
Learning from Experience

**Working In Collaboration With People With Lived Experience
To Deliver Psychiatric Education**

May 2021

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Foreword

“ The involvement of people with lived experience of mental illness either as a patient or carer in educational programmes can provide unique and relevant learning opportunities and teaching experience for doctors and psychiatrists in training. The Royal College of Psychiatrists recognises this and welcomes initiatives that involve people with relevant lived experience in both undergraduate and postgraduate teaching programmes.

This document offers guidance for NHS training organisations that will support them on their journey towards the integration of patient and carer voices into educational programmes. It is not intended to be prescriptive; rather, it is a resource that informs discussion and offers guiding principles about a range of levels of engagement and collaboration from co-designing to co-delivering and co-evaluating. Medical students and trainees must be afforded opportunities to gain first-hand learning and a deeper understanding of the training and clinical approach necessary to support the delivery of compassionate person-centred care.

We fully recommend this document and affirm the collaborative process that went into creating it. Knowledge and understanding comes from many different places – including from having lived experience of mental illness. Accessing knowledge and understanding from a range of sources in educational programmes will allow for improving experience and outcomes for both patients and carers. ”

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Dean's Endorsement

“ I am delighted to endorse this guide to working together with people with lived experience to deliver psychiatric education. When reflecting back on a career in medicine many doctors will acknowledge that their most important teachers were their patients and families that they looked after. Whilst this is undoubtedly true, this aspect of learning has often been left to the vagaries of fate and not explicitly included in a systematic or adequately resourced way in many teaching programmes. The following guide seeks to address this. Our hope is that this will be the start a conversation about how we move forward together to ensure that patients and carers remain first and foremost in our thinking throughout training and beyond. ”

Kate F. Lovett

Dr Kate Lovett

Dean of the Royal College of Psychiatrists

1. Why involve people with lived experience in teaching and training in psychiatry?

Involving people with lived experience in teaching and learning in psychiatry: a review of the literature

In considering how best to involve people with lived experience in teaching and learning within psychiatry, a starting point is to look at the published literature. This should shed light on what has been done before and what potential barriers might have to be overcome. However, in order to effectively evaluate the literature, it is important to clearly define terms. In this review we were interested in actual patients or carers, bringing their real-life experiences to a medical education setting. This is distinct from simulated or standardised patients, which rely on actors or patients utilising pre-set case vignettes. In addition, we focussed on literature from the past 20 years (i.e. 1999 onwards). This time period captures a general shift in healthcare policy towards greater patient involvement in service delivery and training (e.g. National Service Framework for Mental Health, Department of Health, 1999).

For this review, literature was sourced from the MEDLINE database using key words including “lived experience” and “patients as teachers”. Results were screened for relevance and additional papers found from the reference lists of papers already included. Three broad themes relating to involving people with lived experience in teaching and learning emerged:

- Benefits of involving people with lived experience
- Barriers/difficulties to involving people with lived experience
- Practical considerations in involving people with lived experience

Further details of each of these themes are outlined below. Please note that in this write-up, the terms ‘patients’ and/or ‘carers’ and ‘people with lived experience’ are used interchangeably to convey the same meaning.

Benefits of involving people with lived experience

Jha et al (2009 [1]) conducted a qualitative study looking at the views of students and educators about patient involvement as teachers in medical education. It was felt that patients could offer a unique viewpoint that came from experiencing symptoms and the healthcare system first-hand. Hearing from patients themselves could be particularly memorable and powerful, meaning that students were more likely to remember key messages. Patient-teachers were also well-equipped to help students understand how theory fits into real practice and provide feedback to students on certain skills, like communication. Patients playing an active role in teaching were seen to challenge traditional hierarchies with the doctor-patient relationship and modelling a more patient-centred approach.

Systematic reviews – e.g. Wykurz & Kelly, 2002; Towle et al, 2010; and Jha et al, 2009 [2] – additionally highlight potential benefits from the patient perspective such as a feeling of empowerment, raised self-esteem and improved understanding about their illness. Stacy and Spencer (1999) used semi-structured interviews to ascertain patient views on their role as teachers. Patients in this study had been involved in a project where students visited them in community settings on several occasions to learn about their experiences of chronic illness. Patients highlighted how they were experts in their condition and could teach students about the whole illness, including the social and psychological aspects. They felt that they could help students to develop their communication skills. They additionally acknowledged more personal benefits such as enjoying the company; learning more about their condition; and being able to give something back by helping students with their education.

While the studies discussed so far all included medical students, none of them specifically considered teaching in psychiatric settings. Thus, it is useful to look more widely at studies involving other health professionals. Byren et al conducted a qualitative study based on interviews with psychiatric nursing students who had received teaching from an educator with lived experience. Students reported the teaching had helped to challenge preconceived ideas about mental health and encouraged more personal reflection on their approach to clinical practice. As it can be difficult to conceptualise the experience of mental illness, students felt having a teacher with lived experience made it easier to connect and engage with the course content. The approach to teaching gave theoretical concepts a “human face” and reinforced the importance of the therapeutic relationship to the patient experience. A further potential benefit was students being able to see, through their tutor, that patients with mental illness can respond well to treatment and recover.

Barriers/difficulties to involving people with lived experience

A common concern raised in the literature is that repeated re-telling of experiences of being unwell could be distressing for patient educators (e.g. Towle et al, 2010; Jha et al, 2009[1&2]; Wykurtz & Kelly, 2002). Felton & Stickley (2004) conducted interviews with university lecturers on mental health nursing programmes. All ten participants suggested that the “attributes of people with mental health problems” might make it particularly challenging to step into a teaching role. They gave the example that mental health patients might find taking the lead in the classroom environment anxiety provoking. Interestingly in the introduction to their paper, the same authors highlight that a longstanding “occupational culture” has tended to downplay the capabilities of people with mental health difficulties, creating a barrier to increased patient involvement in teaching.

A further issue raised in several studies is that patient educators might have a hidden agenda (Felton & Stickley, 2004; Livingston & Cooper 2004). In their literature review, Towle et al (2010) highlighted it can be difficult when

patients present contradictory information to students. Another potential challenge is ensuring representativeness. While an advantage of patient-teachers is that they can draw on their own experience, it is also important students realise not all patients are the same (Towle et al, 2010; Felton & Stickley, 2004). Towle et al (2010) suggested that representativeness can be affected by selection strategies for educators which prioritise certain skills such as communication. Tew et al (2004) emphasised how certain groups tend to be particularly absent from teaching programmes (e.g. BAME groups, young people, older adults, and carers).

A further suggestion from Felton and Stickley (2004) is that as patient-teachers become more experienced they could become less authentic. This is because they effectively become professional educators so are further removed from being a patient. However, this was a small-scale qualitative study of mental health lecturers who did not necessarily have extensive experience of working with patient-teachers. Thus, it perhaps remains a more theoretical concern rather than being based on clear evidence.

Other considerations include ethical concerns like confidentiality and consent (Jha et al, 2009 [2]; Towle et al, 2010). Clearly it is crucial that patients get involved in teaching out of free choice rather than because they feel obligated or because they think they will get better care (Towle et al, 2010). Students need to be reminded that confidentiality and professional behaviours and values apply as they would in routine clinical practice (Jha et al, 2009[2]. Finally, awareness of the potential psychological impact of patient-led sessions on students is important. Both Jha et al (2009 [1]) and Towle et al (2010) suggest that students can feel burdensome, especially if the health of their patient-tutor deteriorates during the period of the teaching programme.

Practical considerations in involving people with lived experience

A key question is the exact role that people with lived experience should play within teaching programmes. According to research (Jha et al, 2009 [2]; Coulby et al, 2015), patients are mostly involved as teachers rather than in other areas such as assessment or course and curriculum design. Several papers point out how traditionally patient involvement was passive – being “wheeled out” to demonstrate symptoms to students (Tew et al 2004; Felton & Stickley 2004; Livingston & Cooper, 2004). There is a consensus that patients should play a more active part in teaching students as they have expertise that other educationalists cannot offer. As such, they can provide direct teaching that goes beyond being subjects for students to examine or question (Livingston & Cooper, 2004; Towle et al, 2009; Coulby et al 2015).

Tew et al (2004) emphasise how it is possible to engage people with lived experience in all aspects of medical education. This includes both course development and delivery as well as evaluation of teaching programmes. They suggest setting up a steering group to get things started, ensuring there is a good balance between different types of contributors – managers educationalists, patients and carers. They highlight that pilots can be helpful

for 'testing the waters' as well as being more feasible in terms of resource allocation. Towle et al (2009) also advocate for a more systematic approach to involving patients with lived experience in teaching. They similarly underline how a representative steering group is necessary to help build a sustainable and inclusive teaching programme.

Several papers, including Tew et al (2004), raise how it may be important to provide training for people with lived experience on teaching skills such as giving constructive feedback. This is clearly important in terms of providing high-quality teaching. In their literature review, Jha et al (2009 [2]) found limited information about training, but suggested it more often focussed on specific skills rather than general educational principles. While the literature review by Towle et al (2010) revealed variation in the amount and length of training sessions, it also underlined how training is valued by patients and helps to relieve anxiety about teaching.

A further issue is how best to support people with lived experience, given the potential for stress related not only to the teaching role but also to reliving past experiences. As with training, practices appear to differ from place to place (Jha et al, 2009 [2]). However, it is generally acknowledged that some form of support is essential, although the format – e.g. individual, group, email or phone – can be tailored according to the teaching programme (Towle et al, 2009). Tew et al (2004) suggest that in including people with lived experience on committees, patients may feel more comfortable attending meetings if they are not on their own. They also highlight how it is vital to consider the specific needs of patients when planning the length and location of sessions.

Another aspect discussed in the literature is the recruitment of people with lived experience to teaching initiatives. Both Tew et al (2004) and Jha et al (2009 [2]) propose approaching established patient or carer groups. This may help with sustainability as programmes are less reliant on certain enthusiastic individuals (Towle et al, 2009). Other strategies might include asking healthcare professionals to approach potentially interested patients (Tew et al, 2004; Jha et al, 2009 [2]) or advertising the opportunity, for example in newsletters (Jha et al, 2009). Several papers mention how particular attributes may be sought when approaching patient contributors. These might include possessing skills in communication; having the time to commit to teaching; or being reasonably stable in mental state (Jha et al, 2009 [2]; Wykurz & Kelly, 2002; Tew et al, 2004). Towle et al (2009) acknowledge that the exact recruitment strategy will depend on the role. However, they indicate that in some cases more formal methods (e.g. an interview) may be appropriate.

The question of remuneration also features in many papers, although there is no clear answer as to what the approach should be. Tew et al (2004) propose that all contributions – teaching, attendance at meetings etc. – should confer payment as this helps to formalise and consolidate the role of people with lived experience. However, they also caution that the impact of payments on other sources of income, such as state benefits, needs to be accounted for. In

their literature review, Wykurz and Kelly (2002) found variable practices in existing teaching programmes with payments ranging from a tokenistic compensation of time to a fee at an hourly rate. Towle et al (2009) acknowledge that payment styles may reasonably differ between programmes. Yet they urge transparency and suggest any strategy is agreed by the steering group, which as described above, should include patients.

As well as Stacy and Spencer (1999), which is outlined above, some other papers give specific examples of existing teaching initiatives involving people with lived experience. For instance, Butterworth et al (1999), describe a carers lecture at UCL medical school where four carers with varying backgrounds and experiences ran a session in a 'question and answer' format with one of the carers acting as the facilitator. Towle et al (2014) give details of a programme in which a patient living with chronic disease or disability acted as a mentor to a group of students training in different health disciplines. Each session was led by the patient-mentor who oversaw discussions among the group on a series of suggested topics. Finally, Coret et al (2018) conducted a study to see if patient narratives – videos where patients describe their experiences – could help in teaching about intellectual disabilities. Their results were overall positive about this teaching approach.

Critique and Conclusions

The literature provides an insight into the various factors to be considered in setting up teaching initiatives involving people with lived experience. This includes not only general benefits and potential drawbacks, but also practical issues like how to train, support and pay contributors. However, the literature does not provide conclusive answers on the exact way to proceed, meaning that there is no blueprint for the optimal way to incorporate input from people with lived experience into medical education programmes.

In addition, much of the literature is relatively old, meaning it may not reflect current curricula. Also, many papers are not specific to psychiatry and are not written from a UK perspective, limiting the generalisability of the results. Papers that are focussed on psychiatry tend to be about the education of nurses, not doctors, which again raises questions about the applicability to the precise settings we are interested in. However, these factors are unlikely to affect the general principle that the input of people with lived experience can improve and enrich the education of psychiatrists.

As highlighted by Jha et al (2009 [2]), many studies demonstrate benefits of involving people with lived experience in terms of both student and patient satisfaction. However, longer-term impacts for example on student attitudes or patient outcomes are harder to assess. This question was addressed in a study of trainee social workers, although not specifically in a psychiatry setting (Tanner et al, 2017). Participants had sessions involving people with lived experience and were then asked in questionnaires six to nine months after qualifying how this part of their course had impacted their real-life practice.

Findings from this study were that students had made efforts to incorporate learning from people with lived experience into their day-to-day work-life. However, they found that efforts could be hampered by working within resource-stretched systems and with colleagues that appeared demoralised. Given the current climate in the NHS, it is likely this finding is also relevant to medical students. Perhaps the conflict between ideal situations and the reality of what is possible in practice should be addressed explicitly in sessions between medical students and people with lived experience.

Another limitation of this literature review is that much information on specific teaching programmes involving patients with lived experience is likely unpublished and so not accessible in the literature. This would clearly provide more details on the sorts of approaches that work and how any challenges were overcome. Thus, while the literature provides a good starting point, many questions remain unanswered. An important next step would be to attempt to access unpublished data regarding ongoing teaching initiatives taking place within psychiatry settings in the UK. This would greatly enhance our knowledge about how best to involve people with lived experience in the context of current psychiatry curricula.

The following guide aims to produce best practice guidance based on both the current research base and additionally draws on expertise from those involved with ongoing teaching initiatives taking place within psychiatry settings in the UK.

The involvement of people with lived experience in training: lessons from research

The last decade has seen a dramatic increase in the engagement of people with lived experience, carers and the public in both the design of research and the dissemination of findings. Funding applications now require statements on both PPI (patient and public involvement) and PPE (patient and public engagement) and co-production of research proposals is increasing.

There are many stakeholders in this area including the Health Research Authority (HRA) and the National Institute of Health Research (NIHR) who have stated that patient involvement in research contributes to principles of:

- making the research more relevant to the people it is trying to help
- helping to define what is acceptable to participants
- improving the process of informed consent
- improving the experience of participating in research
- communicating findings to participants and the wider public.

These principles should be translated into educational settings.

To find out more about this programme and to access resources available please visit NIHR Involve www.invo.org.uk

2. So how do you go about it? The principles of involving people with lived experience in teaching and training

Co-production

One of the fundamental principles in the successful involvement of people with lived experience in teaching and training is that of co-production which helps facilitate the delivery of person-centred care (RCPsych College Report CR215). As with any collaborative project, success depends on effective relationships between those involved. In order to maximise trust and collaboration, the value of respect from all involved will define that there needs to be an equal partnership between people who design and deliver services and teaching programmes and people who have experience of using services and delivering training from this perspective. Co-production removes hierarchies, challenges stigma and promotes respect, while acknowledging and making the most of the experiences and skills of people with lived experience (RCPsych College Report CR204; NCCMH, 2019 and RCPsych Circular 2019). It is essential that where lay people are involved, they must have access to support, training, resource and reward.

The values and principles of the shared purpose of working together is based on the Royal College of Psychiatrists' core values of communication, dignity, empathy, fairness, honesty, humility, respect and trust (RCPsych College Report CR204) and the principles of equality, diversity, accessibility and reciprocity (NCCMH, 2019).

Values underlying the approach to co-production are collaboration (RCPsych Strategy 2021-2023), partnership, shared responsibility and ownership, recognition and reward in a process that is designed to create, design, deliver and evaluate education together (NCCMH, 2019). In developing materials which reflect these values, language should be chosen with thoughtfulness and shaped by the principles outlined in Guidelines on the Use of Language (RCPsych Wales) of person-first, inclusive, balanced and consistent.

What do we call people with lived experience involved in teaching and training?

There are various terms in common use. A flexible approach to the name can be given to the role and will recognise a person's preference. For example, patient educator, lay educator, lived experience educator and carer educator can be used interchangeably and should be agreed locally in agreement with those involved in designing teaching programmes.

In developing programmes together with people with lived experience, it is important to remember what value they bring in order to champion their role across the wider faculty.

Their key strengths are:

- providing a different perspective on experience of health and care services from those who work in healthcare, although it is important to remember that many staff will have their own lived experience of mental health care which they may or may not choose to reference in teaching environments
- an ability to provide insights on the realities of 'the patient journey', the potential barriers and gaps, the importance of continuity of care and a knowledge of the outcomes that matter for a patient and for a carer
- providing an independent perspective, not representing a particular medical discipline or organisation
- offering a range of cultural contexts and perspectives
- in addition, they will offer a wide and unique range of other skills alongside their lived experience of mental illness depending on other life experience, qualifications, work and career.

For all involved in working in the field, careful considerations need to be made to the following common pitfalls:

- Awareness of not being valued in the following three areas: skills and contributions, lack of recognition and reward and a 'tokenistic attitude' as opposed to being viewed as an integral team member.
- Being over focused on personal experience; losing the wider principles, purpose of engagement and learning objectives with measurable outcomes.

In employing people with lived experience care needs to be taken with:

- the selection of lay educators for this particular role. Thought should be given to ensuring representation from across the age range, socio-economic backgrounds, ethnic diversity and inclusion of people with lived experience of mental illness, developmental disorders, co-morbid physical illness and intellectual disability
- the provision of adequate and ongoing training, supervision, evaluation and most crucially support in their role is key.

Support for expert educators (those with lived experience)

"For the junior student in medicine and surgery, it is a safe rule to have no teaching without a patient for a text, and the best teaching is that taught by the patient himself" (Osler W., 1905)

If we have constructed a cogent argument for the involvement of people with lived experience in medical education, it is appropriate to consider the impact of involvement on those people who take part. Whilst the public-speaking aspects of teaching are anxiety-provoking for many people, it is not difficult to

understand further impact on patient educators: the content of teaching is based on their own lived experience of mental illness or distress.

Although for many patient educators the benefits that they perceive that they bring to the educational offer ('by acting as 'experts' in and/or exemplars of their condition, showing and telling, aiding the development of professional skills and attitudes, and boosting learners' confidence', Spencer and McKimm, 2013) outweigh potential harm to themselves through participation, it is clear that in any ethical educational process that those risks of harm are mitigated wherever possible.

In an era of person-centred care (RCPsych College Report CR215) it is important that there is a 'one size fits all' approach to support. However, Tew et al., 2004, argue that a general approach of involving two people in committees and the like is best practice as it allows for a degree of mutual support through the process. Beyond this, other appropriate support could include:

- development of an induction session so that the person with lived experience has a clear idea of what is involved
- ensuring that people with lived experience are aware that involvement, or otherwise, will not impact on their treatment
- having staff on hand to provide support after educational sessions if needed
- adequate record keeping and discussion with the person with lived experience so that it is agreed that any concerns about their well-being can be directed to their care team if appropriate.

When planning educational activity that involves people with lived experience, organisers should consider the level of support that is necessary to avoid causing harm to the well-being of their patient participants. Adequate resources should be allocated to ensure that support is always available despite possible clinical pressures.

Contractual Arrangements

Learning in a real clinical environment from people with lived experience and from carers provides a deep and powerful learning opportunity for trainees and students. However, delivering training in a clinical setting does have an impact on patient experience and on clinicians' time and clinical resources.

An increase in clinical needs of the population along with an increase in the numbers of medical students and healthcare trainees without an increase in the number of clinical trainers can make the challenge of delivering training in clinical settings even more acute. In psychiatry, historical difficulties with recruitment and the institutionalisation of dispersed community-based care have added to the resource pressure impacting on the delivery of clinical training.

Job plans should clearly outline the educational responsibilities and time be factored for fulfilling these. In under-resourced clinical environments, learning from people with lived experience and from carers can easily give way to classroom teaching without direct involvement of people with lived experience and carers to the detriment of all involved.

Delivering training safely and effectively with the active involvement of people with lived experience and carers requires a deliberate and planned effort and cannot happen by merely asking clinicians to train others while they provide a clinical service. Engaging the expertise of people with lived experience and carers in training inevitably incurs costs. These will be determined by the level of involvement, which can vary from an Expert Patient sharing their lived experience with learners on an ad hoc basis or delivering a teaching clinic to an embedded model where Lived Experience Development workers are employed to work as active members of faculty, contributing to the design and delivery of the curriculum and to the assessment of learners.

Funding for both undergraduate and postgraduate medical education is made available to NHS organisations to acknowledge that the delivery of clinical training is not resource-free. However, often such educational budgets are not ring-fenced for training and concerns have been raised that educational funding can be diverted to resource-pressed clinical services.

Ring-fencing of educational budgets and linking them to explicit financial and educational accountability and quality assurance frameworks is important in order to deliver high quality education sustainably. Ring-fencing of educational budgets is necessary to support the development of faculty including appointment of educational leaders and the funding of innovations (Dave et al., 2010). One such example is University of Nottingham, Derby, which has developed an Expert Patient Programme, and appointed Lived Experience Development Workers who are involved in both the design and delivery of clinical training (RCPsych College Report C215).

Leadership

At the time of writing, it is clear that there is a lack of consistent involvement of people with lived experience and carers in much psychiatric education. Without leadership to drive change, however laudable a model is, it will remain as a set of values and ideas whilst the practice of psychiatric education will remain unchanged.

To shift educational practice, a leader may need to carry their colleagues over a number of challenges. Within the clinical world, time and other resources are at a premium; within medical education things are no different. A degree of lateral thinking may be required to secure the resource necessary to cover the extra costs that will be incurred from the involvement, and support, of patients and carers in psychiatric education.

It is also critically important to recognise that the involvement of people with lived experience and carers in education involves an acceptance of the validity of people with lived experience and carer knowledge. Their importance and involvement may not be traditionally valued within psychiatric education. Against this backdrop, it is not unexpected for some educators to have preconceived ideas and concerns about how people with lived experience will fit within the faculty. Fears of 'militant patients' taking antipsychiatry stances may be common. In this regard it is essential for a leader to have a sufficient amount of authority to make decisions but also to be sufficiently engaged with the training workforce to convey the benefits that can be achieved. The adoption of QI principles which demand measurable outcomes is helpful to demonstrate benefit and win over doubters.

Having established ways of working that integrate people with lived experience and carers into psychiatric education, it is important that projects are sustainable and long lasting. Each time a project fails, for whatever reason, it becomes harder to convince others of the benefits of involvement in the future. A leader must, therefore, seek to ensure that people with lived experience and carer partners in educational projects are fully respected and that all those involved have sufficient support in place to allow a sense that the benefits of involvement outweigh any potential harms.

Within medical education, leaders are traditionally clinicians who have an interest in the education of the future medical workforce. However, as non-traditional sources of knowledge become increasingly recognised and people with lived experience and carer partners begin to take up roles in psychiatric education, those holding leadership positions could start to emerge from non-medical backgrounds. Increased diversity in educators has the potential to create a more holistic and patient-focussed learning experience for learners that should be embraced.

3. Summary

Working in collaboration with people with lived experience to deliver psychiatric education can significantly enhance the learning process for medical students and provide important authentic insights into the delivery of a holistic person-centred approach to clinical care and a perspective on experience of health and care services. This potentially will lead to improved outcomes for both patients and carers and a fulfilling experience for new doctors in the delivery of care.

This document outlines the values and principles that underpin the collaborative model of engagement; the learning from a literature review and from research; the key strengths of lay educators; the support and contractual structure that is required and the visionary leadership that is necessary to develop and deliver a sustainable model of engagement with people with lived experience in medical education. There are several levels of collaboration and engagement in this educational process from co-designing to co-delivering and co-evaluation.

Going forward, we should seek to promote, explore and implement relevant opportunities to 'learn from experience' by incorporating people with lived experience as lay educators in the delivery of educational programmes for medical students and trainees. The guidelines in this document will strengthen each stage of the process and build a strong, safe and empowering model of engagement.

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