



## REVIEW ARTICLE

# Consumer involvement and guiding frameworks in mental healthcare: An integrative literature review

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**Abstract**

Perspectives of healthcare have, in past decades, focused more on active citizenship, human rights and empowerment. Healthcare consumer involvement as a concept is still unstructured and consumers have no apparent opportunities to participate in their care processes. The focus is often on the expertise of professionals, even if mental health consumers are willing to become involved and have sufficient decisional capacity. The aim of this integrative literature review was to construct an understanding of consumer perceptions and guiding frameworks of consumer involvement. There was no previous synthesis of mental health consumer perceptions combined with guiding frameworks. An integrative review methodology was employed, following Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines. The quality of the 18 studies included was analysed with the Whittemore and Knafl approach. By following Braun and Clarke's guidelines, an inductive thematic analysis was conducted to collate the themes from the selected papers. Mental health consumers' perceptions of involvement included expectations of person-centred care, such as respect, dignity, equal interaction, supportive environments and being part of a community. This research did not find any single established framework to give clear guidelines for consumer involvement in mental healthcare, but similar determinants describing various frameworks were uncovered. This review also shows how the terminology has changed throughout the years. The perceptions of mental health consumers need to be considered to enable the implementation of person-centredness from guidelines through to practice. Paying more attention to the education of professional mental health caregivers and the involvement of mental health consumers in their care provides better opportunities to co-develop successful mental health services and recovery processes.

**KEYWORDS**

consumer involvement, experience, framework, mental health, social interaction

## INTRODUCTION

Perspectives of healthcare have, in past decades, focused more on patient and public involvement, active citizenship and human rights (Dent & Pahor, 2015; European Committee for Standardization [CEN], 2020; National Health Service, 2022; Organisation for Economic Co-operation and Development [OECD], 2021; World

Health Organisation [WHO], 2022). The key element in this is a person-centred approach, where consumers' expertise gained from experience is seen as an important factor in their involvement in healthcare (Bombard et al., 2018; CEN, 2020; Jørgensen & Rendtorff, 2018; Millar et al., 2016). In mental healthcare, this usually means their participation in various activities, decision-making processes or research.

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Despite their mental health illness, most consumers have sufficient decisional capacity and are willing to become involved in a meaningful way (Calcedo-Barba et al., 2020; Millar et al., 2016; Tambuyzer et al., 2014). Consumer involvement is necessary for the improvement of mental healthcare systems, structures and services (Bombard et al., 2018; CEN, 2020; WHO, 2022). Furthermore, increased involvement has been shown to improve consumer satisfaction and result in better health outcomes (e.g. Bergerum et al., 2019; D'Agostino et al., 2017; Millar et al., 2016).

The concepts behind consumer involvement in healthcare are still unstructured and complex (Bergerum et al., 2019; Dent & Pahor, 2015; Tambuyzer et al., 2014). Millar et al. (2016) define involvement as a broad partnership between consumers and professionals on individual, group, service, organisational and policy levels. Partnership is the final step of collaboration and constructs a trusting reciprocal relationship and respect between consumers and professionals (CEN, 2020; Scambler & Asimakopoulou, 2014). When involvement is considered on the policy and organisational level, there is a higher possibility of involving consumers in their own care on an individual level. This determines the outcomes and forms of involvement and influences the resources and time that are invested. Structured involvement requires policies, protocols, guidelines and vision statements (CEN, 2020; Tambuyzer et al., 2014).

However, there are still challenges to implementing consumer involvement in practice in mental healthcare. Consumers are still expected to use the service, but they have no clear opportunities to be involved in service development processes. The focus is often organisation-based and emphasises the expertise of professionals (e.g. Bergerum et al., 2019; Marcussen et al., 2020; Stomski & Morrison, 2017). It is necessary to take more advantage of consumers' perceptions and accrue a comprehensive knowledge of different frameworks and concepts that describe and provide guidance on consumer involvement.

An integrative literature review was chosen to obtain an overview of different types of studies related to consumers' perceptions of their involvement in mental health services and the guiding frameworks, i.e., theories, frameworks, approaches and models. Studies on how involvement takes place in mental healthcare exist, but there are no previous syntheses of mental health consumers' perceptions combined with guiding frameworks.

## Aims

This integrative literature review focused on consumer involvement in mental healthcare. The aim was to construct an understanding of consumers' perceptions and guiding frameworks, approaches and models of consumer involvement. The research questions were as follows:

1. How do consumers perceive their involvement in mental health services?
2. What are the frameworks, approaches or models guiding the involvement of mental health consumers?

## METHODS

This review was guided by Whitemore and Knafl (2005) and Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines (PRISMA) 2020 guidelines (Page et al., 2021). Table 1 shows the selection of search terms and phrases. Only non-indexed terms and phrases were used in the literature search. The research questions guided the definitions of the inclusion and exclusion criteria.

## Data sources

The literature search was conducted by two authors (AA and KM) in June 2022 from the databases

**TABLE 1** Search terms and phrases.

People-centredness		Involvement		Mental health		Framework
People-cent*		Co-creation*		Mental*		Framework*
Person-cent*		Co-production*		Mental health patient*		Model*
Patient-cent*		Co-design*		Mental health client*		Theoretical model*
Client-cent*	AND	Shared decision-making*	AND	Mental health service*	AND	Theoretical framework*
User-cent*		Patient participation*		Mental health care*		Approach*
Customer-cent*		User involvement*		Psychiatric care*		Participation model*
		Involvement*		Psychiatric nursing*		
		Patient involvement*		Psychiatric service*		
		Consumer participation*				
		Collaborative care*				

Note: Within a column, OR terms were used.



PubMed, CINAHL, PsycINFO and SCOPUS. The database search was supplemented with a manual search, targeting the reference lists of the selected papers and Google Scholar. The data evaluation and analysis phases were an iterative extraction process conducted by two authors (AA and KM). They first compared the data to the inclusion and exclusion criteria individually and secondly, discussed several rounds to extract the final data.

### **Inclusion and exclusion criteria**

Studies were included in the review if (a) participants were mental health consumers, (b) they were related to consumer participation or involvement in mental health or psychiatric care, (c) they were peer reviewed empirical studies, (d) they included a framework, an approach or a model in relation to consumer involvement and (e) they were published in English between 2000 and 2022. The review excluded publications if (a) participants were other than mental health consumers or only healthcare professionals, (b) they described other than consumer participation or involvement in mental health or psychiatric care, (c) they were not carried out in mental health or psychiatric care, (d) they were carried out in primary healthcare or education or (e) they were not a peer reviewed empirical study, such as a protocol or review. Studies that focused only on medication or shared decision-making were also excluded.

### **Screening**

The database search resulted in 1777 records. A total of 932 records were removed before screening, leaving 66 articles for full-text review. The PRISMA flow chart in [Figure 1](#) illustrates the search and screening process.

### **Quality assessment**

To assess the reliability of the studies included in the review (Whittemore & Knafl, 2005), the quality of the eligible studies was assessed with a mixed methods appraisal tool (MMAT) independently by two researchers (AA and KM). The researchers compared their assessments, discussed any disagreements and made mutual decisions about the quality. The data included in this integrative literature review were assessed under the guidance of MMAT guidelines (Hong et al., 2018) with the scores 'yes', 'no' or 'cannot tell'. The quality of the studies included was evaluated as 'good', even though examples of the analysis's paths were not presented in most of the qualitative studies.

### **Thematic analysis**

To analyse the first research question about how consumers perceive their involvement, Braun and Clarke's (2006) six-phase framework of thematic analysis was utilised. The inductive analysis was conducted to collate the themes from the selected papers and was based on the meaning given by the paper's author (Braun & Clarke, 2006). During the first phase, the initial ideas were generated based on reading and rereading the selected papers. The second phase provided an initial coding of the significant features. A semantic approach was utilised to identify the sub-themes, themes and main theme through the explicit meanings of the data (Terry et al., 2017). By using a thematic analysis, three themes of consumer perceptions of involvement in mental health services were developed. The themes have been shaped in the dialogue between the researcher, other authors, and the material. To investigate the second research question about the guiding frameworks, an iterative process was employed, and categories of significant features and contexts were made in an Excel table.

## **RESULTS**

### **Study characteristics**

[Table 2](#) describes the key characteristics of the 18 studies included in the review. Fifteen studies were qualitative and three were mixed methods in design. Fourteen of the 18 studies were conducted in Europe, of which seven were in Nordic Countries. Three studies were conducted in Australia and one in the United States of America. Four of the papers were published between 2005 and 2010, four between 2011 and 2015 and ten between 2016 and 2022. Twelve studies included consumers from outpatient mental health services, five from inpatient psychiatric services and one from mental health housing services. In total, 782 informants participated in the selected studies.

### **Consumer perception of their involvement in mental health services**

Aligning with the first research question, one main theme was developed relating to consumer perceptions of involvement in mental health services, i.e., expectations for interaction between consumers and professionals, which included partnerships between consumers and professionals, supportive structures of mental health and disorganised participation. [Figure 2](#) illustrates the 11 subthemes and the three themes from which the main theme was developed.

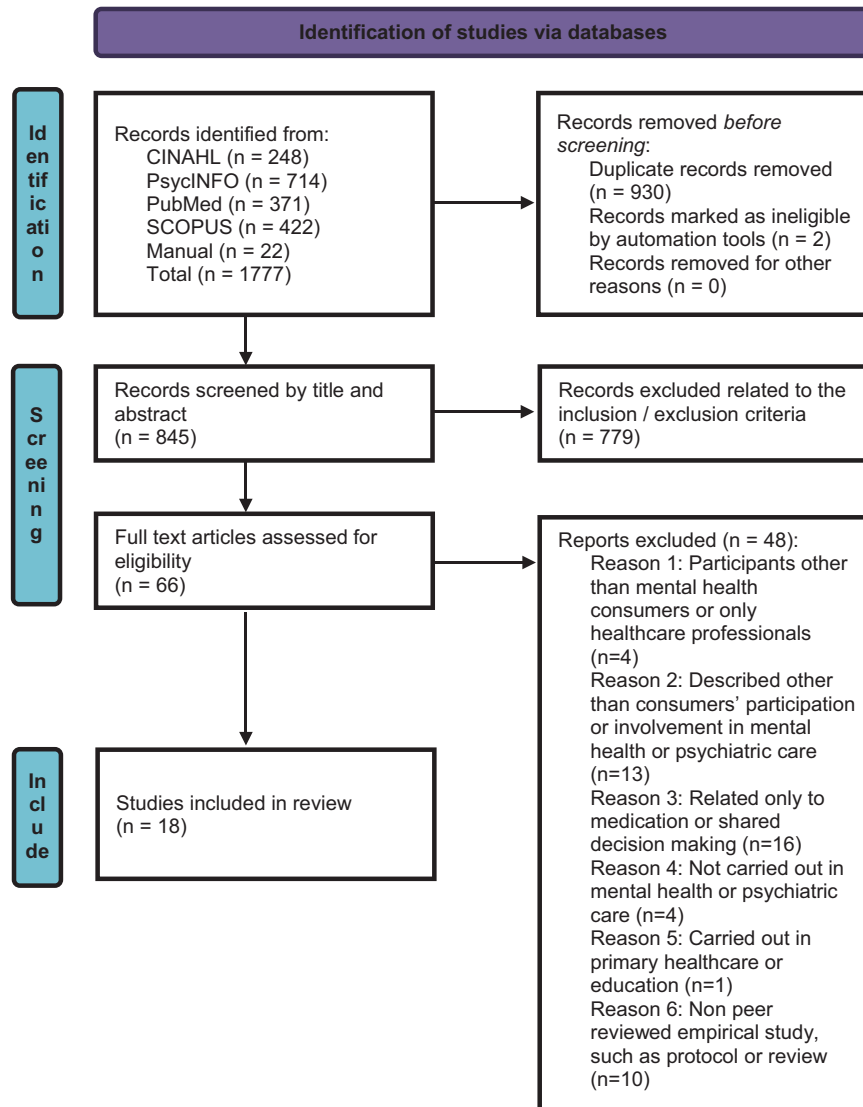


FIGURE 1 PRISMA flow chart of study search and selection process (Page et al., 2021).

## Partnership between consumers and professionals

Partnership with professionals meant the following to consumers: (1) dialogical communication, (2) respectful relationships, (3) a balance in power and responsibilities and (4) meaningful participation.

Consumers felt it was important to have the possibility to negotiate and make choices in dialogue with professionals. The terminology and language used by the professionals, media and online services should be respectful and not based only on their mental health diagnoses (Connor & Wilson, 2006; Dorozenko et al., 2018; Grim et al., 2017; Laitila et al., 2018; McCloughen et al., 2011; Stephenson et al., 2020; Wright et al. 2016). The need to encourage the expression of individual needs, also in group settings, was highlighted (Dorozenko et al., 2018; Grim et al., 2017; Jormfeldt et al., 2014; Lwembe et al., 2017; Stephenson et al., 2020). The development

of professionals' communication styles and promote more transparent communication protocols and practices on organisational, team and individual levels was recognised as a requirement (Grundy et al., 2016; Larsen et al., 2022; McCloughen et al., 2011). Face-to-face communication and personal contact with professionals were seen as important. Consumers felt that an online service, such as eHealth, could be used voluntarily and as an add-on service (Lorenz-Artz et al., 2021).

Developing a respectful relationship was seen as a flexible, democratic and reflective process and as a main characteristic in a successful mental health service (Connor & Wilson, 2006; Dorozenko et al., 2018; Elstad & Eide, 2009; Grundy et al., 2016; Jormfeldt et al., 2014; Laitila et al., 2018; Larkin et al., 2015; Lwembe et al., 2017; McCloughen et al., 2011; Sajatovic et al., 2005; Stephenson et al., 2020). Consumers felt it important that professionals had the responsibility to take an active role in understanding the demands in consumers' everyday



**TABLE 2** The studies included for this review.

Authors (year), country	Aim	Consumers as participants (n)	Data collection method	Data analysis method	Key findings
Connor and Wilson (2006), Northern Ireland	To obtain mental health service users' views on user involvement.	n=31	Focus group discussions	Grounded theory	The importance of acceptable language and communication, social inclusion and appropriate training of mental health professionals was highlighted. Service users felt that user involvement was in its very early phase and the medical model was still prevailing.
Daremo and Haglund (2008), Sweden	To describe patients' opportunities to be active and participate in their own treatment in psychiatric institutional care.	n=61 answered the questionnaire n=10 were interviewed	Questionnaire, semi-structured interviews, activity schedule	Stat Fischer's exact test Qualitative content analysis	The value of environment and atmosphere in the ward was highlighted. Taking responsibility for themselves and conditions supporting engagement were seen as important factors in participation. Patients felt frustration at the lack of natural meeting places and the passive everyday life in the ward.
Dorozenko et al. (2018), Australia	To evaluate the West Australian transitional supported housing service for mental health consumers.	n=8	Semi-structured interviews	Thematic analysis	Meaningful involvement, co-production and trusting relationships were seen as essential for the mental health recovery process. Consumers were involved in service design and delivery, including the hiring of new staff members.
Elstad and Eide (2009), Norway	To make visible the experiences of user participation in a community mental health context and to add to the understanding of user participation.	n=10	Observation, individual interviews, group interview	Grounded theorising applied to ethnographic studies	The atmosphere and environment that increases users' self-determination and participation were considered important.
Grim et al. (2017), Sweden	To use participatory design in developing a user-generated web-based decision aid for psychiatric services.	Phase I n=42, Phase II n=5, Design phase n=3	Focus group interviews, individual interviews	Constructivist grounded theory	Involving end-users as testers and informants to recognise usability challenges in the use of decision aid was considered benefiting.
Authors (year), country	Aim	Consumers as participants (n)	Data collection method	Data analysis method	Key findings
Grundy et al. (2016), UK	To explore users' views on meaningful involvement in the mental health care planning process	n=27	Focus group discussions, individual interviews	Framework analysis	Service users described meaningful user involvement and provided a clear structure for their involvement in care planning in practice. Users hoped for more personalised and tailored care planning processes to identify their health needs and goals.

(Continues)



TABLE 2 (Continued)

Authors (year), country	Aim	Consumers as participants ( <i>n</i> )	Data collection method	Data analysis method	Key findings
Jormfeldt et al. (2014), Sweden	To describe clients' experiences of the Boston psychiatric rehabilitation approach.	<i>n</i> = 10	Semi-structured individual interviews	Qualitative content analysis	Clients had a need to share their thoughts in collaboration with a trusted person, to be able to recognise and verbalise their goals, to get new perspectives and to enhance self-understanding.
Laitila et al. (2018), Finland	To explore the service users' experiences of user involvement in the mental health service.	<i>n</i> = 21	Semi-structured focus group interviews	Qualitative content analysis	Service users called for more information about their own care, involvement in decision-making and better care planning. Service users described concrete promoting or inhibiting factors in user involvement.
Larkin et al. (2015), UK	To describe experiences using experience-based co-design based on involvement of inpatient service users, staff and families and to understand and improve their hospitalisation experiences.	<i>n</i> = 6 Feedback groups <i>n</i> > 150 (did not specify the service users separately) Co-design event <i>n</i> = 50 (did not specify the service users separately) EIS-users <i>n</i> = 3	In-depth interviews with feedback, group discussions	Interpretative phenomenological analysis, thematic analysis	Participation in the service design process was viewed as a positive possibility for working towards change. Respectful relationships with professionals and a safe environment were identified as the main characteristics of a successful mental health service.
Larsen et al. (2022), Norway	To make visible the critical conditions for co-production interaction in public mental health care.	<i>n</i> = 109 (did not specify the service users separately)	Focus group interviews, individual interviews, dialogue seminars	Qualitative conventional and directed content analysis	The importance of open dialogue, communication platforms and mutual learning processes was highlighted in achieving a balance in power. Professionals' defensive routines, subordination and ignoring of consumers were experienced.
Lorenz-Artz et al. (2021), Netherlands	To define the challenges and prerequisites for the implementation of eHealth in person-centred and community-based care models.	<i>n</i> = 10 Interviewed participants <i>n</i> = 29	Semi-structured interviews	Thematic coding approach	Clients experienced face-to-face and personal contact with professionals and eHealth could not substitute it. Motivation to use eHealth was connected to their experiences, skills and attitude.
Authors (year), country	Aim	Consumers as participants ( <i>n</i> )	Data collection method	Data analysis method	Key findings
Lwembe et al. (2017), UK	To evaluate the use of co-production approaches when delivering mental health services in a cross-sectoral pilot.	Patients <i>n</i> = 6, Community group <i>n</i> = 1 Mental health champions <i>n</i> = 3	Semi-structured interviews, focus group	Thematic framework analysis approach	The importance of expert patients, joint decision-making and cultural competency in a co-production context with minority ethnic communities was highlighted by the patients.



TABLE 2 (Continued)

Authors (year), country	Aim	Consumers as participants (n)	Data collection method	Data analysis method	Key findings
McCloughen et al. (2011), Australia	To identify experiences and an understanding of nurse-consumer collaboration.	Consumers n = 13, Survey completed and returned n = 18/113 consumers	Focus groups, survey	Thematic analysis	The collaboration with nurses was seen as a democratic process where both parties had an active input. Service users felt professionals need to be empowered by the organisation to be able to share power with service users.
Sajatovic et al. (2005), USA	To explore patients' attitudes towards the collaborative care model.	n = 52	Quantitative measures of treatment adherence and treatment attitudes: Drug Attitude Inventory (DAI). Participant feedback, randomised, institutional review board-approved trial	Thematic approach	Individuals emphasised the interactive relationship with providers, especially in more symptomatic illness phases. They highlighted the importance of flexibility to allow individual differences and realities of daily life with illness.
Sharma et al. (2017), Australia	To provide an understanding of vulnerable customers' participation in the co-creation of healthcare service delivery.	n = 17	In-depth interviews, focus groups	The Gioia methodology	Hedonic and eudemonic wellbeing was experienced when involved in various co-creation activities. As active community citizens, service users felt they were able to help other people and create a positive influence in the community.
Solbjør et al. (2013), Norway	To explore mental health service users' and providers' experiences of patient participation in different illness phases.	n = 20	Qualitative interviews	Grounded theory	The poor illness phases were experienced as an obstacle for the patient's participation. Involvement was seen particularly important at the outpatient clinics to feel some control of themselves.
Authors (year), country	Aim	Consumers as participants (n)	Data collection method	Data analysis method	Key findings
Stephenson et al. (2020), UK	To explore participants' experiences of ADM and co-production of ADM materials.	n = 10 Consultation process: participating individuals n = 5	Focus group interviews, feedback from the consultation process, structured field notes	Focus group data: thematic analysis	Co-producing with professionals was seen as a reflective process with thoughtful discussions and authentic engagement from all participants. Service users felt the co-creation process helped them to enhance self-management and built a shared understanding with the nearest persons of their life with mental illness.

(Continues)



TABLE 2 (Continued)

Authors (year), country	Aim	Consumers as participants (n)	Data collection method	Data analysis method	Key findings
Wright et al. (2016), UK	To explore the nature of service user involvement in the transition points of acute inpatient mental health care.	Total number of participants = 52 (did not specify the consumers separately)	Focus group interviews	Conventional thematic qualitative techniques	The service users felt they were dehumanised and bypassed in the key transition points in and out of acute inpatient care.

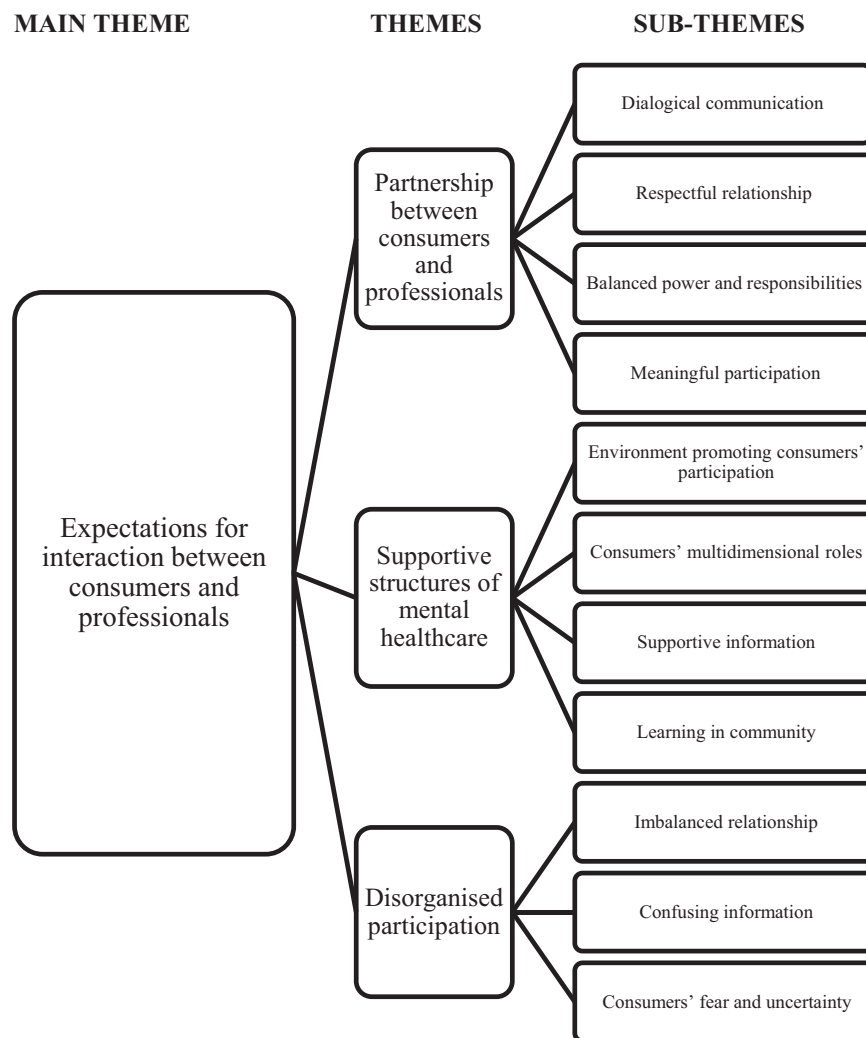
lives (Elstad & Eide, 2009; Grundy et al., 2016; Sajatovic et al., 2005). Consumers also highlighted the need for practical organisational and professionals' more informal ways of working respectfully with them (Connor & Wilson, 2006; Dorozenko et al., 2018; Grundy et al., 2016; Sajatovic et al., 2005). Balance of power and responsibilities were seen as core characteristics in the partnership with professionals (Dorozenko et al., 2018; Elstad & Eide, 2009; Grim et al., 2017; Jormfeldt et al., 2014; Lwembe et al., 2017; Sharma et al., 2017). Consumers stated that professionals needed to be empowered by their organisations to be able to share power with them (McCloughen et al., 2011). They described feelings of empowerment and self-efficacy when given opportunities to express their ideas and participate voluntarily and in a meaningful way. The importance of maintaining respect and dignity was also highlighted (Dorozenko et al., 2018; Elstad & Eide, 2009; Grim et al., 2017; Jormfeldt et al., 2014; Larsen et al., 2022; Lwembe et al., 2017; Sharma et al., 2017; Solbjør et al., 2013). Only in the severest illness phases or on admission to hospital, did consumers feel that the professionals had better competence to take responsibility for their involvement (Solbjør et al., 2013; Wright et al., 2016).

### Supportive structures of mental healthcare

Supportive structures of mental healthcare meant the following to consumers: (1) environments that promote consumer participation, (2) consumers' multidimensional roles, (3) supportive information and (4) learning in the community.

A stable and secure environment played an important role in consumers' experiences of equal participation (Dorozenko et al., 2018; Elstad & Eide, 2009; Larkin et al., 2015; Lwembe et al., 2017; Stephenson et al., 2020). The organisational support and consultation in the co-creation of care options made consumers more confident and gave them a sense of autonomy (Sharma et al., 2017). They enjoyed volunteering and felt a sense of fulfilment when helping other people. They felt they were able to co-create a positive influence in the community and increase their sense of competence when they became involved in various activities as co-producers, strategic partners or members of a community (Sharma et al., 2017). Peer support enabling the connections between consumers and professionals were also highly appreciated (Lwembe et al., 2017). It helped consumers to feel accepted and increased the sense of community (Connor & Wilson, 2006).

Consumers mentioned that they enjoyed being involved in various co-creation activities and wanted to participate in a meaningful way and take an active role in service design and delivery (Dorozenko et al., 2018; Sharma et al., 2017). Being involved was perceived as a positive thing and it gave an opportunity to influence their own care and develop



**FIGURE 2** The result of the thematic analysis of consumers' perceptions of involvement in mental health services.

their future care (Connor & Wilson, 2006; Daremo & Haglund, 2008; Elstad & Eide, 2009; Laitila et al., 2018; McCloughen et al., 2011; Stephenson et al., 2020). Consumers felt confident when integrating resources with others. This enhanced their belief in their own knowledge and skills. (Dorozenko et al., 2018; Larkin et al., 2015; Sharma et al., 2017). The experience of involvement helped consumers to understand the opportunity to reflect on their own experiences of illness, strengthened their self-management and helped to understand other consumers' experiences (Stephenson et al., 2020).

Supportive information on mental illness or healthcare systems was seen as an enabling characteristic of consumer involvement on the system level (Grim et al., 2017; Laitila et al., 2018; Solbjør et al., 2013; Stephenson et al., 2020). Consumers found supporting follow-up processes important for strengthening the relationship between them and professionals (Jormfeldt et al., 2014) and highlighted the need for transparent and clear expectations and agreements to avoid information overflow and stress (Dorozenko et al., 2018; Lorenz-Artz et al., 2021). There was a clear demand for being better

informed when using online services, such as eHealth (Lorenz-Artz et al., 2021). Learning in a community was seen as valuable. Sharing experiences in group settings increased consumers' understanding, feelings of competence and confidence. (Connor & Wilson, 2006; Larkin et al., 2015; Lorenz-Artz et al., 2021). Learning outcomes were experienced from, for example, verbalising individual goals, supporting constructive thinking and learning how to support peers (Jormfeldt et al., 2014). Being involved in communion with others gave a feeling of common ground (Jormfeldt et al., 2014; Sharma et al., 2017). Additionally, consumers saw specific training for professionals and students as a key element to strengthening consumer involvement in mental health services (Laitila et al., 2018).

### Disorganised participation

Disorganised participation meant three things to consumers: (1) imbalanced relationships, (2) confusing information and (3) consumers' fear and uncertainty.



Imbalanced relationships occurred in various ways, such as professionals' poor communication (Daremo & Haglund, 2008; McCloughen et al., 2011), ignoring consumers (Larsen et al., 2022; Solbjør et al., 2013) or dominant and controlling behaviour (Connor & Wilson, 2006; Daremo & Haglund, 2008; McCloughen et al., 2011; Wright et al., 2016). Consumers felt they needed to modulate their behaviour continually to attract professionals' attention and they were uncertain how the professionals would respond to them (McCloughen et al., 2011). Professionals had little or no authority to change care decisions and insufficient time for consumers. Because of this, consumers found negotiation pointless. (Laitila et al., 2018; McCloughen et al., 2011).

Information often felt confusing, because it was difficult to understand, or it was lacking. This caused stress, dependency on professionals and the potential to become 'lost' in the system. (Grim et al., 2017; McCloughen et al., 2011; Solbjør et al., 2013; Wright et al., 2016). Consumers noticed the pressure that the system was placing on professionals, which led to their unreasonable behaviour during transition points and resulted in chaotic emotional responses (Wright et al., 2016). Some consumers were also afraid of their increased involvement leading to a decrease in support from professionals (Elstad & Eide, 2009). They felt consumer involvement in mental health services was at an early stage and their own experience was insufficient (Connor & Wilson, 2006). Using online services was often viewed as being a burden because of a lack of concentration, self-confidence or discipline (Grim et al., 2017; Lorenz-Artz et al., 2021).

### Frameworks guiding the involvement of mental health consumers

This review identified 14 different frameworks that guided the involvement of consumers in mental health services (see Table 3). One of the frameworks was co-developed during the study (Grundy et al., 2016), and two of the studies utilised a previous framework to the co-development processes (Grim et al., 2017; Stephenson et al., 2020). Fifteen studies utilised previous frameworks to provide theoretical insight or to guide consumer involvement in mental health services or processes. Table 3 also highlights the terms utilised to describe consumer involvement.

## DISCUSSION

This integrative literature review assembled previous knowledge of consumers' perceptions of involvement in mental health services and various guiding frameworks. Thus, this review supports the previous evidence that consumer involvement in mental health has been increasingly studied in twenty-first century healthcare

(e.g. Dent & Pahor, 2015; Jørgensen & Rendtorff, 2018). Most of the papers selected for this review ( $n=10/18$ ) were published between 2016 and 2022. It is also worth noting that none of the selected studies were conducted in low economic countries. Twelve of the studies were conducted in Europe, of which seven were in Nordic countries and five in the UK. It could be suggested that in these countries, more research has been conducted on mental health consumer involvement than in other countries. It has been shown that in Nordic countries, the local democratic system is engaging individuals and the public to become more involved. Also, in the UK, the community health councils represent consumers' local views (Dent & Pahor, 2015; WHO, 2022, 2023). Thirteen of the 18 selected studies included consumers from outpatient mental health services and housing services. It is recognised that professionals' attitude towards consumers may be affected more by organisation culture in inpatient mental healthcare (Dent & Pahor, 2015). However, there are also challenges in outpatient care concerning needs-based care (Ryan et al. 2019).

Nonetheless, this review strengthened the understanding that one of the central barriers to consumer involvement appears to be the conceptual complexity. It is necessary to identify effective strategies to enable the realisation of consumer involvement at the organisational or system levels (Bombard et al., 2018; Dent & Pahor, 2015; Jørgensen & Rendtorff, 2018; Stomski & Morrison, 2017). Still, it is essential to understand that there are significant differences between countries, and healthcare organisations' culture reflects a strong cultural and political conservatism even if consumers generally have become more involved in their own healthcare (Kirkpatrick et al., 2016).

### Partnership between consumers and professionals

This review showed that a partnership with professionals meant the values of human interaction and person-centred care to consumers, such as the maintenance of respect, dignity and equality in interactions. Previous studies and policy support the idea that person-centred care is an approach that fulfils consumers' life and health goals in the whole journey of their care (CEN, 2020; Dent & Pahor, 2015; OECD, 2021; WHO, 2022). Evidence also shows that in high-income countries participatory processes with consumers have increased (Semrau et al., 2016). However, partnership is the most demanding phase of collaboration between consumers and professional caregivers and demands skills, time and resources (CEN, 2020; Scambler & Asimakopoulou, 2014). This review indicated that professionals' interaction skills are important. It also supports Jørgensen and Rendtorff's (2018) findings that one main factor in successful collaboration is dialogic and respectful



**TABLE 3** Guiding frameworks of consumer involvement.

Authors	The guiding framework	Purpose of use	Terms describing consumers' involvement
Connor and Wilson (2006)	Method of involvement	Providing theoretical insight	Involvement
Daremo and Haglund (2008)	Client-centred approach	Enabling clients' participation	Participation
Dorozenko et al. (2018)	Housing first approach based on co-production approach	Adopting participatory approaches	Co-production
Elstad and Eide (2009)	User participation model	Supporting user participation	Participation
Grim et al. (2017)	Participatory design	Co-developing new aid in a participatory process	Participatory design and service design
Grundy et al. (2016)	10C framework of care planning	Conceptualising a new framework from the user perspective	Involvement
Jormfeldt et al. (2014)	Boston Psychiatric Rehabilitation Approach	Supporting client involvement	Being in communion with others
Laitila et al. (2018)	Patient involvement	Supporting service users' active partnership	Involvement
Larkin et al. (2015)	Experience-based co-design approach	Improving healthcare services by enabling co-design	Co-design
Larsen et al. (2022)	Co-production approach	Supporting the co-production of public service delivery	Co-production
Lorenz-Artz et al. (2021)	Open dialogue model	Supporting dialogical process	Open dialogue
Lwembe et al. (2017)	Co-production approach	Promoting collaborative relationships	Co-production
McCloughen et al. (2011)	Collaborative partnership	Enabling more equal partnerships in person-centred care	Collaboration
Sajatovic et al. (2005)	Collaborative practice model	Support patients' role as active managers of their illness	Collaboration
Sharma et al. (2017)	Self-determination theory	Promotes consumers basic and universal psychological needs in the social and cultural conditions	Participation and co-creation
Solbjør et al. (2013)	Patient participation	Acknowledging patients experience and the patients as an expert of their health	Participation
Stephenson et al. (2020)	Co-production approach	Creating co-produced documents with authentic engagement from all parties.	Involvement and co-production
Wright et al. (2016)	Patient involvement	Understanding and recognising individuals' experiences	Involvement

communication, and relationships are built on elements such as respect and honesty. It is suggested that improving professionals' interaction skills is an efficient way of encouraging consumers to participate (WHO, 2022). Training professional carers may also increase the cohesive understanding and defining of consumer involvement as a concept (Dent & Pahor, 2015). Additionally, including consumers in education programs has strengthened students' understanding of consumer involvement and high-quality services (Bergerum et al., 2019; Heidke et al., 2018). However, it has been shown that many countries have under trained professionals working with mental health consumers (WHO, 2022).

### Supportive structures of mental healthcare

This review showed that a supportive environment and atmosphere and being part of a community were relevant for successful involvement. It is noteworthy that consumers had positive perceptions of volunteering, sharing and learning with peers, helping others and receiving support from peers. Mutschler et al. (2022) also highlighted an organisational culture with an engaged leadership and atmosphere as essential in fostering peer support. On the other hand, it has also been found that the culture in inpatient settings has not been ready to recognise the value of consumer expertise and accept



peer support (Byrne et al., 2016). Peer support has often been seen as more compatible with non-governmental organisations' recovery-oriented services, and their organisation culture is seen as more flexible than inpatient clinical settings (Gillard et al., 2014). Again, the education and training of professionals have been cited as important factors in enhancing a commitment to peer support (Mutschler et al., 2022). Byrne et al. (2016) noticed that the use of peer support in mental health services led to positive changes on cultural and individual levels. Consumers have also been seen as essential promoters in raising public awareness and acceptance of mental health conditions and combating stigma and discrimination (Smit et al., 2022).

### Disorganised participation

According to the findings of this review, consumers also had various negative perceptions of involvement. They pointed out the fears, stress and uncertainty felt in various situations. In their literature review, Bergerum et al. (2019) found that both consumers and professionals noticed the need for large-scale organisational change to achieve more person-centred management. In their study, consumers saw the gap between healthcare outcomes and their needs as being more severe than professionals did (Bergerum et al., 2019). Similar to this review, Bombard et al.'s (2018) review of patient engagement found that patients viewed involvement as tokenistic when involvement was used to justify decisions that had already been made or their requests had been rejected. Interestingly, their review also found professional carers' scepticism towards consumer involvement and the transfer of more power to them as key barriers (Bombard et al., 2018). Jørgensen and Rendtorff (2018) also showed in their review of perspectives of healthcare professionals that they lacked the skills to involve patients and tended to focus rather on patients' limitations and symptoms. Additionally, Lord and Gale (2014) have previously suggested that the mismatch between the needs of consumers and the needs of the organisation creates a gap between objective processes and subjective experiences. However, it seems that professionals, especially medical doctors, assume that consumers need more education than to be listened to and that the focus within care should be more on compliance than on co-production (Dent & Pahor, 2015). However, there is a need for more equal involvement, resources and training to enable organisations to empower both consumers and professionals (Bergerum et al., 2019).

### Frameworks guiding the involvement of mental health consumers

This review suggests that there is no single established framework that gives clear guidelines for consumer

involvement in mental healthcare. Having said this, some unifying factors were found, such as person-centredness and the consumer's role as an active participant. In this review, consumer involvement was defined using various terms, such as participation, collaboration, co-production, co-design, co-creation and involvement. It is notable that the terminology used has changed throughout the years (Steinhardt et al., 2022). The terms participation and collaboration were prevalent between 2008 and 2013, and co-production, co-creation, service design and co-design became more apparent between 2015 and 2022. Additionally, the term involvement was used more between 2016 and 2018. Interestingly, most of the studies ( $n=17/18$ ) utilised existing frameworks, and only one study conceptualised a new one. However, the consumers' experiences of involvement varied, depending on how the framework was utilised and implemented in practice. There are several existing frameworks that can be utilised in mental healthcare, but structured consumer involvement demands vision statements, policies and guidelines (Bergerum et al., 2019; CEN, 2020; Tambuyzer et al., 2014).

### CONCLUSION

This review synthesises mental health consumers' perceptions combined with guiding frameworks and indicates that these perceptions are not utilised enough on various levels of mental healthcare. Specifically, our findings describe three key themes that express the expectations for interaction between consumers and professional caregivers, namely, partnership between consumers and professionals, supportive structures of mental healthcare and organised participation. However, there is a need to investigate and co-develop more structured frameworks to guide involvement processes. This review provides valuable information for promoting consumer involvement and person-centredness in practice at the organisational level, as well as in individual consumer encounters. The perceptions of mental health consumers need to be considered to enable person-centredness implemented from guidelines into practice. Paying closer attention to the education of mental health professional caregivers and the involvement of mental health consumers in their care provides better opportunities to co-develop successful mental health services and recovery processes.

### RELEVANCE FOR CLINICAL PRACTICE

This review raises awareness of the significance of consumers' expertise and consumer involvement in mental healthcare. The findings could improve consumer



involvement in practice by helping organisations to identify development needs, to develop concrete plans and processes by involving different local and regional stakeholders. Organisations should ensure workable partnership between consumers and professional carers, as well as supportive structures of mental healthcare, and avoid disorganised participation of consumers. The results verify benefits of consumer involvement, while also may strengthen the quality of person-centeredness in mental health services. To be able to co-develop a cultural change within mental healthcare organisations and allocate resources more efficiently and also ensure meaningful partnership in practice, there is a need for further research on consumer involvement. The focus could be on co-creation and service design processes involving mental health consumers, professional caregivers, social and healthcare students and other stakeholders as equal partners. In addition, there is a need for further investigation into mutual learning processes between consumers and professional carers. There is also a necessity for research focusing on how frameworks succeed in guiding involvement in mental healthcare practice. By increasing understanding, there are possibilities to co-create new and more structured methods of working in equal partnership.

#### AUTHOR CONTRIBUTIONS

All authors contributed to the conception and design of this study and data analysis. Data collection and evaluation was contributed by two researchers (AA and KM). AA drafted the manuscript, and all authors contributed to refining and/or critically reviewing the manuscript. All authors agreed with the manuscript.

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No conflict of interest.

#### 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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