Training and/or Support Mechanisms for Both Educators and Patients in Mental Health Education: A Narrative Review

University of Twente

Master thesis Positive Clinical Psychology and Technology (PCPT)

Iris Ruel

First Supervisor: PhD Y. Namer

Second Supervisor: Dr. E.J. de Bruin

Date: 30/06/2024

Words: 12.143

APA 7th Edition

Abstract

In recent years, there has been growing recognition of the value of incorporating patient perspectives and experiences into healthcare education, however, for mental healthcare education the studies on this topic are still limited. This study aims to create an overview of the training and support mechanisms for patients and educators involved in mental healthcare education. Through a narrative literature review, various training- and support mechanisms for both patients and educators were identified and analysed. For patients, the focus in training mechanisms is on empowering individuals to share their unique experiences effectively, emphasizing communication, boundary-setting, and self-care practices (examples are UNTRAP and CAPITAL in the UK, as well as the Grenoble Patients' School). Educator training highlights the importance of creating a safe environment for patient involvement, facilitating student participation, and translating patient narratives into meaningful learning objectives. Support mechanisms for patients include institutional support, dedicated staff advocacy, and debriefing sessions, while educators are encouraged to prepare students for patient involvement and facilitate productive interactions between patients and learners. Key findings underscore the importance of readiness, communication, and meaningful engagement in successfully implementing patient experiences in mental healthcare education. As patient involvement becomes increasingly integrated into mental healthcare education, understanding and implementing effective training and support mechanisms are crucial for optimizing learning outcomes and promoting patient involvement.

Keywords: patient involvement, training mechanisms, support mechanisms, mental healthcare education

Training and/or Support Mechanisms for Both Educators and Patients in Mental Health Education: A Narrative Review

The almost 4000 students per year in the Netherlands (CBS Statline, n.d.) who graduate with a Master in Mental Health Care Psychology followed various courses, including mental health courses. However, a thing that is often still missing in most of these curricula is the involvement of patients in education, which is linked to hands-on learning experiences. According to Eijkelboom et al (2023) patient involvement is increasingly used in the curriculum, but still very new. However, in England, there is already a policy created for nursing schools which emphasizes the importance of including patients in education (Patient and Public Involvement in Nurse Education, 2018). Next to this, medical studies are often involving patients in their educational program through an active level of participation (Dijk et al.,2020). These are some examples that show the possibilities of involving patients on a larger scale.

This paper will use the term 'patients' to describe people who used mental health care for psychological problems at some point in their lives as it describes a more non-permanent state in healthcare (Priebe, 2021; Bennet-Weston et al, 2023).¹

The benefits and negative effects of patient involvement

Patients play an important role in medical but also mental health education, however, patients are typically used as passive illustrations of interesting conditions in textbooks or sometimes in cases as part of students' hands-on learning in clinical settings in which it is a role-play (Towle et al., 2010). The involvement of patients in education is a way to increase the real-life experience for students. By sharing their personal experiences with students,

¹ Another term that could be used is 'service users'. However, according to the paper by Priebe (2021), the term 'service user' should be avoided to describe people in mental health care. First of all, it is discriminatory, secondly, it is cynical and lastly, it is patronizing.

patients are positively influencing health professional students, resulting in the provision of better health services (Lauckner et al., 2012 & Kangas et al., 2022). For example, the mixed-methods design study of Kangas et al. (2022) shows positive outcomes from patient involvement in diabetes management, including increased student knowledge and skills, confidence in and motivation to treat diabetic patients and teamwork competency.

Not only do students experience benefits from including patients in education, but also the patients themselves could possibly experience certain benefits. According to Eijkelboom et al. (2023), patients could gain a better understanding of their own condition, improve their relationships with healthcare professionals, meet peers, and feel valued and empowered. These points are also supported by the literature review of Minogue et al, (2009). That study states that involving patients could boost their self-esteem, confidence, and general well-being. Next to this the study also states that patients could develop new skills when they are involved in mental health education, for example, skills such as communication and confidence.

On top of this, the program benefits as well from including such patient experiences. This is consistent with the call for social accountability, implying that education should be directed toward addressing societal needs and health concerns (Var, 2002). Early contact with patients in education helps students to develop comfort with patients, learn the fundamentals of clinical skills, fostering career interest in primary care and specialization knowledge. This promotes active learning in preclinical settings and lessens the "shock of practice" that some students encounter upon starting an internship. Research indicates that early experience with patient's experiences can improve the relevance of fundamental science courses and help students become ready for internships (Dornan et al., 2006; Godefrooij et al., 2010; Windish et al., 2004).

Despite the benefits, including patients can also have some negative effects. Patients could realize that their stories contain personal information and they struggled with the social stigma around their complaints. This would mean that sharing these stories with students could be emotionally risky, and depending on how students respond, some patients may feel vulnerable (Liamputtong & Rice, 2021; Howe, 2003).

According to the framework of Towle et al. (2010), six stages of patient participation were described in the curriculum (Table 1). These stages vary from low engagement, which involves only including patient cases on paper, to high engagement, which involves patient participation in institutional decision-making processes. Patients advance through several roles in educational activities, such as observers, advisors, participants, facilitators, and educators, with varying degrees of impact. This framework shows that patient involvement is not only limited to physical presence during classes. For example, including them in designing the curriculum of a study is another way to involve patients in education. In the scoping literature review of Lathlean et al. (2006) it mentioned that at universities in the UK, patients are involved in curriculum planning and development of nursing programmes.

Table 1
Stages of Towle's framework (Towle et al., 2010)

Level	Degree to which the patient is actively involved in the learning encounter
Level 1	Paper-based or electronic case or scenario
Level 2	Standardised or volunteer patient in clinical setting
Level 3	Patient shares his/her experience with students within a faculty-directed curriculum
Level 4	Patient-teacher(s) are involved in teaching or evaluating students
Level 5	Patient-teacher(s) as equal partners in student education, evaluation and curriculum
	development
Level 6	Patient(s) involved at the institutional level in addition to sustained involvement as
	patient-teacher(s) in education, evaluation and curriculum development for students

Limited implementation

A focused ethnography by Alberti et al. (2024) explained the multifaceted aspect of involving patients in mental health education. This article, but also the articles of Charles et al. (1997) and Solomon et al. (2016) explains that patient involvement in mental health care remains limited due to various factors stemming from the complexity of mental health education and practice. Unlike other medical conditions, mental health issues often involve sensitive and stigmatized topics, making it challenging to involve patients directly in educational settings. For example, it may be more difficult to find patients with personality disorders willing to be involved due to the disorder's severe and long-lasting social functioning problems and slow remission. This could impact the ability of patients to stand in front of a classroom, be part of a discussion or be possible to teach a group of students (Ennis and Wykes, 2013). For patients who struggle with social anxiety it would be nearly impossible to stand in front of a group of students. Similarly, because mental health education also involves patients with learning disabilities, it may be difficult to involve patients in developing a curriculum, asking them for an evaluation or including them in classes or discussions (Ennis and Wykes, 2013). Additionally, mental health education traditionally relies heavily on theoretical knowledge and clinical expertise, which may overshadow the value of experiential knowledge that patients and caregivers can offer. Moreover, mental health education often entails addressing complex psychosocial dynamics and therapeutic relationships, which may require specialized training and expertise beyond what patients and caregivers typically possess (Evans, 2023, Grundman et al., 2020).

Next to patients, also educators in mental health care may exhibit hesitancy towards involving patients in educational initiatives due to several concerns. Educators may be wary of potential shifts in power dynamics within educational settings if patients assume teaching roles (Happel et al., 2012; Boutillier et al., 2011). Davidson and Roe (2007) delve into these

complexities, highlighting how the incorporation of patient perspectives challenges traditional notions of professional identity and expertise. This complexity and lack of clarity in roles may contribute to educators' hesitancy to involve patients in education, as they may feel unsure about how to effectively incorporate patient perspectives into educational settings.

Nevertheless, patient involvement in mental health education is not fully absent, there are cases where patients are involved. These cases were a success because patients provided students with real-life insights into the realities of living with mental health problems. Patient participation in mental health education might take the form of panel discussions or guest lectures (Carroll, 2018; Happell et al., 2013; Bennett & Baikie, 2003). Teachers might ask people who have firsthand experience with mental health issues to talk to their pupils about their struggles, triumphs, and personal narratives. In the explorative study of Bennett & Baikie (2003), it is discussed that patients may also provide insights on navigating the mental health care system, coping mechanisms, and helpful recommendations. However, logistical challenges and resource constraints, such as finding suitable patients willing to participate and allocating resources for training and support, complicate the integration of patient involvement into mental health education, as discussed by Happel et al (2012) and Van Oort et al. (2024) in their examination of narratives of community and academic collaboration in mental health partnerships. This shows the importance to identify the training and support mechanisms in order to implement patient involvement.

There have already been numerous studies done on the topic of patient involvement in medical education (Lathlean et al., 2006; Howe & Anderson, 2003; Suikkala et al., 2018). However, the information on patient involvement in mental health education is still limited. Next to this, a more critical engagement with current literature is needed to identify the training and support mechanisms for both educators and patients to implement this kind of education successfully. This is also needed to see what information is still missing. This

narrative review will merge information from studies that have been focusing on the training and support mechanisms that are necessary for both educators and patients in education and will make a bridge to mental health education in the discussion to ensure the successful implementation in mental health education. The goal of this study is to identify what we can learn from studies that are already implementing patients in their education. And which training and support mechanisms for both patients and educators are necessary to successfully implement patient involvement in mental health education.

Methods

This narrative literature review is informed by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines as updated in 2020 (Page et al., 2021).

Eligible criteria

A variety of education in which patient involvement is implemented is included in this literature review. The reason for this is that different studies can learn from each other, keeping their own study context in mind. Also grey literature is included in this study, for example, government reports or conference proceedings. Grey literature is included to give a broad overview of the topic and also cover documents that are important for the research but that are not (yet) peer-reviewed. A variety of study designs are included in this review, ranging from quantitative to small sample studies and case studies. This narrative review excludes other literature reviews and book chapters for the final analysis of this study. As this review is about active involvement of patient experiences, articles that include only levels one and two (Towle's framework), in which the patient is either a paper case or a very scripted situation are not included. Lastly, the following criteria have been added: published between

1998 and 2023 (the last 25 years) and published in English. This is done since the educational system is very dynamic and changes considerably over time.

The definition of patient involvement used in this paper is patients' active participation and engagement in the education of students in various studies in a variety of roles, both formally and informally, using their unique experiential knowledge of living with disease, illness, or disability and receiving healthcare (Eijkelboom et al., 2023). For a study to be included in the narrative review, it needed to include patient involvement in the education of students. For example, patients could be involved in the assessment of students, could take leading roles in workshops or could give a lecture in front of a big group of students.

In many researches "patient involvement" is described in different terms. One of these ways in interprofessional education, which is defined as a collaboration of professionals which could improve patient care (Buring et al., 2009). Therefore, interprofessional education is not directly an indicator of patient involvement in education. It could also indicate that different professions in general learn from each other. Therefore, education that is interprofessional needs to be reviewed further to see which professions are included in the study. The article was included when part of the interprofessional education involved patient participation.

Search strategy

SCOPUS, PsycINFO, and PubMed electronic databases were searched for relevant articles on 03-01-2024. PsycINFO was used because this database also includes grey literature, for example, government reports, conference abstracts and theses. PubMed was included because many of the studies done about patient involvement are in the medical world. Lastly, SCOPUS was used because it gives a broad overview of the articles available, as interprofessional education is included in the search string SCOPUS includes a broad scope of studies and disciplines.

One of the key terms that was included in the search string was patient involvement, also interprofessional education was included to not limit the options. A broad scope of educations was included to get the most articles possible that are relevant to the research question, including, mental health education, education and health education, psychiatry, social work, psychology and nursing. Since multiple terms are used for patients in the different studies terms like 'service user', 'client', "expert by expertise" and 'consumers' are included. The search string included relevant search terms for specific outcome measures: Training mechanisms, support mechanisms, patients and educators. A pilot was executed with the search string to get an overview of the studies that would be included using this search string. When the results were satisfactory the final search string was consulted with the supervisor. After consultation with the supervisor, the final search string resulted in: (("Patient involvement" OR "interprofessional education" OR "Client involvement" OR "service user involvement" OR "expert by expertise involvement") AND ("Mental Health Education" OR "education" OR ("Mental" AND "Health" AND "Education") OR ("Social Work "AND "education") OR ("Nursing" AND "education") OR ("Psychiatric nursing" AND "education") OR ("Psychology" AND "education") OR ("Psychiatry" AND "education") OR ("Psychotherapy" AND "education")) AND ("Training mechanisms" OR "Support Mechanisms" OR "training" OR "support" OR "mechanisms") AND ("educators" OR "Trainers" OR "Teachers" AND ("patients" OR "clients" OR "service-users")).

Table 2

Search strategy

Search terms

Patient involvement OR Interprofessional education OR Client involvement OR service user involvement OR expert by expertise involvement AND

Mental health education OR Education OR Social work Education OR Nursing education OR Psychiatric nursing education OR Psychology education OR Psychiatry education or Psychotherapy education AND

Training mechanisms OR/AND Support mechanisms AND

Educators OR Trainers OR Teachers AND

Patients OR Service users OR clients

Inclusion criteria	Exclusion criteria		
• Grey literature	• Literature reviews		
 Peer reviewed 	 Book chapters 		
• English language	• Levels 1 & 2 of patient		
 Published between 	involvement		

Resources searched

- PubMed
- SCOPUS
- PsycINFO

Study screening and selection

either patient or

educator

1998 - 2023

Mentioning training or

support mechanisms for

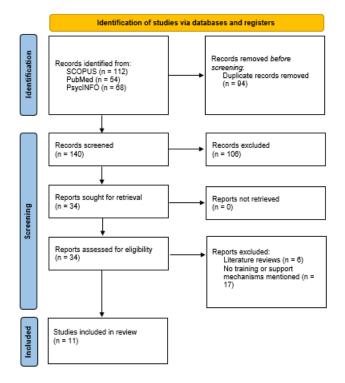
The results of the digital searches were uploaded to Covidence (Covidence, 2024). The duplicates were automatically removed from the list with articles while importing the various results from the databases. After removing duplicates, potentially eligible papers were chosen from the articles that remained. To begin, the titles and abstracts of the articles based on the search terms were screened to obtain a comprehensive overview. Following that, articles that passed the first selection were partially or completely screened by one screener. The relevant articles were documented in a corresponding study database.

In total, 234 articles were initially documented through electronic search. After excluding duplicates, 140 articles were kept for further analysis. The first session led to an exclusion of 106 articles, resulting in a number of 34 that were left. Based on the title and abstract many of the excluded articles did not include patients in education or were not

indicating training or support mechanisms. After the first session of reviewing the 34 articles were read in more depth. In this second session, 23 articles were excluded that did not meet the inclusion and exclusion criteria. Of these, 17 articles did (after further reading) not include training or support mechanisms and 6 articles were identified as literature reviews, which was a reason of exclusion. A final number of 11 individual studies were used for the final review. The flow diagram can be seen in Figure 1.

Figure 1

Flow Diagram literature review



Data analysis

According to the study of Popay et al. (2006) a narrative synthesis is a method for a systematic review and synthesis of findings from multiple studies that primarily relies on the use of words and text to summarize and explain the findings. The data from the disparate sources in this study were be systematically combined, which provided a thorough picture of patient participation training and support mechanisms across a range of educational environments. The methodology comprised four steps: Theory Development, Developing a

preliminary synthesis, Exploring relationships within and between studies, and assessing the robustness of the synthesis (Popay et al., 2006).

Theory Development: The creation of the review question and the kinds of research to be included are supported by theory development, which serves as the foundation for the systematic review (Popay et al., 2006). The training and support mechanisms for patient involvement served as our foundation. Research indicates that patient involvement might enhance the overall education and student experiences (Dornan et al., 2006; Godefrooij et al., 2010). This has already been applied in medical research, but mental health education lags behind. Thus, the objective is to determine which mechanisms for assistance and training can be applied to its implementation in this field of instruction as well. As a result, a wide variety of studies were included. The narrative synthesis that was done will help us improve our theoretical foundation and enabled the use of the findings of this review (Popay et al., 2006).

Developing a preliminary synthesis: An initial summary of the findings from the included research is developed in the preliminary synthesis, which is arranged so that a pattern can be explained in terms of effects or impact (Popay et al., 2006). Tabulation, grouping and clustering, and textual descriptions were used to accomplish this. The subsequent stages of the narrative synthesis required the input of this first synthesis (Popay et al., 2006).

Exploring relationships within and between studies: A more thorough investigation of the patterns that surface from the preliminary synthesis was done, focusing on examining the connections between and within the included research. A review is conducted on the correlations between the reported findings and the characteristics of various research. This narrative synthesis component aimed to explain how and why a specific intervention works, as well as to help discover potential contributing aspects (Popay et al., 2006).

Assessing the robustness of the synthesis: Examining the reliability of the findings is the goal of the last component of narrative synthesis. The volume of the supporting data as well as the methodology employed all have an impact on how reliable the synthesis is.

Consequently, an evaluation is conducted to determine the quality of the data supporting the conclusions and to generalise them to various demographics and environments (Popay et al., 2006).

Data extraction

From all the articles that were included in the final review demographic information (year of the study and country of origin), the kind of education and the level of patient involvement were extracted. The extraction of the level of patient involvement has been done based on the framework of Towle et al (2010), in which six levels of involvement are identified. From these articles, also the training and support mechanisms for both patients and educators were identified. For training mechanisms, the definition used in the study of Lindsay & Creswell (2017) is used in this study. With a training mechanism, it is meant that there is training with one or multiple classes to prepare a patient to use their experience in the educational program. This could either be as an assessor of assignments or as a leading teacher during a workshop. Support mechanisms in this study means that there is any kind of support possible for the patients and educators who are involved in the implementation of patient experiences (Hickmann et al., 2022). These categories are used as basis for the extraction forms that can be seen in Appendix A.

Results

Study selection

In total, 35 studies were screened, leading to a final amount of eleven studies that described training and/or supporting mechanisms for educators or patients. Four studies were conducted in England (Anka & Taylor, 2016; Garwood & Hassett, 2019; Hayward et al,

2005; Scott et al, 2021), two were from Canada (Lauckner et al, 2012; Towle & Godolphin, 2013), and the other studies were from the Netherlands (Eijkelboom et al, 2023), Israel (Kraus & Moran, 2023), France (Merle et al, 2022), Italy (Ferri et al, 2019) and the United States of America (Rees et al, 2017). Detailed information about these studies is given in Table 4. All of the studies were conducted between 2005 and 2023.

Study Characteristics

Ten of the studies used qualitative research methods to get to their goal. Most of these studies involved interview techniques to receive information from their participants (Anka & Taylor, 2016; Eijkelbook et al, 2023; Kraus & Moran, 2023; Lauckner et al, 2012; Merle et al, 2022; Rees et al, 2007; Scott et al, 2021; Towle & Godolphin, 2013). These participants could be educators, patients, students and other stakeholders such as directors of a university. Two of these studies set up a workshop or workshop series which involved patients as educators, these workshops were reviewed if they had any effect (Garwood & Hassett, 2019; Hayward et al, 2005). One study used a randomized controlled trial in which they looked for the effect of patient involvement on empathy in students (Ferri et al, 2019).

The studies that were conducted were mostly in four fields, the most common study that involved patients in education was health/medical studies (Eijkelboom et al, 2023; Ferri et al, 2019; Lauckner et al, 2012; Merle et al, 2022; Rees et al, 2007; Towle & Godolphin, 2013). Two studies were conducted in studies about mental health (Garwood & Hassett, 2019; Hayward et al, 2005) and two studies on Social Work (Kraus & Moran, 2023; Anka & Taylor, 2016). One study focused both on health and mental health studies (Towle & Godolphin, 2013).

Patient Involvement

The eleven studies that were used in this literature review provide an overview of the many possibilities of patient involvement. The six levels of involvement, as explained in the study of Towle et al (2010), form the basis of the identification of the involvement in the eleven studies in this review. The study of Merle et al (2022), expressed the highest level of patient involvement of all studies in this review (level 5). This study evaluates a course in France in which patients get a two-day course about tasks, skills and knowledge they need to have an active role during lectures, designing the curriculum and assessing students.

Three studies involved patients in a way that is classified as level four (Anka & Taylor, 2016; Eijkelboom et al, 2023; Towle & Godolphin, 2013). In their studies, patients were involved in an active way as teachers and assessors. The study of Anka and Taylor (2016), involved patients as assessors in the curriculum. This gave mixed reactions, especially from students who were suspicious about the way they were graded or assessed as the patients did not have an educational degree. Therefore, the final decision of a student's progression was not made by the patients but by the teachers themselves (Anka and Taylor, 2016).

Patients were also involved in other parts of the curriculum in studies that can be seen as level three involvement. In the studies of Ferri et al (2019); Garwood & Hassett (2019); Hayward et al (2005) and Kraus & Moran (2023), patients had an active role during workshops or lectures, in which they shared their experiences, either about their condition or about the care they got during their condition. During these workshops or lectures, students were able to ask questions to the patient about their experience (Ferri et al., 2019; Garwood & Hassett, 2019; Hayward et al., 2006; Kraus & Moran, 2023).

Three of the studies did not fully specify which roles the patients had in the curriculum, these studies focused more on the experience of the patients during their involvement (Lauckner et al, 2012; Rees et al, 2007; Scott et al, 2021). However, all the

patients that were involved in these studies were active on level three or level four based on Towle's framework of involvement (Towle et al, 2010). According to the synthesis, these studies involved focus groups consisting of multiple patients in various roles, not one level is fitting in these situations. Patients were sharing their stories, had some say in the assessment of the students and sometimes were asked for their opinion on the curriculum.

Training mechanisms

Patients

One of the training mechanisms that is mentioned in the study by Anka & Taylor (2016) is UNTRAP, a service user organisation in partnership with the Centre for Life Long Learning at the University of Warwick, Coventry (UK). This organisation offers UNTRAP support and trains patients who want to teach. Training in teaching allows for the interchange of ideas and experiences among health, medical, social care, and social work students, as well as the exploration of various teaching approaches and future potential in university and community settings (Universities/User Teaching and Research Action Partnership, 2004). Another official training that is offered in the UK is CAPITAL. Whereas UNTRAP focuses on a wide variety of patients (Universities/User Teaching and Research Action Partnership, 2004), this training, mentioned in the study of Hayward et al (2005), focuses solely on individuals with mental health issues (Faulkner et al., n.d.). CAPITAL empowers individuals with mental health issues to improve services through training, consultation, evaluation, collaboration with professionals, patient councils, and informal peer support (Faulkner et al., n.d.). According to the synthesis, both of the official trainings mention that skills such as communication, presentation and reflection are essential to bring the implementation of patient experiences to a success. A third official training is mentioned in the study of Merle et al (2022), which is about the Grenoble Patients' School (GPS) that is a part of the Université

Grenoble Alpes (UGA). This school provides two kinds of training for patients to use their experiences optimally. The first training is about becoming a peer educator in chronic somatic conditions, which entails thorough training and preparation in order to advocate for the needs of people with chronic somatic diseases, raise awareness and understanding of these disorders, and successfully educate others about them (Merle et al., 2022). The second training is more specific about becoming a mental health peer educator, which involves courses about university courses and curriculum, de-stigmatization and future prospects (Merle et al., 2022).

Both Eijkelboom et al (2023) and Kraus & Moran (2023) mention in their studies that training is necessary, however, they did not recommend a specific institution or organisation. According to the synthesis, the training for patients would involve teaching patients to share their unique and autonomous experiences in teaching situations instead of shaping them into teachers (Eijkelboom et al., 2023; Towle & Godolphin, 2013). This would involve teaching patients empowerment in which patients would be urged to acknowledge the value of their narratives and the possible influence they may have on students' academic progress (Kraus & Moran, 2023). Next to this, it would also include teaching patients to set boundaries, recognizing when and how to disclose private information, and using self-care practices to deal with any emotional difficulties that may surface (Laukner et al., 2012). These same elements are acknowledged by Towle & Godolphin (2013), who state the importance of that patients establish limits and know when and how to provide personal information. Also Eijkelboom et al. (2023) and Kraus & Moran (2023) explain that patients should be taught how to set limits in learning environments and when and how to provide personal information without jeopardizing their emotional security or privacy. Additionally, Lauckner et al (2012) mentioned that monitoring disclosure is a topic that needs to be included in the training. Next to monitoring disclosure, patients should also get information about perceived student

learning (Laukner et al., 2012). According to the synthesis, including this in a training would prevent patients from sharing too much of themselves with the students. Both UNTRAP and CAPITAL incorporate comprehensive training elements that align well with the recommendations in the referenced studies. They empower patients, teach them to set boundaries, manage emotional well-being, and in the case of CAPITAL, understand student learning to enhance the educational impact while protecting their personal boundaries.

Educators

Whereas for patients there are already some training organisations, educators are often not trained to include patients. However, multiple studies included in this review express the importance of training educators to optimally use the experiences of the patients. Eijkelboom et al (2023) mention that teachers would need the training to get up to date with this new method of teaching, and teachers would especially need training about creating a safe environment for the patients to safely share their experiences. Next to this both the studies of Garwood & Hasselt (2019) and Scott et al (2021) emphasize the importance of trained teachers on student experiences. According to those studies, a training for educators should provide educators with tools to encourage participation among students but also prepare them for the patient's story. A trained teacher would give students the tools to reflect on their experience with the patient (Garwood & Hasselt, 2019; Scott et al., 2021). Lastly, the study of Rees et al (2007), emphasized the importance of training educators in such a way that they know the benefits for patients sharing their stories. If they are aware of these benefits they can make sure patients reach these benefits in their classroom (Rees et al., 2007).

According to the synthesis, for patients, training focuses on empowering them to share their unique experiences effectively. This includes teaching communication, presentation, and reflection skills, while also emphasizing boundary-setting, self-care practices, and awareness of disclosure boundaries. The Grenoble Patients' School, UNTRAP and CAPITAL offer specialized programs for peer educators. Many studies mention the importance of training for educators to effectively facilitate patient involvement. This involves understanding the significance of patient narratives and creating a safe environment for sharing experiences.

Trained educators can encourage student participation, facilitate reflection on patient experiences, and maximize the benefits of patient involvement.

Support mechanisms

Patients

An important support mechanism patients expressed in the study of Scott et al (2021) is a dedicated member of the staff that supports them and behaves as their advocate within the faculty. In the study of Scott et al (2021), patients explained that it can be hard to express what you need when you are not familiar with the educational system. This dedicated member could be anyone involved in the educational program, for example, a dedicated staff member, a faculty member or someone from the administrative staff (Scott et al., 2021). This dedicated person would support a patient in expressing their needs, but could also be a point that patients could turn to whenever they feel like sharing troubles they experience (Scott et al., 2021). Also the study of Eijkelboom et al. (2023) mentions that it is important to set up institutional support. Towle & Godolphin (2013) add in addition that it is also important that the dedicated staff member would be able to articulate the message the patient wants to bring across. When patients have an active role during workshops or lectures in which they share their stories, it could be experienced as emotional. Therefore it would be convenient to prepare patients to know what they can expect and what is expected from them (Towle & Godolphin, 2013). Towle & Godolphin (2013) expressed the urgency to prepare patients before they share their stories in front of students. In order to enable patients to confidently

and successfully share their stories in educational settings, preparation for patient storytelling should place a high priority on clear communication, rehearsal, alignment with educational goals, and support for emotional well-being (Towle & Godolphin, 2013). In accordance, Eijkelboom et al. (2023) and Scott et al. (2021) mention that preparation is one of the key support mechanisms. Lastly, in the study of Lauckner et al. (2012), it is expressed that patients find their work more valuable when they feel like students took something away from their stories. Meaning that it is important that meaningful conversations and thoughts between patients and students should be the main goal of a support system. Whereas the study of Lauckner et al. (2012) does not mention a specific support mechanism for this need, Eijkelboom et al. (2023) mention that debriefing sessions following patient narrative sessions are a way in which students' experiences can be discussed with the patient.

Educators

Towle & Godolphin (2013) explain that it is important for teachers to articulate what patients want students to learn from their stories and translate this to the students. What is addressed in all the studies that included information about support mechanisms for educators is that preparation is the key (Eijkelboom et al, 2023; Garwood & Hasselt, 2019; Kraus & Moran, 2023; Rees et al, 2007; Towle & Godolphin, 2013). Eijkelboom et al (2023) explained that is important to talk about expectations. When an educator knows what is expected from him/her, he/she is better able to support the patient as well as possible. On the other side, when a patient knows what is expected from him/her, he/she knows how and when to share their experiences (Eijkelboom et al, 2023). Within this preparation, Rees et al (2007) mention asking patients how they want to be called during the class. Some patients prefer calling them patients, but others prefer expert-by-experience. Knowing what the patient prefers can optimise their experience. Garwood & Hassett (2019), expressed the urgency to prepare students for the involvement of a patient, as this can be an emotional experience. Therefore it

is important to prepare students what they can expect, but also explain to them how they can approach the patient with questions (Garwood & Hassett, 2019). Lastly, Kraus & Moran (2023), explained in their study that preference should be given to activities that both maximise the sharing of knowledge as well as the interaction with patients.

Ferri et al (2019), suggest a support mechanism that applies to both patients and educators. In their study, they suggest a checklist that would check if a patient is suitable to share their story. This checklist involves a check based on a few characteristics: Good awareness of one's health problem, no feelings of hostility toward nurses, motivation to teach students and good communication and interpersonal skills with the ability to reflect. Patients could check if these characteristics apply to themselves, but also educators can check if they find the patient suitable (Ferri et al., 2019).

According to the synthesis, in general, institutional support, readiness, and meaningful interactions are the main focuses of patient support mechanisms, whereas educator support mechanisms place more of an emphasis on readiness, patient comprehension, and encouraging productive connections between patients and students.

Table 3Overview of Training and Support mechanisms

	Training mechanisms	Suppo	ort mechanisms
Patients	UNTRAP (Anka & Taylor, 2016)	•	Dedicated staff member (Scott et
	CAPITAL (Hayward et al., 2005)		al., 2021; Eijkelboom et al.,
	GPS (Merle et al., 2022)		2023)
	Aspects included in the training:		Preparation (Eijkelboom et al.,
	 Sharing autonomous experiences 		2023; Scott et al., 2021; Towle &
	(Eijkelboom et al., 2023; Kraus &		Godolphin, 2013)
	Moran, 2022)	•	Debriefing sessions (Eijkelboom
	• Empowerment (Eijkelboom et al.,		et al., 2023)
	2023; Kraus & Moran, 2022)	•	Checklist (Ferri et al., 2019)

- Setting boundaries (Eijkelboom et al., 2023; Kraus & Moran, 2022; Towle & Godolphin, 2013)
- Monitoring disclosure (Lauckner et al, 2012)
- Perceived student learning (Lauckner et al, 2012)

Educators Aspects included in the training:

- Creating a safe environment (Eijkelboom et al., 2023)
- Tools to encourage participation among students (Garwood & Hassett, 2019; Scott et al., 2021)
- Knowing benefits for patients (Rees et al., 2007)
- Articulation what patients want to bring across (Towle & Godolphin, 2013)
- Preparation (Eijkelboom et al., 2023; Garwood & Hassett, 2019; Kraus & Moran, 2022; Rees et al., 2007; Towle & Godolphin, 2013)
- Use activities to maximise the sharing of knowledge (Kraus & Moran, 2022)
- Checklist (Ferri et al., 2019

Table 4 Study characteristics

Author	Location	Study Characteristics and outcomes	Education Characteristics	Level of patient Involvement ²	Support mechanisms mentioned	Training mechanisms mentioned
Anka & Taylor (2016)	England	Qualitative semi- structured interviews, face-to-face interviews, n = 21 Outcome: It is necessary to provide joint training to support patients and carers in the role of assessors. ³	Social Work study (undergraduate)	Level 4 Assessor (moments in which the assessment affects the progression of a student is still with the academics)	-	For patients: UNTRAP ⁴ , accredited training, service user involvement, teaching, research, certificate
Eijkelboom et al, (2023)	Netherlands	Qualitative, collaboration with different professions (students, patients and educators), n=13. Outcome: A practical guide with 12 tips.	Healthcare professions education (undergraduate)	Level 4 Teacher	For educators: Patient expectations, preparation, workshop assistance, debrief, evaluation	For patients: Patient preparatory training, autonomy For educators: Educator guidance, collaboration, safe environment, emotional discussions
Ferri et al. (2019)	Italy	Randomized controlled trial (n = 144) in which the effect on empathy was tested in the students that received	Healthcare professions education (undergraduate)	Level 3 Patients shared their story in a lecture-like setting	For both educator as patient: Patient-educator assessment, awareness, retaliation, motivation,	-

Based on Towle's Framework of involvement (Towle et al, 2010)
 A more in-depth description of the aim and outcomes of the study is given in the extraction forms (Appendix A)
 A service user organisation in partnership with the Centre for Life Long Learning at the University of Warwick, Conventry (UK)

		expert-patient education Outcome: Involvement of patients in teaching is effective in improving empathy levels.			communication skills, reflection	
Garwood & Hassett (2019)	England	Qualitative, semi- structured interviews (n = 6) Outcome: Participant's appraisal of their learning from patient involvement is influences by how they accommodate the emotional impact of the experience.	Mental Health practice (specifically CBT education) (postgraduate)	Level 3 An active involvement of patients in a training including workshops	For educators: Emotional involvement, trainee preparation, learning optimization	For educators: Teacher training, reflective practices, experiential learning
Hayward et al. (2005)	England	Qualitative, a pilot study on a 2-day training Outcome: The involvement of patients emphasised the significance of the impact that user views have on mental health workers.	Mental Health practice (postgraduate)	Level 3 An active involvement of patients in the workshop during the 2-day training	-	For patients: CAPITAL ⁵

_

⁵ Clients and Professionals in Training and Learning (CAPITAL): a service user organisation active within training and service development in West Sussex.

Kraus & Moran (2023)	Israel	Qualitative, interviews with student and service-users Outcome: Three working mechanisms for a conceptual framework are identified.	Social work study (undergraduate)	Level 3 A active role in classes in which patients share their story and questions can be asked	For educators: Experiential knowledge, interaction, experts- by-experience, preference	For patients: Expert-by-experience, training, experiential insights
Lauckner et al. (2012)	Canada	Qualitative, semi- structured focus group discussions and individual interviews Outcome: Main challenges, benefits and factors that influenced patients to participate were identified.	Health professional study (undergraduate)	Level 3/4 Various roles of patients were discussed during the focus groups and interviews	For patients: Student impact, positive experience, meaningful interaction	For patients: Vulnerability management, disclosure monitoring, training topic
Merle et al. (2022)	France	Qualitative, case reports of patients that followed a course at GPS ⁶ . Outcome: GPS is successful in their training.	Health studies (both undergraduate & postgraduate)	Level 5 Peer educator in Chronic Somatic Conditions, Mental Peer Educator are both active in various roles, lecturers, workshops and as promoters of social integration of	-	For patients: Grenoble Patients' School, recovery narrative, destigmatization, peer- to-peer support, skill development

⁶ Grenoble Patients' School (GPS)

				patients in education		
Rees et al. (2007)	USA	Qualitative, focus group discussions Outcome: More active collaboration will lead to a new level of knowledge production.	Medical study (undergraduate)	Level 3/4 The patients that were included in the focus group discussions have had multiple roles in education (passive roles but also teaching, designing and developing the curriculum)	For educators: Patient preference, terminology, active involvement	For educators: Service user education benefits, training, acknowledgment in sessions
Scott et al. (2021)	England	Qualitative, focus groups and interviews Outcome: Supportive university and community are of key importance.	(Mental) healthcare and (Mental) healthcare- related programmes (undergraduate & postgraduate)	Level 3/4 Being involved in multiple ways in the curriculum	For patients: Dedicated staff support, patient advocacy, faculty liaison	For educators: Student participation, patient engagement, preparatory training
Towle & Godolphin (2013)	Canada	Qualitative, several pilot workshops were followed and reviewed Outcome: Workshops were highly rated by students.	Health profession study (undergraduate)	Level 4 Patients were involved in workshops as leading teachers but also in the planning of the workshops and determining objectives	For patients: Preparation, support For educators: Articulate, objectives, translation, patient needs, student learning	For patients: Prepare, educator role, authenticity, teaching style, academicization

Discussion

The goal of this study was to identify which training and support mechanisms for both patients and educators are necessary to successfully implement patient involvement in mental health education, learning from other studies that are already implementing patient involvement in their education. For this, a narrative review has been done which resulted in eleven articles. These eleven articles have been analysed using narrative synthesis to identify all support and training mechanisms mentioned.

The key findings of this study are:

- Training mechanisms for patients involve empowering them to effectively share their experiences, focusing on communication, presentation, and boundary-setting skills.
- Educators require training to facilitate patient involvement, emphasizing creating a safe environment and understanding the significance of patient narratives.
- Both patients and educators benefit from preparation and clear articulation of expectations.
- Support mechanisms for patients include institutional support, preparation, and debriefing sessions, while educator support mechanisms prioritize readiness, patient comprehension, and fostering productive connections between patients and students.

As this study also included studies that were done in medical education instead of mental health education (Eijkelboom et al, 2023; Ferri et al, 2019; Lauckner et al, 2012; Merle et al, 2022; Rees et al, 2007; Towle et al, 2013), it is important to carefully assess the training and support mechanisms mentioned in these studies. According to the synthesis, the training and support mechanisms mentioned in the studies are not specifically tailored towards patients in medical studies. Therefore a change to make them suitable for patients that share their experiences in mental health education is not necessary. CAPITAL (Faulkner et al, n.d.), UNTRAP (Universities/User Teaching and Research Action Partnership, 2004) and GPS

(Merle et al, 2022) are all organisations that teach patients how to bring across their story, these are not specifically made for patients that are involved in medical education. The knowledge and practice in these trainings are generally about bringing across the experience, which does not differ between a physical or a mental illness. Next to this, the training and support systems for educators, as described in the results section, are not specifically focused on educators in medical studies, therefore it is not necessary to make any adjustments to the mechanisms mentioned in order to apply them in mental health education. To conclude, the mechanisms mentioned in the results section are all applicable to mental health care education as they are (as featured in the results section) all supported by studies that focus on mental health care education or are not tailored to any specific study.

One of the remarkable results of this study is that the studies in England already provide a good support and training system for patients who are involved in education (UNTRAP and CAPITAL). The reason that studies in England are already implementing more patient experiences could be because it is taken up in the United Kingdom policy (General Medical Counsil, 2007). This policy is based on the principle that involving patients and the public in healthcare decisions leads to better services and outcomes. In recent years, there has been a growing recognition of the value of incorporating patient experiences into healthcare education and training. As a result, initiatives to involve patients in education and training programs, such as CAPITAL and UNTRAP, are influenced by the policy framework in the UK. Multiple studies such as social work, nursing and medical studies involve patients as these studies require a certain amount of patients to be involved in their study (Patient and Public Involvement in Nurse Education, 2018).

The most important support mechanism that was found in this narrative study is preparation. Preparation of patients, students and educators is very important when implementing patient experiences in mental health care education. When educators and

patients together (but also apart from each other) prepare, a more successful workshop, lecture or assessment is assured. Next to this, it is important that the message that the patient wants to tell must be brought across. Educators are essential in assisting patients in expressing themselves and making sure that students understand what they are trying to say (Von Heimburg et al., 2021).

The limited amount of articles specifically on mental health education could be seen as a limitation of this study. This limited amount of articles could be because of the stigma around mental illness. If people do not feel comfortable enough, because of the stigma, to share something about their mental illness, they would be hesitant to share their stories in front of students as well. Next to this, according to Oexle et al. (2017), this self-stigma (the internalization of negative stereotypes) also leads to a longer recovery period, if people even recover. This would be another barrier to not sharing the experience of a mental illness in the educational system. Which makes that patient involvement in mental health education is limited, and therefore there are limited articles about it.

One strength of this study is that it focuses on a gap in the literature. As discussed at the beginning of this study a good overview of the training and support systems to ensure successful implementation of patient involvement was missing. Therefore, this study aimed to close this gap in the literature. Another strength of this study is that it is one of the first studies to create a good overview of training and support mechanisms necessary for the successful implementation of patient involvement.

Recommendations and Future Research

As the studies mentioned in this narrative review did merely mention the support and training mechanisms but did not research the effect of them specifically, future research is necessary. Future research would need to focus on creating a pilot implementation study involving patients in mental health care and applying the training and/or support mechanisms

(table 3) and test if further or different support is necessary. Another possibility for further research would be to research what students would need in order to make optimal use of the patients involvement. This narrative study solely focused on patients and educators, but students could also need support. Furthermore, this study also has a practical use. The results of this study, an overview of the support and training mechanisms, can be used in an educational setting. Whenever educators are thinking of implementing patients, it is beneficial to implement the training and support mechanisms to make optimal use of this additional tool in the educational curriculum.

References

- Alberti, S., Vannini, V., Ghirotto, L., Bonetti, L., Rovesti, S., & Ferri, P. (2024). Learning to teach with patients and caregivers: a focused ethnography. *BMC Medical Education* (Online), 24(1). https://doi.org/10.1186/s12909-024-05197-5
- *Anka, A., & Taylor, I. (2016). Assessment as the site of Power: a Bourdieusian interrogation of service user and carer involvement in the assessments of social work students.

 *Social Work Education, 35(2), 172–185.

 https://doi.org/10.1080/02615479.2015.1129397
- Bennett, L., & Baikie, K. (2003). The client as educator: learning about mental illness through the eyes of the expert. *Nurse Education Today*, 23(2), 104–111. https://doi.org/10.1016/s0260-6917(02)00193-4
- Bennett-Weston, A., Gay, S., & Anderson, L. (2022). A theoretical systematic review of patient involvement in health and social care education. *Advances in Health Sciences Education*, 28(1), 279–304. https://doi.org/10.1007/s10459-022-10137-3
- Boutillier, C. L., Leamy, M., Bird, V., Davidson, L., Williams, J., & Slade, M. (2011). What does recovery mean in practice? A Qualitative Analysis of International Recovery-Oriented Practice Guidance. *Psychiatric Services (Washington, D.C. Print)*, 62(12), 1470–1476. https://doi.org/10.1176/appi.ps.001312011
- Buring, S. M., Bhushan, A., Broeseker, A. E., Conway, S. E., Duncan-Hewitt, W. C., Hansen,
 L. B., & Westberg, S. M. (2009). Interprofessional Education: Definitions, student
 competencies, and guidelines for implementation. *American Journal of Pharmaceutical Education*, 73(4), 59. https://doi.org/10.5688/aj730459
- Carroll, S. M. (2018). Destignatizing Mental Illness: An Innovative Evidence-Based

 Undergraduate Curriculum. *Journal of Psychosocial Nursing and Mental Health*Services, 56(5), 50–55. https://doi.org/10.3928/02793695-20180108-04

- CBS Statline. (n.d.).
 - https://opendata.cbs.nl/statline/#/CBS/nl/dataset/83893NED/table?dl=410E0
- Charles, C., Gafni, A., & Whelan, T. J. (1997). Shared decision-making in the medical encounter: What does it mean? (or it takes at least two to tango). *Social Science & Medicine*, 44(5), 681–692. https://doi.org/10.1016/s0277-9536(96)00221-3
- Collins English Dictionary. (2024). In *Collins Dictionaries*.

 https://www.collinsdictionary.com/dictionary/english/supportmechanism#:~:text=any%20formal%20system%20or%20method%20of%20providing
 %20support%20or%20assistance
- Covidence. (2024, February 1). *Covidence Better systematic review management*. https://www.covidence.org/
- Davidson, L., & Roe, D. (2007). Recovery from versus recovery in serious mental illness:

 One strategy for lessening confusion plaguing recovery. *Journal of Mental Health*,

 16(4), 459–470. https://doi.org/10.1080/09638230701482394
- Dijk, S., Duijzer, E. J., & Wienold, M. (2020). Role of active patient involvement in undergraduate medical education: a systematic review. *BMJ Open*, *10*(7), e037217. https://doi.org/10.1136/bmjopen-2020-037217
- Dornan, T., Littlewood, S., Margolis, S. A., Scherpbier, A. J. J. A., Spencer, J., & Ypinazar, V. (2006). How can experience in clinical and community settings contribute to early medical education? A BEME systematic review. *Medical Teacher*, 28(1), 3–18. https://doi.org/10.1080/01421590500410971
- *Eijkelboom, C., Brouwers, M., Frenkel, J., Van Gurp, P., Jaarsma, D., De Jonge, R., Koksma, J., Mulder, D., Schaafsma, E., Sehlbach, C., Warmenhoven, F., Willemen, A., & De La Croix, A. (2023). Twelve tips for patient involvement in health

- professions education. *Patient Education and Counseling*, *106*, 92–97. https://doi.org/10.1016/j.pec.2022.09.016
- Ennis, L., & Wykes, T. (2013). Impact of patient involvement in mental health research: longitudinal study. *British Journal of Psychiatry*, 203(5), 381–386. https://doi.org/10.1192/bjp.bp.112.119818
- Faulkner, A., NSUN, Mind, CAPITAL Project Trust, Primary Care Trust, NHS Trust,
 Ockwell, C., & Pearce, H. (n.d.). *Peer support case studies* (Watson & Meddings,
 Eds.). https://www.nsun.org.uk/wp-content/uploads/2021/05/CAPITAL_PS_CS.pdf
- *Ferri, P., Rovesti, S., Padula, M. S., D'Amico, R., & Di Lorenzo, R. (2019). Effect of expert-patient teaching on empathy in nursing students: a randomized controlled trial
 Psychology Research and Behavior Management, Volume 12, 457–467.
 https://doi.org/10.2147/prbm.s208427
- *Garwood, P. T., & Hassett, A. (2019). Service user involvement in cognitive behavioural therapy training: an interpretive phenomenological analysis. *The Journal of Mental Health Training, Education and Practice*, *14*(3), 186–198. https://doi.org/10.1108/jmhtep-02-2018-0014
- Godefrooij, M., Diemers, A., & Scherpbier, A. J. J. A. (2010). Students' perceptions about the transition to the clinical phase of a medical curriculum with preclinical patient contacts; a focus group study. *BMC Medical Education*, *10*(1). https://doi.org/10.1186/1472-6920-10-28
- Happell, B., Byrne, L., McAllister, M., Lampshire, D., Roper, C., Gaskin, C. J., Martin, G.,
 Wynaden, D., McKenna, B., Lakeman, R., Platania-Phung, C., & Hamer, H. P. (2013).
 Consumer involvement in the tertiary-level education of mental health professionals:
 A systematic review. *International Journal of Mental Health Nursing*, 23(1), 3–16.
 https://doi.org/10.1111/inm.12021

- Happell, B., Scott, D., Platania-Phung, C., & Nankivell, J. (2012). Should we or shouldn't we? Mental health nurses' views on physical health care of mental health consumers.
 International Journal of Mental Health Nursing, 21(3), 202–210.
 https://doi.org/10.1111/j.1447-0349.2011.00799.x
- *Hayward, M., West, S., Green, M., & Blank, A. (2005). Service innovations: Service user involvement in training. *Psychiatric Bulletin*, 29(11), 428–430. https://doi.org/10.1192/pb.29.11.428
- Howe, A., & Anderson, J. (2003). Involving patients in medical education. *BMJ. British Medical Journal*, 327(7410), 326–328. https://doi.org/10.1136/bmj.327.7410.326
- Kangas, S., Rintala, T., Hannula, P., Jämsen, E., Kannisto, R., Paavilainen, E., & Jaatinen, P.
 (2022). The impact of interprofessional education on students' current and desired competence in diabetes care. *Nursing Open*, 10(1), 264–277.
 https://doi.org/10.1002/nop2.1301
- *Kraus, E., & Moran, G. S. (2023). The working mechanisms underpinning mental health experts by experience involvement in direct teaching: an abductive conceptual framework. *The British Journal of Social Work*, *53*(8), 4002–4022. https://doi.org/10.1093/bjsw/bcad124
- Lathlean, J., Burgess, A., Coldham, T., Gibson, C., Herbert, L., Levett-Jones, T., Simons, L., & Tee, S. (2006). Experiences of service user and carer participation in health care education. *Nurse Education in Practice*, *6*(6), 424–429. https://doi.org/10.1016/j.nepr.2006.07.012
- *Lauckner, H., Doucet, S., & Wells, S. (2012). Patients as educators: the challenges and benefits of sharing experiences with students. *Medical Education*, 46(10), 992–1000. https://doi.org/10.1111/j.1365-2923.2012.04356.x

- Lindsay, E. K., & Creswell, J. D. (2017). Mechanisms of mindfulness training: Monitor and Acceptance Theory (MAT). *Clinical Psychology Review*, *51*, 48–59. https://doi.org/10.1016/j.cpr.2016.10.011
- *Merle, R., Pépin, J., Palombi, O., Pariset, A., Allenet, B., & Pison, C. (2022). Successful training of patients to intervene in health education and clinical research at Grenoble Patient School. *Journal of Patient Experience*, *9*, 237437352110698. https://doi.org/10.1177/23743735211069810
- Minogue, V., Holt, B., Karban, K., Gelsthorpe, S., Firth, S., & Ramsay, T. (2009). Service

 User and Carer Involvement in Mental Health Education, Training and Research—A

 Literature Review. *Mental Health and Learning Disabilities Research and Practice*,
 6(2), 211–227. https://search.informit.org/doi/10.3316/informit.673811211455615
- Oexle, N., Müller, M., Kawohl, W., Xu, Z., Viering, S., Wyss, C., Vetter, S., & Rüsch, N. (2017). Self-stigma as a barrier to recovery: a longitudinal study. *European Archives of Psychiatry and Clinical Neuroscience*, 268(2), 209–212. https://doi.org/10.1007/s00406-017-0773-2
- Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T., Mulrow, C. D.,
 Shamseer, L., Tetzlaff, J., Akl, E. A., Brennan, S., Chou, R., Glanville, J., Grimshaw,
 J., Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E., Mayo-Wilson, E., McDonald, S., .
 . Moher, D. (2021). The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ*, n71. https://doi.org/10.1136/bmj.n71
- Patient and public involvement in nurse education. (2018, May 31). Health Education England. https://www.hee.nhs.uk/our-work/patient-public-involvement-nurse-education
- Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, M., & Britten, N. (2006). Guidance on the conduct of narrative synthesis in systematic Reviews. A

- Product from the ESRC Methods Programme. Version 1. *ESRC Methods Programme*. https://doi.org/10.13140/2.1.1018.4643
- Priebe, S. (2021). Patients in mental healthcare should be referred to as patients and not service users. *BJPsych Bulletin*, 45(6), 327–328. https://doi.org/10.1192/bjb.2021.40
- *Rees, C. E., Knight, L., & Wilkinson, C. (2006). "User Involvement Is a Sine Qua Non, Almost, in Medical Education": Learning with Rather than Just About Health and Social Care Service Users. *Advances in Health Sciences Education*, 12(3), 359–390. https://doi.org/10.1007/s10459-006-9007-5
- *Scott, L., Hardisty, J., Cussons, H., Davison, K., Driscoll, H., Powell, S. K., & Sturrock, A. (2021). Exploring a collaborative approach to the involvement of patients, carers and the public in the initial education and training of healthcare professionals: A qualitative study of patient experiences. *Health Expectations*, 24(6), 1988–1994. https://doi.org/10.1111/hex.13338
- Solomon, M. Z., Gusmano, M. K., & Maschke, K. J. (2016). The ethical imperative and moral challenges of engaging patients and the public with evidence. *Health Affairs* (*Millwood*, *Va.*), 35(4), 583–589. https://doi.org/10.1377/hlthaff.2015.1392
- Suikkala, A., Koskinen, S., & Leino-Kilpi, H. (2018). Patients' involvement in nursing students' clinical education: A scoping review. *International Journal of Nursing Studies*, 84, 40–51. https://doi.org/10.1016/j.ijnurstu.2018.04.010
- Towle, A., Bainbridge, L., Godolphin, W., Katz, A. M., Kline, C., Lown, B. A., Madularu, I., Solomon, P., & Thistlethwaite, J. (2010). Active patient involvement in the education of health professionals. *Medical Education*, *44*(1), 64–74. https://doi.org/10.1111/j.1365-2923.2009.03530.x

- *Towle, A., & Godolphin, W. (2013). Patients as educators: Interprofessional learning for patient-centred care. *Medical Teacher*, *35*(3), 219–225. https://doi.org/10.3109/0142159x.2012.737966
- Universities/User Teaching and Research Action Partnership. (2004). UNTRAP

 (Universities/User Teaching and Research Action Partnership) information [Report].

 https://warwick.ac.uk/fac/cross_fac/healthatwarwick/untrap/untrap.pdf
- Van Oort, P., Maaskant, J., Luttik, M. L., & Eskes, A. (2024). Impact of a patient and family participation education program on hospital nurses' attitudes and competencies: A controlled before-after study. *PEC Innovation*, *4*, 100249. https://doi.org/10.1016/j.pecinn.2023.100249
- Var, R. M. L. (2002). Patient involvement in education for enhanced quality of care.

 *International Nursing Review, 49(4), 219–225. https://doi.org/10.1046/j.1466-7657.2002.00128.x
- Von Heimburg, D., Langås, S. V., & Ytterhus, B. (2021). Feeling Valued and Adding Value:

 A Participatory Action Research project on co-creating practices of social inclusion in kindergartens and communities. *Frontiers in Public Health*, 9.

 https://doi.org/10.3389/fpubh.2021.604796
- Windish, D. M., Paulman, P. M., Goroll, A. H., & Bass, E. B. (2004). Do clerkship directors think medical students are prepared for the clerkship years? *Academic Medicine*, 79(1), 56–61. https://doi.org/10.1097/00001888-200401000-00013

Appendix A

Extraction form

Study title: Assessment as the Site of Power: A Bourdieusian Interrogation of Service User and Carer Involvement in the Assessments of Social Work Students

Date: 05-01-2024 Reviewer: I. Ruel

First author	Ann Anka
Year of publication	2016
Country of publication	England
Publication type	Journal

Study Characteristics

Type of study	Qualitative semi-structured individual
	interviews, face-to-face interviews
Participants	N=21, service users (n=3), carers (n=2),
	social work students (n=5), social work
	employers (n=6) and social work educators
	(n=5)
Education	Social Work (undergraduate)
Aim	The study focused on the positioning of
	service users and carers in relation to other
	stakeholders involved in the assessments of
	social work students in England
Study outcomes	In social work students' assessments and a
	lack of confidence among service users and
	carers in making failed assessment
	recommendations. Therefore, the paper
	concludes that it is necessary to provide
	joint training to support service users and
	carers in their role as assessors of social
	work students.

Level of Patient involvement

Level	Tasks of the patient
Level 4	Assessing projects of students

Training mechanisms patients mentioned ☐ Yes ☐ No

Mechanism	Effect
UNTRAP	Not mentioned

Assessor training (important to mention is	Not mentioned
that this needs to be given by other patients	
to not loose the authentic voice of the	
patients)	
Training mechanisms educators mentioned	Yes
Mechanism	Effect
Support mechanisms patients mentioned	Yes □ No
Mechanism	Effect
	X7
Support mechanisms educators mentioned	Y es □ No
Mechanism	Effect

Study title: Twelve Tips for Patient Involvement in health Professions Education

Date: 05-01-2024 Reviewer: I. Ruel

First author	Charlotte Eijkelboom
Year of publication	2023
Country of publication	Netherlands
Publication type	Journal

Study Characteristics

Type of study	Qualitative
Participants	N=13, patients, students, educators,
	researcher, health professionals
Education	Healthcare professions (undergraduate)
Aim	The purpose of the 12 tips is to offer
	practical guidance for educators on how to
	involve patients in their education
Study outcomes	A guide of 12 practical tips. These tips can
	be used as a tool to start with or reinforce
	patient involvement in education at the level
	of organization, teaching staff and
	individual lessons
	1. Foster a culture of openness
	2. Set up institutional support
	3. Include patients in all educational roles
	4. Aim for diversity
	5. Forge bonds with patients and
	patient organizations
	6. Appreciate patients for their
	educational efforts
	7. Think beyond the traditional patient lecture
	8. Start from day 1 and never stop
	9. Teach teachers how to involve
	patients
	10. Support patients and students in their
	role
	11. Broaden your perspective
	12. Just do it!

Level	Tasks of the patient
-------	----------------------

Level 4	The patients that were included in the study worked as teachers in the education
Training mechanisms patients mentioned	Yes □ No
Mechanism	Effect
Training to become an autonomous teacher	
Training about how to become a teacher,	
how to bring across the message	
Training mechanisms educators mentioned	Yes □ No
Mechanism	Effect
Guidance	
Support mechanisms patients mentioned	Yes □ No
Mechanism	Effect
Support mechanisms educators mentioned	Yes □ No
Mechanism	Effect
Patient preparation	
Workshop assistance	
Debrief sessions	
Evaluation with the patient	

Study title: Effect of Expert-patient Teaching on Empathy in Nursing Students: A

Randomized Controlled Trial

Date: 05-01-2024 Reviewer: I. Ruel

First author	Paola Ferri
Year of publication	2019
Country of publication	Italy
Publication type	Journal

Study Characteristics

Type of study	Randomised controlled trial in which the
	effect of empathy was tested in the students
	that received expert-patient education
Participants	N=144
Education	Health care profession (undergraduate)
Aim	Evaluate the effect of expert-patient
	teaching on empathy development in
	nursing students
Study outcomes	There were statistically differences between
	the mean scores over time in both scales in
	the experimental group. Male students who
	presented significantly lower levels of
	empathy at baseline in comparison with
	females, showed increased in empathy after
	training on the Balanced Emotional
	Empathy Scale in Both the experimental and
	control groups. Involvement of expert
	patients in teaching is effective in improving
	empathy levels in both male and female
	students

Level of Patient involvement

Level	Tasks of the patient
Level 3	Patients shared their story in a lecture-like
	setting

Training mechanisms patients mentioned

Yes

Mechanism	Effect

Training mechanisms educators mentioned □ Yes □ No		
Mechanism	Effect	
Support mechanisms patients mentioned	Yes □ No	
Mechanism	Effect	
A checklist in order to see if the patient- educator is able to present/teach based on a few characteristics - Good awareness of one's own health problem - No feelings of retaliation towards nurses - Motivation to teach students - Good communication and interpersonal skills with the ability to reflect	Not mentioned	
Support mechanisms educators mentioned	Yes □ No	
Mechanism	Effect	
A checklist in order to see if the patient-		
educator is able to present/teach based on a		
few characteristics		
- Good awareness of one's own health		
problemNo feelings of retaliation towards		
nurses		
- Motivation to teach students		
Good communication and interpersonal		
skills with the ability to reflect		

Study title: Service User Involvement In Cognitive Behavioural Therapy Training: An Interpretative Phenomenological Analysis

Date: 05-01-2024 Reviewer: I. Ruel

First author	Peter Thomas Garwood
Year of publication	2019
Country of publication	England
Publication type	Journal

Study Characteristics

Type of study	Qualitative, semi-structured interviews
Participants	N=6
Education	Mental health Practice (specifically CBT
	education). (postgraduate)
Aim	How an individual service user led training
	sessions is experienced and how this differs
	to routine CBT training
Study outcomes	Data revealed three subordinate themes
	1. Predisposing influenced on learning
	2. Factors associated with emotional
	processing of experience
	3. Impact upon learning outcomes
	The results suggest that participants'
	appraisal of their learning from service user
	involvement maybe influenced by how they
	accommodate the emotional impact of the
	experience.

Level	Tasks of the patient	
Level 3	An active involvement of patients in a	
	training including workshops	
Training mechanisms patients mentioned	□ Yes □ No	
Mechanism	Effect	
Training mechanisms educators mentioned	□ Yes □ No	
Mechanism	Effect	

The teacher should be trained in helping trainees reflect on their experience	When educators are properly trained in integrating these reflections it has a positive effect for the insights students are getting
Support mechanisms patients mentioned	ı Yes □ No
Mechanism	Effect
Support mechanisms educators mentioned	□ Yes □ No
Mechanism	Effect
Preparation, to maximize the learning	
opportunity	

Study title: Service innovations: service user involvement in training

Date: 05-01-2024 Reviewer: I. Ruel

First author	Mark Hayward
Year of publication	2005
Country of publication	England
Publication type	Journal

Study Characteristics

Type of study	Qualitative, pilot study on a 2-day training
Participants	Community menal health outreach team
	consisting of approximately 20 workers
Education	Mental health practice (post-graduate)
Aim	Adding to evidence regarding the successful
	involvement of service users & clarifying
	the process by which involvement can be
	safely achieved
Study outcomes	The involvement of service users
	emphasised the significance of the impact
	that user views can have on mental health
	workers.

Level of Patient involvement

Level	Tasks of the patient
Level 3	An active involvement of patients in the
	workshop during the 2-day training

Training mechanisms patients mentioned ☐ Yes ☐ No

Mechanism	Effect
CAPITAL was used to facilitate the service	It was seen as very positive by the patients.
user session and assume responsibility for it	But also the participants expressed the need
thereafter	to support CAPITAL because it was very
	valuable in their eyes

Training mechanisms educators mentioned □ Yes □ No

Mechanism	Effect

Support mechanisms patients mentioned	les □ No
Mechanism	Effect
Support mechanisms educators mentioned	Yes □ No
Mechanism	Effect

Study title: The working Mechanisms underpinning mental health experts by expertise involvement in direct teaching: An abductive conceptual framework

Date: 6-1-2024 Reviewer: I. Ruel

First author	Eran Kraus
Year of publication	2023
Country of publication	Israel
Publication type	Journal

Study Characteristics

Type of study	Qualitative, interviews with student and
	service users
Participants	Mental Health Expertys by Expertise
	(n=10), Social work educators (n=10),
	Bachelor of social work students (n=10),
	Master of social work students (n=9)
Education	Social Work (undergraduate)
Aim	Presenting a conceptual framework of the
	working mechanisms underpinning Experts
	by Expertise involvement in the mental
	health context
Study outcomes	Three working mechanisms
	- Sharing experiential knowledge
	 Meeting and interacting with the
	mental health experts by expertise
	 Challenging traditional roles and
	power/knowledge hierarchies

Level of Patient involvement

Level	Tasks of the patient
Level 3	An active role in classes in which patients
	share their story and questions can be asked

Training mechanisms patients mentioned ☐ Yes ☐ No

Mechanism	Effect
An expert by expertise training that teaches	Not mentioned
patients to share their experiential based	
practical insights	

Tr	aining mec	hanisms ed	lucators n	nentioned	□ <i>)</i>	es es		V	(
----	------------	------------	------------	-----------	------------	-------	--	---	---

Mechanism	Effect
Support mechanisms patients mentioned	Yes □ No
Mechanism	Effect
Support mechanisms educators mentioned	Yes □ No
	100
Mechanism	Effect
Preference should be given to activities that	Not mentioned
maximise the interaction between sharing	
experiential knowledge and meeting and	
interacting with experts by expertise	

Study title: Patients as educators: The challenges and benefits of sharing experiences with students

Date: 06-01-2024 Reviewer: I. Ruel

First author	Heidi Lauckner
Year of publication	2012
Country of publication	Canada
Publication type	Journal

Study Characteristics

Type of study	Qualitative semi-structured focus group
	discussions and individual interviews
Participants	Patient educators with chronic conditions or
	disabilities (n=30)
Education	Health professional (undergraduate)
Aim	Identify the positive and negative factors
	that contributed to the experiences of
	patient-educators in health mentor
	programme for health professional students
Study outcomes	Main challenge: potential vulnerability
	Main benefits: personal learning and making
	a valued contribution
	Two factors that influenced participant's
	sense of whether the potential benefits
	outweighed the challenges of personal
	sharing in the programme: Monitoring
	disclosure and perceived student learning

Level of Patient involvement

Level	Tasks of the patient
Level 3/4	Various roles of patients were discussed
	during the focus groups and interviews

Training mechanisms patients mentioned ☐ Yes ☐ No

Mechanism	Effect
Vulnerability management	Not mentioned
Monitoring disclosure	Not mentioned

Training mechanisms educators mentioned □ Yes □ No

Mechanism	Effect	
Support mechanisms patients mentioned	Yes □ No	
Mechanism	Effect	
Patients feel like students took something	Leads to a more positive experience	
from their story		
Support mechanisms educators mentioned	ı Yes □ No	
Mechanism	Effect	

Study title: Successful training of patients to intervene in health education and clinical research at Grenoble Patient School

Date: 06-01-2024 Reviewer: I. Ruel

First author	Raymond Merle
Year of publication	2022
Country of publication	France
Publication type	Journal

Study Characteristics

Type of study	Qualitative, case reports of patients that
	followed a course at GPS
Participants	N=45 patients
Education	Health studies (both undergraduate and
	postgraduate)
Aim	Review the effect of GPS
Study outcomes	The study showed that training patients at
	GPS is very successful.

Level of Patient involvement

Level	Tasks of the patient
Level 5	Peer educators in Chronic Somatic
	Conditions, Mental health Peer educators
	are both active in various roles, lecturers,
	workshops and as promotors of social
	integration of patients in education

Training mechanisms patients mentioned	□ Yes	□ No
--	-------	------

Mechanism	Effect
GPS	Positive effects

Training mechanisms educators mentioned □ Yes □ No

Mechanism	Effect

Support mechanisms patients mentioned □ Yes □ No

Mechanism	Effect

Support mechanisms educators mentioned □ Yes □ No

Mechanism	Effect

Study title: User involvement is a sine qua non, almost in medical education: learning with rather than just about health and social care service users

Date: 06-01-2024 Reviewer: I. Ruel

First author	C. Rees
Year of publication	2007
Country of publication	USA
Publication type	Journal

Study Characteristics

Type of study	Qualitative focus group discussions
Participants	Service users (n=19), medical students
	(n=13) and medical educators (n=15)
Education	Medical study (undergraduate)
Aim	What are the views and experiences of
	multiple stakeholders about service user
	involvement in medical education?
Study outcomes	Service users are legitimate peripheral
	participants within the community of
	medical education practice. With more
	active collaboration between students,
	qualified healthcare professionals and
	service users a new level of knowledge
	production may emerge within the medical
	education community of practice.

Level	Tasks of the patient	
Level 3 and 4	The patients that were included in the focus	
	group discussions have has multiple roles in	
	education (passive roles, but also teaching,	
	designing and developing the curriculum)	
Training mechanisms patients mentioned Mechanism	□ Yes □ No Effect	
Tarinia a a da a i a a da a da a da a da a	_ N.	
Training mechanisms educators mentioned	□ Yes □ No	

Get training in the benefits to patients about participating in education for students so	Not mentioned
that these benefits can be acknowledged	
during sessions	
Support mechanisms patients mentioned	Yes <mark>□ No</mark>
Mechanism	Effect
Support mechanisms educators mentioned	Yes □ No
Mechanism	Effect
Ask patients how they want to be called	Not mentioned
Include patients with an active level of	Not mentioned
involvement	

Study title: Exploring a collaborative approach to the involvement of patients, carers and the public in the initial education and training of healthcare professionals: A qualitative study of patient experiences

Date: 07-01-2024 Reviewer: I. Ruel

First author	Lesley Scott
Year of publication	2021
Country of publication	England
Publication type	Journal

Study Characteristics

Type of study	Qualitative, focus groups and interviews
Participants	Sample of members of the PCPI group with
	a history of mental ill-health was invited
	(n=14)
Education	(Mental) health care and (mental) healthcare
	related programmes
Aim	Exploring patients experiences of their
	involvement in the design and delivery of
	interprofessional education interventions
Study outcomes	A supportive university and community and
	s designated academic PCPI coordinator
	facilitate a supportive environment for
	patients and carers to develop as educators

Level	Tasks of the patient
Level 3 and 4	Patients were involved in multiple ways in
	the curriculum. Involved in the design of the
	teaching and learning initiatives that this
	study was focused on
Training mechanisms patients mentioned Mechanism	Yes □ No Effect
Training mechanisms educators mentioned	Yes □ No
Mechanism	Effect

A training should implement that teachers can encourage participation and better prepare students to work with patients	Not mentioned	
	<mark>Yes</mark> □ No	
Mechanism	Effect	
A dedicated member of the staff to support patients and act as their advocate within a faculty	Not mentioned	
Support mechanisms educators mentioned □ Yes □ No		
Mechanism	Effect	

Study title: Patients as educators: Interprofessional learning for patient-centred care

Date: 07-01-2024 Reviewer: I. Ruel

First author	Angela Towle
Year of publication	2013
Country of publication	Canada
Publication type	Journal

Study Characteristics

Type of study	Qualitative, several pilot workshops were
	followed and reviewed
Participants	142 students from 15 different faculties
Education	Healthcare professions
Aim	Identify issues involved in creating an
	educational intervention designed and
	delivered by patients and document
	outcomes
Study outcomes	The workshops were all highly rated by the
	students. The study demonstrated the
	feasibility and impact of an educational
	intervention led by patient educators
	facilitated but not controlled by faculty

Level of Patient involvement

Level	Tasks of the patient
Level 4	Patients were involved in workshop a
	leading teachers, but also in the planning of
	the workshops and determining objectives

Training mechanisms patients mentioned ☐ Yes ☐ No

Mechanism	Effect
Prepare for the role as educator while	Not mentioned
allowing them to remain true to their own	
ways of teaching and learning and not	
turning them into academics	

Training mechanisms educators mentioned □ Yes □ No

Mechanism	Effect

Support mechanisms	patients mentioned	□ Yes	□ No

Mechanism	Effect
Preparation	Not mentioned
Support	Not mentioned

Support mechanisms educators mentioned ☐ Yes ☐ No

Mechanism	Effect
Articulate what patients want students to	Not mentioned
learn and help patients translate this into the	
form of objectives familiar to students and	
faculty	