables policy documents to position them as the active drivers of reform, modernisation and increased choice. Choice coupled with increased competition is high on the current government's agenda as it prepares for the upcoming health and social care reform. Indeed, the claim is that people are demanding for more choice, although the WHO survey on responsiveness in healthcare documented that only 6% of Finns considered choice as the most important aspect of non-clinical care (Valentine, Darby, & Bonsel, 2008). Patients already have the opportunity to choose between municipal health centres and private healthcare providers commissioned by the municipalities, but less than 10% of the population have used this right (Sinervo, Tynkkynen, & Vehko, 2016). Defining involvement merely in these terms can limit the future possibilities involvement could bring and creates a distinct possibility of choice becoming a proxy for involvement (Tritter, 2009). Applying consumerist categories to patients and the public has faced criticism, as there are few circumstances where individuals can accurately be classified as consumers in relation to healthcare (Goldstein & Bowers, 2015). However, the most recent category included in policy documents, the expert, could enable policy makers to argue that people do possess the knowledge, skills and capacity to make informed choices, even within an increasingly market-orientated healthcare setting.

Nonetheless, the expert category can create new involvement opportunities for people otherwise described as risk groups. Those willing and able to adopt the expert role are able to take part in direct involvement activities such as strategy work, service evaluation

or become members of governing bodies of service units. However, in order to bring out a wider selection of voices, it is important to acknowledge that increased professionalisation of users can lead to only choosing those who have the required competencies and capacity to influence (Van de Bovenkamp, Trappenburg, & Grit, 2009). In order to engage marginalised groups, there needs to be more proactive measures, and also capacity building in order for people to feel a sense of entitlement to participate (De Freitas & Martin, 2015). Failing to include marginalised groups can exacerbate health inequities as policies and services are increasingly adapted to the needs of vocal majorities (El Enany, Currie, & Lockett, 2013). This development would be in direct conflict with the clearly stated policy aim of reducing inequalities.

Despite policy documents naming involvement a central aim, Finland continues to lack a systematic approach to involvement. There are no guidelines or criteria for evaluation of involvement activities, although this could potentially hinder future development and create a lack of confidence among the public and health professionals. Policies do address some of the major issues such as the representativeness of those involved or how to engage "invisible" groups or those who rely on others to facilitate participation. Overall, policies construct involvement on assumptions that patients are willing to participate; possess similar opinions; and are able to access relevant information. However, people experiencing pain and suffering due to their illness may not have this capacity (Moffatt, Higgs, Rummery, & Jones, 2012) and even if they do, people may not want to participate. Development of involvement activities has thus far been largely reliant on active individuals, which means that there is potentially a great deal of regional variation in available opportunities and unclear guidance on how to facilitate involvement activities effectively on a practical level.

Although this study has focused on the health policy perspective, we acknowledge that different stakeholders possess varied views and aims, which are outside the scope of this study. If and when more experts by experience and peer support workers are integrated into decision-making processes and service delivery, they are likely to have a stronger voice in how involvement should be developed further. The large-scale reforms taking place in Finland in the near future are also likely to impact on involvement. Local-level legislation currently guarantees municipal residents' rights to have a say on the development of public services. Whether these rights will remain as the new regional authorities are formed is yet to be seen.

5 | CONCLUSIONS

In this study, we have argued that although involvement has become a central theme in health policies, different policy categorisations can have consequences to the involvement opportunities associated with certain groups. In the Finnish policy context, involvement is intertwined with the political agenda to increase choice and competition. Policies have begun to categorise people as experts, suggesting that they possess experiential knowledge, which health services could utilise. Additionally, there are differences related to age categories, as the health policy documents do not apply involvement rhetoric to

children. In contrast, involvement is expected of working aged adults and elderly people, but their opportunities to participate rely heavily on their ability to adapt into preferred categories and they are rarely in a position to set agendas. Issues such as evaluation methods, systematic planning, and potential barriers, which can prevent effective participation and risk tokenism, remain unacknowledged. The upcoming large health and social care reform is likely to impact on involvement, making this a vital time for different stakeholders, including patient organisations, patient and the public as well as professionals working in healthcare services, to present their opinions and views.

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PUBLICATION

II

Alignments and differentiations: People with illness experiences seeking legitimate positions as health service developers and producers

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Abstract

Health policies and strategies promote the involvement of people with illness experiences in service development and production, integrating them into settings that have traditionally been domains of health professionals. In this study, we focus on the perspectives of people with personal illness experiences and explore how they justify involvement, position themselves as legitimate actors and forge collaborative relationships with health professionals. We have used discourse analysis in analysing individual interviews conducted with peer support workers and experts by experience ($n=17$) who currently work in Finnish health services. The interviewees utilised discourses of empowerment, efficiency and patient-centeredness, aligning themselves with the justifications constructed by patient movements additionally to those found in current health policies. Both groups wanted to retain critical distance from professionals in order to voice criticisms of current care practices, yet they also frequently aligned themselves with professionals in order to gain legitimacy for their involvement. They adopted professional traits that moved them further from being lay participants sharing personal experiences and adopted an expert position. Although national-level policies provided backing and legitimacy for involvement, the lack of local-level guidance could hinder the practical implementation and make involvement largely dependent of professionals' discretion.

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Keywords

expert by experience, Finland, health services, patient involvement, peer support worker, qualitative

Introduction

The involvement of people in health care decision making has become a guiding principle of public health service reforms in a number of western countries (Coulter and McGee, 2003; Martin, 2008). Involvement has been described as a way to foster services that are more responsive by including the ‘patient perspective’ (Rowland et al., 2017). Hence, both members of the public and people with personal illness experiences are now increasingly included in *service development, evaluation of services, education and training* of health professionals and *co-production* of services (Tritter, 2009). In some countries, they are also able to take part in *health policy planning* and *research activities* (Dent and Pahor, 2015). Consequently, lay people are now able to participate in decision making on a service level and deliver services jointly with professionals. In this study, we will explore patient and public involvement from the perspective of people with personal illness experiences who are actively participating in service development and production. Involvement can be seen as an empowering process that provides a voice for illness experiences and helps make health services more patient oriented. However, integrating people with illness experiences into health services as developers and co-producers is a pursuit that raises conflicts and tensions. It also requires motivation and tactical skills from lay participants who need to justify their involvement to different stakeholders, negotiate entry into service settings and then attempt to establish a position as legitimate actors.

Involvement can be justified in a number of ways that consequently influence its practical implementation. Newman and Kuhlmann (2007) have argued that on a policy level involvement is often interpreted as a cost-cutting activity that transfers more responsibility onto the people utilising services. The rise of chronic illnesses and ageing populations has led to governments implementing reforms that are committed to cost effectiveness, accountability, competition and consumer choice (Starr and Immergut, 1987). Hence, people with lived experiences that engage with health services are expected to contribute to the enhancement of service quality and cost reduction. From the perspective of health services, involvement fits with the ethos of patient-centred care and joint decision making that have been integrated into clinical practice. Involvement can be justified by arguing that it leads to patient empowerment. However, there are issues that often remain unaddressed such as unequal power relationships between patients and practitioners (Barnes and Cotterell, 2012). Involvement and the cultivation of individual choice and agency can provide professionals with valuable capital, yet involvement does not automatically translate into new or empowering forms of practice (Leppo and Perälä, 2009).

In addition, a great number of patient organisations and user groups in the form of critical self-help groups and social movements, such as the women’s health movement or gay rights activism in relation to HIV/AIDS (Barbot, 2006; Dent and Pahor, 2015), have created a pressure to democratise health-related decision making. These movements

have addressed issues ranging from provision of services and health inequities and challenged science on etiologic, diagnosis, treatment and prevention for a number of decades (Brown et al., 2004). Although involvement in health service development and production is a relatively new development, these movements have paved the way for patients to be seen as experts in relation to their own bodies and health conditions. The apparent rise of consumerism has also led individual service users rejecting or being encouraged to reject a passive trust in medical expertise and medical reputations, expressed in among other things through more involvement in decision making (Elston and Gabe, 2013).

On a more practical level, prior studies have highlighted the lack of clarity and the tensions associated with people with illness experiences entering health services. Some of the tensions arise from the attempts to establish experiential knowledge as a valid form of expertise in a setting where (bio)medical knowledge and research-based information are considered to form the basis of reliable and legitimate expertise (Caron-Flinterman et al., 2005; Greenhalgh et al., 2015). Collins and Evans (2007) have described an increasingly disembedded world where who is considered an authority or an 'expert' and what types of knowledge are regarded as credible and trustworthy are contested. People with personal illness experiences can be seen as part of this challenge as they claim to have experience-based knowledge and expertise, which needs to be incorporated into healthcare. However, despite the increase in involvement opportunities, people with illness experiences lack a clear position within health services where the medical model continues to prevail.

Second, the people who participate in health service development and production are faced with unclear and at times conflicting expectations. Martin and Finn (2011) have suggested that service users who are included as team members can be particularly vulnerable to role blurring as they lack the identity and skills base that defines a profession. Gates and Akabas (2007) have argued that professionals can experience role confusion and have difficulties relating to workers with personal experiences if they are not sufficiently prepared for their arrival or are unclear what their work should entail. This lack of clarity can lead to mutual powerlessness experienced by health professionals and people with personal experiences as they struggle to find ways in which this new group of workers could contribute in health service settings (Broer et al., 2012). People with illness experiences can become integrated into healthcare teams, where they can demonstrate personal recovery and enhance the team's skill-mix (Gillard et al., 2013). However, as they adopt a more professional position the 'giving of personal experience' can become less appropriate or viewed as unprofessional (Gillard et al., 2013). Third, the overall aims relating to involvement can vastly differ between stakeholders. For example, Rutter et al. (2004) have argued that people with illness experiences who participate in development work want to make concrete changes and improvements, whereas service management may expect them to conform to set agendas.

As demonstrated above, entering health service settings as newcomers and with a considerably different knowledge base is not a straightforward task. We wish to contribute to the growing literature on patient and public involvement within health services by focusing on the perspectives of people with illness experiences who are attempting to engage with professionals, and become integrated into health services. Our first aim is to explore the ways in which they justify their involvement as different justifications can

offer an insight into ways in which people interpret the aims and underlying values related to involvement. Justifications can also be utilised tactically to provide a legitimate base for involvement. Our second aim is to study how this new group of participants attempts to establish a legitimate position for themselves within health service settings that are historically hierarchical and operate from a different knowledge base.

The data used in this article have been collected in Finland, which is a relative newcomer when it comes to involving people on service-level developmental work and service production. Although the Act on the Status and Rights of Patients (785/1992), strengthening people's right to be involved in decision making on individual care, was passed as early as the 1990s, it was not until the 2000s that involvement in a service level rose on to the policy agenda. During the 2000s, the mental health and substance abuse strategy begun to actively promote involvement (Ministry of Social Affairs and Health, 2009). Following the parliamentary elections in the spring of 2015, the newly appointed centre-right coalition government continued to include involvement into their Strategic Programme (Prime Minister's Office, 2015) for health and welfare. During this period, several developments took place. First, experts by experience were increasingly involved in managerial groups, training of health professionals and service delivery. The position of experts by experience within mental health and substance abuse services has been further cemented as the Ministry of Social Affairs and Health (2018) published a statement that their involvement is to become a legal requirement. Second, training of experts by experience widened in scope as several regional health service authorities began to offer training to patients and coordinate involvement activities. Peer support work is also being increasingly recognised as a valuable asset and support workers are moving more into hospital settings, where they can be in closer contact with patients and health professionals. Several hospital districts have founded patient information centres where trained volunteers can provide support and information to patients. In addition, there has been an increase in patient forums that are used in the assessment and development of care services. Ollila and Koivusalo (2009) have argued that concurrently with these developments business and economic interests were taking a guiding role in health and social policy choices. Indeed, Finnish health policies tend to frame involvement as a measure through which services can become more cost effective, customer orientated and of enhanced quality (Jones and Pietilä, 2017).

We have chosen to focus on two participants groups: experts by experience, working in mental health services, and peer support workers, working in cancer services, which are offered the most direct service-level involvement opportunities. Peer support worker is a term commonly used in cancer services and cancer patient organisations. Peer support workers undergo a short training course that qualifies them to provide peer support to others. Cancer peer support workers have a long tradition of providing support through third-sector cancer and patient organisations. These organisations operate independently from health services and peer support workers have not been present within health service settings. Over the past few years, there has been a slow change, particularly within larger cities, and support workers have entered hospital settings. Examples of this include giving talks at events organised by hospitals for newly diagnosed cancer patients and their family members. Some larger hospitals also have patient information points, where patients can meet peer support workers. The term expert by experience is not yet widely used among people with lived experiences of cancer. However, some cancer organisations have also

begun to utilise the term and train people to become experts by experience. Experts by experience either work in community services as paid team members or hold a seat in management/development groups within community and hospital settings. The term expert by experience has become widely used within mental health services and among people with lived experiences of mental health problems.

What also strongly connects our interviewees is their emphasis on lived experiences. They have embodied experiences, which cannot be read about or taught. Embodied experiences are at the core of experiential knowledge and, as Brown et al. (2004) have argued, the experiences lend moral credibility both in the public sphere and in the scientific world. In addition, all our interviewees had been involved in development work and/or provided services to patients. As prior studies indicate, involving people with personal experiences is becoming a more common practice in a number of countries (e.g. Broer et al., 2012; Gates and Akabas, 2007; Martin and Finn, 2011; Shuval et al., 2002). In order to make involvement meaningful to these groups of participants and to health services, it is important to study their position, contributions and experiences of collaboration in more depth. The aims of this article are to explore (1) what justifications do people with illness experiences provide for their involvement and (2) what kind of strategies do they adopt in order to establish a position within healthcare services.

Methods

Interview materials

We have analysed in-depth interviews conducted with experts by experience and peer support workers (n=17) that currently participate in the development and production activities within mental health and cancer services in Finland. By involvement in service development, we refer to participation in any work that includes service planning (participation in managerial/planning/development groups). By service production, we refer to work, which takes place in health service settings such as hospitals and health centres where people with illness experiences provide support and advisory services to patients. The participants were aged 23–71 and all of them had personal experiences of mental health problems or prostate cancer. The first author (M.J.) recruited interviewees by contacting patient organisations, which provide training and act as the main points of contact for health services for recruitment. Prior to the interviews, ethical approval was sought from the relevant ethics committee. All the participants gave verbal and written informed consent. M.J. conducted the interviews during autumn 2016 and spring 2017. A topic guide covering different themes (such as motivation, experiences of working in different settings, training and content of different work tasks) acted as a basis for each interview, but it was used loosely to allow participants to freely discuss their experiences and introduce issues, which they regarded as important.

Analysis

In our analysis of the interview materials, we have taken a discourse analytic approach that views language as a means to construct social understandings of the issue in question (Potter and Hepburn, 2008). Our focus has been on the ways in which peer support workers

and experts by experience justify their involvement and how they position themselves within health service settings. We have studied the patterned ways of thinking that can be identified in the verbal communication of our interviewees. Their ways of talking are also connected to the sociocultural and political context in which they occur (Lupton, 1992). As discussed earlier, service user involvement and the integration of people with illness experiences into health services is a new phenomenon in Finland. Our interviewees have been using services as patients, but as collaborators and joint decision makers, they are newcomers. Following the initial stage of familiarising ourselves with the interview materials and discussing tentative findings, more specific research questions were formulated: First, what justifications do peer support workers and experts by experience provide for their involvement? Second, what kind of strategies do they use in order to establish themselves within health services? These questions were used to direct in-depth reading of the data.

At this phase, we focused particularly on parts of the interviews where participants discussed their work in health services and described their entry into service settings. Davies and Harré (1990) have defined positioning as 'the discursive process whereby selves are located in conversations as observably and subjectively coherent participants in jointly produced storylines'. Positioning is closely connected to the way in which one compares and evaluates self with other as 'we become and are ourselves only in relation to others' (Shotter, 1993). Focusing on the ways in which the interviewees described themselves in relation to professionals and patients enabled us to explore the strategies they adopted to establish themselves as similar and yet distinctly different from these groups. These differentiations also made it possible for them to argue for increased involvement and present themselves as vital and important actors in health service planning and production. While analysing the interview materials, we noticed that although peer support workers and experts by experience talked about issues in very similar ways, there were also differences. Although this is not a comparative study as such, in the section 'Results' we have at times contrasted between these two groups. At the final stage of the analysis, we grouped data extracts under core ways in which peer support workers and experts by experience justified their involvement and described their entry into and positions within health service settings.

In the next section, we will discuss the ways in which peer support workers and experts by experience attempt to negotiate access to healthcare settings and establish a position for themselves. The part is divided into three parts: the first part explores the ways in which interviewees justified the need for their involvement; the second part focuses on their attempts to gain access into healthcare environments and the ways they attempt to produce themselves as legitimate actors; the third part focuses on the issues that can hinder involvement and position peer support workers and experts by experience as outsiders, even when they appear to be working in collaboration with health professionals.

Results

Empowerment, efficiency and patients' needs – justifying involvement

The interviewees provided a variety of justifications for their involvement, some of which were deeply personal, while others utilised similar justifications to those provided by health policies and patient organisations. On a personal level, involvement entailed

rehabilitative aspects. Being involved signified a new stage in recovery and interviewees could argue that their involvement sent out a sign that people with illness experiences could provide important perspectives and challenge preconceptions associated with different illnesses. Indeed, all the interviewees argued that involvement was a way to challenge presumptions, address shame and provide others with hope:

Expert by experience: What I consider as the most important duty is removing the shame from the mental illnesses and then the other one is giving hope.

Some of the justifications stemmed from personal experiences. Participants described the feelings of confusion associated with navigating the care system and making treatment decisions. They felt that it was important to ensure that current patients had the opportunity to receive more guidance, talk to someone with the same experience and be provided with information about different options available. One of the main arguments for the inclusion related to enhanced communication with patients. The interviewees argued that health services were overstretched in terms of resources. The inclusion of people with illness experiences could ease the pressure on professionals and allow patients much needed time to talk:

Peer support worker: It [the health care system] is stretched so tightly (...) They [people working in health care] are being rushed and then you have to prioritise your work. Possibly this kind of volunteer could have more time to spend. And that's just what a person needs when they've gotten ill.

Peer support workers described themselves as peers, who had a strong embodied understanding of what it is like to live with cancer. They knew about different care pathways, managing side effects of treatments, and how difficult it could be to talk about the illness. As the interviewees had all experienced prostate cancer, they also talked about the potential shame and embarrassment that some men experience as prostate cancer treatments can lead to urinary incontinence and sexual dysfunction. Professionals were depicted as authoritative figures whose knowledge was often limited to clinical issues. In contrast, peer support workers described themselves as 'equals', 'more practical' and 'down to earth'. Similar argumentation was also used by experts by experience who worked in close contact with patients. The assumption was that people would have less trouble opening up to them:

Peer support worker: ... doctors will tell you if you ask them, but as I said, these are incredibly difficult things for most men to be asking about from others. However, one to one with a peer, who is after all a stranger to them, but has been through the same, it can be easier to open up.

All the interviewees referred to health professionals' knowledge base as limited in some ways. Health professionals lacked the lived illness experience, and even if they had personal experiences, they were often unable to share them within the boundaries of

professional practice. Experiential knowledge was described as a new resource, which could benefit professionals and patients. It also differentiated experts by experience and peer support workers from health professionals into a distinctly different group that, in the words of the interviewee below, have their 'own expertise':

Expert by experience: I was just talking to a psychiatrist and they had run out of ideas with a patient. They could adjust medication and such but they didn't really have the tools for anything else. So they were thinking that I could meet the patient. (...) And I feel that my encounters [with professionals] have been such that I have my own expertise and they have the expertise of their own field.

The justifications provided above stem from the distinct nature of experience and discourses of empowerment and inclusion. However, within health services, experiential knowledge is often at a disvalued position and hence justifications stemming from experience alone were insufficient. Hence, interviewees utilised health policy rhetoric such as patient-centeredness and cost effectiveness. In the extract, the interviewee lists a number of benefits for involving people with illness experiences, suggesting that it can bring benefits on personal, service and national levels:

Expert by experience: Well, it's cost efficient and then it's a rehabilitative activity. (...) And they've emphasised, probably because of the health and social care reform, customer orientation. What could be more customer orientated than experiential expertise.

Overall, the interviewees discussed how meaningful involvement had been in terms of their personal recovery and how it provided them with opportunities to challenge shame and stigma. Nevertheless, the justifications that stemmed from the ideas of empowerment were not sufficient. Here justifications and the need for legitimacy overlap, as the interviewees utilised policy rhetoric in order to both justify involvement and construct themselves as legitimate actors. They produced an image of health professionals as clinical and distant, lacking lived experiences of coping with an illness. Health services were described as overburdened and incapable of responding to the varied needs of patients. Involvement and inclusion of experiential perspectives were described as the way to provide a truly patient-centred and efficient service, which could take into account clinical aspects and psychosocial support needs. By utilising multiple and varied justifications, the participants were also able to form a more solid argument for their involvement. In addition, partial alignment with health policy aims could also support them as they were attempting to negotiate access in health services.

Legitimacy and access to health service settings

As prior studies have shown, practical implementation of involvement is often a challenging process and different stakeholders can hold conflicting views on the aims of

involvement. In our study, the interview participants acknowledged that involvement in Finland was a new development and, in many ways, they were the forerunners who could pave the way for others. This also meant that they needed to negotiate with health professionals in order to gain access into new service areas and present themselves as legitimate actors whose views should be taken into consideration. In order to do so, the interviewees used varied strategies that both aligned them with and differentiated them from health professionals and patients. Peer support workers were still at a beginning phase when it came to entering health service settings. They work actively within the voluntary sector; however, their entry into health services is currently limited to hospitals. In hospitals, they face further confounds, as the physical spaces in which they operate are limited to communal areas. Patient information centres operate within hospital lobbies and information events for new patients are held in auditoriums and other public areas. Entering a hospital in the first place was described as a demanding task. Access to healthcare settings was not automatically granted. It needed to be negotiated and often required backing from more authoritative figures. In the extract below, the peer support worker describes using backing from the head of the organisation:

Peer support worker: At the [local hospital] there is this patient information centre. (...) It's like a booth at the end of the hospital. (...) and my idea is that I'm gonna push my way in there with a help form the [head of the patient organisation]. (...) I also know that when a man comes from there and he has lots of questions that he didn't think of asking and the doctors are busy. They are experts in their field but they don't have time to comfort or explain. (...) But definitely they should provide something and I'm trying. I've got a mission that I could infiltrate that place and the people would know who I am and what I'm doing.

Those who had managed to enter into hospitals were slowly trying to widen the physical space that they were able to access as support workers. One interviewee describes his attempts to gain access into the part of the hospital where patients receive prostate cancer diagnoses:

Peer support worker: I've really tried to get in there, from the cancer clinic to the urology clinic where the diagnosis place is. That I could get to the start of the path. But there are certain barriers clearly and those need to be broken one way or another, with persistence if nothing else.

In contrast to peer support workers, the interviewees who worked as experts by experience had been able to gain access into a variety of health service settings. They held seats in service-level planning groups in hospital and municipal services and worked as paid members of community care teams. Whereas peer support workers were attempting to find a way past the hospital lobby, experts by experience had managed to open these doors. This also meant that their work duties were more varied and most of the work was

not done with patients, but also in collaboration with health professionals. Nevertheless, 'breaking down doors' was also a feature in the expert by experience interviews as they were attempting to both secure their positions and create new work for themselves and others:

- Interviewer: Would you tell me a little bit about the different forms of work you've been involved in so far?
- Expert by experience: Well, for example I've been in this research project where they test, it's a joint study between the [university] and [hospital district]. There are three rounds and I'm in the middle one and I run a support group for eight weeks as an expert by experience at a psychiatric polyclinic. And then there's a comparison group who just fill in forms about how they feel and a professional run activation group. I hope that this study could show the benefits and how much group treatments can help and how much experts by experience or using this kind of service can benefit patients. And I hope it will increase job positions for example at the psychiatric polyclinic. I've got large-scale plans in mind. (laughs)

The interviewees wanted to be seen as legitimate actors, able to comment on services, provide advice and work jointly with health professionals. However, they did not have professional qualifications, the content of their work lacked clear definition and many of them were voluntary sector actors, not paid employees. They attempted to differentiate themselves from other service users as well as health professionals by emphasising their training, knowledge and skills. Experts by experience had undergone training that lasted for several months and they expressed strongly that training should be a prerequisite for the work that they did. Peer support workers' training only lasted for a few days, but all the interviewees agreed that it needed to be compulsory. Past training and work experience were also described as sources of knowledge and skills that could be applied in the healthcare contexts:

- Expert by experience: And now I'm undertaking this training in substance abuse work and that's an important step. You can build yourself up and maybe it gives you more credibility in these working groups and projects.

In addition, interviewees attempted to create wide networks to gain influence and, during the interviews, they drew attention to their connectedness by namedropping well-known doctors or describing involvement in high-level service management groups. These activities aligned the interviewees closely with professionals and involvement opportunities appeared to be dependent on personal networking abilities. However, active involvement also required the interviewees to constantly learn more and train themselves further. Many of them used professional terminology, were familiar with the

latest treatments, talked about new medications and their availability and explained what the care pathways for different patients were. Although they emphasised their knowledge of the everyday life, they were also required to adapt to institutional settings by understanding the professional lingo:

Expert by experience: I always google the terms at the table when I'm listening to organisational level stuff, so that I don't lose face by asking hey what are you all talking about.

The interviewees talked about their experiential knowledge base, which was a combination of personal illness experiences, experiences of other patients, knowledge of the care system and information that had been gathered from both scientific and non-scientific sources. Despite utilising personal experiences, they emphasised the importance of distance and the ability to adjust to different service settings where new specialist knowledge and skills needed to be obtained.

(Un)equal collaborators – working with health professionals

In health service settings, the interviewees came into close contact with professionals. Some of them worked side by side, while others worked in the same physical area but not necessarily in collaboration. Both peer support workers and experts by experience discussed their interactions with health professionals in positive terms and many had felt that their views were valued. Nevertheless, there were also barriers to joint working. These could include physical barriers such as limited workspace within hospitals or barriers related to their position within the professional hierarchy. In the extract below, the interviewee describes how he is invited to speak at information events aimed at newly diagnosed patients. However, his talk is always scheduled last, after talks from all the health professionals:

Peer support worker: I've been to these information events that they have at the hospital every two months. I've signed up for those and I gladly go there to visit. At the end of the day when everyone is alert and has been listening to those lectures all day then I'm the last one who talks there. I look at my watch to see how much time I have before it's 4 o'clock. Then I do a small thing about peer support groups, although there aren't many people there then.

Although, experts by experience had gained entry into a wider variety of health service settings, their place within these services continued to be vague and a source of confusion among professionals:

Expert by experience: It's been a few years since I signed a contract with them. And some of the nurses I've known since I started going to there, but there are also new people. And at first, they

didn't really know how to take me, like is she a patient or a client or a care worker or an agency worker. So first, it was like that. Then they accepted me and sometimes I even get praise. But then it's things like, I cannot give out medication and such. So even if they are grateful then I still feel that they are professionals and I'm just a peer or an agency worker or. No, no, I don't think they consciously do it.

Practical implementation of involvement was still very much reliant on professionals' attitudes. One of the interviewees who was working in a service development group alongside professionals talked about some of the other members choosing not to communicate with him:

- Interviewer: You've worked in a lot of places. What has the reception been like from the different professional groups?
- Expert by experience: It's been varied. I've been lucky that a couple of years ago I got into the psychosis services management group. (...) I've been lucky to meet a few people who are positive about experts by experience and understand the meaning of experiential knowledge. You notice that the reception has been varied and you notice that with some people there just hasn't been any communication. And when you meet them it can be just like hi, nice to meet you. But then there are those who are in touch on a weekly basis and want to know what's going on.

These examples do not show an outward rejection of peer support workers or experts by experience. However, these subtle things can reflect certain ambivalence towards involvement. Although service strategies present involvement as a necessity, there is very little concrete guidance on implementation, which can lead to confusion and uncertainty. Our interviewees were eager to engage with health services, but their views could also differ in relation to the level of integration they wanted to achieve. Some were striving to become paid employees, whereas others were only willing to engage as voluntary actors who may lack a legitimate position but are able to maintain a critical distance to services. The country context can also be a factor, as in contrast to countries such as Canada, the United Kingdom or the United States peer support workers in Finland do not receive pay for their work. All the interviewees had completed training to become peer support workers, spent a considerable amount of time engaging in support work, attended lectures and followed new research developments. Yet, some of them saw themselves as volunteers and even suggested that receiving a wage could compromise their credibility:

- Peer support worker: But this cannot become a job, because once you start doing it as a job, you're just doing it for the pay and it loses its meaning.

In the above extract, the interviewee also makes a difference between support workers and professionals who do receive pay. Support work is described almost as a calling and doing it voluntarily highlights their commitment to helping patients. However, this is not a view shared by all the peer support workers and some were hoping that they could become a more established part of health services. Experts by experience currently have many more paid work opportunities available to them and hence a legitimate position within health services can appear much more achievable. However, these arguments over pay highlighted the conflicting feelings our interviewees held in relation to integration. Some of the interviewees were afraid of losing their connection with patients or not being able to voice criticism if they became paid employees. Others argued that the lack of pay placed them in a differential and potentially less valued position and in the extract below the interviewee questions whether it is fair that people whose resources are limited due to the illness as expected to work free:

Expert by experience: I gladly do things on a voluntary basis, but when you think that you're a rehabilitee and only have a limited amount of resources that you're using on something. Then in a way, you're doing a lot of stuff free when you're not able to do actual work. And maybe your work would be more highly appreciated if you were paid for it.

Another aspect that could influence peoples' views on pay was their position in the job market. Some of our interviewees were retired and were not actively looking for a second career, whereas others had lost their previous jobs due to the illness and for them gaining paid employment could be seen as an important goal or a benchmark.

Discussion

Integrating people with personal illness experiences into health services has become commonplace in a number of countries and involvement is high on the health policy agenda. Hence, in this study we have focused on involvement from the perspective of lay participants and explored the justifications they provide for involvement, how they attempt to negotiate access into varied health settings and establish themselves as legitimate actors and collaborators. Based on our results, we would describe involvement as a balancing act as people with illness experiences are expected to represent the voice of experience and align themselves closely with other patients. However, attempting to become legitimate actors in health service settings places new requirements on them and can lead participants to adopt more professionalised traits. Our interviewees appear to move fluidly between service settings, stakeholder groups and different roles. In order to find their own distinct position, they need to both align with and differentiate themselves from patients, patient organisations, health professionals and health policies.

The interviewees also displayed a high level of discursive competency, as they were both aware of the different justifications provided by patient groups and policy makers and able to utilise them effectively. They aligned themselves with the empowerment discourses of patient movements that place emphasis on recovery and hope (Hui and

Stickley, 2007). However, they also utilised rhetoric that was borrowed from Finnish health policies and strategies (Jones and Pietilä, 2017). They acknowledged that policy documents provided backing for their inclusion and due to this the language of empowerment was often mixed together with patient-centeredness, quality and efficiency. They also provided concrete examples, arguing that patient-centred care required people with illness experiences to be included in service planning and development. In addition, they claimed that having someone with personal experiences working in care settings offered patients opportunities to share their feelings and experiences more openly. One of the central justifications for involvement contained criticism of health professionals' abilities to respond to patients' needs and challenged health professionals to take into consideration the emotional and social aspects of illness. Hence, the interviewees aligned themselves with the long-standing criticism that biomedicine in particular fails to locate the body within its socio-environmental context (Nettleton, 2006). Some were even involved in ongoing research studies in order to gain evidence that involvement in service production could produce direct benefits to patients. By doing so, they were able to tactically produce a more solid foundation from which they could argue for involvement and attempt to establish themselves as legitimate participants within health services.

Although involvement receives a lot of support from policies and strategies, at least on a rhetorical level, it does not automatically secure entry into community and hospital settings. Gaining physical access to hospital settings proved to be rather challenging and peer support workers in particular were often confined to communal areas such as lobbies. Access to hospital wards required further negotiation, which highlights the position of experiential workers and experiential knowledge in relation to the position of health professionals and their knowledge base. Shuval et al. (2002) have argued that hospital medicine in particular represents the 'ideological, epistemological, and institutional core of biomedicine' (p. 1745). Hence, without thoughtful planning and facilitation, it can be difficult for people with illness experiences to become integrated into an institutional setting with its existing customs, norms and cultures. The strategies utilised by our participants included networking and collaborating with professionals who were keen to promote involvement. Through these networks, they could gain access into new areas and gain new work opportunities, which in turn helped them become more established and recognised among professionals. However, based on our findings, health services' commitment towards involvement appears rather ambivalent. Involvement is promoted, but its success is not actively facilitated by anyone. One consequence is the feeling of not fully being part of the team or being confused about one's position within a service that bears similarities to 'mutual powerlessness' described by Broer et al. (2012). These feelings can stem from lack of guidance and planning, which can lead to confusion over job duties and responsibilities. Poorly defined job roles can also hinder integration into the workplace and can make it difficult for participants to be successful in their work (Jacobson et al., 2012). Although joint working with professionals was described in positive terms, involvement was often reliant on the professionals' discretion. In order to be seen as a legitimate participant, the interviewees were expected to adjust and learn the institutional lingo and practices.

People with illness experiences are required to create close relationships with health professionals in order to gain access into services. As mentioned before, participants can

also be expected to adapt their behaviour. In our findings, we can see elements of professionalisation of lay participants (El Enany et al., 2013) as many of the interviewees frequently used professional terminology, actively sought the latest information on service developments and treatment options and differentiated themselves from other patients. Integration into health services can limit the amount of criticism that participants can voice and potentially depoliticise involvement. Indeed, prior studies have suggested that involvement in health care raises a risk of services colonising experience-based work (Rebeiro Gruhl et al., 2016) and limiting the sharing of personal experiences (Gillard et al., 2013). In order to be seen as legitimate actors, our participants differentiated themselves from other patients by imposing their own requirements for involvement. Maguire and Britten (2017) have talked about the lack of specialist knowledge and education being central requirements for involvement, as participants are expected to provide lay perspectives on issues. Although our participants emphasised that the importance of experience training had become an unwritten requirement among both groups, allowing them to enhance their skills, process their experiences and produce a story that they could use as a tool in different working environments, they also highlighted other qualifications, communication, IT and media management skills, which were deemed as necessary. The strong emphasis on training may be due to the country context, as Finland has a strong cultural tradition of valuing education. However, these 'qualifications' also produced boundaries and access requirements that can lead to others being excluded from involvement activities.

Despite aligning themselves with other professional groups, the participants also wanted to ensure that they could maintain a sense of independence and freedom to express critical opinions. They wanted to ensure that they did not lose their authenticity as people with embodied illness experiences. Our participants expressed their determination to discuss their personal experiences openly, describing it as a central part of their work and crucially important in their attempt to challenge stigma and provide hope. In the future, it would be important to consider the steps that can be taken to ensure that participants are able to maintain their distinctiveness that stems from having personal experiences.

Although our study has highlighted the similarities in experiences by peer support workers and experts by experience as they attempt to work within health services, we acknowledge that there are differences between these groups that do not relate to their work or job title. Our study participants have all experienced prostate cancer or mental health problems (depression, bipolar disorder, schizophrenia and psychosis). Mental illnesses continue to carry stigma and negative preconceptions that continue to be associated with these illnesses can have a strong impact on people's lives and social relationships. These illnesses can be cyclical in nature, which means that the person never feels fully recovered although they may not experience any symptoms. Illness experiences vary greatly between individuals. However, prostate cancer usually occurs much later in life, and although it is associated with shame and embarrassment, it is unlikely to impact on the person's social life or work prospects in the same manner as mental illnesses. Varied personal illness experiences and how specific illnesses are treated or perceived in society are also likely to motivate people to participate in different ways.

Conclusion

This study has focused on the justifications they provide for their involvement that include the need to be cost effective, increase patient orientation and provide holistic care to all patients. They also challenged health services by highlighting the lack of resources and the limitations of health professionals' knowledge base. Common experiences shared with other patients enabled them to argue that health services were unable to respond to emotional or social needs of patients or help them to navigate the complex care system. There were differences between the two groups, as peer support workers described difficulties in entering service settings and were more likely to work alongside professionals than in collaboration with them. Despite integration into service settings, the participants were still facing challenges due to the vagueness of their position and did not feel fully integrated even when they were paid team members. Overall, the position of people with illness experiences appeared to be a fluid as it could change and vary depending on service setting and the interpretations of the work content. Fluidity is also a reflective term to describe the positions peer support workers and experts by experience adopt in relation to professionals and patients. It was a balancing act to be seen as legitimate actors as it required aligning and differentiating themselves from these other groups, finding a space somewhere in the middle. On a practical level, it is important for services to develop guidelines and clearer job descriptions jointly with people with illness experiences and patient organisations. This can alleviate role confusion and 'powerlessness', which can be experienced by experiential workers and health professionals. Local-level guidance is also required to reduce people with illness experiences having to rely on professional discretion to become involved.


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PUBLICATION

III

Personal perspectives on patient and public involvement – stories about becoming and being an expert by experience

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Personal perspectives on patient and public involvement – stories about becoming and being an expert by experience

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Abstract Patient and public involvement activities bring ‘lay participants’ and their accounts of lived experiences to the centre of health service development and delivery. For individuals, these accounts can provide an important resource, offering a sense of control and an opportunity to re-frame past events. Furthermore, as involvement activities and the use of personal accounts have become more prominent, it is timely to examine the involvement process from the perspective of the ‘lay participants’. Hence, the aim of this study is to explore how people become involved and how they construct the accounts of their lived experience. We analyse the stories of people with lived mental illness or caring experiences, who have become experts by experience ($n = 13$). We argue that becoming an expert by experience can help to re-contextualise past experiences and support the re-discovery of skills and expertise, leading experts by experience to construct both professionalised and politicised identities. The process has the potential to enforce narratives that portray illness experiences as motivators for social action and change. Additionally, we claim that the stories experts by experience share with health services and the public are not ‘lay accounts’ or ad hoc tales, but accounts constructed to serve specific purposes.

Keywords: identity, mental illness, narratives, patient and public involvement, personal stories, recovery

Introduction

Bury (1982) has famously described illness as a biographically disruptive event that can force people to re-evaluate their life, values and behaviour. One way to make sense of a disruptive event and to regain control is for people to become storytellers and ‘recover the voices that illness and its treatment often takes away’ (Frank 1995: xii). On a personal level, stories have the potential to support recovery and self-empowerment. However, stories can also have wider significance. The ‘narrative turn’ in society has shifted attention onto reflexive, subjective and culturally engaged first person stories (Grant *et al.* 2015). Concurrently, the growing prominence of patient and public involvement initiatives, taking place in a number of countries (Dent and Pahor 2015), places personal experiences to the centre of service development. Personal stories about living with an illness or caring for an ill family member can be used to

inform practice, health policy and the research agenda (Nielsen *et al.* 2013). Involvement opportunities have enabled a group titled experts by experience (Meriluoto 2017, Noorani 2013) or lived experience workers (Byrne *et al.* 2016) to participate in health service development and delivery. Experts by experience have lived illness or caring experiences that form the basis of the expertise and, which are utilised through different involvement initiatives. They can work as trainers, co-planners and co-producers alongside health professionals. There has been extensive research on patient and public involvement focusing on issues such as the conceptualisations of involvement, benefits of involvement for health services, problems related to implementation and attitudes of different stakeholder groups (e.g. Dent and Pahor 2015, Lehoux *et al.* 2012, Sholz *et al.* 2017). In this study, we will take a personal perspective on the involvement process and focus on the narrations of becoming and being an expert by experience. These personal stories also enable us to explore the opportunities and tensions associated with becoming involved, and how the process can influence the accounts experts by experience share with health services.

A central aspect of becoming an expert by experience is constructing a personal story, which can be used as a resource in involvement activities (Jones 2018). Prior studies have argued that becoming an expert by experience can be an empowering process that transforms the person from a patient into an expert of their own condition and acts as a stepping stone back to “regular life” (Rissanen 2015: 123). Toikko (2016) has suggested that becoming an expert by experience consists of individual and collective processes that include sharing experiences and creating distance from them, combining experiences with existing competencies and developing an orientation towards the future. However, as Meriluoto (2017) has highlighted, this process may also curb the participants’ freedom by creating standards and expectations on their narrations and making alternative ways of knowing appear ‘irrational’. Additionally, experts by experience are expected to be in charge of their experiences and associated emotions. Näslund *et al.* (2019) have suggested that experts by experience need to learn to express their experiences in a way that produces ‘affective intensity, while not spilling over into uncontrolled illness’ (Näslund *et al.* 2019: 10).

In this study, we suggest that becoming an expert by experience can act as a springboard into a new life stage, where the illness experience is seen as a source of knowledge, expertise and a motivator for social action. However, the process of becoming requires individuals to share and produce a structured account of their lived experiences. Additionally, we argue that the process of becoming and the expectations placed on being an expert by experience can potentially marginalise certain narrative types, whilst enforcing the idea that illness experiences should act as sources of motivation and an opportunity for self-discovery and personal development. Before introducing our analysis and results, we will discuss the importance of personal stories for people trying to overcome a disruptive life event, which for our participants has been the experience of a mental illness or caring for an ill family member. Following this, we will briefly outline the policy and legislative context that guides involvement within Finnish mental health services and provide more information about the training process that prepares people to become experts by experience.

Personal stories, identity construction and cultural narratives

Serious illness can have a number of long-term consequences for individuals and their family members, leading to personal and lifestyle changes (Reynolds 2003) including loss of employment, reduction in social networks, intrusion of medical treatments to daily lives and the need to interact with an array of services. Additionally, mental illnesses can carry strong social connotations and conditions tend to vary in their severity, disruption and stigmatisation. Through personal stories, people can give meaning to their experiences, regain a sense of control (Kelly

1994) and re-establish legitimacy outside of illness (Charmaz 2000). Personal stories can also act as tools for identity construction (Bamberg 2011, Grant *et al.* 2015). However, the identities produced through narration can change over time and vary according to the situation. Hence, as Meretoja (2018) has suggested, they are temporal, situational and shaped by social and interactional contexts.

Although personal stories are based on individual experiences, they are not produced in a sociocultural vacuum. Frank (1995) has suggested that while stories are individual, people compose them by adapting and combining culturally available narrative types. Some of these narratives can be described as culturally dominant (Kirkpatrick 2008). The dominant narratives regarding people with mental illness continue to relate to poverty, homelessness or being involved in the criminal system, which can sustain discrimination and stigma (Kirkpatrick 2008). Existing side by side with these narratives are the historically dominant biomedical ways of understanding illness experiences. Although people with personal experiences have not constructed these narratives, they have the potential to be the paradigm through which we understand illness experiences and a standard against which people with personal experiences compare themselves (Bell 2014). In this study, we use the term narrative, when referring to larger collections of individual stories that follow similar form and structure.

The stories told by experts by experience, combined with the growing body of research conducted by people with personal illness experiences, have the potential to challenge biomedical and psychiatric narratives on mental health and distress (Landry 2017), as well as the identities imposed by dominant cultural narratives. Frank (1995) has focused on the personal stories told by people with an illness experience and described three 'narrative types' that people may adopt as they attempt to make sense of their experiences. The *restitution narrative*, often seen as medicalised, begins with health, followed by illness and looks for a return to health in the future. The *restitution narrative* stands in stark contrast to the *chaos narrative*, which lacks a specific sequence of timing and 'reveals vulnerability, futility and impotence' (Frank 1995: 97). Lastly, the *quest narrative* portrays the illness as useful and has three subtypes: (i) memoir in which events are related simply; (ii) manifesto in which illness becomes a motivator for social action or change; and (iii) automythology in which illness is universally expanded to reveal faith or destiny (Frank 1995). Frank's narrative types offer one way to understand the form of personal experiences. However, these narrative types are focused on the illness experience and subsequent recovery period. Nunes and Simmie (2002) have suggested that people have begun to move beyond the recovery paradigm to incorporate the experience into a larger life story. More recently, Kirkpatrick and Byrne (2009) and Martin *et al.* (2014) have written about the narrative of *moving on* that allows the individual to conceptualise the illness or other life event 'as one of the many disruptions that can occur in daily life.'

We will focus on the stories told by people who have either personally experienced mental illness or cared for an ill family member, and who have subsequently trained as experts by experience. We will explore how they describe the process of becoming and being an expert by experience and how they construct their identities within these stories. Their stories relate to patient and public involvement, which has grown into a multifaceted phenomenon, implemented in numerous and heterogeneous ways (Bherer and Breux 2012). These developments have allowed 'lay participants' to engage with health services in a new way. Hence, our participants are members of a small but increasingly growing group of people, who are able to contribute to service development and delivery. The emphasis of this study is to explore stories of becoming and being an expert by experience that focus on life after a disruptive event. However, we cannot completely dismiss the stories about their illness and caring experiences. After all, the illness and caring accounts are processed during training (Toikko 2016) and the experiential knowledge derived from these accounts forms the knowledge base of experts by

experience. Through involvement activities, experts by experience are using their experience-based knowledge to influence services. Hence, in addition to analysing the stories about becoming and being an expert by experience, we will also discuss how this process can have consequences on ways in which lived experiences are verbalised and presented. Before introducing the materials and methods used in this study, we will provide a brief description of the training of experts by experience and introduce the policy and legal framework that guides their involvement.

Experts by experience in the Finnish context

Patients' rights to participate in decision-making regarding their treatment were strengthened through legislation in the early 1990s. However, service level involvement (i.e. involvement in development and delivery) only became a prominent feature of health policies during the 2000s and 2010s (Jones and Pietilä 2017). The government, elected in 2015, continued to promote involvement in their Strategic Programme (Prime Minister's Office 2015) for health and welfare. Currently, health service organisations are not legally bound to involve patients, but many of them have adopted policies that support involvement. A statement published by the Ministry of Social Affairs and Health (2018) suggests that the inclusion of expert by experience in mental health and substance abuse services could become a legal requirement in the near future.

The use of the term expert by experience can be traced back to the 1990s, when a mental health organisation began to train people with lived experiences. Nevertheless, the term did not become widely adopted until 2009, when it was included in the National Programme for Mental Health and Substance Abuse (Ministry of Social Affairs and Health 2009). Since then, several voluntary sector organisations and hospital districts have begun to train experts by experience. Additionally, in 2012, a group of trained experts by experience founded their own organisation, which now provides training, manages work bookings and participates in public discussions regarding involvement. The training is not compulsory and one can adopt the title of expert by experience even without the training. Nevertheless, the training courses are popular and provide a clearer pathway to those who wish to become actively involved. Training can also be seen to provide experts by experience with additional legitimacy to work within health services, alongside established professional groups (Jones and Pietilä 2018).

Due to the large number of training providers and the lack of mutually agreed content or standards, there are variations between training programmes. For example, the lengths can vary between 2 and 9 months, with the participants attending training sessions approximately once a week. The training sessions are group based and commonly include information about working as an expert by experience, knowledge of the service system and legislation, information about mental illnesses (provided from the professional perspective) and practical support such as media management, marketing and presentation skills (Hirschovits-Gerz *et al.* 2019, Toikko 2016). Another core element of all training is disclosing personal experiences with the other group members, gaining feedback from them and constructing a personal story, which is rehearsed during the training. Although each individual participant develops their story from personal experiences, Meriluoto (2017) has highlighted that the training process can contain practices, such as the requirement to re-frame experiences as neutral or objective, which restrict the participants' freedom to reconstruct themselves.

Materials and methods

The individual interviews ($n = 13$) analysed for this study were collected in Finland between winter 2017 and summer 2018 by the first author. Eleven of the participants had personal

experiences of living with a mental illness (e.g. bipolar disorder, schizophrenia, psychosis, depression), one of them had experienced mental illness and cared for family members, and one had been a carer for their spouse. The participants were aged between 23 and 62. Four participants held professional healthcare qualifications, and had worked in health or social services prior to their illness. A vast majority of the participants had not been able to continue in their previous profession following the illness. All of them identified themselves as experts by experience. However, two of the participants had not taken part in formal training. Instead, they took part in a group where personal stories were shared and constructed in a similar manner to 'formalised' training sessions. The participants had been involved in the assessment and development of services and care pathways, training of health professionals or worked as co-producers, i.e. they were providing care services to patients jointly with health professionals. The first author recruited participants by contacting organisations, which provide expert by experience training and act as the main points of contact for recruitment. Prior to the interviews ethics approval was sought from the relevant ethics committee. All the participants gave verbal and written informed consent. The interviews were recorded and transcribed verbatim. In order to ensure anonymity, the participants have been given pseudonyms, which are used in the results section.

Analysis

The initial idea of this article was sparked by our interest in 'lay participation' in Finnish health service development and delivery. More specifically, we wanted to focus on a growing group of people, who title themselves experts by experience, and explore how they construct their expertise and use their lived experiences. With these ideas in mind, the first author conducted interviews with people, who identified themselves as experts by experience. A topic guide covering different themes (such as motivation, experiences of working as an expert by experience in different settings, training and content of different work tasks) acted as a basis for each interview. However, it was used flexibly to allow for free discussion of topics the participants considered relevant or important. At the beginning of each interview, the participant was asked the question: Could you tell me how you became an expert by experience? Instead of providing a technical account of their training, the participants began to talk about their lives prior to becoming ill, their treatment experiences, the recovery process and subsequent training as expert by experience. Their experiences and work as experts by experience were further explored by asking questions that facilitate the telling of stories (e.g. could you tell me about the work you have done as an expert by experience; would you tell me about the challenges/rewards related to being an expert by experience). The interview materials were not initially gathered with a narrative analysis in mind. However, whilst reading through the materials, we noticed that the interviewees often talked at length about their experiences, providing examples, telling anecdotes and outlining how they 'transformed' from patients or carers into experts over a period of time. We found this process particularly interesting and wanted to explore it in more depth. Hence, we decided to approach the interview materials as stories about the experiences and accounts of being an expert by experience after reading through the transcribed texts.

Our aim was to explore the ways in which these of active 'lay participants' are constructing their lives and identities following a disruptive event. Hence, we focused specifically on the types of stories told and the ways in which the participants positioned themselves within these stories, and also during the interview situations (Bamberg 1997, 2006, De Fina 2013). The questions we set out were: (i) *How do people with lived experiences describe the process of becoming and being an expert by experience;* (ii) *What kinds of identities do they construct for themselves through their stories;* and (iii) *What kinds of narratives do their stories draw*

from? In the analysis, we approached the stories told during interviews as verbal acts that are performed in situated and interactional contexts (Bamberg 2011). The analysis was informed by Bamberg's (2006) suggestion that stories have different temporal levels and positioning can occur within the story as well as during the interactional situation where the story is being told. Additionally, Bamberg (2006) argues that people also position themselves in relation to the question 'who am I?' and through this they take part in the construction of normative discourses.

The analysis began by first identifying stories describing the thematic content of becoming an expert by experience and working as an expert by experience. These accounts followed very similar patterns as the interviewees usually talked about their past illness or caring experience, their decision to attend training (or equivalent) and working within different health related environments. These events were not always told in the same order, but they were featured in all the interviews. Following this, we analysed how the interviewees position themselves within their stories and over the different periods their stories covered. Moreover, we took into account how they position themselves within the interview situations. They are told by people who have gone through a disruptive life event and now wish to engage with health services as experts. However, their position within health services is not fully established and their claims to expertise are not always recognised (Jones and Pietilä 2018). During the interviews, the participants often emphasised their expertise and knowledge, portraying themselves as capable and competent. Hence, the interview situations were partially seen as opportunities to present oneself positively and to promote the work done by experts by experience. Due to this, some of the more negative experiences and emotions may not have been expressed during the interviews. Lastly, we explored whether the stories told by the participants about becoming and being an expert by experience have similarities with larger narrative types (described e.g. Frank 1995, Kirkpatrick and Byrne 2009, Martin *et al.* 2014), as people are often influenced by, and draw from, culturally available narratives when they are telling their personal stories (Ahmed 2013).

Results

We have divided the results into two parts. In the first part, we will explore the process of becoming an expert by experience that includes sharing lived experiences and constructing them into a structured personal account. This process enabled the participants to *re-discover* their expertise by re-connecting with prior skills and combining them with new knowledge. The emergence of this re-discovered identity was deemed necessary by the participants as it formed the basis for the next stage in their stories. The second part focuses on being an expert by experience. In these accounts, the participants construct both *professionalised* and *politicised* identities that allowed them to establish themselves in new working environments and as credible advocates. We also recognise that there were nuances between the stories, as some of the participants were more inclined to seek an established professional role, whereas others described being an expert by experience more in terms of societal action. Despite these differences, the stages of being and becoming as well as the identities described in this section, featured in all the accounts.

Becoming an expert by experience and the re-discovered self

The participants commonly began their accounts by talking about their lives prior and during the acute illness period. They described the disruptions by the illness, such as having to give up work, reduced social contacts, spending time in hospital or experiencing treatment side-

effects. Those caring for a family member had experienced losses, feelings of helplessness and they had needed to dedicate much of their time to understand how to navigate the health and social care systems. During the recovery period, they had found out about expert by experience (or equivalent) training and had decided to apply. Meeting others in a similar situation was described as a significant experience that allowed the participants to reflect and begin to verbalise their experiences. Attending the training sessions provided them with a meaningful activity and an opportunity to work through difficult emotions. Through this process, the participants could also start to construct identities, not as patients or carers, but as experts of their own lives and conditions. In the extract below, Anna has been asked about the training she had attended. She begins by describing the time she attended the first training session:

Anna: I remember how timid I was, going there for the first time. Although I had performed publicly before and been a trainer, I was at rock bottom, lacking any self-esteem. You could say that it provided a path back into this society and away from complete isolation. It was a turning point when I began to formulate my life story, and that's where all rehabilitation stems from. We started to practice telling our own stories. I felt that I was being treated as an equal and I received admiration and respect, like "wow, you've gone through that."

In her account, Anna describes how the training had changed the way she felt about herself and her past experiences. The encouragement she received during training and her encounters with others allowed her to transform. During the interviews, the participants emphasised that these encounters with others allowed them to share embodied experiences, compare different ways of coping and navigating health services. Caron-Flinterman *et al.* (2005) have suggested that through this process, lived experiences can be combined and turned into a collective pool of experiential knowledge. The training process enabled participants to view past life-events as challenges that they had overcome. The participants also highlighted that they had gained ownership of their experiences and re-contextualised them as positive resources. Hence, the illness experience could be interpreted as useful (Frank 1995) or as one of the participants described, *before the training, psychosis was a really difficult thing, but once I've started this expert by experience work, it's a treat talking to people about it.* As Anna's story above reflects, there was a significant difference in how the participants described their past and present selves. The past selves were often referred to as isolated, confused or low, whereas the present selves had more self-esteem, knowledge and resources to cope. Like in Tomi's story, the training period was described as a rehabilitative process that provided coherence and a new sense of direction:

Tomi: The past 5 years were a dark period in my life. I was at home too much. Not enough social contacts and I began to fear people and life. But becoming an expert by experience has provided me with a set of keys. I can turn the key in a lock and get back into the light. For many, it can be a turn for the better and a reason to go forward in life. When you asked me what it means to me. Well, I would never talk about something like a leather sofa in the same way [as personal experiences]. We're talking about important issues here. The first lecturing jobs [were rewarding for me], since I'd done a lot of acting before, but had to stop because of my illness. I started to enjoy performing again, in a different role of course, but there are similar elements.

Tomi emphasises that becoming an expert by experience has been personally meaningful for him. He has been able to re-connect with some of the skills he already possessed and he was

able to start using them as he took his first steps as an expert by experience. The personal recovery aspect was not as strongly highlighted in the stories told by the participants with caring experiences. However, they also talked about the importance of turning experiences into a structured account and finding value in the skills and knowledge of the care system that they had accumulated. Tomi's story also highlights another common feature of the interviews. During the interviews, the participants wanted to create distance between their past and present selves by emphasising how skillful and capable they had become. Despite the rehabilitative and supportive aspects, the main aim of the training was to prepare the participants for future work. In order to become an expert by experience, the participants were encouraged to construct a clear story, outlining their illness or caring experience. Hence, through practice and feedback, they began to create structured accounts, aimed at wider audiences such as health professionals, policy-makers and the general public.

Marko: The experience is structured for you during the training and you give practice lectures and as you work on it you gain different perspectives. This training is definitely good and a great springboard. The practice lectures give you certainty and following them the trainer says, "you've given three lectures here, how about trying out with an audience?"

Marko continued to explain that in order to become an expert by experience, one must learn to articulate experiences clearly. Otherwise their message would sound incoherent, like *porridge* to outside listeners. The same idea was echoed in the other accounts of the re-discovery phase. The participants wanted to be able to relay their embodied experiences to others, yet emphasised the need to step back and distance themselves from what had happened. They talked about using these structured stories in a multitude of different ways depending on the audience and explained that these stories were tools through which they can *give hope* or *provide an example* of overcoming challenges. As these structured stories are the main 'tools' experts by experience use in their work, questions arise on whether the training process could reinforce certain forms of illness narratives, such as the restitution and quest narratives that portray the illness as an opportunity for growth and development (Frank 1995). In order to become an expert by experience, the participants needed to show that they had overcome past challenges and were now able to move on, which can potentially marginalise certain narrative types, such as the chaos narrative that 'imagines life never getting better' (Frank 1995: 97). One of the participants, Heidi, directly addressed this issue, recognising that becoming an expert by experience requires proactivity from individuals, which means that those who lack hope and motivation may not become experts by experience. Those who are not willing or able to participate in the process and formulate a story with a clear message may be less likely to participate, which means that more chaotic stories may be less unlikely to filter through to health services.

Overall, in the stories that outlined the process of becoming an expert by experience, the participants constructed themselves as experts of themselves and their lived experiences. They were able to re-discover strengths and combine what they already knew with their newly acquired knowledge. Despite recognising some of the challenges related to the training process, this phase was described as a necessary first step that created a foundation for professionalisation and motivated the participants to influence societal issues.

Life as an expert by experience – the professionalised and politicised self

Following the initial training and story construction phase, the participants had entered health services and taken on a variety of roles such as peer group leads, members of managerial

groups, trainers and developers. The level of involvement varied, as some were more comfortable with occasional work, whereas others actively viewed this as a stepping stone into a new career. However, the position of experts by experience within health service organisations remains unclear (Jones and Pietilä 2018). Trying to gain acceptance and appreciation in an environment dominated by established professional groups was not easy. Perhaps due to these reasons, the participants emphasised the importance of training *to set personal boundaries and express yourself clearly* and explained how they were constantly educating themselves further. During the interviews, they often listed their training and work experience, with some of the participants even bringing work portfolios to the interviews. In the next extract, Jenni talks about the importance of being trained and possessing professional traits, such as adaptability:

Jenni: I've participated in the expert by experience training and I am also a trainer. But currently the title is not protected so the service providers can receive varied service if they get an expert by experience who hasn't completed the training. I'm sure some of them are skillful and great people but if you order an expert by experience through us then quality has been verified and the person can manage this type of work. You need flexibility and adaptability to work with in different situations. And you need to adapt your story and your speech so it's not just the same 30 minutes and there are no other versions. Professional skills should be developed further whilst working. [Lists different development and research projects she is involved in currently] I have distance from my experience, so I see things differently. Even staff and doctors can ask me questions that they could not ask a patient. I am not acutely ill, so I can take things differently and I can tell what people might need in those kinds of situations.

Jenni had been able to establish herself and had created a wide network of contacts. In her story, she emphasises the importance of training, skills and continuous development. Jenni argues that she has successfully left the raw illness experience behind and is no longer a patient, but a fellow 'professional' able to work in a multitude of specialist roles. Indeed, those who were actively engaged in involvement activities expressed that they wanted experts by experience to be seen as a legitimate participant group or even a 'professional title'. Those who lacked the correct 'qualifications' were not always considered legitimate experts by experience and their ability to participate could be questioned.

The illness had prevented many of the participants from returning to their previous profession. However, as experts by experience, they could return to work at least part time and in some cases to similar working environments as before. Four of the participants held health or social care qualifications and this 'dual-qualification' they now possessed enabled them to reconnect with their previous knowledge and skills and combine them with their experiences. In the following extract, Katri talks about the transition back into work following the training:

Katri: I just finished my expert by experience training last April. I was selected to the management group and then the opportunities have arisen from that, like getting to work in partnership with a nurse in the acute services. I've got a background in health care, working as a specialist nurse in an operating theatre and in the acute service. So I've been able to continue that kind of work.

Some of the participants without a 'dual-qualification' had been motivated to educate themselves further and gain health professional qualifications in a field such as therapy or substance abuse work. One of the participants explained that his new degree *provides more credibility in these working groups and projects*. Additionally, the participants sought information from a

number of sources, which enabled them to become highly specialised in their self-proclaimed fields of expertise. Every time the experts by experience participated in involvement activities, their knowledge and networks expanded. Professionals and managers then requested them to participate in new projects, many of which required specialist knowledge of the healthcare system, care pathways and complex needs. Although working within health services could be demanding, it was predominantly described in positive terms.

Leena: At the first meeting when I introduced myself, I said that I'm not quiet and I'm here to get noticed. So from the start they were like "ok." Some were a bit suspicious at first, questioning whether I understood what's going on or knew what I'm talking about. But respect must be earned and very quickly I was a full-fledged member of that group.

Much like Katri's seemingly smooth transition back into work, Leena's story is also that of success. She was able to triumph despite being met with suspicion. This was a common feature in all the accounts of working in professional setting. Some of the stories contained descriptions of health professionals doubting or belittling the experts by experience. However, these accounts often ended with the expert by experience becoming an accepted participant. The participants made small references to other experts by experience, who had not been as successful and had no longer been invited to managerial groups or offered new work opportunities. This can indicate that the acceptance of experts by experience is still largely reliant of professional approval. Those who are able to establish themselves needed to balance between being critical and able to compromise. This created some tensions in the construction of the professionalised self, as the participants wanted to ensure that they could also voice criticism. As one of the participants expressed it, experts by experience wanted to be legitimate collaborators without becoming *poodles* who uncritically accept the agenda set by others.

Entering health services as experts by experience was also a signal that the participants had 'moved on' with their life, stepping further away from the personal. However, working within health services and developing them from within was not the only path available for experts by experience. The process of re-discovery had provided the participants with an opportunity to compare experiences and uncover collective grievances. They were able to draw from embodied and social experience and make the personal political. Some of the younger participants identified themselves firstly as *mental health activists* and they drew ideas for action from shared collective experiences. In the following extract, Heidi explains her motivation for becoming involved with a group of experts by experience and combining her personal experience with the experiences of others to *change things*.

Heidi: When I got involved, I thought that I've got difficult experiences and the care system has not worked at all for me. I was not cared for and I could see a lot of problems. I wanted to do something to change things. We meet every 2 weeks and talk about what we want to do. We had this idea for a board game that would demonstrate what it's like to live in this system. During the game you wander around and the game instructors give you guidance and tell you the rules, but the players get into situations where they really don't know what to do and there are all these barriers that prevent you from getting where you want to go. We've developed this game based on experiences gathered from lots of people.

Heidi and the other group members gave lectures and they had created a game, which they played with professionals and policy-makers. By using their lived experiences, they wanted to

highlight the barriers that people with mental health problems can face in their daily lives. The socially and politically motivated activities could take on several forms, such as the promotion of experiential knowledge and challenging stigma by telling one's story in the media. A group of experts by experience had formed their own organisation that was trying to provide practical guidelines for experiential work and promote a clearer pay structure. Additionally, they shared information about ongoing training around the country, answered queries and acted as a point of contact for organisations who wanted to employ experts by experience. After her training, Jenni had joined the organisation, worked in a number of different involvement projects and had taken on an active role promoting expertise by experience in the media:

Jenni: This [work of experts by experience] has been raised into public discussion. I have been in charge of communication [for an expert by experience organisation] and worked hard to make this a more visible phenomenon in Finland. Maybe that has helped. I don't get paid for it, but I've really enjoyed that I get to do this and bring about some change. Some people may think that this is challenging and opens up old wounds. But I know how to stay within my own comfort zone even when I talk about terrible things that have happened to me. I'm at peace with it.

Jenni emphasises that she has processed her experiences and is now able to advocate for others. She describes her work almost in terms of a calling. However, advocating for others in this very public way turned experts by experience into the public faces of illness and caring experiences. Sharing their stories in newspapers, magazines and TV shows was described as an integral part of being an expert by experience. Nevertheless, it also created some tensions:

Leena: When you open yourself up, you have to be careful where to draw the line. Do you say "my father" or do you say "this one man." There's a difference. And you have to remember that Finland is a small country. If you don't know how to draw boundaries then you can tire yourself out pretty quickly. Sure it's flattering at first when you're asked for interviews and lectures. It would be flattering to anyone and that's normal. But what surprised me is that they wanted to know much more than what I was willing to share.

When Leena was asked to share some of the challenges she had faced as an expert by experience, she talked about her experiences with the media and how she had to learn to set boundaries to protect her privacy. Although the illness accounts shared were personal, they often included other people and the participants needed to decide whether or not to share information relating to family members. Leena had been an expert by experience for several years and in the extract she presents herself as reflexive and capable of staying in control, even in challenging situations. The worry about oversharing and becoming a face of illness experience was also raised by one of the younger participants, as she wondered whether her openness would backfire if she applied for a job outside of experiential work. Overall, issues around stigma were addressed in all the interview accounts.

In the stories, politicisation and professionalisation processes co-existed and even fed into each other as the participants gained more knowledge, skills and self-assurance from working both within and without health services. Overall, the decision to become an expert by experience had provided the participants with opportunities to process their own experiences and then enabled them to reconstruct a story that did not focus merely on personal recovery or health service improvement, but wider social and attitude change. A common feature of these stories about life as an expert by experience was their positive tone. Indeed, the participants

expressed that they felt proud of their work and were happy about the direction their life had taken after a difficult period. However, they may also feel the need to present a positive image of themselves and the work of expert by experience in order to promote it and ensure that their involvement continues to be supported.

Discussion

In this article, we have explored stories told by people with lived illness and caring experiences about the process of becoming and being an expert by experience. Based on our findings, we argue that the process of becoming provides opportunities for people to re-contextualise their past experiences, *re-discover* their skills and begin to construct *professionalised* and *politicised* identities. We also claim that the process of becoming an expert by experience can influence the way in which lived experiences are structured and presented. We will now discuss these findings in more depth and relate them to prior research on involvement and experiential expertise.

Thompson *et al.* (2012) have claimed that patient and public involvement ‘can provide opportunities for those involved to reconstruct reflexively positive subject positions based on their involvement and the acquisition of skills, knowledge and experience’ (p. 617). Additionally, Rissanen (2015) has highlighted how the process of becoming an expert by experience can act as a stepping stone into new opportunities. Our findings support these ideas, as the participants of this study expressed that sharing and verbalising experiences had supported their recovery. They also highlighted that the process of becoming an expert by experience had strengthened their self-esteem and reminded them of all the knowledge and skills they possessed. However, their stories also suggested that as a prerequisite for involvement, people need to become experts of themselves (Meriluoto 2017). During the training, they are expected to disclose personal experiences and to distance themselves from them. Indeed, Näslund *et al.* (2019) has suggested that people with lived experiences need to learn how to tell stories that convey vulnerability and resonate with listeners on an emotional level. Nevertheless, it needs to be told in a manner which shows that the narrator is in control of their story and emotions (Näslund *et al.* 2019). This was also advocated by our participants as they emphasised the importance of distancing themselves from the personal and constructing a clear, coherent account of their lived illness and caring experiences. According to the participants, this was done for two reasons. Firstly, they wanted to retain a sense of control, which meant deciding what to share and what to keep private. On a personal level, the construction of a structured account can provide coherence to past events and help to build a positive sense of self (Lysaker *et al.* 2010). Secondly, the participants expressed that the information and knowledge they shared with health services needed to be polished and structured. This may create pressure on the experts by experience to structure and present their experiences in ways that health professionals and health services find acceptable and relatable (Jones 2018). If the accounts are incoherent or difficult for the audience to understand, then they may not be regarded as ‘fit for purpose.’ Hence, the participants needed to make active choices about what they share and how they share their experiences. Based on these findings, we suggest that processing and constructing an account of past experiences may influence how past experiences are articulated. If the personal account needs to be neat and structured, then narrative types that lack coherence or imagine life never getting better (e.g. chaos narrative, Frank 1995) may not fit in with the ethos.

Whereas the re-discovery phase focused inwards, providing a meaning-making framework and preparation for the future, the politicised and professionalised identities directed activities towards health services and the wider society. Although our participants recognised some of

the challenges and tensions associated with becoming an expert by experience, their stories were largely positive in tone, highlighting how the participants had overcome adversities. Hence, the stories about being an expert by experience often followed a similar form to Frank's (1995) quest narrative, which portrays the illness experience as a motivator for social action or change or even an automythology in which the illness experience reveals a new destiny. For our participants, the illness experience became a stepping stone that allowed them to become experts by experience, re-connect with old skills, return to work and discover issues in society or the care system that they wanted to change. Additionally, working within health services could be an empowering experience and a signal that the participants were *moving on* (Martin *et al.* 2014). However, we also acknowledge that during the interviews the participants were not only providing accounts of their experiences and activities, but also advocating for the increased involvement of experts by experience. Additionally, they were familiar with the stigma and negative perceptions associated with people who have experienced mental illness. Perhaps due to these factors, they wanted to present themselves as capable and knowledgeable, and to construct identities that highlighted how active and skilled they were.

When describing their work as experts by experience, the participants no longer referred to themselves as patients or carers, but as educators, developers and service producers. They talked about the importance of specialist skills and knowledge that often exceeded personal experience and were continuously educating themselves further. Indeed, being interested appears to be an integral part of being involved and lay participants often draw from their experiential, cultural, social and relational resources as they become engaged with involvement activities (Lehoux *et al.* 2012). However, the patient and public involvement imperative has made it possible, and perhaps even necessary, for the participants to seek a more professionalised position within environments where established professional groups have traditionally been the decision-makers. Our findings suggest that involving lay participants more actively in health services may lead to them pursuing a more professionalised role and status. Unlike the interviewees in Maguire and Britten's (2018) study, who emphasised their 'layness', our participants tended to emphasise their specialist expertise and qualifications. This may lead to the development of hierarchies among the 'lay participants'. As El Enany *et al.* (2013) have argued, a segment of articulate participants who pursue a professional status can lead to the creation of a distinct body of 'experts' and exclude others that are considered as 'less expert'. Additionally, some of our participants formed an interesting subgroup for they possessed a 'dual-qualification.' In other words, they were trained as experts by experience and had professional training. This group of participants can blur the lines between lay and professional even further. As experts by experience, they had been able to re-enter the health services as experiential workers. They also had the additional benefit of understanding the norms, structure and terminology of health services, which could benefit their work prospects. However, even their stories highlighted that experts by experience were required to prove themselves in the eyes of the established professionals.

Prior studies have questioned whether patient activism can continue to exist alongside the professionalised self (Lakeman *et al.* 2007). Although there were tensions associated with adopting a professionalised identity, the participants appeared to combine the professionalised and politicised identities. This suggests that being an expert by experience is not only about influencing health services, but includes elements of activism and advocacy. Much like the expertise by experience in Noorani's (2013) study, the politicised self was based on authority and expertise that stemmed from collective meaning-making and connecting of experiences. Personal and collective experiences were gathered and verbalised by experts by experience and used to highlight problems, grievances and criticism. However, making the personal political

meant giving up some privacy for being an expert by experience often included sharing personal experiences publicly.

In this study, we have focused on the process of becoming and being an expert by experience. However, we acknowledge that our interviewees represent a group who have managed to secure a position as participants. They wanted to have a critical stance, but chose to actively collaborate and forge a working relationship with health professionals. Hence, these are stories told by people who have been successful in their attempts to become experts by experience. Those who have completed the training but have not been as successful integrating into health services may tell different stories, which are equally worth exploring. Overall, our findings highlight that becoming involved in health service development and delivery can be a transformative and meaningful experience. Nevertheless, as more people are trained to become experts by experience, attention needs to be paid to the content of the training, the ways in which lived experiences are processed and the potential stratification that the training requirement can create among lay participants.

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Data availability statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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PUBLICATION IV

**Representing the ‘voice’ of patients – how third sector organisations
conceptualise and communicate experiential knowledge in health service
planning and development**

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Representing the ‘Voice’ of Patients: How Third Sector Organisations Conceptualise and Communicate Experiential Knowledge in Health Service Development

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Abstract The growing prominence of patient and public involvement in health services has led to the increased use of experiential knowledge alongside medical and professional knowledge bases. Third sector organisations, which position themselves as representatives of collective patient groups, have established channels to communicate experiential knowledge to health services. However, organisations may interpret and communicate experiential knowledge in different ways, and due to a lack of inherent authority, it can be dismissed by health professionals. Thus, drawing on individual interviews with organisation representatives, we explore the definitions and uses of as well as the ‘filters’ placed upon experiential knowledge. The analysis suggests that whilst experiential knowledge is seen as *all-encompassing*, *practical* and *transformative*, the organisations need to engage in actions that can *tame* experiential knowledge and try to balance between ensuring that the critical and authentic elements of experiential knowledge were not lost whilst retaining a position as collaborators in health care development processes.

Keywords Experiential knowledge · Health care · Finland · Patient and public involvement

Introduction

Patient organisations and advocacy groups, made up of and representing people with lived experiences, have become important influencers in matters related to health and illness, health care and policy (Brown et al. 2004; Jongsma et al. 2018). As representatives of the ‘voice’ of patients, they bring knowledge derived from lived experiences into decision making and aggregate individual interests into collective interest through participation, deliberation and representation (Jongsma et al. 2018). Landzelius (2006) has suggested that these groups can be placed along a spectrum, ranging from informal (e.g. loose networks, online communities) to formal (e.g. organisations with governing structures, strategic targets and official planners). Although the groups and activists at the informal end of the spectrum can influence attitudes and mobilise action, the more formal organisations are the ones that are often granted access to decision making in relation to health services and policy. Indeed, in several countries third sector organisations are included in the planning and development of health services (Van de Bovenkamp et al. 2010; Martin 2012; Pavolini and Spina 2015). As patient and public involvement has become an integral aspect of many health developed health systems (Fredriksson and Tritter 2017), the role of these organisations in health service planning and development may be further solidified. These developments have also led to *experiential knowledge* being viewed as a distinctive form of knowledge and a contribution that patients make to decision making in the health field (Blume 2017). Experiential knowledge is founded upon people’s individual and collective experiences of illness and service use (Beresford 2019). However, prior studies have highlighted the heterogeneous nature of experiential knowledge, and how

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it is often underused and undervalued in health care (Noorani et al. 2019). Therefore, it is important to ask how the organisations claiming to represent experiential perspectives understand the concept of experiential knowledge and its' uses in health services. Thus far, experiential knowledge has mainly been explored from the perspective of patients and carers (e.g. Caron-Flinterman et al. 2005; Boardman 2014; Castro et al. 2019). By focusing on third sector organisations, we widen the perspective and deepen the conceptual understanding of experiential knowledge. We begin by introducing the concept of experiential knowledge and highlight the various ways in which it can be interpreted. Following this, we will discuss the role of third sector organisations as representatives of patients and their experiences in involvement activities.

Experiential Knowledge

Lived experiences can be described as the embodied, social and emotional experiences of living with an illness. Additionally, they can include experiences of treatment and services use. These experiences can offer insights into the everyday management of illness and recovery (Rowland et al. 2017). Lived experiences and experiential knowledge are closely interlinked, as the illness experiences are the basis upon which experiential knowledge is formed. This suggestion was made already in the 1970s by Borkman (1976), who argued that “experiential knowledge is truth learned from personal experience with a phenomenon rather than truth acquired by discursive reasoning, observation, or reflection on information provided by others”. Over the following decades, academics, people with lived experiences and groups representing them have adopted this concept and developed it further. Borkman (1990) herself continued to redefine the concept, describing experiential knowledge as holistic rather than piecemeal (like folk/lay knowledge) or specialised (like professional knowledge), emerging from the continuous and layered experiences of living with a problem. However, since Borkman's initial analysis, the concept of experiential knowledge has become less clear-cut (Boardman 2014). It has been suggested that experiential knowledge can support coping, as it helps with practical aspects of involved with living with a problem, including dealing with service providers, financial costs and how to deal with poor but well-meaning advice (Vennik et al. 2014; Noorani et al. 2019). Additionally, experiential knowledge can include experiences of stigma, interpersonal relationships, emotions and key existential-spiritual questions (Noorani et al. 2019). Moreover, it has also been described as embodied and situated knowledge about vulnerability (Rowland et al. 2017), a way to challenge underlying assumptions about

illness and to create a more nuanced understanding of the lived illness experiences (Faulkner 2017). Thus, experiential knowledge can comprise of several types of experiences and information, including embodied and social aspects. Another aspect that can be added to the mix is that of ‘systemic knowledge’ described by Willis et al. (2016) who argue that people acquires knowledge regarding the health care system and how to navigate it.

Although anyone with an illness can be regarded as having personal lived experiences, some authors have argued that experiential knowledge goes beyond the personal and is created through sharing and distilling personal experiences together. Rabeharisoa and Callon (2004) have argued that single experiences do not necessarily make valid experiential knowledge, as its production requires a process in which the experiences of a broad and diverse group are collected, aggregated and formalised. Caron-Flinterman et al. (2005) have suggested that people can generate experiential knowledge by processing their lived experiences, which can lead to new insights and ways of coping. For decades, third sector organisations have provided a basis for this knowledge to form and develop through peer support groups and other activities that bring patients together. These activities facilitate the creation of a shared pool of knowledge that is produced by combining peoples' lived illness experiences (Caron-Flinterman et al. 2005). However, Blume (2017) has suggested that there are numerous constraints that ‘filter’ the experiences, which come to function as experiential knowledge. This means that although experiential knowledge could be viewed as a wider pool of understanding, certain experiences may be excluded or deemed less valued. The emphasis placed on sharing and pooling experiences together to produce experiential knowledge suggests that although it is deeply rooted in embodied and social experiences, it not merely tacit. Experiential knowledge can be explicated and applied to provide new insights for the benefit of health services.

Despite the growing prominence of experiential knowledge in health services and in academic literature on lived experiences, it has also been argued that due to its subjective nature, the application of experiential knowledge to expert fields such as medicine should be limited. Indeed, Prior (2003) has argued that although people may have knowledge of their personal circumstances and may be able to challenge medical professionals on issues, their knowledge base is limited, they are unable to distinguish which issues require attention and may be plain wrong about the course and management of illnesses. Indeed, for some people the sources of information regarding illnesses may be rather limited. These ideas may be at least partially shared by health services as studies have highlighted that knowledge derived from lived experiences can often be dismissed, disregarded or included as a token gesture

(Daykin et al. 2007; Boivin et al. 2010; Greenhalgh et al. 2015; Noorani et al. 2019). Thus, it can be challenging for organisations to use experiential knowledge in environments where it is not viewed as valuable or legitimate. Mazanderani et al. (2012) have suggested that there needs to be more exploration into how experiences are turned into different forms of knowledge and used in health care. Studies regarding experiential knowledge have largely focused on the perspectives of the individuals with lived illness experiences (e.g. Caron-Flinterman et al. 2005; Boardman 2014; Noorani et al. 2019). Our aim is to explore how organisations claiming to represent the ‘voice’ of lived experience define experiential knowledge and what are their experiences of using experiential knowledge in health services.

The Role of Third Sector Organisations

Despite the current role of many organisations as representatives and advocacy groups, lived experiences have not always been valued as a source of knowledge by the third sector. Indeed, the organisations and associations founded during the 19th and early 20th century were the realm of philanthropists and society women, far removed from the experience of illness (Barbot 2006). Self-help groups and increasingly specialised organisations founded that sprang up from the 1960s and 1970s onwards, were more susceptible to personal experiences. However, it was still largely the doctors and researchers that were considered to possess expert knowledge (Barbot 2006). Over the later part of the 20th century, groups organised around health-related issues have been able to influence both policy and service delivery by altering conceptions and broadening the rights of patients (Brown et al. 2004).

In this study, we will focus especially on patient and illness specific organisations, which have increased in numbers particularly throughout the Nordic countries (Winblad and Ringård 2009). The core duties of these organisations include the provision of peer support and self-help, informing members of new policies and providing medical/research information concerning specific illnesses (Ternhag et al. 2005). On a more general societal level, the organisations can seek to raise awareness and influence cultural norms and attitudes in order to reduce stigma (Baggott and Jones 2018). The close interaction with the membership and the provision of different activities enable the organisations to gather the experiences and views of people with lived experiences. Setälä and Väliwerronen (2014) have coined the term *field expert*, to describe a group of people who have become mediators of scientific expertise. In many ways, this term also applies to representatives of third sector organisations whose role is

twofold. They act as ‘translators’ or ‘knowledge brokers’ (Meyer 2010), translating medical information regarding specific illnesses and treatment to the organisation’s membership. However, towards health professionals and decision makers as their role is to provide ‘experiential representation’ (Martin 2008) and communicate experiential knowledge forward. Hence, organisations inhabit a somewhat hybrid space, where they often incorporate both clinical and experiential perspectives (Näslund 2020). In order to fulfil this role, the organisations need to ‘stay in close contact with the patient population they represent, verifying the mutuality of demands, ideas and judgements regularly’ (Caron-Flinterman et al. 2005: 2582). Although organisations are nowadays much more inclined to value lived experiences as a source of knowledge and even expertise, they may have very different understandings of the content of lived experiences, and they adopt different styles of communicating experiences within health service planning and development. Indeed, Rowland et al. (2017) have highlighted that concepts such as the patient perspective, and patient experiences can be interpreted in different ways, which in turn can create dilemmas in the implementation of involvement activities.

In this study, we explore how collective groups representing people with lived experiences describe the content and uses of experiential knowledge. Third sector organisations have, at least in theory, become channels through which patients can influence health-related decision making (Torjesen et al. 2017). They act as partners and collaborators in the planning, management and delivery of services and often have a seat at the table at the level of policy development (Martin 2012) in Finland and elsewhere. Therefore, it is important to examine experiential knowledge also from their perspective. Mankell and Fredriksson (2020) have described the roles of organisations in terms of support, service-provision and representation. In this study, we will focus specifically on the support and representation aspects as experiential knowledge can be constructed and gathered through the supportive activities and disseminated through the representative role. It should also be added that during the 2000s and the 2010s, many organisations have begun to train people as experts by experience (i.e. people with lived experiences who can participate in service and policy level development work) in addition to training peer support workers or provide training that prepares patients/people with lived experiences to participate in research processes.

We will focus on organisations dedicated to two large and varied patient groups (cancer and mental health problems) which have established relationships with political decision makers and have engaged in involvement activities. Gathering examples from cancer and mental health organisations provides interesting insights into these issues

as there is a great variety of organisations representing people from these illness groups. Additionally, cancer and mental health organisations have established positions as active participants in service development and they currently provide training for people with lived experiences. Some have even formed networks for their respective ‘diseases’ within parliament (Toivaiainen et al. 2010) and are regularly consulted during policy making processes and included in the planning, organisation and delivery of health services (Ministry of Social Affairs and Health 2011; Finnish Institute for Health and Welfare 2014; Ministry of Social Affairs and Health 2019).

Although the organisations can vary in composition and size, they all use and promote lived experiences and act as representatives of the ‘voice’ of patients. In this study, we will firstly ask: (1) *How do representatives of third sector organisations describe the content and scope of experiential knowledge and what arguments do they provide for its use in health services?* As prior studies have suggested, the promotion and use of experiential knowledge within health service planning and development can be challenging, posing prerequisites on experiential knowledge (Blume 2017; Jones 2018). Therefore, we will also explore: (2) *What kinds of ‘filters’ are imposed on experiential knowledge as it is communicated to health professionals by organisations?*

Materials and Methods

In order to gather a range of perspectives, we conducted individual interviews with representatives from small- and large-scale, national and regional level organisations e.g. with membership ranging between 100 to 20,000, and the number of paid employees ranging from zero or one to dozens. We chose organisations, which represent two common and wide illness groups, cancer and mental health. The involvement of people from these illness groups and the involvement of organisations representing their interests have been actively promoted in Finnish health policies and health service strategies (Ministry of Social Affairs and Health 2011; Jones & Pietilä 2018). Therefore, the representatives from cancer and mental health organisations have experiences of involvement in health sector and have been required provide ‘experiential representation’ (Martin 2008) and communicate experiential knowledge to health services. Despite representing different patient/illness groups and varying in size and structure, there were also many similarities. Providing information and support were among their core functions, together with advocacy and raising awareness. As mentioned before, the organisations communicate information to varied groups as they transfer and translate scientific/medical knowledge to their

membership and offer experiential knowledge to health services and policy makers. The organisations participating in this study used a variety of methods to gather lived experiences. They created spaces where experiences were shared, such as online platforms and peer groups, conducted surveys and posted questions in online chat forums. The organisations also trained people with lived experiences to become peer support workers and experts by experience, which in turn supported the creation of experiential knowledge. The knowledge gathered from members was used to inform the organisations’ agenda. Experiential knowledge provided legitimacy to the organisations’ claims that they were representing patients and their lived perspectives.

The interviews analysed in this study were conducted with representatives ($n = 11$) of seven different organisations. Four of these were cancer organisations, and three organisations represented people with mental health problems. All the interviewees were either the managers of these organisations or employees whose work was directly related to the organisations’ involvement activities. Four of the participants also possessed lived illness experiences. The interviews were conducted during 2017 and 2018 by the first author. Prior to the interviews, ethical approval was obtained from the Academic Ethics Committee of the Tampere Region and all the participants gave verbal and written informed consent. A thematic interview guide was used in all the interviews in order to cover similar issues with all the participants (e.g. organisations aim and functions, services and training provided, collaboration with health services). However, the guide was used loosely for the participants to freely discuss the themes and issues they regarded relevant. The interviews were recorded and transcribed verbatim. All names and references to places have been removed from the extracts used in the results section in order to ensure anonymity (Table 1).

This study draws on methods of discourse analysis and focuses on how language is being used, and the functions that language has (Potter and Wetherell 1987). During the first stage of analysis, notes were written in the transcripts, and preliminary coding was done to identify parts of the interviews, where participants discussed the gathering and uses of experiential knowledge. Once we had identified these extracts in the transcripts, we focused specifically on them. The aim was to find recurrent patterns of talk—i.e. similarities and differences in the participants’ descriptions of experiential knowledge and how they talked about the organisation’s role in providing experiential representation in health service development. During this process, we noticed that the participants talked about different limitations and prerequisites that were placed on experiential knowledge as they were communicating it to health professionals. Hence, we decided to look at both the

Table 1 Interview participants

Interview no	Interview conducted in	Participant's role (C = cancer org., MH = mental health org.)	National/Regional organisation
1	2017	Organisational representative (C)	National
2	2017	Organisational representative (C)	National
3	2017	Organisational representative (C)	National
4	2017	Organisational representative (C) with lived experiences	National
5	2017	Organisational representative (MH)/Expert by experience	National
6	2018	Organisational representative (MH)/Expert by experience	National
7	2018	Organisational representative (MH)/Expert by experience	National
8	2018	Organisational representative (MH)	Regional
9	2018	Organisational representative (MH)	Regional
10	2018	Organisational representative (C)	Regional
11	2018	Organisational representative (C)	National

similar patterns in their descriptions of experiential knowledge and the expectations posed on experiential knowledge. From the abstracts, we analysed how the participants described the content and uses of experiential knowledge, and the different stages of gathering, processing and communicating experiential knowledge. Using Blume's (2017) term, we titled the restrictions and expectations placed on experiential knowledge at these different stages as 'filters'. The term 'taming' was chosen to highlight the overall challenges faced by organisations as they attempted to represent lived experiences. By imposing different 'filters', experiential knowledge was to a degree being 'tamed' as it was processed and structured. Concurrently, the participants also wanted to ensure that the transformative power of lived experiences was not lost and as organisations they wanted to maintain their autonomy despite working closely with health services. At the final stage of the analysis, the findings were grouped under two sections, first of which focuses on the ways in which the participants described and understood the content of experiential knowledge. The second section explores the filtering and taming of experiential knowledge.

Results

We have divided the results into two sections. The first section introduces the three ways in which the interview participants described experiential knowledge—*all-encompassing*, *practical* and *transformative*. The all-encompassing descriptions related to the nature of experiential knowledge. It was argued that in relation to other forms knowledge (e.g. clinical) experiential knowledge could offer a multilayered understanding of health, illness and care. Thus, it could be used to expand the perceptions of health professionals. The other two descriptions were more

connected to the functions of experiential knowledge. The suggestion was that individuals' lived experiences can be translated into practical information about concrete issues and practices that could be enhanced the treatment and care experiences. However, the main aim was not to use experiential knowledge only for practical purposes, but to transform the way in which health services function, and how decisions are being made. Despite these aims, experiential knowledge continues to lack inherent authority in health services, which can lead to a need to *tame* it.

Experiential Knowledge: Providing All-Encompassing, Practical and Transformative Perspectives

First and foremost, the participants highlighted that experiential knowledge is strongly founded upon lived experiences. The organisations ran several groups and networks through which these experiences could be shared, gathered and processed. Therefore, in order to become experiential knowledge, experiences needed to be verbalised and structured. There were some ambivalences in the participants descriptions on whether experiential knowledge could be based on individual experiences alone or whether it was a combined pool of knowledge, consisting of several peoples' experiences. Despite some of the conflicting descriptions, experiential knowledge was mainly discussed as a combination of different experiences and perspectives. It provided an insight into the everyday life of living with and managing an illness and took into consideration the embodied, social and emotional aspects of these experiences. A common feature of the interviews was that the participants repeatedly contrasted experiential knowledge with medical and professional knowledge. In these comparisons, the participants claimed that by its very nature experiential knowledge was *all-encompassing*, offering a

more rounded and nuanced understanding of illness and treatment. These comparisons also contained criticism towards the clinical and highly specialised ways medical and professional knowledge view illness and treatment:

You know exactly how a surgeon is going to treat you. They may not have any interest in the person at all, since they are just interested in the specific part that's being operated.

In contrast to this distant, narrow and clinical approach, where the individual and their experience are forgotten, experiential knowledge was described as providing a grounding in 'reality'. The participants emphasised the need to view people as wholes, considering their life experiences and situations. As opposed to knowledge that could be learned, experiential knowledge was also described as authentic. It could be used to convey deeply personal emotions and embodied sensations. This all-encompassing knowledge could convey people's vulnerability and fragility during periods of distress. It was described as particularly powerfully when it was relayed by someone with personal experiences, as it allowed the listeners to connect to the illness experience on a personal and emotional level. As all-encompassing, experiential knowledge could also serve to expand professionals' perceptions of illness and care:

When health professionals are trained, doctors are trained, specialist doctors, then well... there should be a shift from science to the realities of life, as it would enhance understanding. I remember as a nursing student how it was always great when someone came to give a talk and explained that they had an illness and came to talk about what it's like. There were only a few of [these talks] back then, but sometimes they happened. And they provided a sense of realism, how the diagnosis or the illness or these issue have an impact, when there's a real person talking about it.

Although, experiential knowledge was compared to medical and professional knowledge, it was not positioned as a replacement. On the contrary, the participants argued that different forms of knowledge should be combined and used together, in order to gain a fuller understanding of lived perspectives and services use. Therefore, experiential knowledge was described as a piece that was currently missing from health service development. Involvement practices enabled the organisations to work in closer collaboration with health professionals, managers and decision makers, creating new practices and approaches. When discussing the contributions that experiential knowledge could offer to health services and existing practices, the participants argued that experiential knowledge could

translate into *practical* suggestions to enhance care and the service user experience. These practical uses of experiential knowledge could provide help with issues such as improving hospital parking instructions, guidance about accessing information, patient facilities within hospitals or functioning of care pathways:

At least on issues related to cancer it can benefit patients, since they are experts by experience on how the care pathway is functioning. So, this kind of expertise of customer experience, it can provide feedback on cancer services as a product. What went well and what could be improved. So it's good for that at least... What else could it be used for? Well, at least that was a clear area, customer feedback, from an expert by experience.

In the above extract, the interviewee refers to people with lived experiences as experts who can and ought to be consulted on practical issues related to treatment and care. They also use rather market-oriented terminology in relation to involvement and experiential knowledge. The person with lived experiences is positioned as a customer, whose knowledge and information need to be gathered to enhance the 'product' (i.e. cancer care). This type of terminology was not as strongly present in the other interviews, nevertheless, other participants also provided examples of experiential knowledge containing practical information about service performance, which is only possessed by people who have used that specific service. Although the participants felt that experiential knowledge could be translated into these highly practical improvement suggestions, they also argued that it was not enough to use experiential knowledge merely for these purposes. Indeed, they voiced concerns that if experiential knowledge was only viewed from this narrow perspective, much of its' content and potential would be lost. Hence, the participants expressed that it should also "*have an impact on the [health service] structures and not just be cosmetic, like picking the right colours for chairs or tablecloths*".

This idea was further supported in the descriptions that highlighted experiential knowledge as *transformative*. It offered unique and at times critical information that could benefit health services and health professionals. Experiential knowledge was created outside of health services, and it can offer a new perspective on issues. The aim was to challenge the 'old culture' within health care and integrate experiential knowledge into all decision making processes. In the next extract, the interviewee places experiential knowledge on an equal footing with research knowledge and argues that despite their differences, these forms of explaining and understanding health and illness should be used in conjunction:

In my opinion, involvement is extremely important. That you start to discover, without dismissing the old culture that is good and continues to exist, but you start adding to it. [...] And if we want to really change something, like structures, then the thinking needs to change first. [...] At the end of the day, it's a beautiful and a logical, unalterable point that research knowledge and experiential knowledge need to start interacting. And that can be made to happen by thinking about structures and doing concrete collaboration and trying to understand. And that can produce something that is more [...] but there's still a lot to do in relation to structures and in relation to getting organised.

In the above extract, the participant acknowledges that structural changes would need to occur for experiential knowledge to be viewed in equal terms. However, he suggests that the acceptance and use of experiential knowledge could lead to brand new innovations. The extract also highlights some of the problems that participants faced as they tried to integrate experiential knowledge into health services. Feeling that experiential knowledge was not valued caused frustration amongst the organisations as they were unable to get important points across. Overall, the different descriptions provided by the interviewees contained an underlying suggestion that the knowledge possessed by health professionals and decision makers was important but somewhat insufficient. Adding experiential perspectives could improve the services both in practical terms but also create more profound changes in professionals' perceptions of illness and treatment, as well as care and decision making practices. Moreover, the descriptions portray experiential knowledge as critical and authentic, bringing into light the embodied, social and emotional aspects of being ill. However, communicating this knowledge to health services was not as straightforward, and the interviewees expressed that certain adjustments needed to be made. In the next section, we will explore the restrictions placed on experiential knowledge and explore how the participants attempted to manage these restrictions.

The Taming of Experiential Knowledge

The participants identified several actions and choices that could be viewed as attempts to tame experiential knowledge. Therefore, by taming we refer to the varied adjustments made and the 'filters' posed on the ways in which experiential knowledge was communicated. Some of these appeared to be self-imposed, as the organisations were trying to establish themselves as valued collaborators and wanted to entice health professionals to become more

receptive to experiential knowledge. We will initially address the issue of representation and discuss who is considered eligible to communicate experiential views. Following this, we will move on to discuss the issue of language and explore whether experiential knowledge should shy away from adopting professional terminology. Lastly, we will discuss the participants' fear about losing autonomy together with the critical and transformative elements of experiential knowledge.

The participants expressed that they valued and appreciated all lived experiences. However, there were also suggestions that certain 'filters' needed to be applied when deciding who is representing and communicating experiential knowledge to health professionals. In practice, this meant that selected (and trained) patient representatives or professionals working for the organisations, were chosen to communicate experiential knowledge to wider audiences. Although the interviewees described experiential knowledge as all-encompassing and transformative, they expressed that some adjustments needed to be made in order to make it accessible to a professional audience. Blume (2017) has claimed that experiential knowledge has no 'inherent authority'. This was reflected in the interviews, as the participants discussed ways in which experiential knowledge was communicated to health services and professionals. They argued that in order to permeate through to health services, experiential knowledge needed to be polished, audience friendly and clearly articulated:

I've been to lots of events where patients have given talks, which have been awful. So, we need to make sure that the people, who are experts of their own experience, and who we take along to give talks, know how to give them. [...] And I know doctors who say that no one's bothered to listen to the talks given by patients. And I get it. But then it also really annoys me, because there are really excellent ones too.

In the above extract, the participant talks about the difficulty of engaging health professionals. The interviewees provided many positive examples of successful collaboration with health services. Nevertheless, they also referred to instances where health professionals were dismissive or did not appreciate experiential knowledge. In the abstract below, the participant questions public health services' promise of being user oriented. They also suggest that the inclusion of third sector organisations is vital as they can provide the "service users' voice" and enable health services to live up to their promise.

I've noticed, in these meetings about the health and social care reform and such, that when they are really professionally orientated then they don't take this

[experiential views] seriously, which is really weird since this is the service users' voice. This should carry the most weight on whether or not a service is working.

The participants also expressed fears that even though experiential knowledge was important, it would not reach its transformative potential, if it was not communicated effectively:

It's not just about going somewhere to tell a story, which is so damn right and true since it's based on lived experiences. But well, it works on some levels, but it doesn't necessarily work if you want to be in there [health services] ...influencing issues.

These partially self-imposed expectations also led to the organisations providing training, which prepared people with lived experiences to communicate with health professionals and even work in health services as experts by experience. During the training, personal experiences were processed and transformed into stories that could be used into develop services. Additionally, people attending the training could distance themselves from their personal experiences and adopt a stance that could be described as more neutral or even 'professional'.

In my opinion the training is really important as you get to process your experience and how it links up with you being an expert by experience. And well, at the end of the day, I see it as a tool. Your experiences are something that you can place there and study. And they can provide some enjoyment, but in a neutral way. [...] They [experiences] are almost like this coffee cup [on the table]. If they offer some help or are of benefit, then it's damn good if they are of use to others. But it's no longer about me being in the centre [of the experiences].

Despite experiential knowledge conveying vulnerability and emotion, people communicating the knowledge were expected to show a level of restraint and self-regulation. However, the idea that lived experiences needed to be more polished, structured and neutral in order to gain acceptance caused conflicting reactions. The interviewees were at times worried that the critical and countercultural aspects they attached to lived experiences would be lost. This could also lead to the loss of an authentic voice of experience if ways in which lived experiences were communicated began to include professional language or medical terminology:

P: Five or four years ago when I entered this scene, I heard these warnings that when we go into the system, then experts by experience are going to become poodles.

I: Well, that's being suggested now and then...

P: Yeah.

I: Would it be the worst thing then...

P: Well, yes.

I: ...that would automatically happen?

P: Yes. It's true that the danger is that this old dominant culture will eat the counterculture. And then you start to imitate those [professionals] and like your language and everything, more or less, changes. And it's cool and strokes the ego and so forth, but it's not that simple. In my opinion that is also needed. But we need a wider scale of different approaches. That's diversity. So in a way we are different parts of the same wave that is approaching and changing, making the revolution.

As the interviewee in the above extract explains, there were continuing concerns over the position and legitimacy of experiential knowledge. He also acknowledges a fear that by adopting too many professional traits and language, experiential knowledge could lose some of its authenticity and transformative power. The third sector organisations were trying to work collaboratively with health professionals and decision makers. They wanted to position themselves as knowledgeable and reliable partners that could bring new views and perspectives into health service development activities. Nevertheless, there were also fears that if they became too integrated and made too many adjustments, they could lose their autonomous position and the ability to voice critical views founded upon lived experiences.

Discussion and Conclusions

Health care has long been a contentious epistemological space, where questions about what is regarded as a valid form of knowledge for choices, and practices have been debated (Brosnan and Kirby 2016). Although patient-centredness and the importance of listening to patient experiences have been promoted through policies and health care strategies, experiential knowledge has not been able to fully establish its position as a legitimate form of knowledge to be used in decision making. The participants of this study were aware of this and provided arguments that supported the use of experiential knowledge and the value it could bring to health services. However, this study also highlights that organisations have varied definitions of what constitutes experiential knowledge, how it can be produced and how it should be communicated and used.

Experiential knowledge was described as consisting of embodied, social and emotional aspects of being ill and receiving treatment. It was described as ‘real’, authentic and transformative and thus uniquely different from medical and professional forms of knowledge as it was based on lived experiences and knowledge of the care system. It was not seen as narrow and specialised as professional knowledge. In many ways, the participants followed Borkman’s (1990) argument that experiential knowledge was not piecemeal or overly specialised but emerged as a result of numerous layered experiences of living with a problem. It as a unique form of understanding and the organisations played a role in the creation of this knowledge as they provided people with opportunities to meet and share their personal experiences, which were combined and ‘translated’ into practical insights and suggestions for service improvement. This resembles Caron-Flinterman et al. (2005) suggestion that experiential knowledge is produced by pooling together personal experiences. Nevertheless, the participants emphasised that this knowledge should not be used for tokenistic or ‘cosmetic’ purposes, but to inform and influence service delivery. This was highlighted in the descriptions of experiential knowledge as transformative, suggesting that its inclusion could revolutionise health services and decision making processes. The all-encompassing and transformative aspects also contained a suggestion that experiential knowledge has the potential to provide an alternative and critical perspective, which had been produced outside of health services by people who have historically been excluded from decision making. These factors also contributed to the idea that experiential knowledge was authentic, rooted in ‘real’ experiences, unlike professionals’ knowledge base that was constructed through learning.

Nevertheless, the participants identified different restrictions—or filters—that were placed on experiential knowledge. They described actions and choices that could lead to the taming of experiential knowledge and although they were partially due to the marginalised position of experiential knowledge within health care, the organisations also self-imposed certain filters. We will address the taming of experiential knowledge by relating it to issues around representation, language and autonomy. The participants offered varied and at times conflicting views on who could represent and communicate experiential knowledge to health professionals, managers and policy-makers. Some expressed that it was people with lived experiences, who should be directly involved at all levels of health service development and delivery, as they could express experiential views authentically. By expressing these views, they aligned and positioned themselves as part of a much wider discussion and critique, which has emerged from feminist, queer, indigenous, disability,

user/survivor and other social and academic movements regarding representation, and who is able to or has the right to act as the ‘voice’ of lived experience (Voronka 2016) and whether the representation of experiential knowledge or individual experiences by those who themselves lack them can lead to misrepresentation or even further marginalisation (Coles et al. 2013).

However, there were also suggestions that people who communicate experiential knowledge needed to be trained, and that they needed to be able to express views in a clear and concise manner. Hence, the organisations provided training that enabled people with lived experiences to process and structure their personal stories and provided them with communication skills. In some of the interview accounts, it was also suggested that some people are better at articulating experiential knowledge, and that they should be offered more opportunities than people who could not convincingly convey the message. Eriksson (2018) has argued that the tendency of organisations to individualise organisational-level patient involvement and request patients to relay personal experiences may downplay the role of the collective voice. These self-imposed rules and expectations on presentation could also exclude the views of certain groups or individuals, as Blume (2017) has highlighted that not everyone is equally able to articulate or utilise their experiences. Additionally, many of the organisations had employed paid members of staff, who did not have personal illness experiences, but acted as organisational representatives and voiced experiential knowledge to health services. The requirement to communicate effectively could be linked to the wider professionalisation of civil society that shifts focus onto accomplishment and effectiveness rather than the good will of ‘amateurs’ (Hustinx and Lammertyn 2003), who in this case could be the people with lived experiences who are untrained or unable to relay their knowledge clearly. This raises very different kinds of questions of who qualifies to represent experiential knowledge and whether these forms of taming lead to the exclusion of people who are unable or unwilling to act and communicate in the ‘correct’ way.

The issues raised above concerning representativeness and authenticity also relate to language, as the participants expressed that experiential knowledge should be communicated in language that was understandable, accessible and relatable. It should not contain too much medical or professional jargon. These ideas were linked to fears that the essence or authenticity of experiential knowledge would be lost if too many adjustments were made, and that experiential knowledge would be ‘colonised’ by medicine through professional language. Concurrently, there were worries that the organisations or experiential knowledge would not be taken seriously if they did not adapt professional ways of communicating. After all, knowledge that

was deemed overly critical or completely incompatible with medical views may not be deemed worthy and authoritative by health professionals (Blume 2017). Both (Näslund et al. 2019) and Meriluoto (2018), who suggest that people with lived experiences are expected to position themselves as experts and adopt a 'neutral' stance. Although the interviewees argued that one of the main values of experiential knowledge was that it offers an insight into the everyday life of living with an illness, showing people as fragile and vulnerable, some adjustments needed to be made. It appears that when used in a health service environment, the communicator of experiential knowledge needed to adopt a more professional manner and learn to express affective issues in a neutral way.

Overall, it seemed that particularly the transformative aspects of experiential knowledge appeared to be under threat due to taming. Some of the participants saw the work of the organisations only as a part of a wider change or as one of the participants described the 'official' work done by the organisation as a contribution to a *bigger wave* that is *making a revolution* within health services. Although, all the organisations representing experiential knowledge can be seen as part of this wave, this study has highlighted that the wave contains conflicting approaches and interpretations of the different aspects of experiential knowledge and its' uses in health services. Historically, service user movements in particular, have used experiential knowledge to challenge established medical knowledge. However, based on the results of this study and those of Näslund's (2020), it seems that the organisations are using lived experiences, research evidence and clinical knowledge in combination. They are seen as complementary to each other and both organisations and individuals with lived experiences are taking a more consensus-oriented approach. Whether this reflects a more Nordic approach to involvement and experiential knowledge could be worth exploring further.

In this study, the organisations representing people with mental health problems were generally more likely to advocate for direct involvement that enabled people with lived experiences to communicate experiential knowledge. Amongst cancer organisations, the views were slightly more varied but there were no clear lines that could be drawn between organisations representing these different groups. The arguments and views expressed by participants were more likely to stem from the organisation's own agenda and aims, rather than the specific illness groups they represented. Additionally, the findings underline the challenges organisations face as they attempt to balance between their different roles as 'field experts', supporters, service providers and representatives of experiential views, whilst concurrently being viewed as valued and legitimate

collaborators by health professionals and policymakers. The role of third sector organisations as providers of experiential representation is an area of research that will surely resonate in several countries and service settings. Particularly, as collective forms of patient and public involvement have become commonplace in the health sector in several countries, and experiential knowledge is being acknowledged as a source of information (e.g. Castro et al. 2019). In the future, it is important to also explore how organisations and more informal patient networks that are not as closely engaged with health services, use experiential knowledge. In relation to health services, it is also interesting to further study how health professionals relate to experiential perspective, incorporate them to practice and deal with situations where experiential knowledge is used to openly challenge clinical perspectives.

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