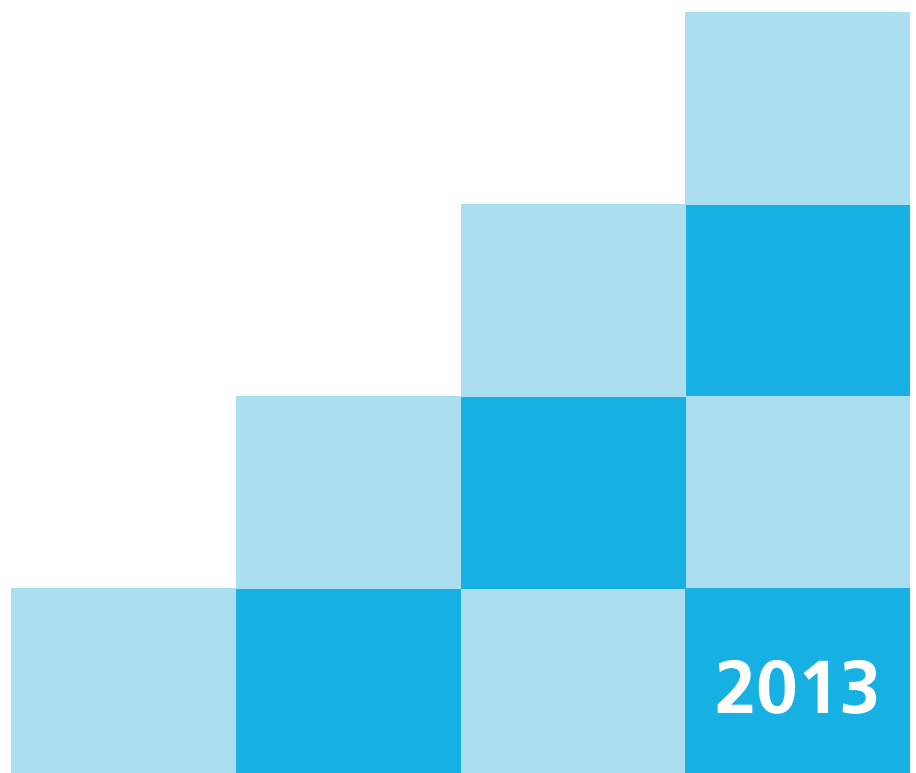


Improving Physical Health and Reducing Substance Use in Severe Mental Illness (IMPACT)

A case study on
carer involvement in
mental health research



Acknowledgements

This case study was written by Dr Sarah Robens, Anthropologist at Devon Partnership NHS Trust, on behalf of the Mental Health Research Network West Hub.

Project summary

IMPACT is a five-year programme grant from the National Institute of Health Research to support the development of a physical health intervention in people with severe mental illness.

IMPACT is a three-phase study. The first phase was a one-year study of the physical health and substance use of a group of people with first episode psychosis. The information gained from this study was then fed into the second phase, which saw the development of a health promotion programme aiming to change negative lifestyle habits, such as substance use and to encourage good nutrition and exercise. The effectiveness of this programme is now being assessed as part of a Randomised Controlled Trial (RCT) that 100 care coordinators and 450 patients are participating in.

The principal investigators are Professor Sir Robin Murray and Dr Fiona Gaughran at King's College London.

Carer involvement in this study

Carers have been particularly influential in stages two and three of this study. In stage two, the programme was defined by an expert panel including carers and service users. Carers were important in ensuring that the programme was feasible and practical to the carers who would be required to support their relative taking part in the study. Coming out of this programme was a manual for care coordinators, a reference guide and a service user handbook. All of these were co-written with carers.

In stage three of the study, the RCT, all decisions about the direction of the study have been made through a steering group which includes two carers and a service user.

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The mechanisms of carer involvement

In order to find the best way of working with carers, the research team contacted the MHRN for advice. The MHRN put the team in touch with FACTOR (Families/friends And Carers TOgether in Research), and they advertised for carers local to the project with a particular interest in the physical health of people with psychosis to join a carer reference group. Once set-up, this group held discussions around the topic with the research team, and after a few sessions, the group nominated two of their members to join the IMPaCT steering group. One of the researchers was also nominated to join the carer reference group to feedback to them.

This led to a two-way sharing of information. The carers group fed into the study through the steering group, and the steering group fed into the carers group through the nominated researcher.

“The carers provided a reality check to a programme that needed to be grounded in practice. ”

There is sometimes a danger that public involvement in research group meetings has little impact because such meetings can be full of jargon and overly complex terminology, and the research team have an ongoing involvement in the project that those coming in to a meeting will not have. In this particular case, however, particular steps were put in place to ensure this did not happen. The carers met with a member of the research team before and after early steering group meetings to ensure that they were in a position to fully partake in the meetings. Before the meetings, the researcher would fill them in on any recent developments, and clarify any potential jargon or technical language that would be used. After the session, the researcher would debrief the carers, ensuring that they had said all they wanted to say, clarifying anything necessary and providing emotional support if needed. Once the carers had attended the first few meetings, they felt that it was no longer necessary, but it played an important part in ensuring early involvement.

The carers involved in the study have reported how warm, welcoming and helpful the research team have been. They have greatly valued the induction given to explain the study and the terms used, and how they have been kept informed throughout. These carers have felt very much part of the team and hugely appreciated for the work they have put in.

The reasons the research team wanted to involve carers

When putting together the physical health support programme, it became very clear to the research team that it would not work for service users if it did not work for carers. There would be little point in promoting good nutrition, for example, if the person with whom the service user lived and ate with did not also recognise the importance or have the knowledge to ensure a healthy diet. There was also clearly the need for carers to support and encourage behaviour change, such as exercise. Above all, the carers were seen as a test of validity. They are there day in and day out, and can say what is practical and what is not.

The carers provided a reality check to a programme that needed to be grounded in practice. And the carers involved had been recruited because they were particularly interested in this particular area. They could therefore see what the problem was and had a lot to add to how the problem should be considered. By bringing in the carer perspective, the researchers were able to consider the world beyond the service user more closely, thus ensuring the psychiatrists understood and included the wider contexts that impact on physical health behaviours.

Impacts of carer involvement on the research

The feedback from the researchers is that the carers were “hugely influential to the project”. Their input covered “the whole project”, and they had a big impact on the decisions made and how the project moved forward.

The carers also recognised their own impact on the research, which goes some way towards demonstrating how well they knew the project, the decisions made and how they were made, and so could recognise what it was they were doing as part of the project. In terms of specific impacts, they reported the following:

- putting together the training manual,
- suggesting a group was set up to support carers who are part of the trial,
- explaining about the best ways to engage and support service users (for example, not underestimating the level of fear that may be felt in asking someone to do something unusual, or considering the difficulties people have in getting up in the morning and so arranging for sessions later in the day),
- speaking at conferences,
- giving insights into substance misuse and self-reporting of substance use,
- providing a link with other projects.

The motivations of the carers to get involved, and the impacts of their involvement

When asked about their motivations to get involved in research, one carer said, “the prime motivation for joining research is information. The way I and some of the others got into it was – there was a conference, three or four years ago – it was run by FACTOR. It was a really good conference, with some fantastic academic speakers. We were so impressed because they were talking to us as equals. That made a huge impact. If you are treated like a proper researcher and thought to be able to talk about these ideas then, I thought, I’ll have some of that.”

Information on mental health

Information is a key motivation for carer involvement. As one carer said, “carers are hungry for information, at any point really, but especially early on in the journey. The whole thing is baffling and huge and they don’t tell you things straight. You’re in the dark – the medication – why has this happened – is it your fault?” Being involved in research is a way of getting information, and also of influencing the type of information you can get hold of.

Mutual support

The carers provide support to each other. They listen to each other’s stories, empathise with each other’s situations and provide information and advice. This support is hugely important and decreases feelings of isolation.

Giving something back

There is a sense from some carers that they feel that they have something to offer others. They understand the difficulties faced by service users and carers, and feel they can offer something to try and change those difficult experiences.

As one carer said, “we have benefited by our links with others, we are usually well down the road and we think we can put something back in. We want to help other people with our experience.”

Engagement and activity

As one carer reported, her life has completely changed since her child’s diagnosis, and her life has revolved around that diagnosis. Getting involved in research gives added purpose to her life. “It takes you somewhere far from the tragedy, while it is still there.” The research is also something she can share with her child, something that they can both engage with.

Learning from the study

What is learnt by carers during their involvement in this study, for example the benefits of exercise or the impact of vitamin deficiencies and so on, can be adopted to become part of the recovery of the person they care for.

Lessons to be learnt from this study

- Finding carers who are particularly interested in the focus of a piece of research can help maximise the impact of involvement.
- Involving more than one carer in a research study can ensure that the carers involved are able to support each other.
- Mechanisms can be put into place to ensure that carer involvement is not tokenistic or lost during researcher-led steering groups. Examples of these from this study include meeting with carers before and after meetings.
- Encouraging carers to update a group of other interested carers on the progress of the research study can help publicise it more widely. In addition, the group of interested carers can provide support to the involved carers and offer their views on the research study, which the involved carers can feedback to the study team.
- Carers involved throughout a research study as a steering group member gain considerable knowledge about the research topic and methodology. The research study may benefit from carer involvement in other roles not previously considered, for example in delivering training and speaking at conferences.
- The carers bring their experience and knowledge gained from involvement in other groups to the study. In this case for example, a carer brought her knowledge of a project being run by Rethink Mental Illness about pathways to physical health to the study group.



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

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