About the research

The ‘Your Experience in Mind’ survey was commissioned by Mind in 2014. The survey aimed to find out how far local Mind services:

- Promote recovery among people with mental health problems
- Offer a person-centred experience
- Are culturally appropriate and accessible for Black and Minority Ethnic (BME) groups
- Offer opportunities for people to get involved in the design and delivery of their support services

We worked with 17 local Minds to conduct a survey of the people who engaged with their activities and support services. In order to promote the survey and encourage people to take part, we worked with 14 Survey Champions based in 12 of the participating local Minds.

This paper describes the Survey Champions approach and reflects on the usefulness and impact of this for future studies.

The Survey Champion model

Champions were selected and approached by local Minds. All Champions had experience of using and/or volunteering for the local Mind.

Anyone who was interested in becoming a Champion attended a training day run by the McPin Foundation researchers. The training covered: the project aims and design, an introduction to survey methods, ethics and governance issues and telephone interview techniques. The sessions also allowed Champions to meet and share ideas about how they would support the study locally.

Locally, Champions had 5 main roles:

- Promoting the survey through posters, cards and word of mouth
- Answering questions about the survey for local participants, including reassurance around data use and confidentiality
- Helping participants to complete the survey if wanted, particularly for anyone who struggled with reading and writing their responses
- Providing local oversight and links to the study team at The McPin Foundation
- Complete the survey through a telephone survey with participants where requested

After the data collection was complete, Champions were also involved in reviewing the findings, providing local intelligence to interpret results and editing the text.
Summary of costs

<table>
<thead>
<tr>
<th>Item</th>
<th>Description</th>
<th>Unit cost</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Training</td>
<td>Time, travel and staff costs</td>
<td></td>
<td>£1,500</td>
</tr>
<tr>
<td>Survey Champion</td>
<td>Hourly rate of pay</td>
<td>£8.76 per hour</td>
<td>£2,431</td>
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<td>expenses</td>
<td>Travel and other expenses for carrying out local Champion role</td>
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<td>£850</td>
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<tr>
<td>Staff support time</td>
<td>Time spent in communication and supervision</td>
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<td>£2,140</td>
</tr>
<tr>
<td>Direct cost of PPI model</td>
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<td></td>
<td>£6,921</td>
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<tr>
<td>Total project budget</td>
<td></td>
<td></td>
<td>£40,000</td>
</tr>
</tbody>
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How did it work?
Initially, most Champions met with local Mind management and staff, giving them information about the survey and the role of Mind Champion.

Champions spoke to as many service users as possible, both individually and in groups, explaining the purpose of the survey and handing out questionnaires. They visited social groups and activity sessions within venues to promote the survey directly to as many service users as possible. Where it was not possible to speak to clients directly, Mind Champions used other methods of promoting the survey:

- Posting questionnaires with covering letter explaining the purpose of the survey
- Emailing service users with a link to the online survey
- Writing an article or a blog for the local Mind’s newsletter and / or website
- Promoting the survey via social media such as Facebook and Twitter
- Organising a coffee morning specifically to promote the survey
- Encouraging staff to promote the survey and hand out questionnaires
- Using wider networks and friends to promote the survey more widely

Mind Champions visited as many Mind venues as possible, averaging 4.5 venues per Mind Champion, though the number of services visited ranged from one to eleven. Services visited included Housing services, counselling services, peer support groups, day centres, advocacy projects, employment services and respite services.

Promotional materials - posters and business cards - were used to promote the survey. These were left at Local Mind venues and a variety of other places, for example GP surgeries, libraries, local mental health services and local shops. The business cards were also handed out to service users, carers and staff.

Survey postboxes were used too. Generally, these were only left in local Mind main offices due to concerns about confidentiality. Questionnaires with pre-paid envelopes were placed near the postboxes, often with a poster to advertise the survey close by.

A few Mind Champions kept local Mind staff and service users informed of how the survey was doing, in terms of the number of questionnaires returned. Some used this information to help promote the survey, particularly those local Minds who were getting a lot of questionnaires returned.

“We made it into a bit of a competition... kept people involved in where we were - when we were coming first... trying to push that we were one of the only Minds in the NE and how great it would be for our Local Mind to get their message out there... competition... show them how it's done in the NE” (10).

Although the intention was for Champions to conduct telephone interviews with participants who requested this to help them complete the survey, we did not receive any requests for this and so telephone data collection did not take place.
Impact

Of the 17 local Minds that took part, 12 had a Champion to support the survey and 5 did not. This was based on the local Mind’s ability to find someone appropriate and interested in the role within the time available. While this was not intentional, it did provide an opportunity to compare the responses for the two approaches.

Although these look like a considerable improvement in recruitment in those sites where there was a Survey Champion, there is a skew caused by two sites, one (without a Champion) with an unusually low response, and one (with a Champion) with an unusually high response. If these two sites are removed from the figures the average with a Champion becomes 63, and the average without becomes 61, a much smaller difference.

It should also be noted that this does not take into account the number of people per local Mind who could have completed the survey as there were no accurate figures available on the total number of people who engage with the local Mind.

Despite the caveats, anecdotally there is good reason to think that people completed the survey with the support and encouragement of the Champions who would not have done so otherwise.

Getting involved

Roughly half the Champions saw the position advertised at their local Mind and applied. The other half was asked directly by the local Mind Manager whether they would like to get involved. Two people decided against taking on the Champion role after training because they were concerned about the effect of short-term, sporadic involvement on their benefits.

Champions expressed a variety of reasons for getting involved. These included:

- To gain work experience
- Out of interest or curiosity
- To give something back to their local Mind
- As part of their own recovery journey
- Out of pride for their Local Mind
- They felt it was important to give service users a voice
- They liked the fact that the survey was being done by an independent group of researchers
- They wanted to use or develop existing skills
The impact for Champions
We conducted telephone interviews with Champions after the project was completed to find out how it felt to them. We asked what they felt they got out of being involved in the survey as a Champion:

- it was rewarding to be involved in something that would make a difference
  
  “I believed in it and enjoyed giving people that chance to say something confidential; I think that’s really important”

- it improved their own mental wellbeing and one said it gave him a “purpose for the day”
- they enjoyed the feeling of responsibility and being part of a bigger project
- they appreciated the support received from their Local Mind and being treated as a colleague

  “Being made to feel welcome did me a lot of good”

- they enjoyed the opportunity to meet more people and to speak to others from different local Minds

What worked and what didn’t?
Champions told us what they thought worked well about their role:

- They could use their local knowledge of venues and ways to promote the survey
- Being local gave them the opportunity to talk to many people directly, including in groups
- They could work closely with local Mind managers, staff and volunteers
- Some were able to access local resources to promote the survey, including the local Mind website, social media and newsletters

There were also barriers that could be addressed for future surveys:

  “I felt a little out of my depth at first but got good support from the overall manager at Mind. It got easier”

- They faced practical difficulties such as running out of questionnaires or struggling to get permission to put up posters in some venues
- Where the local Mind covered a large area, the Champion could not always talk to potential participants directly which was frustrating
- Some Champions felt that local Mind staff were not as supportive of their role, or of the survey in general, as they would like
- Champions also reflected that some of the Mind users were more skeptical of surveys than they expected, including raising doubts that the survey was free, anonymous and confidential and not seeing it as relevant to them.

About the McPin Foundation’s Methods reviews
The McPin Foundation aims to transform mental health research by putting lived experience at the heart of research.

This is the first of a series of brief papers in which we reflect on different ways of collaborating with the public and with people who have lived experience. They are intended for use by researchers, commissioners, and people who want to get involved in research to learn from models we have tried.

If you would like to see our other McPin Methods reviews, please visit our website: www.mcpin.org.

If you would like to know more about this project, or about the other work we do, please contact us at: contact@mcpin.org

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