

EQUIP study: Reflections on a five-year programme of work designed to enhance service user and carer involvement in mental health care planning...

We held a conference on Friday at the MacDonald Hotel in Manchester to bring the EQUIP project to an end. The research team were invited including all members of our Service User and Carer Advisory Group (SUCAG). We also invited professionals and service users from the Mental Health Trusts involved in the study to share their experiences. It was a day of mixed emotions for everyone. On one hand it was lovely seeing different people we had worked with over the last five years and hearing their experiences, but on the other it was really sad that this project was coming to an end. However we will continue to offer support to the NHS Trusts that we work with going forward.

What was EQUIP?

[EQUIP](#) was a five-year programme of research funded by the National Institute of Health Research (NIHR) led by [Professor Karina Lovell](#). It aimed to improve service user and carer involvement in [care planning](#) by co-producing and co-delivering training for mental health professionals. You can find out more about this work and what we found by watching this short (and we think pretty cool) [video](#).



Why did we have a conference?

This event wasn't designed to share the overwhelming success of EQUIP. It couldn't be because if you've watched the video by now you will know that the study showed that our training did not have any significant impact on service users' experiences of care planning. This was massively disappointing for everyone involved.

We thought it was important though to mark the end of EQUIP and express our gratitude to everyone who has been involved in the study including the over 1200 service users and carers who participated in the study and without whom we wouldn't have had very much to talk about! We also wanted to share our findings and with [The Mental Elf's](#) help get these out to a wider audience by engaging with the [Twittersphere](#).

How did we involve service users and carers in EQUIP?

Was our Patient and Public Involvement (PPI) strategy perfect? No, far from it! Might we do some things different now looking back? Absolutely! But our hope is that by sharing our PPI approach in this blog people can see how we tried to design PPI into all stages of EQUIP from the outset and how we think this activity massively improved the quality of all areas of this program of work. Hopefully this will generate some interesting debate about how we all might improve PPI going forward. You can hear what members of the EQUIP SUCAG felt about being involved by watching their video [here](#).

We developed a plan to include PPI representatives in a variety of different ways within our overall study design:

- Service user and carer co-applicants were named on our grant application and involved in the design and conduct of the study and the PPI strategy.

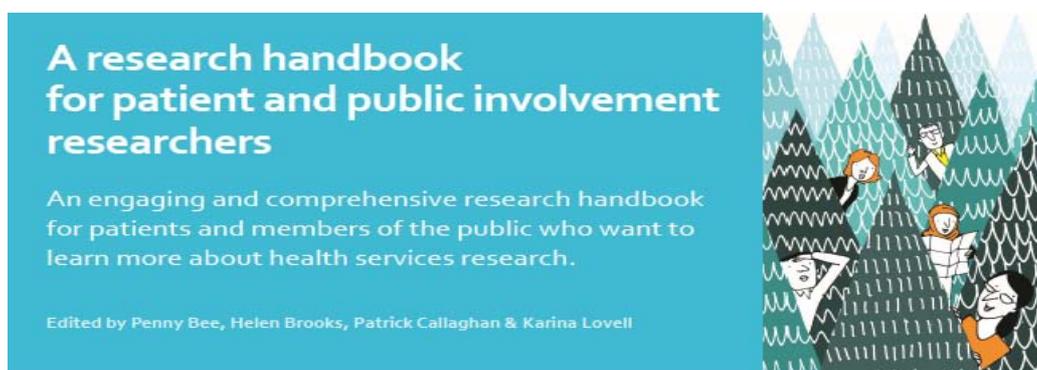
- Service user and carer researchers were costed into our grant to contribute to key areas of the programme such as data collection, analysis and dissemination.
- Service users and carers co-delivered our training intervention to mental health professionals.
- We established a SUCAG at the outset of the study to guide and inform the research. SUCAG members were paid for their time in line with INVOLVE guidelines and were reimbursed any travel expenses.

To try and make it as fair as possible, we openly advertised places on the research methods course (see below) and then offered people who completed the course various roles within EQUIP (co-applicants, consultants, advisory group membership). We know that it must have been disappointing for people if they did not get the role they wanted. It would be really interesting to hear suggestions about how we might have done this differently.

Research methods training

We designed a 6-day Masters-level research methods course which was offered to service users and carers who might be interested in future research, including EQUIP. We did this because we'd be told in the past that a barrier to meaningful PPI in projects was a lack of knowledge about research methods. This course offered an introduction to research and PPI generally before moving to look specifically at systematic reviews, quantitative research and qualitative research. This course has been cited as an example of good practice by the NIHR Clinical Research Network (formerly the Mental Health Research Network) and is included in the NICE shared learning database. The service users and carers who completed the original and subsequent courses seemed to really like it and we have now delivered this course across the UK and in Europe, Indonesia and Uganda.

We have designed a book to accompany the course which will be freely available online soon to support people who want to know more about research but are unable to attend a course. Service users and carers were involved in writing sections of the book and working with an illustrator in its design. You can hear about Lauren and Joe's experience [here](#). Here's a sneaky peak of the book too:



How did PPI improve our project?

STUDY DESIGN - As a group the SUCAG made some fundamental decisions which guided the research. This included a decision that current measures designed to measure service user involvement in mental health services did not adequately reflect service users' experiences and that a new one would be required. As a result, a new [Patient Reported Outcome Measure \(PROM\)](#) was designed. The group also decided that outcome measures in the trial should reflect the different components of recovery and selected the most appropriate measures. They were asked to comment on emerging analysis of interviews and focus groups to ensure that our findings reflected the experience of service users and carers and they were central to our dissemination approach.

DATA QUALITY - Having service users and carers carrying out interviews and focus groups really enhanced the quality of the research data. Additionally having SUCAG input into the

interview schedules and questionnaire design made sure we were asking the right questions of the right people.

STUDY OUTPUTS – Working closely with, and supported by, other researchers, our service user and carer researchers both led and contributed to journal articles. We think the results speak for themselves. Andrew Grundy’s [paper](#) on service user involvement in care planning was given the Paper of the Year Award in 2017. [An animation](#) based on Lindsey Cree’s 2015 paper looking at carer perspectives won the NIHR Let’s Get Digital Award in the video category. You can also read on blogs on [EQUIP](#) and [Andy’s](#) and [Lindsey’s papers](#) to see what other people thought of them.



PATIENT MEDIATED MATERIALS – Our SUCAG and service user and carer researchers were instrumental in developing materials to support collaborative care planning. They developed a pocket sized information leaflet that service users could carry in their wallet which has been very well received by service users and professionals and we have distributed more than 45,000 of these. They also felt strongly that the best way to disseminate study findings was through a short [film](#), which you have already seen and hopefully agree works really well.

And finally...

By no means was our PPI approach perfect or without challenges; however, we are very proud of what we achieved. Our approach has received recognition from a number of sources with the study team winning the 2014 NIHR Clinical Research Network prize for outstanding carer involvement and the 2015 CRN prize for outstanding public engagement. Professor Karina Lovell has also recently been awarded the CRN McPin MQ Service User and Carer Involvement in Mental Health Research Award. We still have a lot to learn and will continue to do everything we can to improve PPI in our research.

We can honestly say we have loved working on this project with our PPI partners and look forward to an ongoing dialogue within the team and in the twittersphere about how we might do this better in the future. Follow the project hashtag on Twitter to find out more [#equipmh](#) or tweet us at [@Care Plan](#) if you have any comments or questions.



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