



***National Institute for  
Health Research***

# A series of case studies illustrating the impact of service user and carer involvement on research

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The Mental Health Research Network is part of the National Institute for Health Research Clinical Research Network which supports research to make patients, and the NHS, better

## **About The Mental Health Research Network**

The Mental Health Research Network (MHRN) is part of the National Institute for Health Research and our mission is to help make research about mental health happen within the NHS in England. We work with everyone who needs to be involved in research projects – researchers, mental health professionals, people with experience of mental health problems, their families and research and development staff based in NHS trusts. We support studies that are based within mental health services, within social care services and within primary care services.

## **About TwoCan Associates**

This report was researched and compiled by Kristina Staley from TwoCan Associates. TwoCan Associates carry out research and evaluations and provide training and support to help voluntary and statutory organisations involve people who use services in their work. Almost all of our work is undertaken in partnership with service users or carers. For further information please see:

[www.twocanassociates.co.uk](http://www.twocanassociates.co.uk)

## **Thanks**

We would like to thank all of the researchers, service users and carers who very generously gave their time to be interviewed and very helpfully shared their experiences of involvement.

## **Disclaimer**

The views and opinions expressed in this report are those of the contributors and do not necessarily reflect those of the funders, NIHR, the NHS or the Department of Health.

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## Introduction

This series of case studies describes how service user and carer involvement has an impact on mental health research. The benefits are wide-ranging influencing all stages of a project, from developing a research question through to implementing the findings. It is hoped these examples will encourage other mental health researchers to involve service users and carers in their work.

These case studies were selected from The Mental Health Research Network's portfolio to include projects that illustrate the wide range of impacts that service user and carer involvement has on mental health research. The aim was to capture the lessons learned from people's experiences, not to evaluate either the involvement or the research.

For Case Studies 1-6, the lead researcher and one or two service users or carers were interviewed using a standard set of questions. For Case Study 7, a carer was interviewed to find out about the impact of involvement on them personally as well as the impact on research. The interview questions were developed with MHRN staff and based the findings of a previous review of involvement in MHRN-supported research projects<sup>1</sup>. All the interviews were recorded and transcribed. The interviewees were able to check the case studies prior to publication.

The interviews were conducted between January and June 2013. The projects were then at different stages - some mid-way through and some nearly completed. Those that were near the end had involved service users in the writing-up and dissemination. Those that were mid-way through had plans for involvement at the later stages, but the impacts were as yet unknown. The different impacts that were reported at the time of the interviews are summarised in the table in the next section.

Further details about the involvement in each of these projects can be obtained by contacting the individuals involved. The contact details of the lead researchers and some of the service users and carers involved are included at the end of each person's story. Further information about the research supported by the MHRN and the work it does to support service user and carer involvement can be found at: [www.mhrn.org.uk](http://www.mhrn.org.uk)

## Terms used

The term '**service user**' is used to include people who use, have used or have the potential to use mental health services.

The term '**carer**' is used to include informal carers and parents / guardians of people who use mental health services.

The term '**involvement**' in research is based on the definition from INVOLVE<sup>2</sup>:

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<sup>1</sup> Staley, K. (2012) [An evaluation of service user involvement in studies adopted by the Mental Health Research Network](#). London: The MHRN.

<sup>2</sup> [www.invo.org.uk](http://www.invo.org.uk)

An active partnership between service users/ carers and researchers in the research process, rather than the use of people as the 'subjects' of research. Many people define involvement in research as doing research 'with' or 'by' service users/ carers, rather than 'to', 'about' or 'for' service users/ carers. This would include, for example, involvement in advising on a research project, assisting in the design of a project, or in carrying out the research.

## Overview of the impact of involvement in each case study at the time of interview

Impact on...	SHIMME Case Study 1	PRIMROSE Case Study 2	FMH Case Study 3	E Sibling Case Study 4	ASSSIST Case Study 5	Super EDEN Case Study 6	CARER Case Study 7
<b>The Research</b>							
The research question	✓			✓	✓		
Funding application	✓	✓		✓	✓	✓	
Design – conceptual elements	✓	✓		✓	✓	✓	✓
Design – practicalities	✓	✓		✓	✓		✓
Patient information and other written materials	✓	✓		✓	✓	✓	✓
Recruitment	✓		✓	✓		✓	
Delivering training	✓						
Intervention development	✓	✓		✓	✓		✓
Data collection e.g. interviews and focus groups	✓	✓	✓				
Data analysis	✓	✓	✓			✓	
Writing-up results	✓	✓	✓			✓	
Presenting findings	✓		✓				✓
Informing campaigns/ implementation		✓				✓	
Management & oversight	✓	✓		✓			✓
<b>The People involved</b>							
Shifts in professional awareness and attitudes	✓		✓		✓	✓	✓
Service user/ carer increased knowledge	✓	✓		✓	✓		✓
Service user/ carer increased confidence/ empowerment	✓	✓	✓		✓	✓	✓
Support for service users/ carers		✓		✓	✓		✓
Service users/ carers making good use of their lived experience		✓	✓	✓	✓	✓	✓

## **Case Study 1: Shared Decision Making in Psychiatric Medication Management (The SHIMME study)**

**About the study:** This study aims to encourage service users and clinicians to make shared decisions about medication (shared decision-making). It aims to help service users feel more involved in treatment decisions, and to make better-informed choices. It aims to help clinicians have a better understanding of each patient's interests and needs.

The study began with a review of best practice in shared decision-making. The team also consulted service users, carers, psychiatrists and care co-ordinators through a series of focus groups. Based on the findings the team developed parallel training programmes for the various stakeholders, as well as written materials to support a shared decision-making process. This intervention is now being tested and evaluated with an adult community psychiatric service in Cambridge.

**How service users and carers have been involved:** Service users and carers have been involved at every stage of the project. They were involved in developing the research question and the funding bid, which took over two years. When the project began, they were involved in planning focus groups and co-led the discussions. There are service user members of the Training Group which developed the three sets of training for service users, psychiatrists and care co-ordinators. Each training programme is co-run by a health professional and a service user trainer. Service users and carers are also members of the Team Management Group, which meets every other month to discuss the running of the project, and the Project Advisory Group which meets less often and provides an overall steer to the project.

**The impact of the involvement:** With many different levels and approaches to involvement in this project, there has been an impact on every aspect of the research and at every stage, from developing the idea for the project through to developing and testing the new intervention.

**Who we spoke to:** We spoke to Professor Shulamit Ramon, at the Faculty of Health and Social Care, Anglia Ruskin University, and Sarah Rae, a mental health service user and trainer in the SHIMME project. Sarah is a member of the Project Advisory Group and the Training Group.

### **Shula's experience**

#### **How did you work with service users and carers when first developing the idea for the project?**

This initiative came out of the work of a community group that focused on psychiatric medication. I was a member of the group and when I was asked what I could contribute, I said research. Gradually the group thought this would be a good idea and we started to develop the project.

It would be fair to say that the service user who ran the group was initially sceptical about research. She didn't think much would come out of it and to some extent feared the ownership would be taken away from service users. I think she was won over gradually, partly because she saw that we were very keen to hear her views, as well as those of other service users - and that we took them very seriously. It wasn't personal. It just took her time. Now she is one of our colleagues.

We applied for funding and were rejected the first time, but with comments we thought we could work on. We took advice from local research people in the Trust who encouraged us to continue. We revised the proposal and were successful the second time. We also worked closely with the Trust person with responsibility for user and carer involvement. She was very active in our bid process, and really supported us.

### **What difference did it make to have service users involved in the bid development?**

We were much more sensitive to what they saw in shared decision-making, their perspective on what it means and how it should be implemented. They also made us think about what would be the best way to move from wanting it, to actually doing it. This is why the project takes the form of participatory action research. It has an intervention – it's not just simply exploring issues. Of course this means it is much more complex. But for the service users it was very important that something was done.

It's also made sure that we are grounded in their reality and know what issues concern them. They not only wanted to see a change in decision-making but also less dependence on medication. Throughout the project we've been presenting alternatives to medication to all of the groups, including the hearing voices network and a Finnish innovation called the open dialogue approach. We've also talked a lot about well-being and the value of exercise and mindfulness.

### **How did you work with service users in the consultation phase? And what difference did this make?**

We held a series of focus groups with service users and carers, psychiatrists and care co-ordinators (mental health professionals working in the community). The groups discussed their views of shared decision making, as well as potential obstacles and opportunities. Service users were members of the Consultation Group that designed and ran the focus groups. They helped with developing some real-life scenarios to discuss with the different groups. So we were very much grounded in their reality both in terms of any scenario and in the way questions were phrased. Also they advised us on how long things could be – they helped with a lot of the practicalities.

Then of course they participated in analysing the data. We recorded each meeting and then transcribed the recordings and shared them with members of the Consultation Group. That made a difference because again the service users expressed their views on how they saw the findings. Our philosophy is that service users are equal partners – so we always asked 'What do you think about that?'

Usually they explained to the rest of us why the majority of the service users took a particular position. So they were very much interpreters of that data.

It shed a somewhat different light on the findings. For example, one very important element for the service users in the group was the relationship between the prescribers and the patients, and whether the service users not only feel respected but also seen as a person and not a diagnosis. That came across very sharply and was not a comfortable realisation for the providers in the Consultation Group. The psychiatrists emphasised that the main obstacle to shared decision-making is a lack of insight - whether people accept that they are ill or not, although I personally do not accept this as a good enough definition of insight. We had problems with this issue because it didn't come up so much in the focus groups. So we had some heated debates. But our discussions were friendly and helped us think about how to tackle these issues in the training, and thus it was a very helpful experience.

### **What has been the impact of involving service users as trainers?**

Any training session we have is led by two people, a service user trainer and a consultant psychiatrist. The service user trainers are in the same role as the psychiatrists. It is essential to the training to get across the view that they are equal – equal in power, equal in knowledge and equal in their ability to lead. We are demonstrating that service users have a lot of knowledge and expertise. The service users we worked with at the beginning really insisted that this is seen very clearly in the project. Part of our assumptions for the project as a whole, is that no doubt professionals know a lot about medication, but that what service users know experientially is also important knowledge – and this is their contribution to the encounter between prescribers and people who take medication. We are showing people that by the way we run the training.

My sense was that in the psychiatrists' training group, they were a bit suspicious of the service user trainer, just the way they were listening and the way they responded. The anonymous feedback from service user participants in the training was extremely positive – much more positive than the psychiatrists, and slightly more than the care co-ordinators.

### **How do service users contribute to the Team Management Group?**

Our two service user colleagues are very active. They make their views quite clear, in terms of what's going well and what isn't and why. They are respected in the group as equal members.

### **How have service users influenced the work of the Advisory Group?**

They were very useful especially at the beginning when we were looking at different options for the consultation, for the training and for our website for service users. We are now working with them around dissemination. We are asking for their support in terms of ideas and also doing things like talking about the project. They help us to reach groups that we are not in everyday contact with. We will be running a final conference in March 2014, so they will be taking an active part in designing the conference and contributing to it.

### **What further involvement are you planning in the remainder of the project?**

After the intervention has been in use for a year, about 20% of the service user participants will be interviewed to evaluate the effectiveness of the intervention - we want this to be done by service user interviewers. We know people in the Trust who are service users and have those interviewing skills, so we won't need to train them, just prepare them for this project. We think this will be important, because service users are more ready to say what they really think, because of the credibility of the service user interviewer.

### **Overall, what do you think has helped the involvement go well?**

We all have the same value base. All of the people working on the project really believe that shared decision-making has to happen. We understand that it is a problematic innovation, because it differs so much from the usual medical intervention, but the service users have been encouraging us to think that it is possible, that it can happen.

What's also important is the fact that the service users are systematically treated as equals and we are really interested in what they have to contribute. We pay them for their time, showing that we value their contribution.

### **Have there been any challenges?**

Some of the people who have been actively involved in running the project are still on medication. So we've had to make sure they do not run groups with the people who are their consultants and also that they are well enough to take part.

It might also have been better to have had more people involved. The people we have involved are very good, but they are in a lot of demand, from different people and different projects. Three years is a long time and it's a big commitment and meaningful involvement all the way through is demanding.

### **What would you tell other researchers about involvement?**

It's very positive, but it needs to be worked at continuously. You can't take it for granted and you need to make sure it happens all the time. You really need to think about how you demonstrate the equality in the structure of your project, in the way the project is managed and in the way you give people opportunities. All of that is important. You have to make it meaningful.

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## **Sarah's experience**

### **How have you been involved in the SHIMME project?**

I've been involved at several levels. My main involvement has been as a member of the Training Group. We developed the materials for the training, although different people specialised in different aspects. I then worked with a clinician to co-facilitate the training for the care co-ordinators. I am also a member of the Advisory Group.

### **What difference do you think your involvement made to the work of the Training Group?**

We grounded the professionals whenever they were thinking of things like recruitment materials or topic guides or feedback forms. You bring them back to what it's like for the average service user who's not in a research world or a medical world. If you get a whole lot of people who are very well-educated together, then what they come up with might not be right for everybody. But you have to develop materials that you can take to anybody in the street and they can understand what you're talking about. So we continually reinforced the service user perspective – otherwise everything could have taken off with a much more academic bent.

They needed to have realistic expectations of service users. There was a lot of discussion about the length of the training groups. Would 2 hours be too long? At one stage someone wanted to go for 3 hours. But people who are really heavily medicated most of the time often struggle with their concentration, so you've got to get into the mind-set of people who get tired very easily.

We also spent a lot of time developing forms for the service users and the prescribers to use in shared decision making. That was where my involvement was very relevant, as I could say I didn't think service users would want to fill in a long form. I had to keep reminding the researchers that some service users, particularly those with on-going issues, might have problems with reading and writing, and if not, they might have issues around their confidence and self-esteem, and might not want to put things in writing. For academic researchers whose whole world is writing... they might not realise that this is quite a challenge for some people.

I also helped to develop the information that went out the service users who were going to take part in the study, because to be honest when I first set eyes on that I thought 'Oh my goodness!' It's got to be accessible and it's got to be simple, and you've got to get over what you're offering in not too many words. Most people, not just service users, don't read wordy documents. They just want the information in bullet points. So I had some input on that.

I still think we could have done a better job on the information, but it was a challenge to get the language right while still complying with the ethical guidelines. That's where service user input is invaluable, because you can look at these words like 'validate' and think that's something which is second nature to a researcher, but it's not something a service user would necessarily think about. And that's important because if the words are wrong, it's just a turn-off isn't it?

One of the other things I constantly said was that not all service users will have access to the website, which is something that tends to be forgotten. If you use the internet all the time and mix with people who use the internet all the time, you can forget that. It was something that needed to be reinforced on occasions that written materials would be important as well.

I think service users being part of the Training Group also challenged some of the other group member's perceptions. The fact that we all worked extremely hard and we kept to all the deadlines, even though we were stressed like they were, it's gone a long way to combat the stereotype of the service user who is just taking meds and not doing a lot else. I know the psychiatrists have changed as well. I was speaking to one of them and she said 'I thought I was one of the forward-thinking psychiatrists, but since doing this project – it has changed me enormously, seeing what the service users have achieved'.

### **The Training Group included a mix of professionals, service users and carers - how well did they all work together?**

The group was very inclusive. So for example when there was some training on offer, we were all offered the training. That came from Shula. She is very inclusive. When someone came to speak, everyone was invited, so it's been very good in that sense.

There was one topic – coming off medication - that's extremely important to service users, which did cause some ructions, because we had psychiatrists in the group and that was a difficult topic for them. For the service users, it's really important this is part of shared decision making, because service users are frightened of saying 'I want to come off my meds'. So they just stop taking them without telling anyone. What we were trying to bring forward is that it would be so helpful if there could be an open discussion about when would be a good time and how they could best do it, so they don't get in a cycle of stopping their medication, becoming ill and having to take it again.

So I wanted to hand out a publication which is a harm-reduction guide to coming off psychiatric drugs to the care co-ordinator and service user groups. But that was one step too far for the psychiatrists. We talked about coming off drugs in the content of the training, but handing out a book about it was too much.

So in the group we all had to step out of our traditional roles and we needed to find a common ground. I had to accept eventually, even though I felt very passionate about it, that it was not going to happen, because it was going to concern the psychiatrists too much. Equally though, probably the psychiatrists came a bit further forward in their way of thinking. Just as I had to compromise they also moved towards the middle ground.

That's what was so good about this group. If we had any discussions that were contentious, it wasn't something that anyone held grudges about, or moaned about outside the group. It was a good stimulating, challenging discussion without it becoming personal. So the group worked very well together.

### **What difference did it make to have you involved in delivering the training?**

When we were talking about things, I could give examples, not only from my own personal experience, but from other service users, because I know and I mix with lots of other service users. So it grounded them. If they hear someone saying 'This is how it was for me', that makes it real for the care co-ordinators who are being trained. It brings it home to them. It's not just an academic paper they're reading – they're being confronted by people who are telling them this.

It was important just to have a service user there as well. Service users are so often seen as needing to be 'done unto', whereas when you're actually delivering training, it makes people look at service users in a different light – particularly for the professionals. We were modelling what we are aiming to achieve through shared decision making – so that service users aren't just people that we tell to take a drug without any discussion, these are people who can think and have their own mind. If you didn't have involvement in the training, it would look pretty hypocritical.

For the service user training groups we were also trying to do something different. We were trying to create an environment that was more trusting and secure because there was a service user there.

When we looked through the feedback forms at the end of the session with care co-ordinators, quite a lot of them had remarked that they'd really valued the service user input. So people found it useful.

### **How have you contributed to the work of the Advisory Group?**

At the beginning we talked a lot about general issues like where service users can get information about medication in a format they can understand. That's quite important in shared decision making. There again as a service user we were able to say this is where we find information as well as which information is helpful and which information is practically useless!

At the last meeting, we talked about publicising of the project and who would be writing papers. My colleague is going to write a paper for one of the nursing journals – she's going to do most of it and I'm going to contribute to it – giving the service user perspective. I'll make sure that the points that are important to service users are included. Again just the fact that the paper is being co-authored by a service user – it's modelling a good way of doing things.

I've already been involved in dissemination and have given presentations to the Network for Psychiatric Nursing Research, at a local PPI (patient and public involvement) event and at the INVOLVE conference. It has an impact on the audience to have a service user presenter. It tallies well with the whole ethos of the project and helps with setting out the standards. We're showing that involving service users is a good way of doing things.

### **Have there been any challenges so far?**

At one stage there was a lot of pressure. Suddenly we were having meetings every week and there was an awful lot of stuff to get ready for the training courses, and we had to do everything in a concerted timescale. We were all finding the pressure

quite intense, service users and professionals alike. It would have been helpful if we'd been told at the beginning that that was how it was going to be, but I don't know if anyone knew that was how it was going to pan out - but we got through it – and now it's not so intense.

### **What has helped your involvement work well?**

Generally the people in the groups have listened well and we've all been treated as equals. Shula sends you papers and all sorts of things. She never thinks 'Oh they're a service user they won't understand that'. She hasn't just creamed off the most qualified people in the group and suggested that they do things – we've all been invited to contribute. It's a good working atmosphere.

### **Is there anything that could have been done better?**

It would have been good at the beginning to have more outlined in terms of the contract, what we were going to be doing and the payment rates. It might have been better if there was someone in the team who had the role of PPI co-ordinator and then some of the confusion around payment might have been ironed out. Also when we were under quite a lot of pressure, it would have been helpful to have someone touching base and saying 'Are you OK with this? Is it going alright or are you finding it too pressured?' If you had someone who was a named individual who was the PPI co-ordinator, then there's someone you can just say anything like that to, such as 'I'm having a problem with this'.

I wonder whether ideally it would have been good to have involved more people from the Rehabilitation and Recovery pathway – which tends to be people who have more severe and long-term illnesses. It's always good to include the type of service users that you're really aiming to help – but that might have been problematic in other ways. Even more realism would have been good, but would they have been able to stand up in the Training Group and make their views clear? That's difficult and even more difficult when your judgement's cloudy and you don't feel that great. So it's a difficult one.

I tried to manage that by trying not to speak from a personal point of view but from a wider service user perspective. You have to think 'How would service users in general think?' They might not all have access to a computer, they might have to go to a library and then if they have to bring up information about medication in a public library – how's that going to feel? You've got to think about all these things.

### **What difference has it made to you to be involved in this project?**

I've gained confidence from it and I've gained a lot from being in the group. I've learnt a great deal about all sorts of topics that I didn't know anything about before. I have not been a lone service user. There's been a group of us so we can support each other. It has been very rewarding.

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## **Case Study 2: Prediction and management of cardiovascular risk for people with severe mental illness. A research programme and trial in primary care. The PRIMROSE Programme.**

**About the study:** This 5-year programme aims to find ways to reduce cardiovascular risk in people with severe mental illnesses by developing an intervention for use in primary care. It began with two years of development work. This included a systematic review, the development of a new cardiovascular risk score and a series of focus groups with health professionals, service users and carers. The findings have informed the design of the new intervention. This intervention will be tested in a clinical trial during the final three years of the Programme.

**How service users and carers have been involved:** The research team includes a service user researcher who is employed via Rethink (a charity for people with mental illness, [www.rethink.org](http://www.rethink.org)). Rethink have also set up a Lived Experience Advisory Panel (LEAP), which is a panel of service users and carers who help steer the project. The whole panel meets once a year. Members of the panel have also joined an Intervention Development Group which meets 2 or 3 times a year and has provided input during the initial stages.

**The impact of the involvement:** Service users and carers have had a major impact on the shape of the research project. They have also had a significant influence on the development of the new intervention and helped to identify ways to overcome barriers to its implementation. Having a service user researcher involved in the project has helped to ensure high quality involvement from a diverse group of service users and carers.

**Who we spoke to:** We spoke to Alex Burton, PRIMROSE Programme Manager, University College London, Ben Gray, Senior Research Officer (service user expert), Rethink and an anonymous member of the LEAP who has also been involved in the work of the Intervention Development Group.

### **Alex's experience:**

#### **How have service users and carers been involved in the project?**

We've had service user input since before the project started. There was a co-applicant who was part of the grant development. She informed some of the key decisions, but we lost her - unfortunately she passed away. That was all before I joined the project.

There was also a lot of involvement from the North London Service User Research Forum. The project was presented to them a few times and their feedback was incorporated into the application.

We also worked with Rethink on the grant application, through to the development stage. We employed Ben, a research officer, through Rethink, who is also a service user researcher. He's been inputting into the development work and he's been

coming to our meetings and helping with the focus group analysis – so it's been at all levels of the project really.

### **What difference did the involvement make in the early stages?**

With SURF, they thought the research was important and we got an endorsement from them. They helped by saying the project was meaningful and worthwhile and something we should be getting funding to do.

They had another comment about one of the interventions for managing cardiovascular risk which is the prescription of statins. There was some concern from SURF that the study shouldn't just focus on drug treatment and there should be more of a discussion with clinicians. The shape of the grant did change so that more behavioural interventions would be offered, and more emphasis would be placed on the communication between the clinician and the service user. So it shouldn't just be 'You're at risk, here's your drug - off you go'.

### **What impact has the LEAP made on the project?**

27 people have joined the LEAP, so it's a good resource to draw on. They can contact the co-ordinator whenever they have an idea and if we've got something we want to share with them, then we can quickly send it out. It works quite well. I've also attended their meetings so I've heard the feedback first hand.

Their feedback has been at all levels really. We've shared our logo, and our acronym to find out whether service users think that is relevant and appropriate. We shared the focus group protocol with them and they suggested that we involve carers, so we ran an additional group with carers. They also suggested that we don't just focus on urban areas, so we included rural GP practices, in case people's experiences are different there.

The Intervention Development Group, made up of a smaller number of LEAP members, has made a big difference to the intervention, especially around the work we've planned with nurses. The Group suggested we include the topic of stigma in the nurses' training programme and also that we ensure that practice nurses feel comfortable working with people with severe mental illnesses. So the mental health side of things is being included in the training and the intervention. This is where there's often a divide – between physical and mental health – and by linking it all together, there has been a real emphasis on holistic care, rather than dividing people up into separate illnesses.

### **How has having a service user researcher on the team made a difference to the research?**

Ben has been co-ordinating our links with Rethink and his remit has been to organise the meetings with the LEAP. He makes the personal contacts with them. So he emails them and they come back to him with individual comments as well as via the group forum.

He was also meant to be co-ordinating and facilitating the focus groups with service users – but unfortunately he became unwell. He helped facilitate one group and then he had to stop. We really wanted to have a service user doing that research, so we

had to quickly try and identify somebody to replace him. We found a service user from another project in our department who was willing to come and help us. We ran five groups with service users but only three of those had a service user facilitator.

He's better now and still co-ordinates the LEAP. He inputs into the written documents we've been producing following the development work. He was attending team meetings up until the time he became unwell. As he's still in recovery, he's stepped away from coming to the meetings, but we try to feedback the minutes and he comments that way. We try to keep him on board as much as possible – but it's been quite difficult to manage at times.

### **What difference has it made to have a service user researcher co-ordinating the LEAP?**

Because Ben is a service user researcher, people feel more comfortable speaking about their experience. He's collected quite a lot of information through people sharing their stories. Being based at Rethink - they have the resources and the networks where they can contact people – and they have good models of involvement. They don't just play lip-service to it – it's worked really well the way that they've set this up. If I'd tried to do it I wouldn't have known where to start.

It's also been really helpful having a bit of separation from the project and having someone else leading that. Having people on the outside is quite useful – it's fresh eyes and an independent view.

The LEAP members are very honest as well because they are a group of people who are comfortable with each other. We've had some very honest views about how we should be doing something or what we shouldn't be doing.

### **How have you made sure that the LEAP's views influence the project?**

I attend part of the LEAP meeting, but the service users also discuss things without me being there, as I might influence the things they feel they can say. Our service user researcher is always present and he will write up the notes and send them through to me – so that we've got documentation of everything.

Recently we've been pulling together all of the development work into evidence tables. Within those tables we've also got all the notes that have been taken at the team meetings and key suggestions from the LEAP – so that we can come to an overall decision about what the intervention should include. We make every effort to ensure that everything is considered at least, but it might not all be taken on board.

Some of the feedback that people have given us hasn't been realistic. Some suggestions have been ones that we can't deliver in the project. I manage that by documenting what the research team has said in the meetings and gathering the responses to the LEAP's comments. Then I can go back and say 'This was considered, but we felt it was not possible', as well as describing the process as to how we reached our decision. I can answer questions or justify why we haven't included what they said.

### **Have there been any challenges?**

The main challenge was when Ben became unwell. Unfortunately it wasn't something that we'd planned for, so we didn't have a contingency plan. The service user aspect of the development work was kind of on hold for the few months he was in hospital until we identified other people to meet our short-term needs. But it wasn't ideal because continuation is always better. Now he's back, it's just about managing whatever he feels comfortable with doing. You want to involve him in every level of the project in the way that you set out to do, but at the same time, you have to respect that he might not feel ready to come to meetings. We've met with him and asked how he wants to take things forward. His strengths are really the writing and running the LEAP. So he's focusing on that side of things.

Part of the challenge was that it happened so unexpectedly. We weren't aware there was a problem and there was a bit of a breakdown in communication. I think it's important to have those conversations early on, even though it's difficult when someone is well. Asking questions like 'If you become unwell how do we manage that?' and emphasising 'We want you to feel comfortable telling us if things are getting too difficult'.

### **How will you continue to involve service users and carers in the remainder of the project?**

We hope to have the manual prepared for our intervention before the next LEAP meeting. We are going to share that with them and get their feedback on whether it's what they envisaged, and see if it sits comfortably with them. We might try out the intervention with some of the users there and see how it works in practice.

We have to give some thought as to how best to involve LEAP members from here on. We need to work out whether we need a trial management group with service users and how we involve them productively and meaningfully. It will probably be about the recruitment to the trial and how we could encourage service users to take part in the research. We're going to try to have service users involved in the training of health professionals and again Rethink have a network of service user trainers that we're hopefully going to work with.

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## **Ben's experience**

### **How have you been involved in the project so far?**

I've mainly been involved in co-ordinating the LEAP. It has taken a hell of a lot of work to co-ordinate 27 people. But it's been really good to bring people together. It's good to have a strong interpersonal relationship with the people on LEAP to understand where they are coming from and their difficulties, and if they are unwell, to try to find ways for them to participate and feel included. It can be very lonely and isolating for people otherwise.

I've also been supporting the Intervention Development Group. It has 8 members and has been oversubscribed. So we have five people as core members to keep continuity and then we invite a different 3 people according to what's being discussed. So people can opt in from the main LEAP and take part in different activities as they want.

### **What difference do you think the LEAP has made to the project?**

The first recommendation they made was to have a blog where people could post their stories and which could act as a project newsletter online. So I've been managing that. That's been a very successful way of keeping people abreast of what's happening and keeping people engaged and included.

Since then LEAP has acted as a critical friend to the project - so it offers pragmatic advice on the research design and ways of increasing opportunities for collaboration. For example, LEAP members commented on the topic guide for the focus groups at the beginning of the project. They took the jargon and complicated words out to make it simpler and more accessible. They also suggested having more time at the beginning and end of the focus groups to have a general discussion – rather than jumping in to specific questions – to relax people and allow them to tell their stories and to bring the group together.

The Intervention Development Group has also helped to make the intervention more acceptable and meaningful for service users. One of the great barriers is that people just don't turn up to these interventions in primary care – so we've been looking at ensuring LEAP's expertise and experience inform that development, so that we get a good uptake.

LEAP members gave examples of good and bad practice in their experiences of primary care – what worked for them and what didn't. Some had found that their GPs lacked an in-depth knowledge of mental health and the side-effects of anti-psychotics, and were concerned that the attitudes of primary care staff had to change. So they suggested that service users and carers should be involved in training the nurses – to address the issues of stigma and exclusion. This is one of the eleven recommendations made by the Group and seven of those are thought to be feasible - we hope they will get incorporated into the clinical intervention and professionals' training. We have written a journal article about this impact of the Group on the research.

### **What helps the LEAP to work well?**

The group is chaired by Alison Faulkner, who is an independent service user consultant who has worked widely in mental health. She's outside the research team so that the LEAP has its own identity and can make recommendations without having to modify them. That adds a critical edge. LEAP can then give an external and critical perspective that it might otherwise lack. We don't just tell the research team what they want to hear.

With Alison as the chair, everyone has their say at the meetings. We do invite members of the research team to come and talk to us and tell us what the state of the work is. They stay to field questions and then leave so we can have our discussion amongst ourselves – to ensure questions aren't shut down and are explored from everyone's perspective. We need close collaboration but also some independence.

It also makes a difference to have a service user co-ordinating the group, as I have much more empathy and understanding of mental health. I didn't really appreciate the suffering of people until I'd experienced it myself. It gives you a good perspective on how valuable it is to include people.

We also pay people for their time. We've been using INVOLVE guidelines on payments to ensure people on benefits can take part and not lose their income. The majority of members are on benefits – and we want them to be able to come and take part.

### **Have there been any challenges?**

It's a challenge to get everyone together at a certain time and date because we have to arrange everything for them - from train tickets through to paying them. We have to chase people up to make sure they'll attend, particularly if they're not doing well. That has been difficult for me as I still have negative symptoms of schizophrenia, so it takes quite a lot of effort. It's been worth the effort and Rethink has been very supportive. They have let me have administrative help to get people to the meeting.

Then unfortunately last year I became unwell again and had 2-3 months off work, spending 1-2 months in hospital. During that time the team were extremely supportive. I continued being paid and my manager was saying they really wanted me back. He said 'You've got great research experience and lived experience that none of us have. You've made a great contribution to Rethink and to the LEAP, so come back as soon as you're ready'. That really motivated me to get better and come back.

### **What further benefits do you hope to come from your involvement?**

It's not just about doing research but also communicating research - getting it out there so people can know about it and implement it. That's where me working at Rethink is very helpful because we have a very good Campaigns and Communications team. I've been working with them already to go to conferences and develop the project web pages.

We're also tying this research into campaigns being run by Rethink. There's a campaign for physical health champions and our '20 years younger campaign' which is raising awareness of the fact that people with mental health problems die 20 years younger from preventable diseases like diabetes and heart disease. This fits with one of the LEAP's recommendations - that we need service user champions to raise awareness of what works and what matters. So I hope my involvement in the project will help with linking into campaigns and activities that go beyond the research, and actually try to change practice.

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Reference: Gray, B., Larsen, J. & Faulkner, A. (2013) Third Sector Facilitation of Lived Experience in Research: A Case Study of Service User and Carer Involvement in the PRIMROSE Project. *Journal of Mental Health Training, Education and Practice*, 8 (3).

## **A LEAP member's experience**

### **What difference has being involved made to you personally?**

For me it's huge - in lots of different ways and on different levels. It's something that I feel really matters - the shocking statistic of people with severe mental illness like myself – the fact that our life expectancy is so dramatically reduced. It feels really important in that way for all service users. It also matters to me personally because I'm trying to reduce my own risk factors for cardiovascular disease. For example, I smoke at the moment and I'm trying to stop, so I am thinking about that.

It's also making good use of my own experiences with mental illness - using it to benefit other people. It's really empowering and helping me to make sense of everything that I've been through and continue to live with. I feel quite emotional saying it – but it does feel really important and valuable. I feel that when I'm in a LEAP meeting, by being part of LEAP, it's not just me I'm representing, but the people I've met, particularly from the psychiatric wards I've been on. I've met some incredible people with severe mental illness who don't necessarily have a voice, so hopefully I can bring some of their voices to this research.

It's still vitally important to me to have contact with other people who talk openly about having mental illness. I really value talking to other people with mental illness – and there's carers involved in LEAP as well, so I'm getting that perspective.

But it's also important to me professionally. In the past I was in the medical profession. Now I'm retraining to re-enter the health service. In-between I've been a

patient in psychiatric hospitals and supported by community mental health teams. I have to say I got quite disillusioned with the professionals, particularly with how they dealt with people like me and mental health in general. I do feel like some of my confidence has been regained through being involved in LEAP. There are clearly medics who are interested in what we have to say and who actually think it matters, and more than that are actually taking action in response. That's really vital professionally as it's something I believe in and want to have in my own practice.

### **What difference do you think the LEAP has made to the research?**

I'm not sure. Maybe that's part of my scepticism. There are a few things that have been passed on, but I'm not sure how they've been received – and am not sure if that has shaped the intervention being proposed at the moment.

There was also quite a lot of discussion about where we can contribute next. We want a bit more involvement. We're getting a bit bolder in a way which was really nice – but whether that makes a difference we'll have to see.

There's a meeting coming up so hopefully at that stage things will be clarified. I expect an update and suspect it's a timing thing.

### **What has helped your involvement to work well?**

Rethink's involvement is really valuable. I trust them and their values and I think that's really crucial. I was wary initially because of my past experience of the medical profession. I was quite critical. But because Rethink were involved it felt less tokenistic. That's something I am wary of with service user involvement. It's a term that trips off the tongue but can be reduced to tokenism.

The way they facilitate the meetings means it works well. One of Ben's real strengths in the meetings is that he's really good at drawing out themes, summarising and pulling it all together – those practical skills are really useful. He does a fab job at keeping us updated in between and encourages us to be involved in other ways as well. It makes a difference that Ben is a service user – there's no two ways about it. That shared experience for me helps with the trust. I feel that he gets it and I feel he adds integrity in a different way.

It's really important that there isn't always someone from PRIMROSE at the meetings. I think we've started to get a bit wider and bolder in our thinking – we are freer to be critical even at a sub-conscious level – so that is very clever in a way. Little things like that matter.

### **Could anything be done to make it work better?**

I would value more communication. I think it goes back to that fear that user involvement might be tokenistic. There's nothing specific to make me feel that about LEAP. I don't mind if things put forward by LEAP don't shape what happens – but I need to hear that there is good logic. I think we deserve that feedback - otherwise it's meaningless and just a gesture really. I need to feel the information flow is more two-way.

Ben is pivotal in that and does a fab job – but I don't feel like I have a full grip on where we fit into PRIMROSE. It would be good to have more updates on progress.

Also it takes me a long time to process things sometimes – so if we only get a verbal update in the meeting, I can't always think about everything there and then, to respond to it or to question. It would be good to have the information further in advance. For me it adds to the fear that maybe the research project is all going on regardless of what LEAP are doing over in a separate bubble.

**Have there been any surprises?**

Personally - just how rigidly I sometimes thought about things. I'm also not very good at on the spot thinking. It's also given me a re-awareness that everyone's lived experience is different, in terms of mental health issues and cardiovascular risks. There's still a wide variety within that – some reflected in the LEAP – which is really valuable.

**What would you say to other service users about being involved in research?**

That if done well it really makes a difference – both personally and in practice. It's that empowerment in forcing change – closing the gap that exists between theoretical research and practice. It's about people and their context and what's in everyone's best interest. The process of being involved is very empowering.

### **Case Study 3: The views and experiences of service users regarding illicit drug use in secure settings.**

**About the study:** This study aimed to understand service users' experiences of using illicit drugs in medium secure units, to find out how often this occurs, when it takes place and how it affects treatment outcomes. The findings have provided information that will help to improve interventions, reduce overall drug use and minimise the likelihood of relapse.

The study involved carrying out in-depth interviews with in-patients in medium secure units. Each participant was interviewed on two separate occasions – firstly to talk about their experiences and attitudes and secondly to review and comment on the findings from the first set of interviews.

This study was funded by the London Strategic Health Authority.

**How service users were involved:** A service user joined the research team and carried out the interviews with the in-patients. He was also involved in the analysis of the qualitative data and the write-up of the findings.

**The impact of involvement:** The involvement helped with recruiting participants to the study, whilst involving service users as interviewers improved the quality of the interviews and gave new insights when interpreting the data.

**Who we spoke to:** We spoke to Doug MacInnes, from the Centre for Health and Social Care Research at Canterbury Christ Church University and George Harrison, a service user with experience of receiving treatment in a medium secure unit. Since completing this project, Doug and George have been working together on a new study, COMQUOL (funded by NIHR Research for Patient Benefit) – which aims to use a structured communication approach to improve the quality of life for people in secure mental health settings.

## **Doug's experience**

### **How did you involve service users in this study?**

We involved service users in interviewing other service users about their experiences. They then went through the analysis with us and helped write up the findings.

### **What difference did it make to involve service users as interviewers?**

It meant that the interviewees were much freer in their discussions and said things they almost certainly wouldn't say to a member of the clinical team. For example, if the interviewee was engaged in some activity that would be considered illegal, they felt OK to talk about it, because they were talking to someone they trusted and who had shared experiences with them. So there was a closeness there that wasn't likely to be gained by a researcher.

Also during the interviews the service user researchers would actually say 'Come on we've both been in the unit together – are you really telling me that?' So they would challenge much more. They were able to challenge because they had insider knowledge of how things were. Basically they were saying 'I don't think you're telling me the truth'. But with a traditional researcher that wouldn't happen.

There were phrases being used that we researchers didn't know about. So there was no sense of a distance between the interviewer and the person being interviewed. But the service user researchers still asked people to explain or elucidate, even though there had already been an acknowledgement those shared experiences. So the service user researchers didn't make assumptions – it was like research, not a conversation.

The service users also wished to be as thorough as possible. They wanted to do a good job. They didn't want the findings to be seen as broad statements, but to truly represent what was going on.

### **What difference did it make to involve service users in the analysis?**

At times their interpretations were different to ours – at times more benign and at other times not. Interestingly it's part of that thoroughness - their interpretations are really grounded in the reality of the situation. For example there was an issue about different ethnic groups being more likely to indulge in different substances – they told us about that so we had some sense of the cultural influences on substance use. That gave us information, but also helped with making interpretations of the major issues involved.

Service users also gave a rationale as to why things were being said or not being said, things that we researchers could only hazard a guess at – as we hadn't sufficient knowledge. One of the service users was piercingly accurate as to why things were the way they were, and came out with some really interesting perceptions – for example how the staff reacted to certain situations and how the staff's ability to cope might inflame situations rather than calm things down. He was able to talk about that clearly from his own experience. He could tell when staff were competent or not, and who he could trust or not trust and he explained the basis for that – so he was able to marry what was coming out of the analysis with lessons from his own experience.

### **What difference did the involvement make to the dissemination stage?**

We've always had a policy that everyone on the research team is involved in all elements of dissemination – service users are often part of presentations and everyone's name is included. When we write articles for journals everyone's name is on those and everyone has a chance to comment. So the service user voice is always there.

It makes a difference to have a service user presenter - as long as they feel confident and supported, and feel part of what presentation is about and know who it's being given to. The service user researchers were heavily involved in the recruitment for this study. They went to the wards and gave presentations about what the project was about. They had more knowledge about what was happening

than the rest of us. It worked very well. But when we did a presentation at the end at an academic conference in Oxford, we were hoping a service user member of the team would come with us, but they said 'No – it's not my environment'. So it's about what each individual feels OK with.

### **How do you prepare service users for being involved in research?**

We involve people who have previous experience of using the service. Quite often they've left school at the minimum age and haven't any prior research experience. Rather than give an academic outlook on research, what we do is give a short presentation on what research is and then focus on what the individual study is about. Then we teach skills that are relevant to that study and teach them at the time when those skills will be required. So for instance when we run focus groups, we run a session on facilitating a group just before the group work and when we need to analyse the focus group data we do a session on analysis after we've got the transcripts – so service users can practice on that data and can take it away and work on it.

We've always work on the premise of keeping any didactic form of teaching to a minimum and also use the practical examples that people are working on - rather than it being a theoretical exercise.

### **What helps involvement to work well?**

Having a good relationship is really important, as is service users feeling that they are an equal part of the team. As well as being able to say either that they agree or disagree with things, they need to feel comfortable to say that they need additional support or for example that they don't want to come to a meeting. We have quarterly meetings and once one of our service user researchers didn't come because there were problems with one of his family. Being OK about things like that is important. Their job is important but there are other things in life and it's OK for them to step out on occasions - though that's true for any employee.

On-going contact is vital – not just on a formal level to keep people up to date with the project, but also informally to check that things are going well. You have to acknowledge the mental health difficulties that people may have, and realise they may not always be totally motivated. The research team can't become too stressed with that. Those issues are quite important too.

I do think giving some reward is essential - in our case it's financial. If everyone else is being paid, then being paid means being able to say you are being acknowledged for your expertise and are acknowledged in similar ways to other members of the team.

The person involved also needs to be aware of what their role is - what are they being asked to do, the sorts of activities that entails and what that means in terms of X days a week or month. Everyone says you must have a job description – but sometimes those can be too formal and there's a human resource speak that comes out. It's more about the person knowing exactly what they are being asked to do and being clear about the commitment.

## **How are you planning to work with George again on the next project?**

George is a member of the research team on the COMQUOL study and will be helping us with the qualitative work. So he will be leading on interviewing the service users about their experiences of the intervention and analysing that data, as well as commenting on other data that is collected. He will also be co-facilitating focus groups of service users with another qualitative researcher. They are currently developing a structured focus group schedule and looking at their roles and responsibilities. Once we've gathered all the data (including all the quantitative and qualitative data), then all the team will be involved in a discussion about the overall conclusions.

As it's a multi-site study, it has been difficult to get George a research passport. For someone who is a forensic mental health service user the whole process is horrendous. Obviously one of the criteria is a lack of criminal convictions. But we think we have managed that – we're ready to go with the first unit and hope we'll be OK with the others. We contacted everyone in the country and no-one had a clear sense of the way forward with that one. We think we've succeeded and are now looking forward to getting started.

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## **George's experience**

### **How were you involved in the study?**

I did the drug experiences survey. I went round the male patients and the occasional female patient and asked them questions about their experiences with illegal drugs and how they think it affected their mental state and their stay in hospital. I did about 18 people.

When it was transcribed I did the qualitative analysis. We set out eight themes and then highlighted all the stuff and then that went off to the people at the University and they did the analysis from that.

### **How were you trained and supported in your role?**

From doctors and people that knew me – the researchers ascertained I had the aptitude for it. We met every 6-8 weeks and you were briefed on the next stage of the research – we were briefed on how we were going to do it before it happened. We discussed everything and all the ideas were bounced around – if anything was

flagged up, if we had insecurities about anything then they would organise something a bit more concrete as far as training was concerned.

### **What difference did it make to have you doing the interviews?**

Because I'm someone who has actually been through the system and has proved they can sustain a level of wellness, I've got first-hand experience of how it all works – so the people being interviewed could relate to me more. Using the language that's passed around just helped to loosen them up and let them really open up and say the truth of the matter.

Not that I was informing on them. They knew they were being recorded and if there was anything that they felt they shouldn't say, it was down to them. The idea of the research was not to inform on people and point fingers. It was just to get an idea of what's happening. So I explained that to them – they knew they wouldn't get into any trouble.

The big thing was I knew a lot of people that were there at the time. So it wasn't just a cold introduction. It was like 'Alright mate? Do you fancy earning twenty quid to do this?' Straight away the money got their attention and the fact that they knew me and we were friends as well. They weren't all friends. Some were total strangers, but quite frequently they were acquaintances.

The incentive is extremely important because a lot of guys in the system are never going to have a golden job and a successful life – so what money they do get is quite important. I know they get well-provided for with the benefits – but other people can have a completely different goal in life – they can have houses and new cars and families – but it's a totally different situation for service users in a lot of cases. The money shows respect. They are doing something for the system and the system should reflect that it values that.

### **What difference did your involvement make to the analysis?**

I was learning on the job. Sometimes they feed the data into a computer and the computer doesn't give them an accurate reflection of the true state of things. I could recollect because I had first-hand experience and had been there myself. So when I was highlighting statements in the transcripts, I could give them a more accurate picture.

I had massive problems with illegal drugs, so I know what's it's like to take them, to be addicted or to self-medicate when you don't know you are mentally ill. So when someone else tells you 'I've just dabbled', you know whether they are telling the truth or not. Some people just say what they think you want to hear because they are trying to get out of hospital – and knowing the difference is everything really.

I also fed in things that could be improved in the system – things that weren't being done. For example, when a patient comes into a medium secure hospital, if the first thing you told them was that if they take illegal drugs or they don't work with the system then their stay will be doubled or tripled – then it would save the system so much money. I don't think that's done. People find it out second or third hand from another patient, who may not be the best qualified person to inform them. In a lot of

the system, they don't see that people have got control over how they act and what they do – they treat them like children. Some people are dying for more responsibility.

A professional researcher, I'm sure they could do a good job, but in that study with the drugs I had so much experience of it – it would be hard to get as close to the truth as I did.

### **What difference has being involved made to you personally?**

If I don't get any problem with my benefits and it leads to a career – that would be a good thing. It's also helped me reflect on my time and capitalise on it and it's made me more confident as a person. I already had good insight into my illness – it magnified that.

I have to watch my stress levels so I can't take on too much – but a little bit of something now and again is not going to kill me.

I've been really grateful to be involved and hopefully make some kind of difference. If they don't listen to me, then they're not going to get to the truth and if they don't get to the truth then the whole thing is a waste of money.

### **How have you been involved in the new project so far?**

There have been a lot of meetings. It took a long time to get the financial situation sorted - the contracts - and then I got into trouble with the benefits. Their computer told the benefits computer that I was earning something somewhere, so I had to have an interview with them. I hope my involvement isn't restricted. We're sorting out all the little details now, like codes to the room I'll be using for the focus group analysis. It's quite a complex project.

### **What difference do you hope to make in the new study?**

I'm going to be helping with the focus groups and I've done that before on another research project run by a charity. When those focus groups happened, it was just me and another lady going round. But with that project there was no financial incentive so the attendance was very poor. The other facilitator was good at the orchestration of it, the flipcharts and the direction of it – but when patients were struggling to get their point across or losing track, I was good at keeping the thread of the whole thing going in the right direction, keeping to the point. I had a better idea of what they were trying to get across.

Someone who hasn't been in hospital wouldn't understand what a patient is trying to say – they probably wouldn't get to the bottom of it – whereas I can give a for instance like 'That's similar to what happened to me... but don't you think this, that and the other...' I'll be good at helping them get to the crux of their point.

### **What would you say to other service users about being involved?**

The people who can do it aren't in abundance. There are people that are highly motivated to be involved in things – but they might have some other problems that stop them doing it well. You might find someone who can get involved but has a

problem with not finishing anything – that’s something that you’ll find. But the end game has got to be there otherwise the whole thing is a waste of time.

But they are out there. On every ward you find someone who is proactive in their care and interested in how it works and how it can be improved. With mental health services and research, it’s like chicken and egg. The research should come before any action, so it should take priority over everything else. They should have service user involvement groups to recruit researchers. They should have some kind of meeting in every hospital to see if there’s an interest in being involved in research because before setting up anything, you need to have involvement.

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## **Case Study 4: Exploratory Randomised Controlled Trial of an Online Multi-component Psycho-educational Intervention for Siblings of Individuals with First-episode Psychosis (The E Sibling Project).**

**About the study:** This study aims to develop online information and support for siblings who have a brother or sister with a first episode of psychosis. The first phase involved developing a web-based resource using the findings from a literature review and focus groups with siblings. The second phase will evaluate whether the new resource promotes siblings' knowledge and well-being.

The study is funded by NIHR.

**The impact of involvement:** The siblings have influenced every stage of the project thus far. They have helped to design the project, resolve some of the practical issues, helped with recruitment and contributed to the development of the intervention prior to testing.

**How service users and carers have been involved:** Siblings have been involved via a Siblings Reference Group that was set up to help develop the project proposal and has had an oversight role ever since. A multi-stakeholder Expert Advisory Group that includes siblings, service users and parents as well as mental health professionals, was set up to advise on the development of the online resource.

**Who we spoke to:** We spoke to Jacqueline Sin, a research fellow at King's College London who is being funded to do this work for her Ph.D., and anonymous members of the Siblings' Reference Group and the Expert Advisory Group.

### **Jacqueline's experience**

#### **How did you work with service users and carers when first developing the idea for the project?**

The whole idea of doing research with siblings actually came from some parents of affected children. They asked me in my clinical practice 'What do we do about our other children?' So I said I'd go away and look it up – but I couldn't find anything. That was in 2006. We didn't know much at that time. So that led me to do an initial piece of qualitative research. We found that siblings are very much affected, and that they usually do a lot to support their brother or sister. In fact the siblings may be the most successful agent to promote recovery, as they take their brother or sister out for social activity. But we don't ever see the siblings in the clinic.

These findings led to the current study. I was already working with parents and service users, but realised I needed to directly involve siblings in the project. So I started working with a group of siblings, recruited via Rethink Mental Illness and other mental health charities, to think about how we could take the work forward. This group became the Siblings Reference Group (SRG) who have been involved throughout.

### **What difference did their involvement make at the early stage?**

They helped with my proposal and planned how we should conduct the project. They helped when I wrote something for ethics applications or when I needed to write a summary of the project for the public. We were concerned that funders might not fund something that wasn't directly about the service users. But the siblings felt quite passionate about the idea.

### **What impact has the Siblings Reference Group had on the rest of the project?**

They have known everything about the project from the start - so they have known where we need to promote the project and how to find other siblings. They helped a lot in terms of thinking about how to recruit people for the Expert Advisory Group. We also went to an event together and they helped to recruit for the focus groups – it did make a difference for them to tell other siblings what the project is about. They were so much more convincing when they said 'I'm a sibling and I'm sitting on a Siblings Reference Group'. This meant the participants were more trusting and knew we would use what they said to build the website.

The SRG also helps with a lot of the practicalities. We meet every three months and I tell them where the project is up to. They check the timeline – so I feel happier that everything has been overseen, every single step along the way. In the last two meetings, we went through the research ethics for the RCT (randomised controlled trial). They checked the information sheet and we made the decision to run a prize draw and also to give the participants a £10 voucher online. When I went to the research ethics committee they were asking why we were paying people. Personally I thought £10 wasn't enough! But I was able to tell the committee that this is what the Sibling Reference Group said has to happen. All the other studies have some incentive, and it's important that the prize is reasonable but not too lucrative – to influence people's engagement. So I could put my hand on my heart and say we have consulted some sensible people and that's what they decided. In the end the committee was very positive about it.

### **What impact has the Expert Advisory Group had on the project?**

This group has a specific role to oversee the website development – so this includes working out the content and what the website should look like. In terms of the content I have a list of what could be included based on the research we have done - but they have a view on what should or shouldn't be there and what's more important and what should come first.

For example, in the literature, there was a lot about the benefits of peer support for siblings. So we thought about having an online forum - but the Expert Advisory Group said that getting reliable information from professionals is more important. So they talked a lot about the ground rules for a forum and asked us to tighten up the security and moderation. They told us that they would want to know if there was a professional moderator and that this would help people feel reassured and interact. For me, I was wondering whether it would feel like being policed and whether young people would want their own space. So we are going to have a moderator in the RCT and see how well that works for others.

There are other topics that the Advisory Group has identified that would not be included in the more conventional interventions targeted at parents. For example, it's important for siblings to understand their own genetic risk and that of their children. So the Group has very much influenced the content.

Right at the beginning, the Group had quite a big debate about what the website should look like and what kind of software to use. They discussed a lot of technical stuff that quite honestly I'd never thought about. If I had approached this resource as a book, it might have been more academic – but because it's a website and I don't know much about that – and because some of the Group know a lot about software – you can completely see the change in dynamic. They have thought a lot about how the site should interact with people – so hopefully by the time it's built, a lot of the things the public want will be on there. I hope all the surprises have already come out – that's the benefit of having a really, really good PPI input.

### **Have there been any challenges?**

There are limitations with the software we have to use - it's more suited to e-learning for students. In one of the first meetings, we showed the Advisory Group a typical page from our university website and that went down like a lead balloon! Not user friendly – not up to date, not fashionable!

It was quite a challenge for some of my professional colleagues, especially from our IT team. I hadn't thought about it because they were funded by the grant, but afterwards they were confused about their remit and asked me 'Are we going to be able to do what the Advisory Group said?' And I explained how we needed to listen to the Group's views, but keep within our resource limitations. Now with hindsight I think I should have prepared the IT team better. They'd never worked on a research project like this before. So the involvement was all quite new for them.

We also had to explain to the Advisory Group that at the end of the day this is a research project – so there are certain things we have to do, things we have to explain to people. They wanted a brief information sheet, one that's not too boring and puts people off, which I do understand. But we need certain things to be there. They also wanted a bright, colourful flashy website – but there's no real budget for it, so we had to use what we had available.

### **What has helped the involvement work well?**

I don't know if we were just lucky or it was the way we advertised the Expert Advisory Group, but we have a couple of sibling members who are working in IT and have provided very valuable expertise when we needed it. I thought it would be difficult to find siblings to get involved, but working with Rethink made it easier – so it has helped having the right networks along the way. I also talked to all of the Group members before they joined. I didn't set out to screen them – but I did try to meet them or at least talk to them on the phone - to be sure it was what they really wanted to do.

We did quite a lot to balance the group, so for example there's equal numbers of men and women. They are very productive. People have strong opinions but at the

same time they are supportive of each other. There is open discussion. They ask 'What do you think? Have you come across this?'

The Reference Group also encouraged me to think carefully about how to facilitate the meetings of the Advisory Group – because it's a big meeting of 16 people. So I made sure to talk to all the members individually and explained the project clearly before they came to their first meeting. Then before each meeting I send the group something to read and check everyone is up to speed. If someone didn't come to the last meeting I chat to them to help them catch up.

I have two sisters on the Reference Group also signed up to the Advisory Group – so they are very committed to the project. I would do the same thing again as they help to keep the Reference Group updated.

### **What impact has the involvement had on you personally?**

Sometimes you have moments thinking about your project, when you really doubt whether anyone apart from you wants to see this done. It's quite humbling and really helpful that every now and again, a group member says to me 'I talked to this person and you should talk to them', or 'They really want to join this'. It's helpful to know that the siblings - the end users - would really like to see it done. It does help us to feel quite grounded as a project.

### **What advice would you give other researchers?**

I would definitely encourage people to do it and plan it quite carefully. Costing the PPI is as important as costing the project – I'd tell them to do that.

I wasn't sure whether having PPI would give the project a worse chance or a better chance of getting funded. I think it should give the project a better chance of funding.

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## **The experience of a member of the Sibling Reference Group**

### **How did you first get involved?**

I was looking on The Rethink Mental Illness website as I was going to give a donation and I saw they had a section on siblings. So I clicked on that and saw Jacqui's details – so I phoned her.

We spoke on the phone about what the project was about and how she was planning to set up a Siblings Reference Group to include people who could give her guidance on how to set up the trial and she sent me something to read.

### **What impact did the SRG have at the beginning?**

We had a meeting and Jacqui explained why she wanted to do this and then asked us what we thought of it. One of the things we talked about was the numbers of participants for the online study. That was something I was worried about - whether there would be enough. One of the other siblings worked for an IT company and commented that Jacqui might not get as many people as she was expecting, based on online recruitment. Only a really small number of people who visit a website will sign up, and I remember Jacqui was quite surprised by that. So then we talked about other ways to recruit siblings.

### **What difference has the SRG made since then?**

We've been able to help plan the EAG. We thought that the numbers were too big to be a functional group, so we suggested that she try to run it with a core group and ask the other experts to drop in to whichever session was relevant to them. We wanted to make sure that it wouldn't be professional heavy, or service user or parent heavy – so that the siblings would be able to speak up.

We were able to give a more sibling-strong voice and not let the project get diluted out by other factors. Other people have a different agenda. That's the whole purpose of Jacqui's research – to make sure that the sibling's don't get left out.

There were also more practical things that the SRG helped with. Every group member was able to bring something from their background. For example one of the group members used to be a proof-reader many years ago – so she was able to make sure everything was grammatically correct and read well. That was important when we were trying to get ethics approval and to write the literature for recruitment. But we all contributed to the writing. It was about trying to find the right language that would appeal to other siblings, but also to have enough science-base for the ethics committee to approve it.

Prior to the focus groups, we were able to generate some ideas, so that Jacqui had a few pointers on the general topics people might want to discuss. She had some ideas from her own work and we emphasised the things that we thought were important. Then some of us took part in the groups as well.

### **What has helped the involvement work well?**

It was helpful that the same group of people kept meeting. Everyone has a different experience. We bring our professional background as well as being siblings. I'm a GP trainee so I have a medical background. We're bringing a wide range of skills to the project – the whole person comes to the project.

Jacqui's personality helps as well - she is very willing to listen to ideas, she doesn't think that she knows best. She's open to hearing what you have to say and what could be improved – she's quick to respond as well. She's always enthusiastic about new ideas.

### **Has the involvement had an impact on you personally?**

It's always good to hear about other people's experiences. Most of us didn't know any other siblings. That was maybe the second time I'd met any other siblings and I'm in my thirties. That was quite good.

But the main difference has been that I've got the message that the more time you spend with your sibling the better it is for everyone. The research shows that if you look after the siblings and try and encourage relationships between siblings and their affected brother or sister, then it's better for the whole family. It seems so obvious but I'd never thought of that before. So I've tried to spend more time with my brothers – and tried to find common things that we all like doing – not feeling like it's a one-sided effort from me – that's the biggest thing I've taken out of it.

### **What would you say to other siblings about taking part in research?**

It's a useful experience and likely to be beneficial for you and your family. To feel like you might be able to help other siblings like yourself is quite empowering. I'm always thinking I wish this project had been done when my brothers first had their diagnosis – it would have helped me. That has been echoed at every SRG meeting – we're always saying this is such a good thing to do.

## **An Expert Advisory Group Member's experience**

### **How did you first get involved?**

I'm the sibling of someone with severe mental health issues. I decided to find out more about it and found the Rethink website. I saw they had a siblings' network event so I turned up to that and found the stall where they were talking about doing this research. I signed up for one of the focus groups and the Expert Advisory Group and that's how I got involved.

### **What experience did you bring to the project?**

I had recently begun working as a project manager on digital projects – so on a professional level and a personal level I felt I had a lot to offer. At times my professional background was useful, for instance, I was able to advise on technical aspects sometimes and I could ask questions of the people I work with when we were thinking about the best way forward.

On a personal level, because my sibling is very severely affected I think I can present some of the worst case scenarios – what's it like to look after someone who is quite difficult to communicate with at times – someone who is confined for long periods in various hospitals.

### **How have you contributed to the work of the Expert Advisory Group?**

One of our tasks was deciding things like colour and font and layout and figuring out what would be most accessible. So I suggested looking at similar websites that had been written for carers – to use what's out there without having to reinvent the wheel. I led a session on that. I gave a presentation of some of the research I'd done, with

screen shots of other websites, to show how other charities had got the right information to a very specific target audience.

We had to realise that none of us is a website designer, so let's not try and do something beyond our capacity. Some agency would have been paid a lot of money to come up with a layout and a colour scheme that meets all the requirements, for example so that someone with a visual impairment can see the contrast. So let's use what they've done. Here's five of the best – let's choose from one of these. Then after that we could all get back to being siblings and thinking about what needs to be on the site.

### **What difference do you think the Expert Advisory Group has made to the project?**

This website is for siblings whose brother or sister has gone into psychosis for the very first time – so it's going to be completely new to them. We were able to draw on our own experiences to think about what's the essential information they'd need – what would they want to have access to?

For example one of the things would be tips on best practice on dealing with someone with paranoid delusions. This is something I didn't read until ten years after my sibling had been diagnosed. I was kicking myself – because once you read it you think 'Oh that's so simple'. Things like that are so key, and it's a bit of an epiphany moment when you get there and realise what you've been doing wrong all those years.

All the group members have got different backgrounds so make different contributions – for example my sibling got ill when I was a child so I'm very focused on how we target our information to different siblings' needs – what does a five-year old child need to know? What does a ten year old need? What does an eighteen year old need to know? Because you have a whole life-span that gets affected.

And taking care of their own health. So many siblings get extremely drawn into the pattern of thinking if they put 100% effort into it, this person will get better. And unfortunately you have to accept that that might not be the case and it's out of your power. You can do yourself some damage if you construct your life around trying to make this person better. Often siblings neglect themselves.

You also hear things in the media that there's a genetic factor and an environment factor. So you hear siblings saying 'Maybe I'm a timebomb'. Maybe in five years' time I'm going to be going through what this person is going through and that's a terrifying thought. When you get rational information – you can put things more into context.

### **Were there any challenges?**

There was a bit of miscommunication at the beginning. We thought we'd have a lot more freedom to design the layout and navigation, but then we saw that in fact there was already a template we had to work with. So that session was about getting everyone back to the point of thinking it wouldn't be that bad. We talked to the tech guy and said 'Can we make that bit disappear and expand that box?' - working on

that kind of thing so that we got to some common ground. The temperatures were running high because everyone felt very passionate about it and the tech guy was getting a bit of a beating! And that's when I drew on my work experience because it was a matter of saying – calm down everybody – we will get there.

### **What helps the group to work well?**

Structured meetings – with a clear agenda and clear objectives – so we know what we have to do. Jacqui sets the agenda so for example she's said 'Here's the findings from the focus groups – let's select the content for the website'.

It's important that we're a mixed group. I like that we've got parents there as well. They had a useful input because they see a different view of what's going on. There are also healthcare professionals and people with mental health problems – it's a really good balance to the group. The more perspectives you get on any one problem or situation – then the better the resolution you're going to get. It will raise issues that you wouldn't necessarily think about. But if you just get everyone with the same point of view it's going to be one-sided.

We've all got views on what needs to be there and we have to work out which bits are personal to us as individuals and where we have common ground, which we agree is highly, highly important.

Jacqui has always been very professional and very approachable, so you can talk to her about anything – openly or privately, about practical stuff or personal experiences. She's aware and always keen to hear and find out. I have a great deal of respect and admiration for her because her research is brilliant. I am so happy to find professionals who are interested in this field and who are trying to do everything they can to help the siblings – because I feel we've been forgotten. Jacqui gave a talk at a conference where she showed that by having siblings who are well-informed and understand what is happening to their brother and sister – this actually improves the recovery rate – so how is this being missed out? It's pretty strange to me. Why aren't we taking care of those brothers and sisters who don't know what's happening or don't know how to cope.

### **What difference has being involved made to you personally?**

Personally it has been very cathartic. It's good to emerge from difficult circumstances and painful memories. I would like to think by doing what we're doing on this group there may be somebody who instead of waiting 10-15 years to look up something on the internet, might be more quickly exposed to the information they need – the information that would make their whole relationship with their sibling much simpler and easier.

### **What would you say to other siblings about being involved in research?**

Absolutely do it. Because the impact on somebody who is going to suffer psychosis is very individual. There are a diverse range of symptoms they are going to experience – so you need to involve siblings from very different cases. In my case my brother is probably not going to get better – but other siblings might have a one-off experience. So there are siblings with very different needs. Having that kind of diversity is essential for the research.

Increasingly more research involves family members. It's exactly what you need – the more of it the better. There's no point in having a one-sided view. This project couldn't have been done by just including health professionals - how would they know what a sibling would want and need? But at the same time, you need the professional input too. They also have information. For example they know that there are NICE guidelines that should be given to each person when they are diagnosed with psychosis – but a sibling may never have seen them. So there are fundamental things we can all bring to the table.

## **Case Study 5: Autism Spectrum Social Stories In Schools Trial (The ASSSIST Trial)**

**About the study:** This study is developing an intervention based on Social Stories to support children on the autism spectrum in mainstream schools. The intervention will ultimately be assessed in a full-scale RCT. The first half of this study involved a systematic literature review and a series of focus groups. These led to the development of a manual and training package to support teachers and parents in writing and using Social Stories. The second half of the study will involve a feasibility trial to determine how best to run the main trial.

The project is funded by the National Institute for Health Research Health Technology Assessment (NIHR HTA) Programme.

**The impact of involvement:** Parents of autistic children provided momentum for the study, helped shape the project plan, contributed to writing the grant application and have been extensively involved in developing the intervention prior to testing.

**How service users and carers have been involved:** Parents were involved in developing the grant application. They are also members of the Trial Management Group with responsibility for the day-to-day running of the project, and the Steering Committee, which has more of a governance role. Along with other professionals, parents were members of an Expert Writing Group that developed the new manual and training package.

**Who we spoke to:** We spoke to Professor Barry Wright, Dr David Marshall and Dr Sam Beeson from Leeds and York Partnership Foundation Trust and Anne McLaren.

## **The Researchers' Experience**

### **How did the study come about?**

We run parent training groups 2 or 3 times a year, where parents talk about what helps their child's development. In some of the groups the parents were repeatedly asking us 'I've heard about this social stories intervention, does it actually work?' They were also asking us to train them in how to deliver it. Then when the HTA released their research call, the two areas of interest came together and that's when we started speaking to parents and said 'Let's put a bid in for it'.

Social Stories were first developed in the US by Carol Gray. If a child is struggling with their behaviour in the classroom for example, then you can write a Social Story, usually with them and their teacher and their parents, The Social Story is about them and you use their own language and pictures in a very positive way that gives them a lot of social information. There are criteria to follow to make it effective.

### **How were parents involved in developing the grant application?**

If we had put in the application without parents we probably would have used one of the existing American manuals to help parents write social stories. But the parents wanted an English manual because the existing manuals were written for US families. The language and examples were all American and some of the concepts didn't fit with our English culture. The parents told us we needed to design our own manual - so we included that within our application.

The parents were also involved in writing the application itself and looking at drafts. The strength of our approach is that we asked parents to look at the whole application and their opinions were weaved in all the way through – not only in the section about involvement. We really needed and wanted to involve our parents meaningfully.

One of the parents was a co-applicant because she was the only parent in the country who had written a paper on Social Stories. The parents involved in developing the application have carried on being involved in the project itself.

### **How were parents involved in the early stages of developing the intervention?**

We held group discussions where we consulted people who'd used Social Stories in the past. There were two groups of parents and two groups of teachers and then a joint group where representatives of those groups met with other experts. This Expert Writing Group helped write the manual.

We purposefully kept the groups separate at first. We were worried that if we placed parents straight into the Expert Group they might feel inhibited. So we gave them an opportunity to work in their own group and say what they wanted to say, so that they would then feel empowered to tell everybody else what they thought.

We also interviewed young people who had experience of Social Stories to ask them what they thought. That threw up some things we hadn't expected. For example Social Stories are often read out in class and several of the young people we talked to said that they didn't like the fact that their story was read in front of other children. That's really helped us in thinking about how we deliver the intervention.

### **What difference has the parents' involvement made?**

We wouldn't have been able to do this study without the parents. It would have been a very different study and it wouldn't have been a good one. The intervention itself requires and needs the involvement of the parents – without them the intervention is a poorer one. It's not always been easy but it has been a genuine dialogue.

In terms of the Writing Group the parents have really been a critical friend – they don't mind telling us what's not working for them. One of the parents would quite regularly say 'I don't understand what you're talking about'. So it's made us use plainer English. They also influenced the content. They wrote the foreword - they contributed some examples and have been involved in editing the whole thing.

The other thing that was really valuable to us was talking to the young people themselves. They often had a parent with them, so that was another important

function of the parents, helping us to access their children. We spent a lot of time talking to parents about how best to interview their children about their Social Stories.

### **How have parents influenced the work of the Trial Management Group?**

It changes the atmosphere in the room. It means the meeting revolves around the parents and they drive the meeting along. They have had a lot of practical insights into how to conduct the feasibility trial so that it's not onerous or stigmatising, as well as thinking about what impact it might have on the children themselves. For example, they make sure questionnaires are in the right format and not too lengthy and are asking the right questions. They also made sure the arrangements were parent-friendly, for example holding meetings after 3:45pm, after they've picked their children up from school.

They have looked at the consent forms and information leaflets for the next stage and checked these are presented in the right way and give the right information. They've also checked that the information written for young people is likely to be accessible.

### **What influence have parents had on the Steering Committee?**

The parent on the Steering Committee keeps us focused on what this work really means for the families who are caring for a child with autism. One of the functions of the committee is to make sure the trial is not damaging to any of the participants. So the parent member has an important function in being able to voice anything they might be worried about – they are there as a mechanism to protect other parents and children.

She's also been reassuring to the other committee members sometimes, in that she's a parent who has used Social Stories in the past, so she can explain to the group how they work.

### **What has helped the involvement to work well?**

We all know each other quite well. We have got a good trusting relationship where people can be honest with each other. At the end of the day, we're all human and we recognise when things aren't working or not going well. Many of the researchers are parents so we understand parents' points of view. Our team is respectful of the fact that parents might have different opinions. There's a lot of mutual respect.

We also make sure there's a space for parents to express their views. That means putting items on the agenda and flagging it up to them. So for example, the Chair might ask them beforehand whether they feel happy to talk about an agenda item. Then during the meetings the parents are constantly asked their views on every aspect on the agenda. It's important for the Chair of the group to have in their mind that they might need to create the space for the parents to express their opinion.

### **What advice would you give to other researchers about involvement?**

It's obvious what makes involvement work well – it's about making sure the parents feel they can have their say and that there's a two-way conversation. The parents

then feel like their point of view is really heard – and at the end of the day they know best about their child. It's working so well for us because there's such a free exchange of information. The input from the parents has made our study much better.

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## **Anne's experience**

### **How were you involved in the study?**

I attended the planning meetings when we were applying for funding initially. Then when we got funding, I joined the Steering Group which meets every six weeks. That's been about deciding how they would do the research – what it would look like, and when and how we'd roll it out on a timeline.

Later I joined the Expert Writing Group and helped write the manual on how to write and use Social Stories.

### **What difference did your involvement make to the research bid?**

I was able to provide the parents' perspective on why the study should be done and how it would help children with autism. I could write it in simpler language and from the heart because I appreciate the problems that people with autism have, and that other people have with them.

Sometimes research can feel a bit far removed from what's going to help people – you've always got to keep your feet on the ground and realise who you are doing this for – is it any practical use to patients and families?

### **What difference has your involvement made to the work of the Steering Group?**

Sometimes the language that researchers use – I don't understand it – I don't think any lay person would understand it. When you're working on something you assume everyone knows what you're talking about, but they don't. So at first I was the one saying 'What do you mean by that? Why are you saying that? Can't we make that simpler? It sounds so complex'.

### **How did you contribute to the Expert Writing Group?**

It was exactly the same impact in terms of using less technical language in the manual. The researchers wrote it and we commented on it. There were also a couple of places where it implied the autistic child was acting like a naughty child - so I

suggested changes to try to avoid those negative stereotypes. Often the autistic child is anxious rather than naughty or has misunderstood what was expected of them. It's important that the Story doesn't create the sense of the authorities being against the child – but makes others more sympathetic, by understanding what it's like to be in an autistic person's shoes.

That would be very important for any parent reading the manual. If they felt that the people writing the manual didn't have an understanding of their child, it would put them off – they would distrust the whole thing. If parents feel the manual is sympathetic, they are more likely to use it to write a Social Story and help their child.

I also helped raise awareness of child anxiety – that is important to understand before a Social Story is written. This explains why the child is behaving in a way we don't want. I don't think the researchers appreciated how much anxiety autistic children have. They were aware of it of course, but sometimes we can see it more clearly, because it's running in the fabric of our veins. You're reading your child all the time.

### **What helped your involvement to work well?**

Going to the meetings helped us work together as a team as we all really cared about what we put out there in our name. All of the researchers were very motivated – but when you're a parent or a carer involved in research, you care 100% because it's about your life.

On a practical level, being able to take the meeting papers home and reply by email – so I didn't have to respond verbally there and then – that worked brilliantly for me, as I need time to think about things.

### **What impact has being involved had on you personally?**

The researchers included us a great deal, and treated us with respect. They made us feel that our opinions were worthwhile and valued. That's incredible and very life affirming. When you have a disabled child you can sometimes feel dragged down by normal life – so it was lovely to feel validated – and to have expertise that's useful.

### **What advice would you give to other parents about getting involved in research?**

Get in there and make changes. We need to make research real - more accessible and practical and more applicable to us the users. Being involved in a project could help other people in your situation to cope or manage better. It might change how you feel about yourself and how you might go about things in the future. It's exciting to hear the experts talk about the condition you live with daily and you benefit from hearing their viewpoints. Sometimes you might change their attitudes and perceptions, which can make an important difference to the research conclusions.

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## **Case Study 6: Sustaining Positive Engagement and Recovery– the next step after Early Intervention for Psychosis (Super EDEN).**

**About the study:** The Super EDEN programme builds upon the Department of Health funded National EDEN Project. It is following up all service users who took part in the original project to help develop the 'next generation' of early intervention in psychosis services (EIS). The study aims to ensure the gains made during early intervention are maintained once users are discharged, to develop a more tailored service to suit individuals and to evaluate a new intervention to help people who show a poor recovery from the first psychotic episode.

The Super EDEN programme includes 3 projects:

Study 1: A quantitative study looking into maximising the impact, cost effectiveness and user experience of EIS.

Study 2: A qualitative investigation exploring users, carers and staff perspectives of transition from EIS.

Study 3: A randomised control trial aimed to improve social recovery in young people with severe social disability.

The programme has been funded by the National Institute of Health Research.

**How service users and carers have been involved:** The research team includes a service user researcher who co-supports a Lived Experience Advisory Panel (LEAP) with Rethink Mental Illness. The whole panel meets 3 or 4 times a year.

**The impact of the involvement:** Service users and carers have had most impact on Study 2 where they helped shape the topic guide for interviewing service users and carers with experience of early intervention services. They also helped with recruitment and subsequently the analysis of the qualitative interview data. They have contributed to academic papers and are developing their work in new directions to help put the findings into action.

**Who we spoke to:** We spoke to Linda Everard, Super EDEN Programme Manager, Dr Anna Lavis, a researcher from University of Birmingham and Kirsty Trigg, a member of the LEAP.

## **The researchers' experiences**

### **How have you involved service users in the project?**

We've had service users involved from when we first submitted the bid in 2009. One of the researchers is an academic with experience of using mental health services. He was influential in developing the bid. Staff from Rethink Mental Illness also contributed.

When the study started we set up a Lived Experience Advisory Panel (LEAP) with the help of Rethink. This is made up of people who have used early intervention services from across the country. They meet 3 or 4 times a year and steer the project.

## **What difference has the LEAP made to the project?**

The LEAP helped with the design of the project when it first got going. They helped with recruitment. All the letters, information sheets and consent forms were passed by them first – and they changed a lot of them so that was really useful.

The LEAP was also involved in devising the questions for the qualitative interviews, especially for the second round. We discussed the themes that had arisen from the initial interviews and their own experiences. From there we drew up a list of topics to focus on in the second stage. Then we went through the questions again, added more and checked the phrasing. So then there wasn't anything that would upset people or could be misunderstood. This topic guide wouldn't have taken the shape it did without the LEAP input. As the interviews progressed and we reflected on our practice - for example how best to ask particular questions - the LEAP helped to resolve any problems, offering valuable insights into our research approaches and processes.

We have also involved LEAP members in analysing the data from the interviews. Working with them has helped clarify our interpretations and given us a richer understanding. It gives us insights that we wouldn't have otherwise – there would be less complexity with fewer voices.

It's not that they give us different interpretations of the data, because we don't fully form our interpretations until we've spoken to them. They are an important step on the road to analysing the data. We don't go to them with an idea which they then say is rubbish! They are very much part of the process.

For example one of the interview themes was around anti-psychotic medication. We went along to the LEAP meeting with some of the quotes – which seemed to be suggesting that our interviewees were not as anti-medication as in previous research. So we spent a long time discussing that. What came out was the complexity of people's relationship with the medication – the nuances of that came out of the LEAP – which is not to discount all the other voices.

This project is all about listening to the voices of people with a first episode of psychosis and learning about their experiences. There needs to be a step in the middle so that we don't just listen to their voices in the interviews and then go away and decide what we want to make of that. The LEAP keeps the dialogue active – so that even in our interpretations of the data we don't make assumptions.

## **How has the LEAP contributed to writing-up and the dissemination?**

We are writing a paper now and it has been shaped by the LEAP group, and that input will be acknowledged and discussed in the paper. We've also talked about using the data to compile a document that says what works and what doesn't in terms of early intervention services - from the service users' point of view. We will definitely do that because we want there to be a tangible impact – something to go to commissioners and service providers. We want the research to reach and influence people.

Working with the LEAP has encouraged us to think about different ways of acting on the findings than we might have thought otherwise. We are thinking at the moment about how the study can become a spring board for other work. For example, we've been talking about making a film or presenting the data to the ambulance service, police or schools. We've not done it yet – but all these things are being discussed – and may depend on funding possibilities.

### **How have they contributed to the next phase of the research?**

The latest phase of Super EDEN, involves a randomised controlled trial, which randomises people to either receiving the intervention or not. One of the concerns was approaching people and saying you might not get anything from this as you might not get randomised to the group getting treatment. The LEAP was very useful - we had a lot of discussion around that – about how to approach it and how to phrase it.

### **What has helped the LEAP to work well?**

It has mainly been down to the lead facilitator. He has been co-ordinating the LEAP since the beginning and he is a great leader and has a good relationship with everyone. Good communication is really important. We ring members up regularly to tell them what is happening at the next meeting. We're working with young adults – so we try to make it more fun and informal.

The numbers tend to go up and down – but there's a core group of people who have stayed throughout and we make sure to keep continuity. For example, we have created a log of what the LEAP has done and its' impact on the study. That keeps it concrete and we plan to publish what we've done.

What has kept the group strong is giving members specific tasks to do at the same time as being flexible and responding to their own ideas. Actually involving them in doing something constructive for the study makes them feel a real part of the bigger picture. One LEAP member has started working with researchers in her local area. Being part of the LEAP has been good for her CV. The service users / carers involved need to get something out of it as and they need to feel valued.

Most importantly though, the success of the group is down to the members themselves. They are a very articulate and dynamic group of people – the continuation of the LEAP speaks to their commitment as much as anything we've been doing.

### **How has working with the LEAP impacted on your personally?**

It has taught us what the experience of going through psychosis is really like. They were instrumental in that – which has informed our thinking on every aspect of the study.

## **Kirsty's experience**

### **How has the LEAP been working with the research team?**

I haven't been on the LEAP for a very long time, but in my view it's different to a steering group. The meetings provide an opportunity for us to reflect on our experience and bring that to the project – which gives the researchers insight into how they might improve their practice and what their findings appear to be saying. The LEAP is also a sounding board for ideas about where the research is going – we give our opinion on how valid we think that is.

### **How has the LEAP had an impact on the researchers' practice?**

One of the tasks the researchers asked us to do was to look at the patient information leaflet for the clinical trial. They wanted us to help write something snappy. The thing that ran alarm bells for me immediately was that the leaflet (which had already been given ethical approval) said right at the top that this was a study for people suffering from severe social disability. That may not be the most sensitive thing to hand a patient who's quite vulnerable!

That's the kind of thing that could send someone into a relapse, because you've thrown a horrible diagnosis at them that they might not even be aware of. You need to be able to understand someone's fears and concerns and be sensitive to where people are at. It's very frightening being really poorly and being given a diagnosis of severe mental illness - so you might make them angry or depressed. You don't want to send them off crying in a corner or even worse. These things might seem trivial to someone doing the research, but they are so important.

We were asked how we would present the information about the clinical trial to encourage people to take part - when some people would receive the treatment and some people wouldn't. We tried, but that's a hard thing to do. We were saying 'You've got to present this as important research that needs to be done'. We wished we could come up with a nice way of saying that people won't lose out – but that's not true – because some people won't get the therapy. The researchers wanted us to tell them how to sugar coat it – but we said 'You just have to be straight and at the same time be careful not to emotionally blackmail people into taking part.'

One of the positive things that came out of those discussions is that LEAP members are now going to work with local researchers in the five different regions where the study is taking place. So there will be more opportunities for us to provide advice on how they can present the research in ways that are acceptable to people with quite severe mental health issues – that's got to help people.

### **How has the LEAP contributed to the analysis of the findings?**

We were called to a meeting to talk about some of the research findings which the team were ready to develop into a paper – and they wanted our opinions. It was all about medication and their side-effects.

The researchers had come up with this expression that taking medication was a 'worthwhile gamble'. This was based on the views of the people they had interviewed

– but I have a problem with that and I expressed it at the time. I prefer the term ‘balanced risk’ - otherwise it implies something a bit indulgent.

We talked about a range of issues including some of the side-effects of medication that are quite personal, things that may be too sensitive to discuss in a one-hour interview with someone you don’t know. So that maybe gave the researchers more insight. Something else was then who takes responsibility for managing those side-effects. In my experience it gets batted back and forth between mental health services and GPs - so no one takes responsibility. Our exploring why that might be, will hopefully influence what is done with the research.

### **How has the LEAP influenced the outputs of the project?**

The LEAP members have all expressed their feelings and experiences around early intervention to help the researchers get a sense of whether the impressions they are gathering are justified. So inevitably we have reflected on the benefits and weaknesses of early intervention services – so the discussions have naturally evolved and now we are planning another meeting to look at issues around the development of early intervention and ways it could be improved. It’s not directly related to the research – but it’s exciting to be involved in that.

I think early intervention is fantastic but there’s a tendency to get stuck in celebrating its development and losing sight of that fact that there are things that could be improved. I was around 30 when I was first diagnosed and much older than the majority of people going through the service. The danger is that you focus on the service rather than trying to meet individual needs – we still need to improve the service so that it is tune with what the individual wants and needs.

My reason for being in the LEAP is that I wanted to see improvements in services – so if that’s something that comes out of our work I’ll be very happy about that. It’s all too easy for researchers looking from the outside to say this service meets service users’ needs and this one doesn’t. The frustration is that service users are expected to like the services that are delivered, without really finding out whether they do or not – so even to be asked is quite exciting.

So the LEAP is now partly about how you take the outcome of the research and use it to make a difference – which is the whole point – there’s no point in doing the research if it doesn’t help anybody.

### **What helps the LEAP to work well?**

It has been quite structured and the researchers are taking on board our observations and criticisms – which gives you a sense of hope for service user involvement. You can do your research, but unless you listen attentively to service users, the opportunities to develop the service are limited by your interpretations of the data.

The researchers have placed a lot of trust and respect in the group and have shown that they’re prepared to listen to what we have to say. Having leaders that genuinely believe in the value of service users’ opinions has been very important. Also the

service user researcher who developed the group and is advocating for the group has been very supportive and enabled the group to have more impact.

**What would you say to other service users about involvement in research?**

Service users must play a role in research. It a really important torch to bear for the future. If they don't take the time and opportunity to show the way by getting involved then they close the door to future developments. That tends to happen with mental health. Some people have the same view of recovery from mental illness as people used to have about leukaemia 20-30 years ago. That it's something you don't recover from – they tend to write people off. To enable more people to recover and for services to improve – we have to do the research. Researchers can talk 'til they are blue in face – but if their work is not meaningful to service users and carers the research won't get done, nor affect the changes that are needed to improve things.

**What would you say to other researchers about involvement in research?**

The goal for any research is to give people a better quality of life – if you can ensure that's what happens by involving service users then that's fantastic!

Historically service users' views have not been recognised as the precious things that they are. I've experienced the use of mental health services and it wasn't how I wanted it to be and I could tell you about that – but if you don't perceive there's a need to talk to me then you won't research it, you won't understand it better and you won't make improvements - because it will might never occur to you.

Don't involve service users for the sake of it – do it because there is something purposeful and useful for service users to offer.

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## **Case Study 7: A carer's experience of being involved in research**

**Who we spoke to:** We spoke to Philippa Lowe, a carer for her son who has schizophrenia. Philippa has been caring for her son for 16 years, since he was first diagnosed aged 20, during his final year at university. Philippa is a Trustee of Rethink Mental Illness ([www.rethink.org](http://www.rethink.org)) and is a member of the MHRN North London and South London & South East Hubs Carer Reference Group. She is a carer representative on the IMPaCT study (Improving physical health and reducing substance use in severe mental illness) and has been helping with the CRESTAR project which is looking at genetic testing in relation to suitability for treatment with clozapine. She used to work as a prison psychologist.

**The impacts of involvement on carers:** Being involved in research brings a number of benefits to carers including greater knowledge and understanding of their loved one's condition, support from other carers, opportunities to make good use of all their skills and expertise and to turn difficult and painful experiences into positive outcomes for others.

### **Philippa's experience:**

#### **How did you first get involved in research?**

As soon as I realised what was wrong with my son I got in touch with Rethink Mental Illness and have never looked back. Now a great majority of my time as a volunteer is taken up with Rethink. I'm a Trustee and I chair one of their committees. At one stage I heard about a conference for FACTOR (Families/Friends and Carers Together in Research – an MHRN network supporting the involvement of friends and family members in research) and I went along to it and it was very impressive. They had a series of talks by eminent people, and I learnt things I hadn't known about and we were talked to like serious professional people. We also discussed what it would be like to be involved and how we would like to be involved. I signed up there and then and ended up on the Carer's Reference Group in London and have been on that ever since.

Through the Carer's Group I became involved in the IMPaCT project. I'm one of the two carer representatives on that study. There's also a service user representative. I've been going to IMPaCT for a few years now. It's coming to an end this year. But because of that work I've got involved in a lot of other things.

#### **How have you been involved in the IMPaCT study?**

We go to a meeting about once a month. They are all beavering away in between – once a month there is a general research meeting where they pile everything in about where they are now and what are the difficulties – so it's about overseeing the whole thing.

There are a number of strands to the research. It's about physical health in psychosis. People with schizophrenia on average die about 20 years younger than the rest of us – more needs to be known about it and especially what to do about it.

One part of the project is to find out what happens to people, to actually put numbers and figures on it. They are following a cohort through from their first episode and seeing what happens to their weight, their diet, BMI, vitamin D levels and things like diabetes – finding out what happens when, and how long it takes.

The second part is an RCT is to test out an intervention, motivational interviewing, delivered by people's care co-ordinators. People will be randomised to care coordinators who have been trained in this technique or just their normal care as usual. That's very good because the one thing people with schizophrenia lack, is motivation. It's like very person-centred counselling – because everyone knows what you shouldn't eat and all that – and it's about working out what people want, even though people aren't motivated, just like my son. Well he is motivated to stay in bed, to watch the telly and eat chocolate biscuits – he's got strong motivations – just not the right ones! So it's working with people where they are...

### **What difference has your involvement made to the IMPaCT project?**

It's not always easy to know. Some of the time, especially early on when they were talking about very detailed things, you think 'What am I doing here?' Not that we couldn't understand them, but it was very much an admin meeting – like how many people have you tested and who dropped out and what happened in Sussex – very administraty! But then you find if you start to question things – they do seem really pleased. We do seem to help them see things in a different light even with a fairly small, simple input. They seem genuinely appreciative and often say 'Oh I see what you're saying', and go off on a slightly different track.

For example, we did a lot of work on the manual that was compiled on how to do the motivational interviewing and give health information to the clients. We were very pleased with that contribution and everyone was very pleased that we made it. Because when researchers write stuff it's not particularly user-friendly either for service users, or their carers or anyone. So we did a lot on that. We felt it was very important and they took notice of us – it was changed as a result.

We've also helped with other practicalities. If the researchers say, 'We'll get in the service users in in the morning for an assessment', we're able to point out that people with psychosis are not good at mornings because of the effects of their medication and you're more likely to get them to turn up to an afternoon appointment. The researchers wouldn't necessarily think of that.

Similarly, if the assessment involves taking blood, you have to remind researchers that their subjects are mostly suffering from some degree of paranoia. None of us like needles put into us – but service users might have extra reasons why they don't like it and may need more explanation or some kind of adjustment or an incentive.

And we're always banging on about getting the carers involved in this piece of work. We say 'They are your biggest ally. What do the carers think? How can you involve them? How can they encourage the subject to come forward at the right time or do the right thing?'

At the other end of scale, I've also been able to feed in the lessons from my son's experience. I fed in a remark that my son said to me quite recently. When my son

was first ill, I took him to a private psychiatrist, who said it was alcohol psychosis, which I didn't think could possibly be true, but my son encouraged this view at the time. He kept saying 'I've been ill because I've been drinking such a lot – I drink every night'. And I thought that just wasn't true. Since then, my son's been properly diagnosed. And I thought the reason why he said he had been drinking more than he had was because of the way his paranoia works. He's not angry with people out there. He's always angry and guilty about himself. Even now he's always blaming himself. But the other day, he said out of the blue 'Do you know why I always said I drank a lot at University and I didn't really, it's because I was beginning to find things difficult. Writing and reading was getting difficult and I had to find a reason so I blamed the alcohol. But it wasn't that was it?'

I was just staggered at this amazing insight. It shows he's getting better. But I also thought that it was really significant for the IMPaCT study, because the assumption is that everyone underestimates their bad habits and isn't honest with their GP about how much they drink. They've recently researched that and we all know that happens. But here's a person with psychosis exaggerating their drinking. It's startlingly obvious why. What a terrible thing to find out when you're 20 that your brain's going and you can't remember - it must have been absolutely terrifying for him. So I came out with this at the IMPaCT meeting. The lead researcher was there and he said to me afterwards 'That was a most important thing you said, I'd never thought of that', and he's a famous psychiatrist!

### **How is your involvement helping with the dissemination?**

There was a big conference and the researchers asked me to help with the presentation of the IMPaCT project. We each had a five-minute slot. They knew they could rely on me to do that, to present to this huge group and to say what I wanted to about the carer's role in my five minutes. That shows you are valued and part of the team.

I think it made a significant difference for me to be a presenter. I'm not blowing my own trumpet – there were some service users speaking as well and they just electrify the audience. The fact that you're not a researcher and they assume you're not used to talking and the fact you're telling them like it is – it amazes them. They are absolutely riveted and lean forward in their seat. I'm always being told 'Everyone appreciated your bit the most'. I'm under no illusion that it's because I'm a better speaker – it's just that I spoke at all. As a real person – you've got it made. There's something very powerful just in who you are.

### **What's helped your involvement to work well?**

The research team did put a lot of investment into helping us on board. A couple of them spent quite some time with us at the beginning explaining what the research was about. We also had a glossary of terms like RCT. That might be particularly important for someone who had less research background than me. I knew a bit about research from my career as a prison psychologist but even I found it a bit overwhelming I must say – because there're all the acronyms. The researchers are part of a big bureaucratic world, so you need to understand all that and they did it well.

Then for a while we always met them for 15 minutes before each meeting started. They were also quite keen to debrief us at the end - very informally – asking us ‘How was that? Was there anything you didn’t understand? Are you alright – are you coming to the next one?’ I don’t think it’s needed now, but it really helped at the start.

During the meeting themselves, there’s a set agenda and the carer and service user input used to be near the beginning. I thought that didn’t make sense if they wanted an overview on what they said. You need time to mull it over. So I asked about that and the researcher said ‘That’s interesting because we used to have it at the end, but so-and-so who was the previous representative was finding it difficult to stay for a whole meeting’. So they’d been responsive to another person, putting them at the beginning so they could say their piece and make a hasty exit – but for me and my colleague it worked better at the end. So that’s a learning point - and they were perfectly willing to accommodate us.

Perhaps the most important thing is that we are listened to very attentively and respectfully. That’s a reward in itself.

### **How has being involved in research made a difference to you?**

This has saved my bacon my really. The early days of all this were really horrible. Rethink helped me with understanding my son. It’s also set me on a new path in life – which has been tremendously helpful. The research work is just another branch of all the stuff I do. It has turned what was an awful tragedy for all of us - it still is tragic as I don’t think my son will fully recover - into something with a positive side. It gives me interest, activity, campaigning zeal – something to do all day – a feeling of doing some good and it is very, very interesting in itself.

We did a survey of the members of the Carer’s Reference Group to ask why we went and what we got out of it. The group’s views were that we got four main things out of it, one of which was information. Us carers are hungry and thirsty for information. We take any opportunity we can to find out what’s going on. We need to understand because most of us are parents or family members with responsibility for our loved ones – so we grasp any opportunity we can to get more knowledge.

The second thing is mutual support. However many interested friends and family you have, you do need people in the same boat to bounce things off. Either for information – I’ve heard about this drug, is it any good? – or just the emotional support. It helps to know there are people who are like you, who have something to do like you have - so you can feel you’re not alone in this.

Then it’s important to feel like you’re putting something back in. We feel from all our experiences we’ve got something to give and to offer – not just our caring experience, but all the skills and experience from our working lives. And you feel like you are doing some good in the world. And finally it’s an occupation and activity – but a relevant one. You can be active in a field in which you are an expert. We’re all busy - using our skills to change the world!

### **What are the next steps for you in terms of being involved in research?**

I've enjoyed doing this very much. So because of that I've taken other opportunities to get involved in more research. I'm already working on another project. The researcher involved me as a carer just twice. The project is about genetic testing. It's a very exciting development whereby they might be able to genetically test people's response to clozapine. It's the best drug for some people, but also potentially the most dangerous one. You've got to have lots of blood tests and monitoring which puts people off. So if they could pinpoint who could benefit and not be endangered, then many more people could benefit.

The researcher's been developing a questionnaire and explanatory leaflet for service users and carers. I did a lot of work on these questionnaires. They needed a lot of proof-reading, put it that way. It was overly technical. Also when you hear the words genetic testing, you do think 'Ooh-er'. Even I was thinking that and I asked myself why. I think there's a question about what bit of you do they take to do it. It turns out it's just a blood sample. The other thing you wonder is whether they would have some information about you that might do you some harm or is fundamental to your very being – I was able to point this out to him. People can do all this stuff for so long I don't think it occurs to them.

Anyway he's just emailed to ask if I would be involved in his carer research – so that should be really interesting - and he's also asked me to do some lecturing at his summer school for trainee psychiatrists. So it already looks like there will be lots of spin-offs.

I'd like to build up a bit of a reputation in mental health research then I can carry on. If one person's used you, they might spread the word. So I'm hoping more things will pop up from time to time...

## Concluding comments

Service user and carer involvement in research benefits the research itself as well as the individuals involved. Based on the lessons from these case studies it appears that involvement:

- Ensures research addresses the issues that service users and carers identify as being important and relevant – to ensure services better meet their needs and questions about their treatment and care are answered.
- Brings credibility to a research project amongst the service user and carer community, facilitating recruitment to the research and promoting greater interest and trust in the findings.
- Ensures that service users' and carers' questions are addressed through the project design, developing valuable lines of enquiry that might not have otherwise been considered.
- Ensures all written information about the project is accessible and speaks to service user/ carer audiences.
- Keeps the project grounded in reality so that expectations of participants are reasonable and the practical arrangements for participation reflect the interests and concerns of service users and carers.
- Identifies potential barriers to the research early on and helps with developing solutions – so that these problems can be avoided.
- Brings a wide range of skills to a project in addition to people's lived experience – as service users and carers also bring knowledge and expertise from their professional lives.
- Ensures any intervention that is developed to benefit service users and carers is better designed so as to reflect their genuine interests and needs.
- Enables research participants to feel more confident in sharing their experience and more likely to be open and honest – involving service users and carers as peer interviewers/ group facilitators helps '*to get closer to the truth*'.
- Allows any differences in opinion between professionals and service users/ carers to be discussed safely in working groups/ project teams and used to foster shared learning and a greater understanding – rather than leading to conflict.
- Engages a range of stakeholders in the analysis of qualitative data – correcting researchers' assumptions, providing the rationale for certain responses and enabling a richer interpretation of the findings.

- Leads to more powerful presentations – involving service users and carers as co-presenters can ‘*electrify audiences*’.
- Ensures research findings are more likely to be translated into action, to bring about change and make a difference to people’s lives – service users and carers place great emphasis on ‘*things getting done*’.
- Provides researchers with a more in-depth understanding of what it is like to live with a mental health problem – which can have a profound impact on how they approach all aspects of their research.
- Motivates researchers to move forward with their research, providing a sense of purpose and endorsing the value of what they do.
- Provides involved service users and carers with greater knowledge and confidence as well as validating their expertise – it enables them to put their make good use of their lived experience.
- Enables service users and carers to learn from their peers, to provide support to one another and an opportunity ‘*to do good in the world*’.



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