Developing a collaborative research strategy: Report of an event held at The McPin Foundation in June 2013

About this report

The McPin Foundation started work as a mental health research organisation in April 2013. The organisation’s ethos is centred around the importance of collaborative, high quality research, where lived experience plays a vital and valued role in shaping, conducting and communicating research.

For the McPin Foundation to develop, it is important that we are guided by people who have lived experience of mental illness as part of their expertise; experience gained by personal experience of mental health problems or as family members or carers. In June 2013, we invited a range of people with personal experience of mental health problems who have been actively engaged in mental health research in some way to meet us and tell us what they thought we should do to deliver on our goals. We plan to hold a separate session with families and carers. That event sparked a vast mix of ideas and suggestions, both for how we as an organisation should work, and how we can contribute to the wider sector of user-led and collaborative research.

Two messages in particular came across loud and clear: truly listen and take our suggestions on board; and tell us what you plan to do about it.

This report comes out of what we heard on that day, and considerable thought and discussion as an organisation about how we should move forward. The McPin Foundation is ambitious in its goals and wants to work with those who gave us their time and shared their experiences and views with us to achieve better impact from mental health research.

At the same time, we have to be realistic. As a small and new charity, we cannot do everything at once. Some things may be quick and straightforward to start, others may take years to develop or may require funding that can take time to find. Equally, some of the suggestions made to us might be better taken up elsewhere or may already be underway in another organisation.

In this report, we have done our best to record all the suggestions that we heard at the event. They reflect the diversity of experiences and priorities of those who attended. From these, we have indicated the way that we propose to take this work forward. Where possible, we have given timescales for this work so that those who are interested can hold us to account. Where we do not feel that we can take suggestions forward right now, we have tried to explain why, and maybe others will be in a better position to pick these up in the short-term.
This report will form the basis of a business plan for the McPin Foundation which will be developed over the coming months. We hope that it will also make interesting reading for anyone engaged in collaborative research and for the many people that we hope will work with us in the future.
About the event

The event was held in London on 20th June, 2013 and 28 people attended.

Attendees brought a wealth of experience and skills having worked across a wide range of organisations and projects. All attendees had personal experience of using mental health services or living with a mental health diagnosis. As well as having taken active part in a range of research, participants were also active as trainers, advocates, peer support workers, writers and activists.

The event was chaired by Emma Harding, a trustee of the McPin Foundation, and herself an experienced researcher with personal experience of psychosis. In the morning, participants were split into three groups and were asked to discuss one of three questions:

1. What are the key challenges for peer researchers working in mental health research – and how might they be overcome?
2. What should the McPin Foundation contribution be to the research agenda? What do you want us to achieve?
3. What are your research priorities for mental health research commissioners – where are the gaps in research?

Following shared feedback from this session, in the afternoon we held a World Café style workshop, in which participants were encouraged to wander between a range of group discussions that were of interest to them. The topics of these were:

1. How should we promote & communicate peer research? What information would you like to see on the website promoting peer research? What types of ‘news’ would you like to see in the McPin newsletter?
2. Should the McPin Foundation facilitate peer involvement by reviewing other researchers’ studies?
3. What support is needed/ helpful and what is lacking for peer researchers?
4. Who should we seek to partner & collaborate with to deliver our ambitions?
5. What matters most to feeling valued as a peer researcher?

The day provided us with a great deal of food for thought and guidance. Feedback from the event is provided in summary in the appendix to this report.
About terminology

We were challenged at the event about our terminology. In particular we were asked to explain:

- What do you mean by user focussed mental health research?
- Why do you use the term mental illness?

The first definition is important. We see user focussed research as a collaborative partnership involving people affected by mental health problems and others in the field of mental health research. Some user focussed research will be user-led, but not all. The important criteria for us is that research beneficiaries are involved in shaping the research at every stage from research design, data collection through to dissemination.

The McPin Foundation has not yet chosen particular terms to describe two important dimensions of its work. First, we talk about mental health problems and mental illness. Our work with young people also talks about mental distress and emotional health problems. We recognise there are strong opinions over which term to use and in this report we use the term mental health problems.

A second term that is proving hard to find is a way to describe the researchers we work with who use personal experience of mental health problems alongside their research skills. Service user researchers, peer researchers, lived experience researchers are all used by different groups in the sector. In this report we do not use a preferred term.
Theme one: Shaping the work and research of the McPin Foundation

Key points:
- The voice of people with experience of mental health problems should be more visible in all McPin’s communication, particularly its on-line presence.
- McPin’s own research priorities should be driven by suggestions from people with experience of mental health problems.
- McPin must be transparent in its decision-making, and show how and when decisions have been influenced by people with experience of mental health problems.
- McPin has a role in conducting user-led research and should look to grow to ensure that the skills and experience exists in the team to lead this work.
- The research undertaken by the McPin Foundation should help to develop and disseminate new models of working and best practice principles.
Developing a more collaborative voice
Currently, the McPin Foundation team has not been recruited for lived experience expertise. As a result, the work it has undertaken has been collaborative, but not user-led. Participants at the event commented that this meant the website had an ‘us and them’ feel by prioritising the ‘professional’ researchers over those people who brought lived experience to the research.

The McPin Foundation intends to expand to create a new programme of work, picking up the suggestions and strategies in this document. We will recruit an experienced researcher with lived experience of mental health problems to lead this programme of work. We aim to have this programme set-up from January 2014. As funding permits, we hope to expand the team to include more people who bring this particular expertise.

As our most public face, it is important that the content of our website reflects our claim to be a collaborative organisation. Participants at the event suggested various ways that we could open this up to include content written by, or approved by, people with experience of mental illness.

The McPin Foundation will, in the short term, look for people with lived experience of mental health problems to contribute content to our website. Already, we have approached a number of the people we currently work with to write blogs sharing their own views about this work. We would like to encourage regular guest blogs from people working in collaborative and user-led research, whether with the McPin Foundation or elsewhere. We would also like this to be an opportunity to debate important issues and to highlight that there is no single ‘service user voice’. We may, for example, invite people to express their personal view on topics where there is disagreement, for example use of terminology or taking pharmaceutical funding for research.

The blog is only one place where people can bring their lived experience perspective to our online communication. We would like to encourage people to contribute to our twitter and facebook accounts and our quarterly newsletter.

We have already begun to ask for feedback on information that is added to the website. In the medium-term, we would like to develop a group of people who would review and approve content before it is added to the webpages.
Widening our own pool of partners

Participants at the event pointed out that it was often the same people who got involved in mental health research projects, and that they may not be typical of people with experience of mental health problems in general. Finding ways to involve a wider range of people was seen as crucial. This was reflected in the day itself which was attended by a majority white and female group. This was recognised as a wider problem in the sector as a whole, but the challenge is posed to the McPin Foundation to reach out to other groups.

The McPin Foundation strongly supports this aim and will look to review its recruitment of researchers. This applies across our practice, from communication and language to choice of partner organisations. It may take some time to build up our networks and practice to facilitate this.

This challenge also feeds into a broader goal of developing a ‘career pathway’ for lived experience researchers, to ensure that there are opportunities for people to get involved at different levels – this is discussed further under Theme two.

Identifying priority areas for research

Participants generally agreed that involvement currently tends to happen after a research topic has been decided and often after a project has been developed and funded. People recognised that the ability of researchers to choose topics was often limited by available funding. There was, however, general agreement that there should be more user involvement in setting research priorities. Participants discussed the possibility of a Delphi study, where a consensus is sought for important research topics. While some liked this idea, others warned that consensus approaches could lead to important minority issues being neglected. Other forms of survey were also discussed.

One of the group discussions focused specifically on priorities for research. The following were raised as important topics and methods for future collaborative and user-led research:

Research methods and approaches

- Qualitative research is important and needs to be given more emphasis as a way to capture learning from lived experience
- Influencing Randomised Controlled Trials and quantitative studies with lived experience should also be a priority
- Influencing and developing outcome measures with lived experience perspective
- There should be a focus on research based on social models, not just medical models
- Need to evidence the benefits of co-production to commissioners and services
- Research needs to address economics if it is going to influence practice
- Need to collaborate more with physical health organisations to achieve greater parity across these areas
- Focus on ‘emotional health’ rather than ‘mental illness’
- Disseminate information more widely than in journal articles – ensure that it is accessible to the public, and particularly to people affected by it.
Research topics

- Creativity and recovery
- The impact of the “mental illness” label
- Sexual dysfunction as a side effect of medication
- Weight gain as a side effect of medication
- Managing mental health in the workplace
- Diagnostic overshadowing
- Impact of recovery-focused interventions, e.g. use of Wellness Recovery Action Plan
- Impact of peer-led support groups
- Experience / impact of first point of contact for mental health
- Diversity and access to services
- Diversity and stigma/discrimination experiences
- Impact of social support networks (not mental health specific networks)
- Access to IAPT
- Withdrawal from medication
- Boundaries and use of disclosure as mental health professionals
- The use of Peer Support Workers in the delivery of MH services and their efficacy

Discussions highlighted the diversity of interests and topics that the McPin Foundation and other researchers could pursue. All ideas will need to be tested by reviewing what is already known, what work is currently underway and feasibility. These give us a useful starting point, however.

The McPin Foundation is currently looking into possibilities for conducting and publishing a set of priority research questions for mental health which have come from people with lived experience of mental health problems. In doing this, we need to be aware of what other organisations are doing in this area currently, and to work with them where possible.

For our own work, we will, in the short-term, identify effective ways to gather people’s views about research projects we might initiate and undertake ourselves, subject to available funding. This may involve on-line polls or other mechanisms for feedback.
Steering our own practice
The McPin Foundation is always looking to involve people with lived experience in specific projects that it delivers. In more general terms, a lived experience perspective should be more embedded in the work that we do. This would allow collaboration at earlier stages in potential projects, and also advise us in our everyday, rather than project specific, practice.

In the short term we aim to set up a user-led programme of work which will make recommendations and contribute to shaping all our practices. We will consider setting up a specific committee as part of the planned user-led programme. We agree that this is an important aspect of ways of working, and will be considering solutions that ensure we have genuine impact.

Hosting and supporting user-led research
The work currently undertaken at the McPin Foundation is collaborative but not user-led. Participants at the event also wanted McPin to host user-led research.

The McPin Foundation is committed to supporting user-led research, alongside the collaborative work it currently conducts and aims to develop. As part of the new programme of work, we would like to help establish user-led research projects. We will start to seek funding and identify opportunities for this in the short to medium term.

Developing and disseminating new models of collaborative research
Our collaborative work provides an opportunity for us to develop and try out models of working with people with lived experience to carry out research projects. These models can be published and disseminated to others to learn from. Participants at the event felt that the McPin Foundation had a role in disseminating best practice, both from our own learning and from across other organisations. There are already several other organisations that also seek to do this.

Participants had a number of suggestions for different models of collaborative research that could be useful. One example was to address the power imbalance in research projects by having a lived experience researcher as Principle Investigator, or having a user-led project with a clinician advisory group in a reversal of the standard model.

In the short term, the McPin Foundation will look to publish reports, presentations and journal papers describing and evaluating our own approaches. In the medium term, we will look into the possibility of collating and publishing examples of best practice and tools for assessing lived experience involvement (see Theme two).
Theme two: Building capacity for user-led and user-focused research

Key points:

- The McPin Foundation must be committed to supporting the work of existing user-led research organisations, not attempt to divert work away from them. The McPin Foundation could have a role in providing resources and promoting the work of such organisations.
- The McPin Foundation could support the development of a ‘career path’ for lived experience researchers, providing support and training opportunities for people who are getting involved in research for the first time, through to PhD study and professional roles.
- Participants at the event felt that there was scope for additional networking for lived experience researchers, especially for those working independently or who hold dedicated lived experience roles in wider organisations.
- Participants felt that the McPin Foundation could provide a useful linking service for research organisations looking to identify lived experience researchers with specific skills.
- It would be useful to do further mapping of the sector, identifying organisations and individuals who are heavily involved in user-led and user-focused research.
Supporting and promoting the work of existing user-led organisations

The event was attended by people who have connections with a wide range of existing organisations that conduct user-led research or provide advice and support to mental health researchers. Among those mentioned at the event were FAST-R (a reviewing service for mental health research proposals, based at the Mental Health Research Network); SURF (Service User Research Forum); SURG (Service User Reference Group); SURE (Service User Research Enterprise); INVOLVE and many, many small, local groups.

The McPin Foundation completely supports the need to promote and support existing groups, and not to attempt to divert resources away from them. The suggestions listed here, which came from participants at the event, are intended to promote and link with these groups. Where suggestions look to engage people beyond our own projects and ventures, we will always look to scope existing work before proceeding with something new. Where possible, we hope to collaborate with existing groups as well as individual lived experience researchers. It is a core principle at McPin Foundation that we are about building capacity, adding to and not deflecting from the work of other collaborative mental health research organisations and groups.

Supporting a lived-experience researcher career path

Participants at the event had a wide range of experience and roles in mental health research. We heard from many that it could be difficult to find opportunities to create a career path which allowed them to develop their own skills and to take on more senior and influential roles within research. Equally, we heard that people may find it difficult to first get involved in research and could benefit from support and training to develop skills and confidence. Opportunities should ideally be available for people with various skills to get involved in research. Specific ideas for areas of training that were raised at the event were:

- Doing ‘peer’ research
- Research methods
- Assertiveness and confidence
- Role boundaries/ professional boundaries
- Managing own mental health
- Appropriate disclosure
- Research terms and definitions
- Writing research proposals

The McPin Foundation has already started to talk with other organisations about increasing capacity for skills and career development at all stages.

In the short-term, the McPin Foundation plans to establish, in collaboration with others hopefully, a number of PhD studentships designated for service user researchers who plan to use a lived-experience perspective in their PhD research. These fellowships would require universities to demonstrate their capacity to support such work. We also intend to establish a peer support network for these PhD students.
In the medium-term, we are looking at how to improve access to training and development for less experienced researchers. We plan to scope out existing training and opportunities and to provide a hub where people can search these opportunities. We will look at current gaps and ways in which the McPin Foundation – perhaps in collaboration with others – may be able to develop and deliver training to meet identified gaps.

**Facilitating lived-experience research networks**
A number of extensive networks already exist, particularly those centred around particular organisations and local groups. Participants did feel that there was further scope for networking, especially for lived-experience researchers working independently or embedded in wider organisations which are not user-led. Such a network could provide a range of benefits for lived experience researchers, including peer support, skills sharing and buddying-up between new and more experienced researchers. An online forum could also provide opportunities to discuss, share ideas and establish collaborations. The network would also be valuable for the McPin Foundation and other research organisations as a place to identify people to work with on specific projects.

The McPin Foundation will, in the medium term, do some scoping work to identify:

A) What networks already exist and who uses them  
B) Who would be interested in a new network of lived-experience researchers, and  
C) What function(s) would people like such a network to perform

Depending on the outcome of the scoping work, The McPin Foundation will look to see whether it is able to host or support such a network. It would most likely be an online network to reach across England.

**Providing a skills-matching service**
Participants felt that the McPin Foundation could provide a useful service in matching lived-experience researchers with a wide range of skills to other researchers looking to collaborate on projects. A number of people at the event work on a range of projects with different organisations and are reliant on finding out about suitable opportunities through existing contacts and networks. Some felt that the McPin Foundation could hold information about independently working lived-experience researchers and enable other researchers and organisations to approach McPin to find suitable collaborators. This could provide benefits both to the lived-experience researchers in finding out about more opportunities, and to other researchers in easily identifying people with the relevant skills for the role. This is particularly important in relation to the McPin Foundation’s efforts to encourage more researchers to engage effectively with lived-experience research.

The McPin Foundation will, again, scope out demand for such a service, both among lived-experience researchers and the wider mental health research community. We also need to ascertain how such a service would be maintained and what the McPin Foundation’s responsibility would be after having linked up research collaborators. If the result of the scoping supports the idea of the McPin Foundation establishing such a service, this would be a medium-term ambition. If it is better held elsewhere, we would encourage that development.
Mapping the sector
The participants at the event had a wide range of experience and involvement with various organisations, including user-led organisations, charities, universities and NHS Trusts. Discussions highlighted that user involvement in research is happening to a greater or lesser extent across diverse parts of the mental health research world. It was suggested that the McPin Foundation could usefully map the work that is currently going on to provide a better overview of who is doing collaborative mental health research, how much is going on, and how far it is concentrated in specific organisations or areas. This mapping would allow us to identify centres of excellence and flag up where more support is needed to get lived-experience embedded into mental health research.

The McPin Foundation believes that this is an important piece of work, particularly in light of recent or upcoming changes in the sector. Researchers at the McPin Foundation have research specialisms in mapping networks and connections and these could be used to develop a helpful resource. This mapping could also be a valuable starting point for scoping out the appetite for some of the other suggestions included in this document. However, a thorough mapping will require time and resource which needs to be identified before such work could start.

In the short-term, the McPin Foundation will look to identify funding opportunities to support a mapping of the sector. This would itself be a collaborative piece of work.
Theme three: Influencing others

Key points:
- Participants felt that there was a need to raise the profile and standing of user-led and collaborative research.
- The McPin Foundation could have a valuable role in reaching out to clinicians, academics and other researchers to promote collaborative research and improve practice. Producing or collating tools and resources could be a valuable way to do this. A key group to target is trainee clinicians and researchers, including PhD students, to bring effective collaborative work into early career research and train up senior researchers of the future.
- There is a need to influence the wider structures within which collaborative research takes place, including the NHS, the Department for Work and Pensions, ethics committees, research funders and journal editors.
- Public and patient involvement in research is still, in some areas, seen to be a tick-box exercise. Kite marks and tools for assessing quality of involvement could help research commissioners and journal editors to identify meaningful PPI.
Influencing research practice
Participants had had a wide range of experiences with research projects; some extremely good and others very poor. People highlighted the need to provide researchers with training and resources to help them to improve their working practices in collaborative research. There is also a need to help those researchers who are not yet engaged in collaborative research to commit to engaging with people with lived experience in their work. Some of the areas mentioned as needing additional training include:

- Recognising the value of doing collaborative research
- Putting in place reasonable adjustments
- Providing good supervision and support for peer researchers
- Using lay language in research
- Basic mental health awareness
- Managing role boundaries (particularly for clinical researchers managing the difference between a clinical relationship and a colleague relationship)
- Sensitive listening skills and being open to challenge
- Measuring impact of collaborative research
- Ensuring that peer researchers get something valuable from the work

The McPin Foundation could help to provide this support for researchers through a combination of training and developing tools and guidance for researchers. In particular, participants mentioned bringing this into training for PhD students, perhaps as an online training module.

The McPin Foundation agrees that there could be a valuable role here. As with many of the suggestions above, the first step for this work needs to be to ascertain what is already available for researchers. In the short term, The McPin Foundation could look to identify and collate existing toolkits and resources and provide a portal on its website to direct people to these. The development of specific training and toolkits would require further resource, and the McPin Foundation will look at how these resources could be found.

Influencing wider structures of research
Several specific groups were identified by participants as key targets for training and influence:

- The NHS – particularly in relation to Agenda for Change, in which employed peer researchers struggle to have their skill level and contribution recognised in the structure pay and reward scheme;
- The Department of Work and Pensions – particularly around managing ad hoc and temporary pay usually involved in research work, and recognising that paid involvement in research should be possible for people on ESA without threatening their benefits;
- NHS ethics committees – these vary considerably in their understanding and support for peer research. There remain some concerns that ethics committees can act as a barrier to collaborative research because of the perception of peer researchers as vulnerable;
- Research funders – again vary considerably in their commitment to PPI in research, but there is seen to be a need to influence the reviewing of proposals and the assessment of meaningful PPI to prevent this from becoming a tick-box exercise;
• Journal editors – just as qualitative research has in the past been seen to be dismissed or treated as less valuable by some journals, so participants felt that user-led and collaborative research is not given adequate space in journals.

Influencing these groups was seen as a role that the McPin Foundation could take on, in support of other user-led and user-involvement organisations. The means of influencing these groups might be quite different, and may include developing training and resources, direct communication with policy-makers, and public campaigning. It would also involve keeping abreast of changes in the research landscape that could affect collaborative research, e.g. changes in benefits legislation.

The McPin Foundation agrees that there is a potential gap here in influencing these wider structures and the benefits to lived experience researchers that could be achieved. This type of campaigning and influencing role is not one that the McPin Foundation has taken on previously, but is an area in which we may seek to develop in the future.

In the short-term, we will look to open new channels of feedback to collect and evidence areas of priority for lived experience researchers. This links to the proposals discussed under theme 1, and may include regular polling or web-based surveys. We hope that this will provide us with a platform from which to make decisions about the most important groups to influence and appropriate ways to do so.

**Developing standards for collaborative research**

Participants told us that an important way to drive up quality for collaborative research is to develop means of assessing and quality approving approaches and projects. This may involve establishing agreed criteria for good quality collaborative research, or publicly recognising best practice.

The McPin Foundation feels that this should be a longer-term ambition, since it relies on credibility and profile of such a standard. This may be something that could come out of our work around developing/promoting toolkits and providing training.
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<thead>
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<th>Ambition</th>
<th>Dependent on...</th>
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<tr>
<td><strong>Short-term plans (begun within the next 6 months)</strong></td>
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<td>Shaping Our Work</td>
<td>Establish funded programme of peer-led work. Recruiting a lived experience Research Manager.</td>
<td>Internal commitment of resources</td>
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<td>Shaping Our Work</td>
<td>Establish group of people with lived experience to review and comment on web-content on an on-going basis.</td>
<td>Interest from volunteers</td>
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<tr>
<td>Shaping Our Work</td>
<td>Invite contribution to website from people with lived experience, particularly through blogging</td>
<td>Interest from volunteers</td>
</tr>
<tr>
<td>Shaping Our Work</td>
<td>Start to proactively build contact with people interested in getting involved in collaborative research to widen pool of engagement</td>
<td>Internal commitment of resources</td>
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<tr>
<td>Shaping Our Work</td>
<td>Conduct research prioritisation exercise, either independently or in conjunction with other organisations currently interested in this work</td>
<td>Discussions with other organisations considering this exercise; internal commitment of resources</td>
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<tr>
<td>Shaping Our Work</td>
<td>Establish methods for gathering views on and contributions to new research project ideas</td>
<td>New peer led work programme</td>
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<td>Shaping Our Work</td>
<td>Begin to produce reports and models based on collaborative research undertaken by the McPin Foundation</td>
<td>Internal commitment of resources</td>
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<tr>
<td>Building capacity</td>
<td>Collaborate with other organisations to establish a number of PhD studentships for lived experience researchers</td>
<td>Commitment of internal and external resources</td>
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<td>Building capacity</td>
<td>Mapping the peer research sector</td>
<td>Internal commitment of resources</td>
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<tr>
<td>Influencing others</td>
<td>Establish mechanisms for two-way communication with peer researchers to gather evidence and views on key influencing priorities</td>
<td>New peer led work programme</td>
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<td><strong>Medium-term plans (begun within the next 6-18 months)</strong></td>
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<tr>
<td>Shaping our work</td>
<td>Aim to develop a range of peer research roles in future project proposals to allow participation at various skills and experience levels</td>
<td>Opportunities for developing new project plans</td>
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<tr>
<td>Shaping our work</td>
<td>Develop effective mechanisms for people with experience of mental illness to review and influence our work</td>
<td>Internal and external consultation</td>
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<td>Building capacity</td>
<td>Seek funding for user-led research</td>
<td>External resources; establishment of peer-led programme to lead on these proposals</td>
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<td>Building capacity</td>
<td>Providing opportunities for other user-led and collaborative research organisations to promote their work through us, including seeking out best-practice examples</td>
<td>Collaboration with other organisations; establishing an effective communication network</td>
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<td>Building capacity</td>
<td>Scope out existing training and resources to support peer-researchers; collate resources for easy access; identify gaps</td>
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<tr>
<td>Building capacity</td>
<td>Consult with wider peer research community about need for, and purpose of, a new network</td>
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<td>Scope out existing training and resources for other professional researchers; collate resources for easy access; identify gaps</td>
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**Long-term plans (begun within the next 18-36 months)**

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<tr>
<td>Influencing others</td>
<td>Develop capacity for influencing work, through internal skills development or recruitment; develop plans for influencing key target audiences</td>
<td>Internal commitment of resources; outcome of consultation with peer researchers</td>
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<tr>
<td>Influencing others</td>
<td>Develop quality standards for collaborative research, probably in partnership with others</td>
<td>Agreed need and usefulness of such a scheme</td>
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Appendix 1: Feedback from the event

The McPin Foundation is keen to learn and reflect from current practices in order to grow and develop expertise. Key to our development will be being transparent, and open to feedback. On this basis, below is a complete collation of feedback from the event held.

What would you like us to do to “transform” mental health research?

We welcome your feedback on today’s event. We have a few questions below to help us understand how you felt about the day and how you would like to engage with us going forward.

For each of the statements below please tick next to the corresponding answer that best describes how you felt:

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<th>Disagree</th>
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<tr>
<td>The venue was comfortable and appropriate for the event</td>
<td>7</td>
<td>15</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>I have been able to put my views across and engage in the discussions</td>
<td>16</td>
<td>8</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have been heard and the points I made were listened to by the group</td>
<td>16</td>
<td>7</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The day was interesting and worth attending</td>
<td>19</td>
<td>5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I know what will happen next with the material discussed today and how I can stay engaged with the McPin Foundation if I want to</td>
<td>10</td>
<td>11</td>
<td>2</td>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>

General comments about the day:

- I found the background air conditioning noise difficult
- The meeting rooms felt ‘underground’, due to going downstairs and lack of natural light. The lighting wasn’t great for me
- I very much felt listened to and very much valued
- Too hot and muggy
- Fluorescent lights gave me problems
• Constant noise
• I am very pleased to hear your ethos is so similar to mine. I am looking forward to working with you. I believe McPin and Vanessa have a good attitude towards partnership working and peer led research. McPin can go far.
• Only downside is the room was too hot
• The day was full of optimism but also grounded in pulling together ideas to form collective action plan
• Very well organised, nice atmosphere. Only bad thing was some rather noisy air conditioning
• Very enjoyable day. I love the McPin ethos
• Room too hot in the morning and too cold in the afternoon
• Well organised day – very happy to be a part of it
• Very interesting and productive
• Very friendly with a good atmosphere of collaboration. Loads of good ideas – impressive
• Difficult to get into rounded discussion in short time in afternoon
• Thank you for the invitation to be involved
• I found it very interesting to meet so many “peers” with so much experience and really hope that the McPin Foundation will thrive and prosper, and that I will be involved
• I hope things have been taken on board – the proof will come in terms of what actually happens next
• There were a lot of strong and meaningful discussions targeted to the specific questions and based on this I feel McPin will make a really important contribution to SU involvement. McPin will make an example of best practice
• Warm welcome very much appreciated
• Valued the fact that there was a strong user emphasis throughout the day
• Excellent idea to use service users right from the beginning in shaping the development of the McPin Foundation
• Hopefully you will lead by example and others will follow
• People needed to be more receptive to the theoretical ideas – to inform the practical ones.
• Felt somewhat marginalised
• Apart from my own feelings of discomfort, I found the day was interesting, useful and that every effort was made to ensure that we were made to feel welcomed and listened to.
• Really enjoyed the day, thank you. A very wide mix of people, a very friendly atmosphere, and very positive and enlightening discussions
• Great event, great energy and drive. High hopes for this venture! McPin could be exactly what we need!
• I found the day very interesting and stimulating. It is always good to have the chance to meet and interact with other researchers with lived experience. I am hopeful that McPin will develop into an organisation that will really be able to promote and support the increase of service user led and collaborative research. Also to promote the real value of what we can offer – i.e. our lived experience.
• Will McPin see part of its role as a campaigning organisation?
• So much useful stuff has been shared. It is unclear to me how much ownership we retain about this. Will it all be given back to us? Write up of the day should be emailed out to all of us.
• The main meeting room is a bit claustrophobic
Please use the space below to write any further comments you would like to share with us that you have not been able to say today or you would like to say again to us, particularly regarding your views on what you would like the McPin Foundation to achieve and how we can best make mental health peer research flourish.

- Action based research – e.g. introduce new recovery programme/ network
- Look at economic costs of implementing recovery programme/ group to show cost benefit of approach
  - NHS listens to money, not us (i.e. not just the benefits to us)!!
- Please keep us up to date with progress even if no progress
- It would be good to have some of us group together to form research projects for potential funding and more forward i.e. some research ideas from today to think in more detail and develop, get funding and conduct.
- Carers/ supporters often have very different views to those struggling with emotional health and can cause difficult team work. If service user led then maybe only one or two carers and vice versa if carer led
- How do we include those who have no research experience and who are still struggling/ lack confidence?
- Being a peer researcher has helped me and it can help others. Getting new people on board is essential and helps us grounded to what is happening in the row??!
- I think supporting the move away from the clinical and medical model of psychology is a fantastic idea
- I would like to see some research about therapies other than CBT e.g. A.C.T, mindfulness etc.
- Research into support groups and their use. Try people who don’t (after using time) even enter secondary MH services
- Need for user input into research ethics process (?) – not now appropriate for mental health research?
- I think McPin could make a real different by tackling attitudes to peer involvement at undergraduate level and above by working with universities – these are the researchers of tomorrow.
- I hope the McPin foundation can look into the problem of compliance and benefits – the fact that recovery can be held back because people fear losing benefits if they get well, and thus not being able to survive financially (physically), and becoming unwell again due to the stress
- Research should (in my opinion) be focused on prevention and treatment. There should be emphasis on investigation into over-use of long-term medication and on alternative forms of treatment
- Research on smoking 0 the importance of lifestyle in recovery. Alternative methods of treatment – CBT for example, rather than medication. Mindfulness Resilience. Fostering skills to improve recovery – concentrating on developing a strong sense of self.
- I would love to become a researcher and would love to be paid – I would appreciate training too, I want to be a professional, not a “professional service user”. I want to help think it is really important to show people by example that there is hope for recovery – but I also need recognition for my contribution
• Keep in touch – not just with your newsletters but piggyback on to other people’s e.g. NSUN weekly bulletin is a good way to get to a lot of people who use services.
• Use smaller localised service user groups as a good source
• Use the resource you have had in the room today
• Payment for work should be the norm, but be mindful of benefits issues – sometimes negotiating a contract with a group may avoid the issue of turning down payment which also could affect benefits (i.e. no named individuals other than one happy to be paid).
• Put results of research on website to engage with people accessing the website
• Make website a platform for communication not a stagnant rigid site (Twitter, Facebook, LinkedIn)
• It is good to hear and understand McPin will use our skills as SU’s to shape the organisation
• Clarity of website and how our involvement makes a difference
• Monetary value needs to be proper research/ equal to others
• Please don’t forget to communicate back to all participants of the workshop
• A ‘Kite Mark’ award to reward researchers on a regular basis, for using SU’s (?)
• Would be great if McPin could now make a strong drive to increase input from people with lived experience who belong to marginalised communities (BME, LGBP etc).
• The group today perhaps had rather more people from majority communities and it would be great to get this majority focus changes now before any problem emerges, i.e. to increase the balance of majority and minority communities consulted by McPin nd involved in it.
• Would be good to see representation of activists from marginalised communities amongst McPin staff and trustees too.
• Speak up at the beginning – we couldn’t hear in the back row
• Highlight the ‘ground rule’ that if people want to speak they should raise their hand – this prevents all the sessions being dominated by louder, more confident members of the group
• Your website should contain a database of all current research in the area for people who would like to be involved
• Disseminate monthly reports on all peer researcher involvement
• Be understanding, flexible and most of all be unafraid to make mistakes in terms of language etc
• Very well done for the day, it has been very enjoyable and I have glad to have a chance to get our opinions voiced.
• Examine social models of disability – research this field
• Examine empowerment model of disability – research this field
• Layers of oppression/ dissemination experience by peers – all in an attempt to measure ‘recovery’
• Is there are way to figure out relative amounts of individuals involved today, or in peer-research with a) depression, b) bipolar, c) etc?
  o Negative symptoms of psychosis are some of the least well-treated; need to know more (e.g. depression, social functioning etc)
  o Much more survey-type research into prevalence of various psychological stressors among those with depression/ anxiety/ psychosis etc (e.g. early
childhood adversity, bullying, traumas, social isolation, family conflicts etc)
  o Establish something similar to the BPS/ DCP statement on the DSUN V tension (?)
    (It’s time for a paradigm shift away from diagnosis to a more person-centred approach)

• Hopefully the recovery agenda can be included in this work. For me, the whole peer support issue needs further research and focus
• Can we use the “reflective process” more in the analysis of data in research projects to make data come alive and more relevant to the service user
• Peers to be able to lead on projects if they want to and are able to
• To nourish and develop networkers and help them grow into involvement working through research
• Making people with experience in mental health “research aware”, even if they’ve no interest in research working themselves
• I would be very interested for McPin to be able to promote service user involvement in my area (university town), as I feel it is a ‘user researcher desert’ where I come from. It would great to feel I could have an organisation where I could access really good evidence that user researchers are valuable and what real impact we can have. How can I – with my peers, approach academics/ mental health professionals with evidence and try to encourage them to involve user researchers.
• I am worried that McPin will end up selling yourself on speaker for Peer Researchers or Service users and the people will start to consulting with McPin as consulting with service users/ service user researchers. This is always a danger.
• Representation’ needs to be clear
• Relationships with ‘peer researchers’ that were not here today need to be pursued
• When I first looked at your website there seemed to be a distinction between McPin Researchers and Peer Researchers – you need to define terms and beware of ‘us and them’ (which came across a bit today). It’s also not clear if any of your researchers are or aren’t explicitly working from lived-experience – it may be that this is the case for good reasons ‘equality’? Coproduction?
• Transparency is important in your recruitment to roles and in your consultation processes, levels of involvement etc.
• There needs to be a link in with discussion of health/ social care policies
• Research shouldn’t be purely for its own sake, but have benefits for service users (or services)
• Side effects of medication is a very important topic (even if it’s a bit medical)
• Review of professional research by people with lived experience is very important e.g. I’ve read understanding/ explaining mental illness by Richard Bentall but not sure he is aware of my kind of experience of “psychosis”