Patient and Public Involvement for the development of a research into the employment of NHS mental health peer workers

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Background to the grant application: We sought funding to facilitate patient and public involvement in the development of an application to The Health Education England (HEE) and National Institute for Health Research (NIHR) Integrated Clinical Doctoral Fellowship for non-medical healthcare professions**.** Expected deadline April 2020.

Proposed research topic: Employment as an NHS mental health peer worker

Background to research topic: Approximately one in six people across Europe experience mental ill health at any one time. Mental health care is best when it is recovery focussed, promoting wellness, social inclusion and meaningful lives. Peer support workers, who use their own experiences of ill health and service use to improve the health and wellbeing of others, are an important component of recovery focussed care.

Peer working is an emerging role within NHS mental health care. Twenty years ago there were no NHS employed peer workers, there are now over 500, and numbers are increasing. The NHS employs peer support workers for four reasons. Firstly, to deliver mental health care to its service users, secondly to improve the health, wellbeing and recovery of the peer workers themselves, thirdly to positively influence NHS culture and lastly to provide cost savings.

This research expects to focus on the second reason, employing people with mental ill health as peer support workers to improve their own health, wellbeing and recovery. There is some evidence that being employed as a peer support worker can increase self-esteem, confidence, social networks and other benefits consistent with recovery. However, there is also evidence that it can lead to stress, emotional burden, feeling stigmatised and have a negative impact on people's identities. Difficulties in retaining peer workers in their posts and integrating their roles into the NHS have also been reported.

To realise the benefits of peer support for the NHS and its service users, peer working must also be beneficial for the peer workers themselves. We do not yet know how to ensure peer workers have a positive experience of being employed by the NHS to provide peer support.

Potential research aims:
1. Increase knowledge and understanding of how peer working affects personal health, wellbeing and recovery
2. Identify factors influencing the outcomes and experiences of peer working
3. Explain what the NHS can do to ensure peer working is beneficial to its peer workers

<p style="text-align:center">Patient and Public Involvement</p>

Purpose of patient and public involvement activities:

Prior to gaining this patient and public involvement grant, we had informally engaged with people to discuss the relevance and importance of the proposed research area. This included discussions with mental health service users, peer workers, those who work alongside them and others who are researching peer support in mental health. We sought funding to enable us to undertake formal involvement activities to further shape the direction of this research proposal. Specifically, to incorporate the views of people who have experienced mental ill health and those who have used these experiences within healthcare, or supported them to do so, into the development of the research proposal, questions and methods.

Identifying and recruiting relevant people:

Potential participants were approached through local organisations that provide mental health peer support:

- Sheffield Health and Social Care NHS Foundation Trust (SHSC)
- Rotherham, Doncaster and South Humber NHS Foundation Trust
- Derbyshire Healthcare NHS Foundation Trust
- Sheffield Flourish
- Sheffield MIND
- South Yorkshire Housing Association (SYHA)

Also, through connections gained from informal networking at national mental health peer support events - "Peerfest" in Essex (led by MIND) and "The future of peer support event" in Derby (organised by National Survivor User Network).

Description of involvement events:

Three discussion groups were organised tailored to the needs of different participant groups:

Group 1: People who are currently, or who have recently, used mental health services, which may or may not have included peer support. This discussion group took place as part of a SUN:RISE meeting. SUN:RISE is an SHSC mental health service user engagement network where research proposals are regularly discussed. It is open to anyone with an interest in Sheffield's mental health services and comprises regular attendees who know each other well, people who attend less frequently and others coming for the first time. The majority are current or previous users of SHSC mental health service users. No specific eligibility criteria were applied for involvement in this group discussion and demographic data was not collected.

The event consisted of an introduction to the researchers, the content and format of the involvement activity. This was followed by a facilitated discussion focussing on three areas; 1) Proposed research questions - are they relevant and important?; How can they be improved? 2) Proposed research methods - are they appropriate, feasible and acceptable?; Would others be better? 3) Research proposal – generally. Cards with pictures of thumbs up / down / middling and associated emojis were used to gather snapshots of opinions on key discussion points.

Group 2: People who have experience of mental ill health and have experience of intentionally using this experience within mental health services.   *AND*

Group 3: Colleagues of people who have intentionally used their experience of mental ill health within mental health services, who may or may not have had mental ill health themselves.

Bespoke events were organised for groups two and three that were very similar, but run separately to enable people to speak more openly. In addition to meeting the group criteria stated above, people attending needed to be over 18, speak English fluently, self-define as mentally stable and not currently receiving any crisis care (hospital or community based).

Events for groups two and three started with an introduction to the researchers, the content and format of the event (including written consent for taking photos and using participants' comments in reports). Paper tablecloths, post it notes and pens were available and attendees encouraged to use them to record thoughts or feelings throughout the event. An introduction and "warm up" activity was carried out. This was followed by a facilitated discussion that was more in depth than for group one. It focussed on the same three areas: 1) Proposed research questions - are they relevant and important? How can they be improved?; 2) Proposed research methods - are they appropriate, feasible and acceptable? Would others be better?; 3) Research proposal – generally, who should participate and what language should be used? People were asked to rank the different proposed options for each discussion area and encouraged to suggest others.

All attendees were thanked for their participation, offered refreshments during the events and high street vouchers afterwards. They were asked if they would like to stay involved in the project and to provide anonymous feedback on the event.

Who got involved?

In order to reduce the potential to identify which individuals said what, information about who attended each group and views expressed has been aggregated as much as possible, and some details left out of this report.

Twenty-two people, fourteen women and eight men took part in these events. Each group had a similar ratio of approximately two thirds women to one third men. The age of attendees varied from being in the 18-25 age group to the 65+ age group, the majority were between the ages of 26 and 55. The vast majority of participants described their ethnicity as White British and had experienced mental ill health. People who attended groups two and three reported that their experience of working in a paid or unpaid role relating to using lived experience of mental ill health within mental health care (or alongside people who do) ranged from less than a year to 30 years+, although about half of people had five years or less experience.

What did people say?

Research topic: Strong support was voiced, across all three groups, for the importance of improving outcomes and experiences for peer workers and for carrying out research into this topic. People described the unique value of peer support to aiding other people's recovery and enhancing their health and wellbeing. They stated that peer workers can engage with people and provide support in a way that other professionals cannot and that sometimes this can be transformational to people's lives. People felt that being a peer worker was a challenging role, that they were a small, often low paid, staff group with huge expectations upon them. Being a peer worker could either be detrimental to, or enhance personal recovery for all sorts of reasons. Relationships with non-peer staff and the organisations in which they work were seen as having the potential to be difficult. Some people said that at times their employment had felt tokenistic, their experiences and skills did not always feel valued by others. Many described experiences of peer workers not having the support required to do their job, or being unsure what support is required. There was general agreement that peer support was a broad term and complex idea, meaning and incorporating lots of different things to different people in different contexts.

Potential research questions: Overall, strong support was given for the importance and relevance of proposed potential research questions.

Group one were asked whether they liked, disliked or were unsure or confused about three potential research questions:

1. How does employment as a peer support worker affect health, wellbeing and recovery?
2. What influences this?
3. How can outcomes and experiences be improved?

Six people stated they liked them, two were unsure, confused or did not express a view.

Groups two and three were asked to rank seven potential research questions by relevance and importance and / or come up other suggestions. The seven proposed were:

1. How does employment as a peer support worker affect personal health, wellbeing and recovery?
2. What are the outcomes and experiences of peer support workers?
3. What influences the outcomes and experiences of peer support workers?
4. How can peer support workers' outcomes and experiences be improved?
5. How does peer support workers' health, wellbeing and recovery influence the effectiveness of the peer support they provide?
6. Is training and employing people with mental ill health to become peer workers clinically and cost effective?
7. How does peer support workers' health, wellbeing and recovery influence organisational culture?

All potential research questions were rated either "very important" or "important" by at least two thirds of participants. Question one: "How does employment as a peer support worker affect personal health, wellbeing and recovery?" was rated "very important" or "important" by all participants. There was more variability in response to the importance of other questions, see figure 1 for detailed breakdown of responses.

Other research questions proposed by attendees were:
- What do peer supporters and those they support see as important in their relationships?
- How can organisations best support people to get the most from peer support?
- How do we increase awareness and understanding among the non-peer staff of peer workers and the importance / benefits of the role?

- Is there a time limit to being defined by your illness as a peer support worker?
- Does vulnerability increase as a result of supporting others in their recovery?
- What history of mental ill health would be most effective?

Other issues that people stated should be addressed within the research (either through proposed questions or development of new ones) were:
- Safety and security issues for peer workers
- Variability in what peer support is and can be
- Effects on whether care is personalised or medical model
- Challenges of drawing on lived experience
- Who chooses how lived experience is used
- Lack of role clarity / consistency / purpose
- How effectiveness is measured
- Addressing prejudice and stigma through the role
- "Us and them" how binary is the role?
- Role of the context and environment in which peer support is being delivered
- Support for peer workers – when does it start, what does it consist of? Is it different to that needed for other staff? Are organisations ready?
- Which outcomes do you focus on for peer workers and their recipients? Symptom reduction not necessarily appropriate? Feeling supported is important
- Very sensitive topic, could it be used against peer workers?
- Relationships with other staff
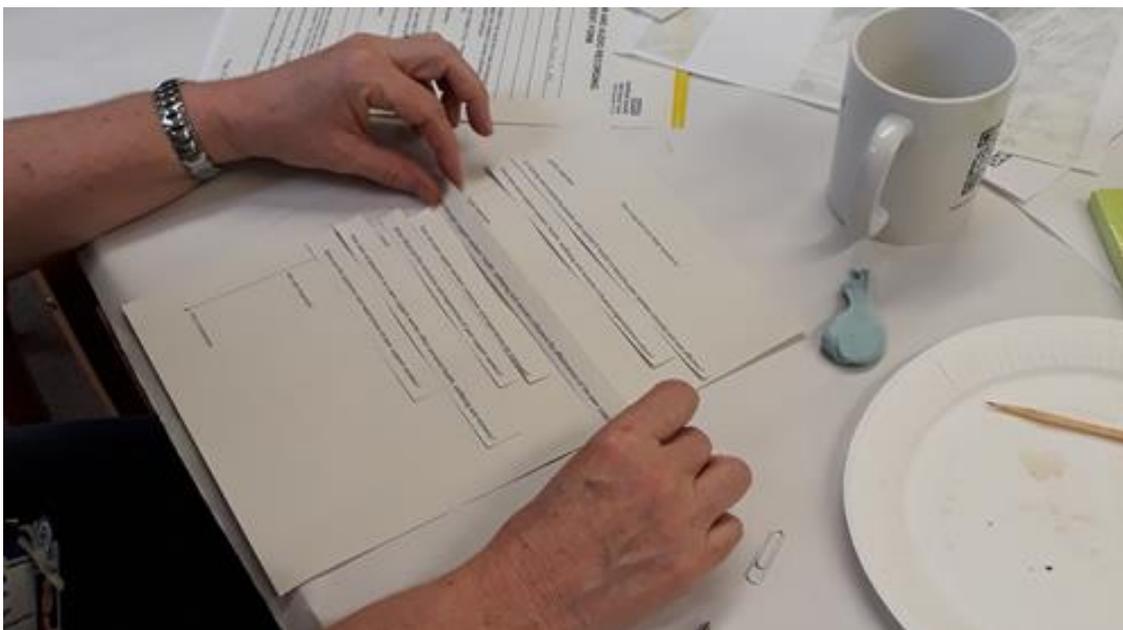
Are the proposed research methods appropriate, feasible and acceptable?

Group one were asked whether they liked, disliked or were unsure or confused about three potential research methods (which were explained):

- Case studies
- Mixed methods
- Realist evaluation

A strong preference for case studies, was voiced, with much less certainty about the other methods. Those who explained their preference for case studies stated that this was because of the need to study the topic in depth and consider the setting and environment in which peers were working.

Groups two and three were asked to rank eight potential research methods (which were explained) by appropriateness, feasibility and acceptability and / or come up other suggestions. The eight proposed methods were:

1. One to one interviews
2. Diaries
3. One off surveys
4. Repeated surveys
5. Outcome measures about health, wellbeing and recovery
6. Gathering background information
7. Small group interviews
8. Focus groups

A strong preference for qualitative methods was expressed. One to one and small group interviews were both rated as "really like" or "like" by all participants. Diaries, focus groups and gathering background information were not disliked by anyone. Surveys (one-off or repeated) and outcome measures were rated with much more variance in response. See figure 2 for detailed breakdown of responses. People provided many reasons for their preference for qualitative methods. These included the need to really listen to the voice of peer workers, which has been underrepresented in research and enable them to be more involved in directing research and practice. The need to address the complexities surrounding peer support and gain an understanding of how the context in which peer support is carried out affects outcomes and experiences for all involved. Also, the need to gather richer, deeper data that explains what is happening for peer workers and to enable more honesty than survey data might give. There was general consensus that using a combination of methods would probably be best.

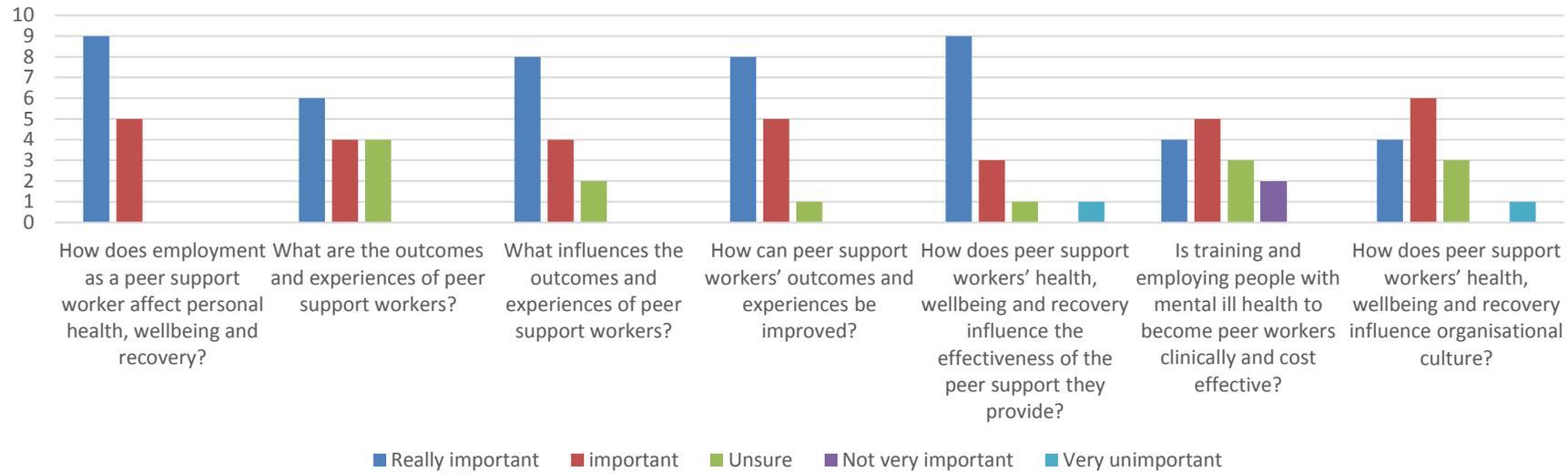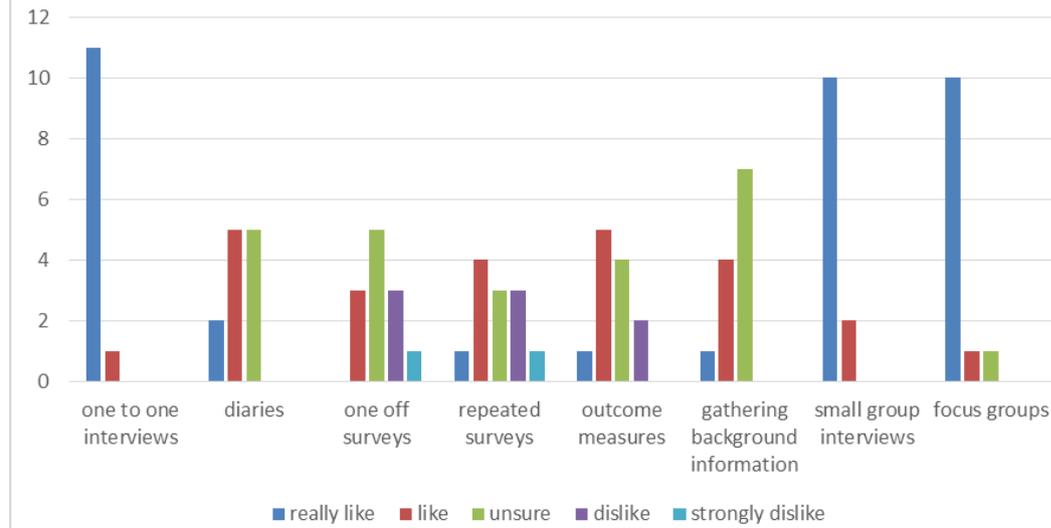Figure 1: How important are these research questions?

Categories (left to right): How does employment as a peer support worker affect personal health, wellbeing and recovery?; What are the outcomes and experiences of peer support workers?; What influences the outcomes and experiences of peer support workers?; How can peer support workers' outcomes and experiences be improved?; How does peer support workers' health, wellbeing and recovery influence the effectiveness of the peer support they provide?; Is training and employing people with mental ill health to become peer workers clinically and cost effective?; How does peer support workers' health, wellbeing and recovery influence organisational culture?

Legend: Really important, important, Unsure, Not very important, Very unimportant

Figure 2: Which research methods?

Categories (left to right): one to one interviews; diaries; one off surveys; repeated surveys; outcome measures; gathering background information; small group interviews; focus groups

Legend: really like, like, unsure, dislike, strongly dislike

Other issues that people stated should be considered in relation to the research methods were:

- Pros and cons of snapshots of experiences
- Strengths and weaknesses of relying on recall
- Potential intrusiveness and burden of different methods
- Representativeness of participants
- Topics addressed within each method as important as the actual methods
- Personal preferences as a participant may not match what is required for the research
- Quantity vs quality of data
- Importance of using empowering and participatory methods
- Consider using phones / cameras / audios for diaries
- Outcome measures could feel like assessments, but can help with self-awareness / reflection, should other staff be asked to complete them too?

**Proposed research participants:**

Groups two and three were asked to rank eight potential research participant groups (which were explained) by appropriateness, feasibility and acceptability and / or come up other suggestions. These would be approached in addition to peer support workers, who everyone agreed were essential research participants:

1. People who have previously been peer workers
2. Peer workers' organisations
3. Peer workers' managers
4. Peer workers' friends and family
5. People in other lived experience roles
6. People who have considered being peer workers
7. Service users of peer workers
8. Peer workers' colleagues

The first four of these participant groups were all rated as "like" or "really like" by at least two thirds of participants. No strong dislike of any participant groups was expressed, although there was variation in response. See figure 3 for detailed breakdown of responses. There was general consensus that multiple participant groups should be included in the research to address the complexities of the topic. Other issues that people stated should be considered in relation to the research participants approached were:

- Who you ask depends on what you're asking
- 360 degree appraisal of peer workers – explore from all angles
- Is it appropriate to ask friends and family of peer workers – differences of opinion on this.

Figure 3: Who else should we ask?
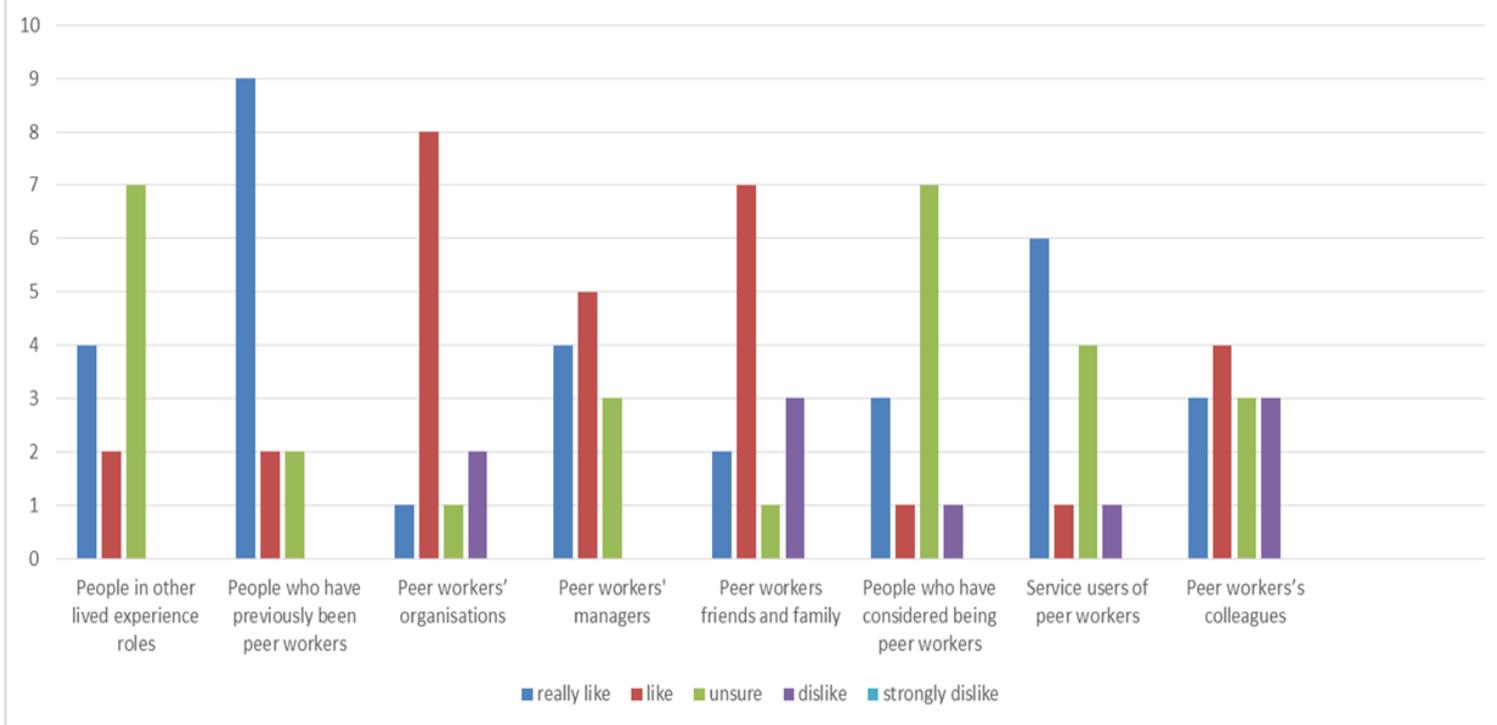
What language should be used in this proposal?

Group three were asked to consider what words they liked, disliked or felt unsure about in relation to this topic. There was variation in response. Figure 4 shows the words that were liked, with the size of the writing corresponding to the degree to which each word was liked by participants.

Figure 4: Language that should be used

Some participants were unsure about using the terms recovery, peer workers and mentors. Some disliked consumers, recipients, patients, therapeutic intervention, inspirational, stigma, cost-effectiveness, peer recovery workers and experts by experience. Some expressed that jargon and analogies should be avoided. However, as with all concepts discussed, there was agreement that the context in which these words were used would affect how appropriate they were.

How will patient and public involvement influence the development of this research proposal and be taken forward should you be awarded funding?

The views expressed at these involvement events will directly influence the development of this research proposal. They will be integrated with information gathered from other proposal development activities, a literature review, scoping of current practice and expert advice. The research proposal will address issues considered important to the end users of this research and approach them in an acceptable way.

We will continue to liaise with those who have attended these events and have expressed an interest in remaining involved. We will invite these people to review the research proposal as it develops. Should we be successful in gaining funding for this research, we will invite them to join the study advisory group and to attend further events. The focus of future events will depend on the design of the study but is likely to include more concrete development of the research paperwork and procedures, reflections on emerging findings and results of the study. Funding to facilitate this work would be sought as part of the HEE / NIHR grant.

Evaluation

Feedback from attendees:

All attendees were invited to feedback on these events. This was largely, but not entirely, positive, with the following comments received:

- Really good, thank you
- Very well organised, a credit!
- Felt safe, valued and relaxed
- The pathway and plans were made clear!
- For me, personally it would have been easier to be solely with other peer workers, often there is some level of debate which leaves me feeling a bit unsure about what I do
- Excellent
- Good engaging presentation
- It was fine
- Good questions
- Would be improved if had questions prior to event, a little more time for group discussions
- Good that asking questions from the peer worker perspective
- Getting it right for peer workers will have knock on effect for service users
- Not sure I totally understood the questions – very academic / research focussed which I struggle with as not familiar with this language
- Good atmosphere and friendly
- Good food and tea
- Very helpful

People who attended groups two and three were asked to complete a formal evaluation form, consisting of six questions:

1. Overall, the research ideas presented were good?
2. Did you feel able to contribute your ideas about the research?
3. Did you feel your ideas were listened to?
4. Did you feel your views were valued?
5. Did you enjoy the experience of assisting the researcher with their research?
6. Did the researcher tell you how they would use your input in their grant application?

Overall the feedback was positive. All stated "yes" to question 6, "Did the researcher tell you how they would use your input in their grant application?" All agreed or strongly agreed that the

research ideas presented were good, that their ideas had been listened to and they had felt valued. All but one person agreed or strongly agreed that they were able to contribute their ideas to the research and that they enjoyed their experience of the events. See figure 5 for detailed breakdown of responses.

Figure 5: Evaluation
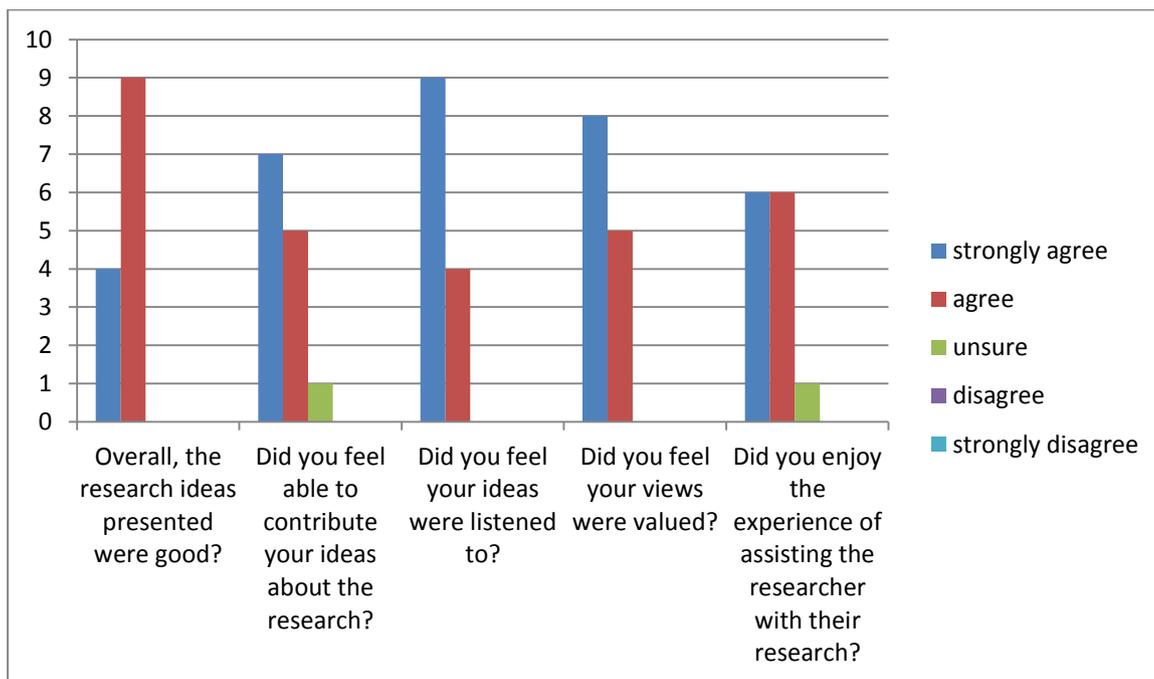
Our evaluation:

We really enjoyed the events and are grateful to everyone who attended and gave their time, thoughts and contributions to developing the research project. Ideally we would have liked more time to really listen to all the attendee's views on all the topics. In some groups we ran out of time to discuss some issues we hoped to cover and all groups would have benefitted from more time for more in depth discussions.

In this report, we have quantified the ranking of different proposed aspects of the research proposal to make it easier to follow. However, this somewhat oversimplifies people's opinions, it does not reflect ranking within each category of response, nor the nuances or complexities of what was expressed. We hope our detailed notes will ensure this more qualitative information will be incorporated into the development of the research proposal.

Appendix 1: How the funding was spent

£20 high street vouchers were offered to all twenty two participants. Thirteen people chose to receive these. Refreshments were provided for all potential attendees at all events, approximately forty people across the three events, including the facilitators. To fit in with the shorter session and existing structure of SUN:RISE, this was snacks only for group one (up to twenty people expected), but lunch and hot and cold drinks for groups two and three (up to twelve people in each expected).

High street vouchers to participants 13 x £20 plus postage	£266.50
Refreshments	£160.93
Total	£427.43