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APPENDIX 1

Practice Review:
Examples of programmes incorporating service user educators in the Sheffield City region
A. University-led Training & Education

1) **Students in Higher Education**

Several training and education courses are targeted at students (medical and non-medical prescribing) across both the universities in Sheffield (University of Sheffield and Sheffield Hallam University) – both collaborate with community partners and organisations such as Storying Sheffield, Sheffield Flourish and Sheffield Teaching Hospitals (STH).

Medical undergraduate students (4th Yr.) considering a psychiatry specialism may choose to take part in the Narrative Masterclass programme, which focuses on strengthening patient interaction and understanding of how individuals with a MH diagnosis cope in their recovery; the programme is designed and led by individuals with lived experiences. Similarly, students studying medical, nursing and dental degrees may experience the Patients as Educators scheme as part of their course, which develops practical and communication skills between real patients and doctors in simulated environments (this is a broader programme covering a range of health diagnosis including MH). Service users take an active role by raising their concerns and expressing their views, preparing students for situations they are likely to expect in their work (history-taking, physical examination, clinical assessment). Service users may also give talks in lectures and participate as actors in student examinations.

2) **Practitioner Training – Psychology trainees**

The Clinical Psychology Unit at the University of Sheffield utilises the lived experiences of service users in the design and delivery of the following courses/programmes;

- Doctorate in Clinical Psychiatry – aimed at Clinical Psychologists
- Improving access to Psychological therapies (IAPT) – aimed at Psychotherapists and Psychological Wellbeing Practitioners

A team of service users are involved in the teaching of personal and professional skills to trainees through workshops and lectures. They are also involved in providing formative feedback on trainee progression, reviewing training material and addressing any further training needs. Some may also form part of the selection team, involved in interviewing potential trainees for entry onto the course.

These university-led programmes primarily aim to improve personal and professional skills, focusing on how interaction with patients can be strengthened. There is also an emphasis on gaining a deeper understanding of the realities of living with a MH diagnosis from the perspectives of the individual.

**Accreditation**

These programmes are all embedded within the course curriculum and therefore confer some assessment/accreditation;

- The Narrative Masterclass forms part of the Integrated Learning Activities (ILA) Phase 3 Module on the MBChB (Medicine) degree.
• Patient as Educators programme contributes to professional competency, a component of the Continuing Professional Development (CPD) module.
• IAPT training contributes to a Postgraduate Certificate or Diploma

**Modes/Methods of Delivery**

These programmes use informal interactive methods, encouraging collaboration and teamwork between service users/patients and students/trainees. There is an attempt to create real-life scenarios through arts based methodology. The narrative masterclass utilises the concept of narrative inquiry, using a range of techniques such as **story-telling, art, free-writing, poetry, film-making, psycho-geography**. The Clinical Psychology Unit uses the ‘Forum Theatre’, working with the University Drama Club, to foster an inter-professional approach to skills training. The Forum Theatre uses **acting, role-playing and story-telling, re-enacting consultations** for example, in front of an audience (other trainees). The audience is then encouraged to **give their views on the ‘show’**, discussing what went well and what can be done better.

**Evidence of Impacts**

It is difficult to assess the impact of these programmes beyond the experiences of those receiving training. The programmes are well-established and have been running for a number of years suggesting that training has been well received. Some recipient feedback includes (taken from video testimonials provided on the website);

• Changing the way in which they would take the history of a client
• Raising issues which they would not have instantly thought of
• Greater confidence as a professional
• More respectful of the challenges faced by patients beyond a simple medical diagnosis

There are some notable achievements that may support the impact of these university-led programmes;

• The Narrative Masterclass Programme was a recent runner-up in the National Haelo Short Film awards, which showcases original public sector film-making.
• The Patient as Educators programme is internationally recognised as one of the largest programmes of its kind in the world, with close to 750 patients and volunteers.

**Web Presence**

There is a clear web presence with information detailing aims of training and how service users play a crucial part in training. This is supported by service user testimonials and short videos, where service users have documented their experiences of being involved.

Summary of University-led Training

<table>
<thead>
<tr>
<th>University-Led Programmes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Providers</strong></td>
</tr>
<tr>
<td><strong>Courses</strong></td>
</tr>
<tr>
<td><strong>Target</strong></td>
</tr>
<tr>
<td><strong>Methods</strong></td>
</tr>
</tbody>
</table>
| **Range of SU Involvement** | · Teaching personal & professional skills  
· Reviewing Training material  
· Lecturing  
· Acting (simulated consultations)  
· Programme evaluation  
· Interviewing |

B. Local Community Organisations – Training & Education

1) **Mental Health First Aid (MHFA) & Youth Mental Health First Aid (YMHFA)**

A number of MHFA courses are being delivered across the region, predominantly by non-profit community groups and charities such as ChilyPEP, Sheffield MIND, Survivors of Depression in Transition (S.O.D.I.T). MHFA follows a national training package (https://mhfaengland.org/) and caters training to different sectors (Workplace, Youth, Higher Education, Armed Forces);

- ChilyPEP – YMHFA training for secondary school/college students, teachers and social workers
- S.O.D.I.T – MHFA for carers, clinical staff, voluntary sector and local businesses (in partnership with Business Boosters Network (BBN)
- Sheffield MIND – Voluntary and public sector organisations, local businesses

Within these examples, some service users have been trained as instructors to deliver these courses. Service users are also involved in instructor training itself, giving talks around their
experiences of mental ill-health (this may also include carers). More widely, the course content has been informed and developed through collaboration with service user groups on a national level. The aim of this course is to provide:

- **In-depth understanding of mental health and factors that can affect well-being**
- **Practical skills to spot the triggers and signs of mental health issues**
- **Enhanced interpersonal skills and confidence to support individuals with MH**

**Modes/Methods of Delivery**

MHFA are delivered as half-day, one-day or two-day courses, with training consisting of a mix of presentations, group discussions and small workshop activities.

2) **Mental Health Awareness and Education**

A series of awareness and education workshops led by local community organisation are also running within the region. Examples include workshops led by; STAMP Sheffield, SAYit: Sheena Amos Youth Trust: LGBT Support, SYHA and Co-Create. These workshops aim to raise awareness of mental health and emotional well-being issues and understanding the needs of individuals with mental health that they may regularly interact with. In addition to providing a broader understanding of mental health well-being, these workshops may be specific to certain areas e.g. SAYit Sheffield addresses mental health issues specific within the LGBT+ community; STAMP focuses on young persons living with mental health. Recipients of these sessions include teaching staff, social workers, housing officers, students and members of the public (as peers). Service users have been involved in delivering sessions to groups and/or shaping the content of training e.g. STAMP members identify what is most important to them.

The Diocese of Sheffield runs a Mental Health Awareness Day across churches aimed at faith and community leaders, pastoral workers, family members and carers. The purpose is to raise awareness of mental health and increase the capacity of faith communities to support people with mental health issues. The day is produced and delivered by individuals with lived experience of mental health issues, whom are responsible for delivering lectures, facilitating workshops and organising topics for discussion.

**Modes/Methods of Delivery**

These awareness and education sessions are mainly delivered through lecture/presentation-based methods, group activities and Q&A discussions.

**Summary of Community based training**
### Local Community Organisations

<table>
<thead>
<tr>
<th>Providers</th>
<th>Sheffield MIND, ChilyPEP, S.O.D.I.T., SYHA, Co-Create, Sheena Amos Youth Trust, STAMP, Diocese of Sheffield</th>
</tr>
</thead>
<tbody>
<tr>
<td>Courses</td>
<td>MHFA, YMHFA, Mental Health Awareness &amp; Education</td>
</tr>
<tr>
<td>Target</td>
<td>Secondary school/college students, teachers, social workers, voluntary sector, local businesses, LGBT+ Community, Faith sector</td>
</tr>
<tr>
<td>Methods</td>
<td>Lectures, presentations, group activities, Q&amp;A discussions</td>
</tr>
<tr>
<td>Range of SU Involvement</td>
<td>· Deliver MHFA sessions  &lt;br&gt; · Deliver awareness courses  &lt;br&gt; · Train instructors  &lt;br&gt; · Shape training content  &lt;br&gt; · Organise MH events/days</td>
</tr>
</tbody>
</table>

### C. Sheffield Health and Social Care (SHSC)/ Sheffield City Council – Training & Education

#### 1) Recovery Education Unit - SHSC

The Recovery Education Unit provides a range of MH training delivered by an academic team, comprising of members with lived experience of mental health (role titles include Lecturers and Recovery Tutors). The team is responsible for organising and delivering training sessions to a range of staff predominantly working within mental health settings. Some training is specific to certain specialisms/stages of recovery and may be delivered in conjunction with external organisations/persons (e.g. Peter Bullimore - Hearing Voices Network, Guy Shennan). The following training is offered:

- Recovery & values-based practice
- Recovery focussed family work
- Solution focussed practice
- PG Diploma in mental health (leading to MSc in advancing professional practice)
- Recovery and mental health – an online introduction
- Mental Health Awareness (Online)
- The Maastricht Interview: Social and biological approaches to voice hearing (Workshop 1)
- The Maastricht Interview: Social and biological approaches to problematic thoughts, beliefs and paranoia (Workshop 2)
• The Maastricht Interview – advanced course (Workshop 3)

Maastricht Interview (Workshop 1,2,3)

Three workshops relating to the Maastricht Interview (a semi-structured questionnaire that is used as a therapeutic approach with individuals who experience problematic thoughts, beliefs or paranoia) are offered by the Recovery Unit, aimed at staff working in mental health and psychiatric services. These workshops are facilitated and delivered by an external specialist (Peter Bullimore), who has personal experience of receiving psychiatric care;

• Workshop 1 introduces the Maastricht approach and underlying principles through tracing its history and evidence of success.
• Workshop 2 develops practical skills of Maastricht Interviewing and basic skills in working with people with lived experience.
• Workshop 3 offers advanced training, looking at how staff can manage the interview process within practice and how they can overcome some of the challenges e.g. disclosure of knowledge, dealing with threatening behaviour.

Modes/Methods of Delivery

A range of methods are employed within these Maastricht Interview workshops including interview role play, emotional therapy, reflective questioning, voice dialogue and several group activities, with each workshop taking place over two/three consecutive days. The purpose of using these methods are to encourage practitioners and staff to explore the experience of voice hearing, in order to build trust, openness and understanding in their work with individuals who hear voices.

Other courses; Recovery & values based practice, Solution Focused Practice....

There is a similar practice-based focus within the training methods employed. This includes extensive group work and discussion, Q&A discussion, role play and group feedback. Training can also be tailored to match each group to the most current practice, therefore making it more realistic and effective. The Recovery Education Unit also utilises online methods for two of their MH awareness courses - the only example we uncovered that utilised this mode of delivery.

2. RESPECT Training

SHSC has introduced nurse-led training for all staff focusing on defusing difficult situations to eliminate face-down restraint techniques in their inpatient wards. The training is ‘co-produced’ by a team of service users, prioritising de-escalation techniques. The programme teaches staff the importance of empathy and compassion in understanding why service users may display disturbed behaviour. The training itself originated from concerns raised by service users (MAAT Probe Group - Afro Caribbean Mental Health Association) around the rising use of restraint techniques. In addition to shaping the content of training, service users have also been responsible for delivering RESPECT training to staff. The trust embarked on an intensive training programme in 2012, which saw all inpatient staff complete the RESPECT course within an 18-week period.
Evidence of Impacts

To date, more than 500 staff have received Level 3 training (highest level). Since the training was introduced five years ago, use of face down restraint has reduced year on year. In the past 18 months, there have been no incidents involving the use of face down restraint. The RESPECT training initiative was recently shortlisted from over a 1000 nominations for the National Health Service Patient Safety Award.

Summary of SHSC/Sheffield City Council Programmes

<table>
<thead>
<tr>
<th>SHSC &amp; Sheffield City Council</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Providers</strong></td>
</tr>
<tr>
<td><strong>Courses</strong></td>
</tr>
<tr>
<td><strong>Target</strong></td>
</tr>
<tr>
<td><strong>Methods</strong></td>
</tr>
</tbody>
</table>
| **Range of SU Involvement** | · Members employed within academic team (lecturers & recovery tutors)  
· Arrange and organise workshops  
· Deliver training courses  
· Shaping training content |
APPENDIX 2

Rapid systematic literature review of research into lived experience in mental health training
3.1. SUMMARY

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. 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’ and became part of the wider team. Gaps identified included exploring the role of the service user in professional groups other than nurses where this type of approach has appeared to be pioneered, assessing the extent to which it impacts on care delivery, the recruitment of service users and their support needs, and the voices of those that remain hidden (those who do not experience recovery, children and adolescents, those who experience difficulties with communication).

3.2. REVIEW OBJECTIVES

- Describe the ways in which Lived Experience is practised, and the underpinning aims and theoretical frameworks of these approaches
- What are the impacts of involving people with lived experience in training on the education and development of professionals who provide services to people with mental health needs
- What is the impact on the attitudes of professionals and is there evidence of attitudinal change.
- What are the process/mechanisms that lead to changes in professional attitudes, behaviour, knowledge and practice
- How might changes in attitude and knowledge lead to improved care quality, experiences and outcomes for service users
- What are the impacts of lived experience initiative on all stakeholders; including service users, careers, and their families?
- To what extent does existing research evidence seek to measure longer term outcomes (compassion, resilience, retention, workforce development) including health outcomes (recovery, self-management) whilst accounting for any unintended and potentially negative effects (e.g. stress and support needs).
- What are the gaps in the research evidence that need to be addressed in order to understand the impact of ‘lived experience’ initiatives, and what types of initiative work, for whom and in what circumstances?
3.3. METHOD

Scoping reviews are suitable for charting new territory between areas of research and in identifying issues worth further attention [43]. Scoping studies are defined as “a form of knowledge synthesis that addresses an exploratory research question aimed at mapping key concepts, types of evidence, and gaps in research related to a defined area or field by systematically searching, selecting, and synthesizing existing knowledge” [44]. In scoping studies researchers can incorporate a range of study designs and address questions beyond those related to intervention effectiveness, and generate findings that can complement the findings of clinical trials [45]. However, the quality of included studies is not assessed, nor are findings synthesized [43].

This scoping review followed the framework proposed by Arksey and O’Malley [43] and further enhanced by Levac et al. [45] and was accordingly conducted in five stages also guided by Peters et al. [46].

Stage 1

In stage 1, our initial research questions were defined. Although these remained more or less the same in foci and objectives, they were adjusted somewhat during the research process to result in those listed above under Objectives.

Stage 2 Search approach

In stage 2, relevant studies were identified based on the research questions and purpose of the study. Systematic searches for articles published from 2007 to 2018 were carried out in the following electronic databases: MEDLINE, PsycINFO, EMBASE and Cinahl. All types of study design were included in the search strategy, which was restricted to articles in English and published in peer-reviewed journals. We also searched the reference lists of included studies and approached topic experts.

Stage 3

Following the Joanna Briggs Institute’s guidance on scoping reviews (2015), an initial high precision search was conducted in December 2017 using PsycINFO and CINAHL.

The search was restricted to results since 2007, and focussed around lived experience of mental health in the training of health professionals. A total of 411 results (220 from PsycINFO, 191 from CINAHL) were sifted in order to explore the topic, make decisions about inclusion and exclusion criteria, and identify additional search terms.

A second phase of searches was conducted in January 2018, this time including Medline and using an expanded search strategy with terms such as those below used to increase sensitivity:

<table>
<thead>
<tr>
<th>Lived experience</th>
<th>Health and social care professions, including:</th>
<th>Training</th>
</tr>
</thead>
<tbody>
<tr>
<td>Life experience</td>
<td>Nurses</td>
<td>Education</td>
</tr>
<tr>
<td>Service user involvement</td>
<td>Counsellors</td>
<td>Courses</td>
</tr>
<tr>
<td>Patient involvement</td>
<td>Psychologists</td>
<td>Workshop</td>
</tr>
<tr>
<td>Consumer participation</td>
<td>Social workers</td>
<td>Programme</td>
</tr>
<tr>
<td>PPI</td>
<td>(etc.)</td>
<td>Degree</td>
</tr>
<tr>
<td></td>
<td>Medical students</td>
<td>University</td>
</tr>
<tr>
<td></td>
<td>Nursing students</td>
<td>(etc.)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Mental health</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental illness</td>
</tr>
<tr>
<td>Psychiatric disorders</td>
</tr>
<tr>
<td>Depression</td>
</tr>
<tr>
<td>Anxiety</td>
</tr>
<tr>
<td>Psychotic disorders</td>
</tr>
<tr>
<td>Schizophrenia</td>
</tr>
<tr>
<td>Bipolar (etc.)</td>
</tr>
</tbody>
</table>

These searches identified an additional 797 results (after de-duplication).
Finally, for the purposes of validating the search approach, the results of the comprehensive searches were checked against included papers from an existing review on a related topic (Arblaster et al 2015). This identified one key journal not indexed by the sources already searched (The Journal Of Mental Health Training, Education and Practice) so a decision was taken to search this source by hand for new articles published since the Arblaster review.

The papers were read in brief by one reviewer (FC)

**Stage 4**

Stage 4 entailed charting the data of the included studies by extracting and coding in Excel each included article according to each of the following variables: intervention’s country of origin, aims, type of paper, type of research, professional group being trained, details of the training programme, how the service users were selected and supported, what roles did they fill, what was the nature of the training programme, whose views were captured in the evaluation, duration of study follow-up and recommendations for further research. This was undertaken by one reviewer.

**Stage 5**

The fifth and final stage of the scoping review entailed collating, summarizing and reporting the results [45].
3.4. FINDINGS

The original search as described above conducted in December 2017 yielded 792 potentially relevant citations. After deduplication and relevance screening 103 citations met the inclusion criteria based on title and abstract. Full-text versions of the 93 citations were retrieved.

*Diagram 1 Flow diagram of search results*

57 papers were included in the scoping reviews. The included papers were published between 2007 and 2018. The number of articles exploring and describing the role of service user involvement in training and developing skills in professionals caring for people with mental health issues has grown considerably since 1995 when the first paper appears.

The majority of the publications (36%, n=20) were written by authors based in the UK (with 28% (n=16) written by authors based in Australia. There was one paper by authors from each of the following countries; Italy, Canada, USA, Israel and New Zealand.
**Table 1: Year of publication**

<table>
<thead>
<tr>
<th>Year</th>
<th>Number of included articles published</th>
<th>Key policy dates and drivers for change</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>NHS Executive (1996)</td>
</tr>
<tr>
<td>2016-2018</td>
<td>15</td>
<td></td>
</tr>
</tbody>
</table>

Thirty-two papers reported the findings of an evaluation of a specific programme, three papers explored attitudes prior to the development of a programme, seven papers reported the findings of surveys of a wider group with experiences of different programmes incorporating lived experience in training. Seven of the included papers were systematic reviews. See table 2.

**Table 2: Purpose of paper**

<table>
<thead>
<tr>
<th>Purpose of included paper</th>
<th>Number of papers</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Evaluation of user involvement in education and training of mental health professionals</td>
<td>32</td>
<td>(1-31)</td>
</tr>
<tr>
<td>Exploring attitudes prior to the development of a programme</td>
<td>3</td>
<td>(32-34)</td>
</tr>
<tr>
<td>Reporting surveys of wider group with experiences of different programmes</td>
<td>7</td>
<td>(35-41)</td>
</tr>
<tr>
<td>Descriptive papers</td>
<td>2</td>
<td>(42, 43)</td>
</tr>
<tr>
<td>Systematic reviews/reviews</td>
<td>7</td>
<td>(44-50)</td>
</tr>
<tr>
<td>Not yet located</td>
<td>4</td>
<td>(51-54)</td>
</tr>
<tr>
<td>Book chapter</td>
<td>1</td>
<td>(55)</td>
</tr>
</tbody>
</table>

**3.4.1. Evaluations of programmes (n=32 papers)**

Most of the included papers were reports of studies evaluating programmes that had introduced service user involvement in training programmes. There was considerable variation in the programmes themselves and how the service user role was incorporated and also in the methods used to evaluate the programmes. Most incorporated different research methodologies in their evaluation. These included action research which aims at solving specific problems within a programme or organization. The research itself becomes part of the change process through engaging the people in the programme or organization in studying their own problems. As a result the distinction between research and action becomes blurred and research methods less systematic. (Quinn-Patton 2001). Six papers (reporting five studies) used quantitative methods to measure changes in learner attitudes with a non-randomised comparative study (18, 31) or using a before and after questionnaires with the same student cohort (4, 7, 56). Five papers reported findings of mixed methods evaluations of training programmes using mental health service users. These approaches commonly adopted both quantitative and qualitative methods such as a questionnaire and follow-up interviews (1, 8, 14, 26, 28). The majority of included evaluations
used qualitative methods to explore the views and attitudes of participants. The most common method of data collection used was interviews. Five studies reported findings based on feedback or descriptions of reflections of participating in programmes using service users and/or carers in training. See table 3 for summary of methods used in evaluation papers.

Table 3: How were educational interventions evaluated?

<table>
<thead>
<tr>
<th>Methodology</th>
<th>Number of papers</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mixed methods</td>
<td>5</td>
<td>(1, 8, 14, 26, 28)</td>
</tr>
<tr>
<td>Qualitative</td>
<td>13</td>
<td>(2, 3, 5, 6, 12, 13, 19-23, 25, 30)</td>
</tr>
<tr>
<td>Quantitative</td>
<td>5</td>
<td>(4, 7, 18, 31, 56)</td>
</tr>
<tr>
<td>Action research</td>
<td>3</td>
<td>(10, 27, 57)</td>
</tr>
<tr>
<td>Based on feedback/descriptive</td>
<td>5</td>
<td>(9, 11, 42, 43, 58)</td>
</tr>
</tbody>
</table>

Table 4: Which professional groups are using service users/carers in training programmes (n=47 papers)

<table>
<thead>
<tr>
<th>Professional group</th>
<th>Number of papers</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nursing students</td>
<td>4</td>
<td>(23, 24, 28, 31)</td>
</tr>
<tr>
<td>Mental health student nurses</td>
<td>7</td>
<td>(5-7, 19, 25, 26, 57)</td>
</tr>
<tr>
<td>Health and social care professionals/multi agency</td>
<td>6</td>
<td>(2, 9, 10, 12, 14, 42)</td>
</tr>
<tr>
<td>Pharmacy students</td>
<td>3</td>
<td>(4, 18, 20)</td>
</tr>
<tr>
<td>Social work students</td>
<td>4</td>
<td>(8, 11, 13, 22)</td>
</tr>
<tr>
<td>Psychiatry trainees</td>
<td>1</td>
<td>(1)</td>
</tr>
<tr>
<td>Clinical psychology trainees</td>
<td>3</td>
<td>(30, 43, 56)</td>
</tr>
<tr>
<td>blanks</td>
<td>4</td>
<td>(3, 27)</td>
</tr>
</tbody>
</table>

Table 5: Whose voices are heard in the included papers

<table>
<thead>
<tr>
<th>Perspectives</th>
<th>Number of studies</th>
<th>Number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Learner views</td>
<td>14</td>
<td>(4-9, 14, 18, 19, 22, 24, 28, 45)</td>
</tr>
<tr>
<td>Service user</td>
<td>1</td>
<td>(26)</td>
</tr>
<tr>
<td>Service user trainer and learner views</td>
<td>6</td>
<td>(1, 2, 9, 20, 23, 57)</td>
</tr>
<tr>
<td>Educator</td>
<td>1</td>
<td>(13)</td>
</tr>
<tr>
<td>blanks</td>
<td>3</td>
<td>(3, 42, 43)</td>
</tr>
</tbody>
</table>

3.4.2. Roles of Service Users (people with lived experience) within Education

In order to understand the types and scopes of the roles that service users undertake in the training of mental health professionals I used the following categories and mapped the roles described in the papers included to these:

1 - design of curriculum
2 - delivery of teaching material
3 - assessment of student competency
I compared the findings of this review with two other surveys (41, 59) also exploring service user involvement in education. Higgins’ et al (2011) survey was conducted in Ireland, with questionnaires sent to course co-ordinators of both undergraduate and post-graduate courses relevant to mental health professionals. Happell et al (2015) study was conducted in Australia with surveys sent to nurse academics that coordinate mental health nursing programmes in universities. I compared their findings with the results of this scoping review. (see table x).

The results suggest that the roles most often fulfilled are in the delivery of teaching.

Table 6: Scope and nature of roles held by service users

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1 curriculum design</td>
<td>15%</td>
<td>15%</td>
<td>17%</td>
</tr>
<tr>
<td>2 delivering teaching</td>
<td>63%</td>
<td>22%</td>
<td>45%</td>
</tr>
<tr>
<td>3 marking and assessment</td>
<td>15%</td>
<td>2%</td>
<td>7%</td>
</tr>
<tr>
<td>4 programme evaluation</td>
<td>4%</td>
<td>15%</td>
<td>15%</td>
</tr>
<tr>
<td>5. LEA</td>
<td>25%</td>
<td>none</td>
<td>none</td>
</tr>
</tbody>
</table>

3.4.3. Who are service users? How are they recruited and how are they supported?

Only six papers (4, 8, 11, 18, 20, 57) reporting an evaluation of an education programme that incorporated service users in training, described how the service users were identified and recruited. In most instances this was through self-help organisations. In one paper they were required to have experience of ‘personal recovery’. Another study reported using networks of contacts with service users and providers.

Four studies (2, 9, 14, 23) described providing some training or preparation for teaching and facilitating discussions. Apart from those employed as LEA’s, payment was only discussed in one paper(11) and some of the challenges of this (such as having an impact on benefit payments) were discussed. One study (28) described offering debriefing for the service user trainers in case the sessions raised issues that were difficult for them.

Overall, there was very little information about the process of identifying, selecting, preparing and supporting service users in their roles. A qualitative theme that arose in a number of papers was the issue of representativeness of the service users appointed.

Table 7: Quantitative Measurements of the Impact of using Service Users in Training on Learners

<table>
<thead>
<tr>
<th>Study</th>
<th>Study design</th>
<th>Measurement Tool</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agrawal et al (2016)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Buhler et al (2008)</td>
<td>B &amp; A</td>
<td>*Survey instrument created to measure 4 aspects of students conceptions of schizophrenia and depression</td>
</tr>
<tr>
<td>Cabiati et al (2016)</td>
<td>B &amp; A</td>
<td>Attitudes to Mental Illness Questionnaire</td>
</tr>
</tbody>
</table>

Happell et al (2014)  | NR comparative study | *Questionnaire designed to measure nursing students attitudes towards people with mental illness; perceived preparedness for, and understanding of mental health nursing, and intentions to enter mental health nursing as a profession.

Nguyen et al (2012)  | NR comparative study | 39 item survey instrument which comprised elements of the Social Distance Scale, the Attribution Questionnaire, items relating to professional service delivery and items relating to specific stigmatizing beliefs.

B & A: before and after study design; NR: non-randomised; * non-validated tool

There are very few RCTs that have endeavoured to demonstrate the impact of using service users on shaping behaviours and attitudes of learners. The designs used most frequently are likely to be at high risk of bias in terms of seeing a positive effect to the intervention. It is also worth noting that the tools for measuring the outcomes have in some studies, been designed for that study and therefore are not validated instruments which also raises questions about the validity of the findings.

3.4.4. Learner views – highlighting some broad themes that arose

Twenty papers (see table 5) 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.

3.4.5. Service User views - highlighting some broad themes that arose

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

3.4.6. Gaps identified by researchers and authors of the included papers

Some of the common themes in the gaps identified by authors of the included papers are 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

• Programme was evaluated, most commonly, at its completion. It therefore did not measure the impact of the intervention on 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 elements of the intervention that contribute to greatest effectiveness?

• Guidelines and theoretical frameworks are needed that allow the model to be applicable to different contexts.

• There is clearly a movement towards further expansion and development of the role into curriculum development and assessment. The role of the LEA is also a further extension of this. There is very little evaluation of the benefits and costs of these developments.

3.4.7. Further Gaps identified by this Scoping Review

This scoping review does highlight a number of areas where the descriptions of interventions are very limited and where little research has been undertaken.

The use of service users in the training of professionals involved in the delivering of care to patients with poor mental health appears to have been mainly developed within nursing, both at pre-registration and specialist levels of training. There is a lack of research showing how the involvement of service users in medical education has been developed or evaluated. One finding suggested that it was difficult for the principles that service user training espouses to be maintained in clinical settings where they were not supported. There is potentially scope to explore greater shared training with a variety of professionals working alongside service users rather than this type of training remaining within professional silos.

There is very little written about the recruitment and selection of service users. Relapse of symptoms is a concern for service users. It may well be that actually many voices are not heard and the most vulnerable may become even further hidden. This includes those who don’t experience recovery, the voices of those who are limited by barriers to communication, those who are too young to qualify for the role.

3.4.8. Existing Systematic Reviews

Seven existing systematic reviews have been published between 2008-2016. The details of these reviews are tabulated below (table 8).
### Table 8: A table of Systematic reviews

<table>
<thead>
<tr>
<th>Review</th>
<th>Objectives</th>
<th>Searches</th>
<th>Inclusion criteria</th>
<th>Findings</th>
<th>Recommendations</th>
</tr>
</thead>
</table>
| Arblaster et al (2015)  | **Objectives**: Addressing the following research questions: 1. What evidence exists to guide mental health consumer participation at each stage of the education process? 2. What evidence exists to support the effectiveness of consumer participation in mental health education in producing graduates with recovery-oriented practice capabilities? | **Searches** were completed in five online databases, one journal and published reading lists on the topic. | **Inclusion criteria**: Addressed mental health consumer participation in health professional education programs, Published in peer reviewed journals between 2000 and 2014 English language | **Findings**: n=36  
All retrieved studies were analysed to identify research findings related to stage(s) of education  
1) Design  
2) Planning  
3) Delivery  
4) Outcomes  
One key finding is the value of a long term partnership between a university and a consumer group, consistent with good practice guidelines for effective consumer participation.  
There is beginning evidence that direct personal contact characterised by power equalisation and a participatory teaching style, e.g. small group facilitator, may be more effective than other approaches, e.g. teaching from the front, or less powerful roles, e.g. standardised patient.  
An absence of published outcome measures relevant to the outcomes under investigation is a significant limitation in this field of research.  
This review has identified minimal evidence to guide consumer participation at each stage of the education process and to support the idea that consumer participation in education produces graduates with capabilities for recovery-oriented practice. | **Research**  
1) Empowerment  
Identification of consumers’ views about the recovery-oriented practice capabilities required by occupational therapy graduates; identification of attitudinal and institutional barriers to consumer participation; consumers’ perceptions of their experiences of participation and exploring the degree to which they consider these empowering.  
2) Added Value  
Directions for future research include longitudinal studies of outcomes arising from consumer participation in education. In particular, whether changed attitudes, knowledge and behaviours are maintained over time in the face of workplace pressures could be investigated. The efficacy of particular pedagogical approaches and specific approaches to consumer participation in design, planning, delivery and evaluation of curricula can be examined. The link between these practices and the degree to which graduates work in recovery-oriented ways could be explored. Underpinning these research directions is the need for a valid and reliable instrument that can measure changes in recovery-oriented practice capabilities. Available evidence is limited in quality and generalisability, and is characterised by small convenience samples, a focus on proximal outcomes, inattention to issues of rigour and the use of instruments not designed for the purpose and with limited validation of their psychometric properties. |
| Happell et al (2014) | The aim of this paper is to provide an updated review of the published work on consumer involvement in the education of mental health professionals. More specifically, this review is focused upon consumer involvement in the tertiary-level education of psychiatrists, nurses, psychologists, social workers, and occupational therapists. | 3 data bases, bibliographic searches, experts | Studies were included in this review if they focused on mental health consumer involvement in the tertiary-level education of health professionals. Both quantitative and qualitative studies were included in this review. Papers that did not report on primary research (e.g. commentaries on consumer involvement in education, descriptions of consumer involvement initiatives, reviews) were excluded. | N= 28  
Findings from three studies indicate that consumer involvement in the education of mental health professionals is limited and variable across professions. Evaluations of consumer involvement in 16 courses suggest that students gain insight into consumers’ perspectives of: (i) what life is like for people with mental illness; (ii) mental illness itself; (iii) the experiences of admission to, and treatment within, mental health services; and (iv) how these services could be improved. Some students and educators, however, raised numerous concerns about consumer involvement in education (e.g. whether consumers were pursuing their own agendas, whether consumers’ views were representative). Evaluations of consumer involvement in education are limited in that their main focus is on the perceptions of students. The findings of this review suggest that public policy expectations regarding consumer involvement in mental health services appear to be slowly affecting the education of mental health professionals. Future research needs to focus on determining the effect of consumer involvement in education on the behaviours and attitudes of students in healthcare environments. | There is perhaps a need for researchers to move away from using simple questionnaires and interviewing techniques to investigate participants’ perspectives on, and experiences of, consumer involvement. |
| Perry et al (2013) Mixed methods systematic review | English language publications from 1990–2010 5 databases | Criteria for inclusion: Population Mental health students undergoing mental health education. Interventions Any educational activity that involves teaching by persons who have experienced mental health problems. Outcomes Any educational outcome pertaining to interpersonal skills including (but not restricted to) changes in skill, beliefs, attitudes, behaviours, empathy and negative effects Study designs quant and qual | N=10 1. Overall this type of teaching was acceptable to students and of value. 2. When service users teach about communication there is a move in student’s practice towards improved attitudes towards people with mental health difficulties. 3. Some students were concerned that the people teaching them were not sufficiently representative of most people with mental health difficulties. 4. This type of teaching made professionals reflect more deeply on the way they communicate. 1. Researchers should use a clear definition of what constitutes good communication. 2. If skill in communication is being measured tried and tested measures should be used to do this and an experimental approach should be adopted. 3. A mixture of methods that both measure changes in skills and behaviour and elicit peoples actual experience of this type of teaching seems to be the best way of researching this area. |
### Scammell et al (2016)
**Mixed methods systematic review**

A systematic review of published studies on service user involvement in undergraduate, preregistration general nursing education (excluding mental health-specific programmes). The objective is to examine how students are exposed to engagement with service users.

**Inclusion criteria**
- **Population:** Prereg nursing students
- **Intervention:** Service users or carers
- **Outcomes:** Education

<table>
<thead>
<tr>
<th>8 databases 1997-2014</th>
<th>N=11</th>
</tr>
</thead>
<tbody>
<tr>
<td>This is the first systematic review to focus on service user involvement in general nurse education. It reveals that service user involvement commenced later and is more limited in general programmes as compared to equivalent mental health education provision. Most of the evidence focuses on perceptions of the value of involvement. Further research is required to more clearly establish impact on learning and clinical practice.</td>
<td></td>
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</table>

There is a need for further larger-scale, multi-centred mixed method research around impact on learning and person-centred care.

### Simons et al (2010)
**Qualitative evidence synthesis**

To evaluate the development of values based education through service user participation

|  | The studies suggest that while opportunities exist for service users to present their accounts, few examples of service user involvement facilitated deeper examination of values underpinning decision-making. Enabling service users to influence values-based practice development requires more authentic participatory approaches. Educators valued the contribution of service users’ experiential knowledge to the learning process, but there was less evidence of educators’ values base that would model commitment to the empowerment of service users. |
| Terry et al (2012) | This paper aims to examine peer-reviewed literature on service user involvement in pre-registration mental health nurse education programmes, with a focus on the classroom setting. | 8 databases 1996 - 2011 | 1. Papers that focused on service user involvement in teaching and learning initiatives in classroom settings.  
2. Papers that identified approaches to teaching and learning involving service users in pre-registration mental health nurse education programmes, which included classroom-based work. | N=8  
• A variety of research methods and designs  
• Necessary prerequisites for user involvement activities in classroom settings  
• The experiences of both student nurses and service users  
• A number of studies featuring different teaching and learning methods that have included service user involvement in the classroom and their findings  
• An increased awareness of ethical implications of user involvement in the classroom | Further longitudinal research is needed to establish the influence of user involvement in the classroom on student nurses’ attitudes and practice over time. The effects of professional socialization must also be considered once students qualify, particularly if they have grasped the nettle of partnership in the classroom, only to find that putting this into practice as qualified nurses is not without its trials. It is now time for nurse educators to rise to the challenge of implementing increased user involvement activities in nurse education, by working in partnership with users, and considering credible approaches to evaluation. |
| Townend et al (2008) | In particular this paper reflects on the literature on user involvement to gain a deep understanding of its status in the education and training of psychological therapists. | 6 databases 2004-2007 | any published papers on user involvement in psychological therapies training. | If service user involvement in psychological therapy training is carefully planned, supported and evaluated, it could improve the trainees’ practice, so that it reflected the priorities and wishes of those receiving the service. Nevertheless, it is currently an underdeveloped area within contemporary psychological educational practice. | None described |
3.5. CONCLUSIONS

3.5.1. Limitations of this review

We deliberately focused on papers published since 2007, this will have meant we have not included all of the work published in this field, but only on work published in the last decade.

The process of screening for papers and data extraction has only been undertaken by one reviewer meaning interpretations of data were not verified, and the potential for error to go undetected is greater.

The nature of this review (scoping review) means that it offers breadth rather than depth of analysis. Its aim is to identify gaps and give a sense of work already done, rather than further more in-depth analysis of the data.

3.5.2. Recommendations

Although there is a clear need to undertake primary research in this area as described above in the gaps identified for further research there would also be value in further secondary research. This scoping review was not designed to look in depth at the findings of the included papers, however there is a need to explore the impact of the interventions and the contexts in which these occur. A realist synthesis or meta-ethnography, would allow the development of a theoretical framework which would address questions such as ‘why and how does the intervention work’ in a particular setting. There are parallels with other bodies of work, including the debates within the patient engagement literature that could inform this field of research.
References

Methods


Included studies


29. Tickle A, Braham L. Meaningful use of service user contributions to professional training


APPENDIX 3

Co-production workshop:
Tables of responses to service user educator positives, challenges and research needs
### Table 1. Positives of Service User Educators

<table>
<thead>
<tr>
<th>Higher-level research themes</th>
<th>Examples of Positive Aspects given by participants</th>
</tr>
</thead>
</table>
| **Impact on mental health trainees** | Empathy  
More likely to co-produce care  
Shared decision making  
Person centred  
Reduces stigma  
A recognition in staff that ‘it could be them’, a few unfortunate events away from being in a similar position  
A feeling that some impact was being made in challenging stigma amongst staff  
Have real potential to challenge orthodox ways of thinking about mental health and service users to make a difference  
Safe place to ask questions and learn how to ask questions.  
Be curious, get them to tell us stories  
Valuable, would not know how work otherwise  
Terminology might change.  
Myth that professionals are ‘invincible’, SU are other. We suffer too.  
More rounded view through SUE – what brings joy as well as sadness.  
Makes you think how different are SU and professionals.  
We were mental health naïve – what do these things mean in real life (e.g. aggression?)  
‘I am wide-eyed’ – SU verbalises the impact on self and wider.  
Patients are ‘featureless’ in textbooks. Hard to get voice heard normally.  
Makes service users and carers more relatable.  
Shows how carers views are also important.  
Big Eyes’ on figure from SUE – perception from their point of view  
Stop thinking about conditions and instead think about person and the complexity of the context |
| **Impact on service user educators** | Educators are committed, passionate, enthusiastic and have a lot of energy to make a difference  
In the hierarchy of care, service users and their carers should be at the top with the power to shape their own services, yet this is often not the case. SU educators important in this.  
A sense that their value is becoming more widely acknowledged |
| **Training design** | SUE gives chance to practice ‘poker face’ before you get on wards. How to show empathy. |

**NOTE:** Red = Service Users, Blue = Service User Educators, Grey = Professional Mental Health Trainees
<table>
<thead>
<tr>
<th>Higher-level research themes</th>
<th>Challenges given by participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Impact on mental health trainees</td>
<td>Risk</td>
</tr>
<tr>
<td></td>
<td>Can be overwhelming when hear SUE – unexpected but a good thing.</td>
</tr>
<tr>
<td></td>
<td>Can feel ‘tokenistic’ sometimes</td>
</tr>
<tr>
<td></td>
<td>Mental health is seen as more risky to discuss</td>
</tr>
<tr>
<td></td>
<td>Staff disclosing own experience is risky</td>
</tr>
<tr>
<td></td>
<td>Staff feeling that if they have had training from someone with bpd, so i know what bpd is like now...Needs to stay person centred</td>
</tr>
<tr>
<td>Impact on service users</td>
<td>Can burn people out</td>
</tr>
<tr>
<td>Impact on service user educators</td>
<td></td>
</tr>
<tr>
<td>Service user educator recruitment and support</td>
<td>Service user educators are people and need to be interacted with as such as colleagues (including rewards / recognition as such) with other skills and experiences over and above those of being a ‘user’ too (versus being patronised).</td>
</tr>
<tr>
<td>Training design</td>
<td>Parity of esteem, “if you broke your leg they wouldn’t talk to you like that”!</td>
</tr>
<tr>
<td></td>
<td>A sense that those who get trained by user educators are probably those with a level of insight and empathy already (e.g. nurses/CPNs) and there are bigger structural barriers to training others who arguably need it more.</td>
</tr>
<tr>
<td>Stakeholders associated with service users</td>
<td>Family and carers voices are often unheard and yet they are relevant to all training and need to be involved more</td>
</tr>
<tr>
<td>------------------------------------------</td>
<td>---------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Health Organisation perspective</td>
<td>Sense that organisations create roles for service user educators to fill and enact in line with what the organisation wants versus the person being able to shape and create the role for themselves (the person has to fit the role) – as a ‘puppet’.</td>
</tr>
<tr>
<td></td>
<td>Often takes place within existing power relationships within the organisation - if power is a zero sum game, for SU educators to be empowered this necessarily needs others to cede power and they are often unwilling to do so.</td>
</tr>
<tr>
<td></td>
<td>Lived experience initiatives needs to embrace the ‘colour’ and detail of peoples’ experiences and stories versus them being squeezed by ‘the powers that be’ and bureaucracy</td>
</tr>
<tr>
<td></td>
<td>Some feelings of ambivalence, since there are opportunities and barriers and real danger of co-optation of lived experience for organisational and policy ends.</td>
</tr>
<tr>
<td></td>
<td>The role and purpose of lived experience is often ill defined and left implicit, therefore is there space for the educator to define and shape this for themselves? The opportunity to create and convey their own message was identified BUT this is also seen as challenging with a wider fear within organisations about users going against the grain within the context of existing power imbalances. In this sense it is recognised the space for voice is constrained where this only happens when, where and how ‘those who hold the purse strings’ decide.</td>
</tr>
<tr>
<td></td>
<td>A concern that there is a space for ‘happy, compliant SU representatives only’, that convey the right message the organisation wants (a managed / constrained space?) – there is a sense that it can descend into being a ‘superficial parade’ of good work that fits certain agendas or stories to be told.</td>
</tr>
<tr>
<td></td>
<td>Two sides or stories – the goodwill and ‘magic’ that SU educators bring can meet the institutional ‘pac man’ that can eat up all this energy and good will (barriers).</td>
</tr>
<tr>
<td></td>
<td>‘Political dimension’ can create tension</td>
</tr>
</tbody>
</table>

NOTE: Red = Service Users, Blue = Service User Educators, Grey = Professional Mental Health Trainees
Table 3. Research questions generated in the workshop and their grouping into higher-level research themes. Figures in brackets show how many participants chose a particular research question as one of the most valuable to explore.

<table>
<thead>
<tr>
<th>Higher–level research themes</th>
<th>Research questions generated during the workshop</th>
</tr>
</thead>
<tbody>
<tr>
<td>Impact on mental health trainees</td>
<td>Does training change practice – dose? (18) Does training change behaviour? (1) Evaluation of training - are students getting the knowledge or the story? Key to changes in practice? (5) Does training affect knowledge, skills, attitude (e.g. empathy) of professionals? Long-term effects of training? What are the different skills that make a ‘good’ health care practitioner? Fear (stigma, taboo, paternalism, socialisation of trainees) -&gt; complexity – Fear for trainees? (5) Fear for educators Relevant theories (e.g. transformational learning) (3)</td>
</tr>
<tr>
<td>Impact on service users</td>
<td>Does training change patient outcomes? (3)</td>
</tr>
<tr>
<td>Impact on service user educators</td>
<td>What difference does it make to educators? (2)</td>
</tr>
<tr>
<td>Service user educator recruitment and support</td>
<td>Structures and power. Practice constrained by ‘The Boot’ (7) Preventing co-option (3) Recruitment, selection of service user educators (3) Training and support for both trainees and educators (4) User involvement in assessment User involvement in design and evaluation</td>
</tr>
<tr>
<td>Training design</td>
<td>When do we do training – pre/post registration? (1) Who gets the training? What is the training trying to do (organisational vs individual aims) (1)?</td>
</tr>
<tr>
<td>Stakeholders associated with service users</td>
<td>Unheard voices (e.g. carers, friends, families) (14)</td>
</tr>
<tr>
<td>Health Organisation perspective</td>
<td>Organisational culture – ‘people in positions of power need to embody and champion and set an example’ (8) Valuing contribution in the organisational structure</td>
</tr>
</tbody>
</table>