Exploring the Role of Lived Experience in Mental Health Training:

A Scoping Project

21/12/18
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Executive Summary

Whilst there is emergent evidence suggesting the benefits of involving people with lived experience in mental health training, this is somewhat patchy and has restricted our deeper understanding of the topic. This report therefore summarises outcomes from a set of linked activities funded through Sheffield Health and Social Care NHS Foundation Trust’s Research Capacity Fund, that sought to synthesise the existing literature, practice knowledge and lived experience of people working in this area, with a view to co-producing relevant research questions to address significant gaps in evidence and making initial recommendations for good practice.

Integrating across our activities, it became clear that key to practice and research is recognising the involvement and interplay between a complex set of stakeholders which we represented as follows:
Our co-production activities prioritised six areas for new research enquiries:

1. How do different ways of involving service user educators influence the learning of trainees?
2. What difference does the training make, down the line, to the trainee, the service user and service user carer?
3. Does story telling enhance the sharing of lived experience?
4. How do we find, prepare and support service user carer educators?
5. How can we involve carers, family and friends in mental health training?
6. How do policy, culture and power in health care settings influence how user involvement is done and it’s impact?

The integrative literature review also indicated nine practical recommendations for improving the value of lived experience in the training of mental health professionals:

1. Health Organisations need to develop an overall strategy to involve Service User Educators (SUEs) in education and training
2. Ensure role clarity for SUEs
3. Provide training for SUEs
4. Target relevant populations for training
5. Ensure co-trainer clarity on need for lived experience in their programme
6. Ensure SUEs are prepared for specific types of sessions
7. Ensure preparation of trainees
8. Allow flexibility in delivery of sessions
9. Provide post-session debriefing and support for SUEs
Overall there is a need for more rigorous evaluation of existing approaches, which takes into account the impacts of lived experience initiatives on all stakeholders (service users, carers and their families in addition to professionals and students), takes a longer-term view of outcomes beyond training delivery including exploration of longer term impacts on educators and recipients (such as compassion, resilience, retention, workforce development, recovery, care outcomes) whilst accounting for any unintended and potentially negative effects (e.g. stress and support needs).
Chapter 1. Introduction

The need to place patients and users at the heart of the design and delivery of mental health services is emphasised in current policy, with the FYFV for Mental Health (2016) placing service users at the heart of transformation plans for improved services where ‘co-production with experts-by-experience should also be a standard approach to commissioning and service design’ such that we can ‘truly produce services which are led by the needs of the individual not the system (p.20).

Both policy and professional bodies are increasingly recognising the integral role of service user lived experience in training and education of the mental health workforce in delivery of these ambitions. Initiatives involving service users in training and education represent a potential challenge to traditional hierarchical relationships and notions of ‘expertise’ and legitimate knowledge, which historically prioritise professional medicalised constructions of mental distress and illness over user experience. Academic and practice literature reports a growing number of diverse initiatives around lived experience (Bee et al, 2015; Fraser et al, 2017, Burhouse et al, 2015). Locally, there are a number of well-established and diverse initiatives in Sheffield and the surrounding region which focus on both the education of students (SU patients as educators, SU Narrative Masterclass, SHSC/RDASH peer workers and SHSC/ Chesterfield peer educators) and the development or training of existing workforce (including SHSC Recovery Education Unit; SHSC Community Recovery Service: SHSC training department).

Whilst there is emergent evidence suggesting benefits of such initiatives, this is somewhat patchy, limited in range and short-term in focus. Many locally-based programmes of work have not yet been exposed to evaluative scrutiny. Overall there is a need for more rigorous evaluation of existing approaches, which takes into account the impacts of lived experience initiatives on all stakeholders (service users, carers and their families in addition to professionals and students), takes a longer-term view of outcomes beyond training delivery including exploration of longer term impacts on educators and recipients (such as compassion, resilience, retention, workforce development, recovery, care outcomes) whilst accounting for any unintended and potentially negative effects (e.g. stress and support needs). This is made more challenging by the diverse ways in which lived experience is both understood and practised within different models with varying degrees of meaningful ‘involvement’ and ‘coproduction’. Furthermore, there is a need for a deeper understanding as to the range of ‘measures’ or outcomes that are both appropriate and available to capture for any assessment of effectiveness, particularly where specific aims of initiatives might be left implicit to a greater or lesser degree.

Overall, there is a need to address these gaps through a critical and comparative evaluation of varied lived experience training and education initiatives to consider models currently being adopted, the benefits and risks delivered, for whom and under what conditions. This is important in order to draw out key lessons as the basis for recommendations and robust framework to guide both policy and practice.

This report summarises the outcomes from a small-scale scoping project supported by Sheffield Health and Social Care (SHSC) NHS Trust Research Capability Fund, which was intended to start
addressing the research gaps outlined above. The project was developed and implemented through co-production with a team comprising service user educators, academics and mental health practitioners.

There were three core aims of the project:

1. Analyse a sample of existing training and education programmes involving service users in the Sheffield City Region in order to develop an understanding of how they can vary in their methods, topics, audiences, role of service users and other relevant dimensions of concern to our wider research interests.

2. Conduct a review of existing research (systematic) to identify existing practice (philosophy/pragmatics/characteristics), evidence of impacts/outcomes (defining ‘effectiveness’; cognitive, affective, behavioural) and the parameters associated with effectiveness and current gaps in evidence.

3. Conduct a stakeholder co-production workshop to explore experiences and impacts of a range of current local practice-based initiatives from the perspectives of service user educators, service users and mental health trainees. This workshop also aimed to ask participants to generate and prioritise research questions based on their own experiences and discussions of the reviews outlined above.

The following chapters summarise the methodology and key outcomes from the three core activities outlined above and the final Discussion chapter will bring together the major themes identified by the research.
Chapter 2. Practice Review

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2.1. AIM

The aim of the practice review was to identify training initiatives and programmes targeted at professionals working within the Sheffield City Region, which had been co-produced with individuals living with a mental health diagnosis. The intention was not to provide an exhaustive list of training programmes, but to provide an insight into the activities and initiatives taking place in order to capture the breadth of variation in how lived experience is being utilised. In doing so, the review aimed to recognise the different aims and characteristics of these initiatives (e.g. what methods and techniques are being employed, target audiences, how service users are involved), whilst noting any evidence of outcomes and impacts that these types of programmes have had.

2.2. METHODOLOGY

The practice review was undertaken in two phases; 1) Desk-based research, and 2) Information-gathering conversations with training programme leads (where possible – following up on desk-based research and word of mouth). A template with a series of questions was created prior to beginning the review to guide data collection. Questions captured programme details (who is involved, the methods and modes used), the contribution of service users and how training was being evaluated/evidence of any impacts. The review was also supplemented by our lived experience workshop (28th Feb 2018, see Chapter 4), with workshop attendees having the opportunity to add their own experiences or knowledge of training being co-produced.

2.3. SUMMARY OF FINDINGS

We identified 25 initiatives delivered between 15 providers, where service user involvement was evident in the design and/or delivery of training. These initiatives were split between Skill Specific training (n=15) and Education and Awareness (E/A) of Mental Health (n=10). It must be noted some providers offered multiple training courses such as the Recovery Education Unit (seven), whilst similar courses were offered by multiple providers e.g. Mental Health First Aid (MHFA).

Involvement of Service Users

Co-production was observed in several ways with service users involved in:

- Delivering training session
- Designing and creating training materials
- Organising sessions and events based on needs identified
- Reviewing training content and material
- Training instructors
Interviewing potential trainees for further training (e.g. Clinical Psychiatry Unit)

Predominantly, service users were involved in the actual delivery of training/education courses either individually or within wider supporting teams - 65% (16/25) of training initiatives identified clear delivery of training by individuals with lived experience of MH.

Target Audience

Along with health and social care professionals, recipients of training include university students (medical, nursing, social care and psychology), early career trainees, social workers, carers, professionals in educational settings (e.g. teaching staff), college students, pastoral staff and local businesses/workplace sector. Naturally, we found skill-specific training was most commonly delivered to staff working in mental healthcare settings, focusing on interaction with patients - 10 (40%) training initiatives delivered to staff specifically working in mental health settings. Others observed include:

- 6 (roughly 25%) training and education initiatives aimed at students (Secondary and Higher Education)
- 2 E/A initiatives delivered to staff in educational settings
- 2 E/A initiatives aimed at the workplace sector/local businesses
- 1 E/A initiative aimed at those involved within the faith sector

Methods used in training

- A range of methods are employed to deliver training from traditional, formal classroom/lecture based teaching to informal creative methods using art and visual methodology.
- All courses being delivered aim to develop a collaborative learning approach, placing emphasis on group activities that foster discussion and sharing of knowledge.
- Skill-specific training for professionals and students working directly with mental health patients often employ the most creative methods (role-play simulation, reflective questioning, storytelling etc) – these aim to help trainees form deeper, emotional connections to understand the realities being faced living with MH
- Only two courses (awareness of MH) were identified that use online modes to deliver training – both by the Recovery Education Unit.

Evaluation and Evidence of Impact

It has been somewhat difficult to attain how programmes have been evaluated and their impact, owing to this information not readily being accessible or not being well-publicised. This is certainly the case for the majority of examples, where we were unable to hold conversations and through which their online presence was our only means of gathering information. Following on from this, web presence of training programmes was not always clear or updated, particularly within the community sector.

For examples of programmes incorporating service user educator please see Appendix 1
Chapter 3. Literature Review

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3.1. METHODOLOGY

This rapid scoping review aimed to describe the literature exploring the role of services users with lived experience of using mental health services in the training of mental health care professionals. The aim of the project was to identify existing research and gaps in the knowledge base in order to inform future research programmes. Extensive searches of electronic databases were undertaken, with a date limit of 2007-2018 used to ensure we included only the most recent literature and due to limited resources. We identified 57 papers to include in the review. This included 32 evaluations of training programmes using service users with lived experience. A range of methodologies were used in the studies including qualitative interviews, surveys, and quantitative evaluations. Qualitative findings were most often gathered from learners, but data was also gathered from service users involved in training.

3.2. KEY FINDINGS

Roles: The roles the service users filled in the training programmes varied from retelling their experiences, to a wider role including design of the curriculum, assessment of students. In some cases the service user became a ‘lived experience academic’ (LEA) and became part of the wider team.

Learner views: Twenty papers (see Table 5 in Appendix 2) sought to explore or measure the attitudes, behaviours and views of the learners whose training programmes included service user involvement. These were undertaken in quantitative studies, mixed methods studies, action research, surveys and qualitative research. Some of the themes that arose from the literature included:

- User involvement in training challenged ways of thinking and attitudes.
- It influenced practice, particularly in helping to improve communication skills.
- Students were uncomfortable with the service user role in assessment of competency.
- Learners found that the unfamiliar boundaries of service users in training roles was at times uncomfortable, for example it made them feel fearful of challenging the service user.
- Some expressed the view that some service users were not equipped with sufficient training in teaching methods and students had as a result poor learning experiences.
- Students experienced a discomfort when the practice that they encountered in the real world did not support the approaches that service user supporting training was seeking to foster.
**Service User Educator views:** Seven papers sought to gather views of service users involved in training mental health professionals. Some of the themes evolving from this work included the following:

- A powerful motivator for getting involved with delivering training was the knowledge that they were improving things for others as a result of their experiences that they were choosing to share.
- There was a strong thread throughout out of the need for adequate preparation of the service users.
- Empowering, sense of achievement, new sense of self, confidence, friendships were all benefits that service users experienced.
- Risk of tokenism, voyeurism were risks of service user involvement.
- Fear of relapse was a concern to service users and what this would mean for their commitment to the training programme.
- Value of face to face interactions.

### 3.3. RESEARCH GAPS

Research gaps identified included the following:

- Many report evaluations of small programmes and there is a need for further replication of studies in order to build a more consistent picture of the impact of these training programmes.
- Programmes were evaluated, most commonly, at their completion and therefore studies did not measure the impact of the intervention on subsequent practice. There needs to be evaluation studies that seek to explore whether changes in attitudes result in changes in practice and hence the quality of care.
- What are the specific elements of the intervention that contribute to greatest effectiveness?
- Guidelines and theoretical frameworks are needed that allow the lived experience paradigm to be applicable to different organisational contexts.
- There is clearly a movement towards further expansion and development of the role into curriculum development and assessment but there is very little evaluation of the benefits and costs of these developments.
- Exploring the role of the service user in professional groups other than nurses where this type of approach has appeared to be pioneered.
- There is very little written about the recruitment and selection of service users.
- There is a need to hear also the voices of those that remain hidden (those who do not experience recovery, children and adolescents, those who experience difficulties with communication; family and friends of service users).
A number of practical recommendations emerged from the literature review and these will be included in Chapter 5 Discussion.

*See Appendix 2 for the methods and detailed findings of the Literature review.*
Chapter 4. Co-production Workshop

4.1. WORKSHOP NARRATIVE

In order to gain a deeper reflection on the findings of the practice review and literature review and their implications for future research, we held a co-production workshop with a range of stakeholders. The event took place on the 28th of February 2018 at the Showroom Cinema in Sheffield and we invited participants across 3 main groupings:

- Service Users
- Service User Educators
- Professional mental health trainees.

There was overlap between groups, in terms of people with lived experience and those who were actively involved in education. The structure of the day is outlined below.

A. INTRODUCTION TO THE AIMS OF THE DAY

After an introductory session to outline housekeeping and the ground rules for the day around confidentiality and respect we described the aims of the day which were to:

- Share our experiences and views of using lived experience in mental health training
- Discuss findings from practice and literature reviews
- Prioritise topics that we need to investigate further
- Start to develop a range of innovative research projects tackling our priority topics

B. PRACTICE REVIEW INSIGHTS

To begin we presented back the interim findings of the practice review, gave three case studies from current work in Sheffield, and invited participants to share their knowledge of other groups currently using lived experience in education across the Sheffield City Region. We did this through a map on the wall and postcards to capture minimal information about other initiatives for us to follow up after the event.
C. SUB-GROUP ACTIVITIES

After coffee, we split the large group up into the three sub groups to give some time and space to explore issues around using lived experience from the different perspectives.

These groups were facilitated by two members of the core team, and where possible used creative means to help people express and share their thoughts and feelings. The questions to each group were tailored to ensure that it reflected how that group would usually experience lived experience in education, and the results captured in the form of both the creative outputs and a transcribed list of responses and key thoughts and themes. The three key foci for each of the sub-groups were the positive aspects of using Service User Educators in mental health training, the challenges and research questions that needed addressing. Below are images generated by different stakeholders in these group activities.

This focus on using creative methods is explicit and draws on the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC) Yorkshire and Humber’s Translating Knowledge into Action (TK2A) theme’s research and practice on knowledge mobilisation. In their recent paper (2018) Langley et al describe the ways that ‘making’, specifically collective making, using creative methods, establishes and enhances the conditions to allow knowledge to be shared. Making also overcomes some of the issues around power differences in coproduction, which is a constant tension when working in this way (Greenhalgh et al. 2016).

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D. PLENARY

After lunch, all participants returned to the main conference room. At this point the literature review was presented to the group with a focus on what work has been done before but also the key gaps. Participants were then encouraged to grab a coffee and return to smaller groups within the room to reflect on what they had heard from the practice review, their own subgroup discussions and the feedback from the other groups and the literature review.

We encouraged people in plenary to share the aspects of the work they had found interesting, challenging, or those where it was clear more work was needed. These were captured on flip charts at the front of the room. The key themes were shared back out to the group from the flip charts to ensure that the points were represented correctly, and then everyone was encouraged to come and vote for their ‘favorite’ or most pertinent topics for further research by putting a tick against them. The votes were collected and verified after the event.

At this point we had planned to explicitly formulate research questions and create teams of interested parties across research projects, but the weather intervened, and with heavy snow forecast we had to cut short the workshop, to ensure everyone could get home safely.

4.2. WORKSHOP ANALYSIS

Due to the workshop being shortened we had not been able to reach the coproduced ideas for the research questions in the way we had planned.

As an alternative, a more traditional approach to analyzing the data produced from the workshops had to be taken, involving the facilitators of each of the three subgroups (RF, KB and DW). The narrative and images from the three subgroups were transcribed and shared in an interim analysis group to establish emergent themes across the groups on the questions of positives, challenges and research needs. An additional aspect to the list of research needs were that participants voted on the ones that they felt were most important to address.

The outcome of this process is shared in the results, including adaptations when the wider project group met and was able to input into the framework. The approach taken thus far does feel consistent with aspects of framework analysis (Hsieh and Shannon 2005) and so would appear to be a valid way of analyzing narrative data, even if not transcribed directly from participants.

(1) initial data familiarization by listening to interviews, reading and re-reading the transcripts;

(2) a thematic framework is identified, reviewed and then systematically applied to all of the text (indexing of the data);

(3) the data is then rearranged into charts according to the appropriate thematic reference or codes based on each organization’s data; and

(4) finally mapping and theorising is applied to the data as a whole. (Ritchie and Lewis 2003)

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This ‘interrupted’ coproduction analysis approach does have challenges, as the research team has undertaken the analysis away from the people who have the specific knowledge of the topic area and expertise by experience, however this has been done for purely pragmatic reasons, and the draft framework was shared, tested and refined with the wider project group before being shared outside the project.

4.3. WORKSHOP FINDINGS

As indicated above, after the workshop, three of the report authors (RF, DW and KB) wrote up the flipchart notes from the three sub-groups and also the highlighted research topics generated in plenary. The authors worked together to sort out the comments and identify the underlying major themes that cut across the three sets of questions (positives, challenges and research needs of service user educators). The following seven themes were generated:

1. Impact on mental health trainees
2. Impact on service users
3. Impact on service user educators
4. Service user educator recruitment and support
5. Training design
6. Stakeholders associated with service users
7. Health Organisation perspective

The following sections will use these seven themes to describe the findings generated with regards to the positives, challenges and research needs of Service User Educators.

4.3.1. THE POSITIVE ASPECTS OF INVOLVING SERVICE USER EDUCATORS

• The largest amount of material was generated with regards to the Impact On Mental Health Trainees. From the Service Users, better development of professionals’ empathy and relatability and reduction in stigma were important features that could then lead to improved shared decision-making about care. The Service User Educators particularly liked the ability to challenge stigma and orthodox ways of thinking about mental health amongst staff. Unsurprisingly, the mental health trainees had the most to say about this aspect, again emphasising how the SUE role helped personalise users, making them more relatable as a person rather than a textbook set of symptoms and reducing the ‘us and them’ boundaries. The trainees also pointed out how they better understood the wider influence of service user mental health on carers, family and friends. From a technical viewpoint, trainees valued the opportunity to be able to practice their communication and therapeutic skills with SUE.

• With regards to Impact On Service User Educators, the SUE themselves pointed out their enthusiasm and energy and their role in helping service users gain
more power over their own care; they also felt SUEs were now becoming more valued.

- The other category pointed out here was Training Design where mental health trainees valued the opportunity to practice their skills with SUE and help develop empathy. Little was said about the other categories that was not covered in these three themes.

See Appendix 3 for Table 1 which details the data from the workshop

4.3.2. THE CHALLENGES OF INVOLVING SERVICE USER EDUCATORS

- The impact on Mental Health Trainees Theme highlighted the issue that discussing and disclosing mental health concerns (both for professional and service user) can be risky - one mental health trainee described it as ‘overwhelming’ but beneficial for understanding. The problems of SUE involvement feeling tokenistic sometimes and complacency from trainees feeling they knew everything about a condition after talking to one person were also described.

- With Impact On Service User Educators, the danger of burning out SUEs from their continual exposure and probing of conditions to professionals was brought up. Furthermore, the SUEs themselves felt that they were often only seen as valuable for their conditions and their other skills and attributes were ignored. This led to the danger of perpetuating a ‘them and us’ divide between mental health professionals and service users.

- A similar issue came up in the Service User Educator Recruitment and Support section, where SUEs felt they needed to be treated the same as any other professional contributor to training and not patronised.

- The need for carers, family and friends to be involved more in the training was the main point from the Stakeholders Associated with Service Users section.

- Challenges for Training Design were developing appropriate communication skills for professionals to talk about mental health and ensuring that structural barriers were overcome to ensure a wider range of relevant people were trained.

- The final theme of Health Organisation Perspective generated a rich discussion on power and politics, particularly from the viewpoint of SUEs. It was felt that SUEs can sometimes be forced to fit a model that suited the Health Organisation’s perspective and agenda and that they were not allowed to go ‘against the grain’. This was thought to constrain the ability of SUEs to fully portray the richness of their experiences and skills. A tension was therefore created between the opportunity to share valuable experiences and the risk of that input being bounded for organisational ends. In the latter case, there was the danger of SUEs becoming ground down.

See Appendix 3 for Table 1 which illustrates the challenging aspects of involving Service User Educators and highlights a different range of perspectives from the positive aspects.
4.3.3. RESEARCH QUESTIONS GENERATED AND PRIORITISED BY WORKSHOP ATTENDEES

During the workshop, a plenary session was held where all participants gathered in the room. Each group fed back its main points on positives, challenges and research needs and through this discussion potential research questions were written up on a flipchart. 23 question topics were generated. At the end of the workshop, participants were asked to read the list of research questions and put ticks against the ones that they thought were the most valuable or interesting to investigate further.

After the workshop, the report authors went through a classification exercise to group the 23 question topics into higher-level meaningful themes and we will highlight the research themes that had the most votes.

- **Impact on Mental Health Trainees:** There was a clear steer from the workshop participants (18 votes) that we need more evaluation on whether SUE involvement in training leads to changes in mental health professional practice (via changes in their knowledge, skills and attitudes) in the short- and long-term. More nuanced aspects included addressing fear and stigma in both trainees and SUEs (5 votes), exploring the suitability of different theories of learning (3 votes) and identifying which specific skills needed to be developed in professionals (1 vote).

- **Impact on Service Users:** Unsurprisingly, there was a desire to see whether the training did change patient outcomes (3 votes).

- **Impact on Service User Educators:** The key point here was exploring the impact of training involvement on the SUEs themselves.

- **Service User Educator Recruitment and Support:** The most popular topic here was to investigate the nature of power and politics in organisations with regards to enacting the SUE role (7 votes) and preventing co-option (3 votes). Recruitment and selection of SUEs (3 votes) and their training, development and support (4 votes) were other highlighted themes.

- **Training Design:** The first theme captured a lot of the interest in training features so here were listed questions around when should the training occur (1 vote), who should participate and what the aims should be (1 vote).

- **Stakeholders Associated with Service Users:** Questions around widening participation to carers, family and friends was a very popular theme with attendees (14 votes).

- **Health Organisation Perspective:** Significant interest was shown in investigating how organisational culture and interests can set the tone for SUE involvement in training and subsequent outcomes (8 votes).

See Table 3 in Appendix 3 for more detailed descriptions of the research areas.
4.4. FINAL PROJECT MEETING

The final project meeting was held on the 25th of September 2018 with nine members of the project team attending (a mix of academics, service user educators and mental health professionals). The outputs of the workshop were shared in summary form, alongside the completed practice review and literature review. The core research team shared the emergent framework for validation and development, and the group were facilitated to reflect on this framework, the relationships between the themes and identify any omissions in perspective.

The group generally agreed with the framework and provided more detailed elaborations on existing research questions but also added in two new important stakeholder perspectives:

- **Co-trainer**: There is a need to examine the interactive role of other (non-service user) trainers on courses in terms of how they influence SUEs and vice versa in the context of training design, delivery and evaluation. As one of the project team pointed out, in their experience the dynamics of interactions with students changed when SUEs were present.

- **External Institutions**: There was much discussion on the need to look beyond the delivering health organisation to also examine the influence of wider institutions. These included Professional Bodies such as the Royal College of Psychiatrists and Royal College of Nursing which set the syllabuses of many formal programmes and also Policy-Making bodies such as the Department of Health and Social Care.

Other conclusions were to merge the separate themes of impact on service user educators, recruitment and support of service user educators and stakeholders associated with service users into one category of Service User/Carer Educators for the purposes of simplification.

The final section of the report will integrate the findings across the three activities undertaken to highlight significant needs for future research

As a follow up to this meeting we have come across some work that already addresses some of these needs. Ben Dorey worked with Sheffield Health and Social Care’s Service User Engagement Group (SUSEG), a mix of staff and people with lived experience, in 2014 to draw up a set of 8 Basic Standards for improving the involvement of those with lived experience in training.
Sheffield Health and Social Care’s Service User Engagement Group (SUSEG) (2014) 8 Basic Standards for improving the involvement of those with lived experience in training (ref Ben Dorey, SUSEG).

1. Those with lived experience are treated as any other employee of the organisation is treated, with a right to expect supervision, reasonable adjustments to meet needs and payment for work undertaken. In return trainers with lived experience will be expected to comply with the values of the organisation in the same way as other staff and to be accountable to their manager and employer.

2. Those with lived experience who are involved in training should be employed on the basis of their skills and potential like any other trainer. Lived experience in itself does not qualify someone to be a good trainer: by appointing solely on that basis organisations run the risk of tokenism and the positive impact such training on staff can have may be lost or even reversed.

3. Those with lived experience must be able to evaluate their experiences critically and to understand where the limitations of their own understanding lie, in the same way as professionals must understand the limits of theirs. Being unable to do this again runs the risk of the training having a negative impact on understanding and stigma for staff. It also risks being distressing for the person with lived experience. This means trainers with lived experience should have access to all data collected in evaluating training they have been a part of.

4. Organisations should move beyond using those with lived experience to provide ‘narrative’ input and towards full integration of all of the person’s expertise into their role. The impact of having someone with lived experience leading training sessions on a variety of subjects can have a large influence on reducing stigma within an organisation.

5. The organisational priority in involving those with lived experience in training must be to enhance the experience and knowledge of learners, not as a way to help the person themselves therapeutically. The fact that often people find the work extremely rewarding and helpful should be seen as an added benefit, not the primary purpose of lived experience involvement.

6. Teams employing those with lived experience should provide adequate training and information about the benefits of user involvement to all team members so that they understand the rationale behind using lived experience to enhance training.

7. Those with lived experience should have some flexibility to shape their role. If recruiters have too firm a notion of what they want from lived experience input they are not truly valuing that lived experience and its uniqueness.

8. Organisations should have a flexible but clear personal development scheme for those in lived experience roles. They should have the same access as other staff to relevant training and qualification programmes to enhance their skills in the role. This helps those employed to continually critically reflect on their roles and impact as well as helping with the individual’s reflective practice in line with requirements for all trainers.
Chapter 5. Discussion

Our scoping project set out to identify potential areas for future research concerning the role of service user educators in the training of mental health professionals. We used three different activities to help us achieve this aim: a sampling of training initiatives involving SUEs in the Sheffield City Region; a rapid systematic literature review; and a co-production workshop with a mix of SUEs, service users, academics and mental health professionals.

5.1. A STAKEHOLDER PERSPECTIVE ON SERVICE USER/CARER EDUCATORS

Integrating across our activities, it became clear that key to the research is recognising the involvement and interplay between a complex set of stakeholders which we represent in Figure 5.1. Here, we show how SUCEs interact with the Co-trainers in the design and delivery of various training programmes to Mental Health Trainees in order to develop their clinical knowledge, skills, attitudes and, hopefully, practice. Through practice with patients, the trainees would hope to influence outcomes in Service Users and also perhaps Service User Carers. Our participants and the literature also highlighted the contextual importance of local and external actors. At the local level, the Health Organisation responsible for delivering the training programme is influential in terms of its vision, resources, culture power and politics in how SUCEs are involved and treated. It, in turn, can be influenced itself by these training programmes. It could be that a health organisation provides both the trainees and the delivery of the training or the training is conducted by an external partner. Wider External Institutions such as professional bodies and policy makers can influence all the aforementioned stakeholders through setting the agenda, policies and emphases on different types of training.
Figure 1. Key stakeholders in the domain of service user/carer educators involved in the training of mental health professionals.

5.2. PRIORITY AREAS FOR FUTURE ENQUIRY

Our key aim was to use our mix of participant experience and reviews of the literature to pinpoint novel and worthwhile areas for investigation and these are described below. Some may be more amenable to investigation through funded research, whereas others may more appropriate for local development and implementation.

A. Identification of which elements of lived experience involvement most influence the effectiveness of training.

Studies have attempted to assess the overall end-of-training impact that lived experience involvement has but it is still unclear which elements of this are most influential. There is therefore a need for deeper comparative investigations of how different approaches to training (e.g. online versus face-to-face; one-off input from SUEs versus extended interactions) influence effectiveness.
B. Longer-term evaluation of Service User Educator training involvement on mental health trainee outcomes and service user and carer outcomes

The question of value of SUCE in training has been raised often times. Although the literature suggests there is positive impact on the knowledge, skills and attitudes of trainees there is a dearth of research looking at the longer-term influence on their practice with, and outcomes of, clients and their families and carers. Longitudinal retrospective or prospective studies are required to assess this extended view.

C. Role of story-telling

We have pulled this out as a specific theme since our practice review suggested that the use of stories and narratives is a method that is substantively used in the Sheffield City Region. The literature barely touches on this approach and questions were posed as to the assumptions or ‘mental models’ underpinning a storying approach, how effective stories were in shaping trainee knowledge, attitudes, skills and longer-term practice and why.

D. Service User/Carer Educator recruitment, support and development

The literature review showed a clear gap in our understanding of how SUCEs should best be recruited and supported in their roles. Our SUCE participants echoed the view that sometimes involvement was opportunistic and was in danger of being viewed as ‘tokenistic’. They also professed the fear of emotional burnout from continually sharing their experiences and the danger of relapse, highlighting the issue of support needed for SUCEs. Furthermore, the role of the Health Organisation was declared crucial also in setting the tone for how SUEs were allowed to be involved. There is therefore scope for a national survey study on recruitment and support policies and practices to identify the best approaches.

E. Involving carers, family and friends in mental health training

The co-production workshop and the literature identified the lack of understanding of the role of carers and other associates in this domain (‘unheard voices’) so further exploration is needed of this topic.

F. Organisational cultures, power and politics around service user educator involvement

Beyond studying the characteristics of a training programme, there was a strong feeling from our participants that the role of the Health Organisation’s culture and its use of power and politics could both support and constrain any benefits from SUCE involvement (the potential importance of context was echoed in the literature review also). More optimistically, SUEs felt their involvement could in turn positively influence the views of the Health Organisation itself. We could
also extend this to the role of External Professional and Policy Institutions as the wider landscape in which organisations, professionals and Sus are located. More nuanced, qualitative studies would be able to tease out the complex interplay of dynamics here.

5.3. PRACTICAL RECOMMENDATIONS ARISING FROM THE LITERATURE REVIEW

In reviewing the findings of the empirical literature, a number of practical recommendations were suggested by authors as a means of optimising the value of lived experience in the training of mental health professionals:

A. Health Organisations need to develop an overall strategy to involve service users / carers in education and training

As Higgins et al. (2011) state, there is a need for meaningful partnerships between higher education institutions, service user groups, health service organisations and professional bodies to develop an overall strategy for the involvement of service users/carers in education and training. This strategy should address a range of issues such as educational preparation, support and payment of service users/carers, as well as a strategy for evaluation. Without the wider involvement of service users and carers in the process of accreditation, commissioning and funding of courses, their involvement will remain at a limited level and has the danger of being seen as tokenistic (Happell et al., 2015).

B. Ensure role clarity for SUEs

In building an effective strategy, it is vital that service user and carer roles are negotiated and agreed prior to delivering training to healthcare professionals so that personal preferences and anxieties can be accommodated (Fraser et al., 2017). Organisations may want to undertake a review of the scope of current roles as a means of exploring these issues.

C. Provide training for service user educators

A significant increase in the capacity and capability of SUEs is therefore required in order to fulfil the more extensive involvement of service users. This means the provision of ongoing training, supervision and support for SUEs (Happell et al., 2016). The training could cover the wider aspects of curriculum development and assessment beyond just contributing their particular experience.

D. Target relevant populations for training

Just focusing training on health professionals may miss a wider group of professions that engage with service users (e.g. police officers, clergy) hence a broader needs analysis on different types of course participants needs to be undertaken (Benbow et al., 2011).
E. Ensure co-trainer clarity on need for lived experience in their programme

Happell and Bennetts (2016) feel that the need for preparation is regarded as equally important for co-trainers (non-SUEs) and therefore there needs to be clarification at the outset why they want SUE involvement and how this links to the broader curriculum. A clear purpose for involvement could reduce the risk of tokenism and enhance the benefits of SUE involvement.

F. Ensure SUEs are prepared for specific sessions

Several researchers in the literature review (e.g. Benbow et al., 2011; Fraser et al., 2017; Gregor & Smith, 2009) provided more specific points for recommendation in terms of preparing SUEs for running sessions:

- Information given to service users needs to be simple and basic—too much information could make people anxious
- Focus the topic of the talk to make it easier
- Prepare an outline of questions that the students want to ask in advance to help in preparation
- Allowing SUEs to observe sessions beforehand can help with preparation and reduce anxiety
- Prepare people for the setting so they can get used to the environment
- Anxiety can also be reduced by service users coming to sessions already prepared with information that they are willing to disclose to students and strangers
- Stress to service users/carers that everyone is different and everyone’s story is different so there is no right and wrong and although it may be difficult to share distressing issues, it helps
- It is important that service users are equipped to deal with potential resistance from staff

G. Ensure preparation of trainees

It was clear from the literature review (Dorozenko et al., 2016; Stacey et al., 2017) and our co-production workshop that trainees themselves needed preparation and support to get the most out of the sharing of lived experience. Useful input here could include:

- Briefing students in advance on the potentially emotionally intense nature of the experiences that they might hear about
- Clarifying how to ask constructive questions of SUEs
- Discussing opportunities to practice their empathic and communication skills with an SUE
H. Flexibility in delivery of sessions

- Be flexible in your approach in accommodating individual service users and carers

- Some SUEs feel fine talking to big groups but others may prefer talking one-to-one, while others might want to make a video or write their narrative rather than be involved in any face-to-face interactions. It is an interesting point that in Benbow et al., ’s (2011) study, the SUEs felt strongly that video teaching does not have the same impact as someone teaching in person as students can’t ask questions and lose the interaction.

- Provide students the chance to ask questions that they would not have the opportunity to ask in their everyday work; these could be given in advance to the SUE.

I. Provide post-session debriefing and support for SUEs

There is a risk that the sharing of experiences may have adverse psychological consequences for SUEs so there is a need for follow-up support for SUEs following presentations to staff, even for those presenters that appear comfortable and confident disclosing their experiences (Dorozenko et al., 2016; Meehan et al., 2007).

In conclusion, there is a need for more rigorous evaluation of existing approaches, which takes into account the impacts of lived experience initiatives on all stakeholders (service users, carers and their families in addition to professionals and students), takes a longer-term view of outcomes beyond training delivery including exploration of longer term impacts on educators and recipients (such as compassion, resilience, retention, workforce development, recovery, care outcomes) whilst accounting for any unintended and potentially negative effects (e.g. stress and support needs).