

# WE ARE FACTOR... a network of 160 people who have experience of supporting a relative or friend who has a mental health problem. We are willing to share our experience and knowledge with researchers to help them plan the practicalities of their projects, and to carry out their research in a more realistic and relevant fashion.

FACTOR was set up by the Mental Health Research Network (MHRN), which is part of the government's National Institute for Health Research. The MHRN supports research projects that are recruiting participants through NHS services throughout England. Any researcher working on an MHRN-supported study can ask FACTOR for advice.

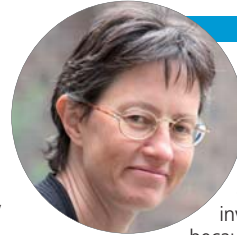
The FACTOR members featured on this poster are part of a Carer Reference Group that meets once a month in London to advise on research projects. Other members of FACTOR go to focus groups, or one-off consultation meetings, or sit on committees and steering groups that meet regularly. Anyone who does work for FACTOR is paid for the hours they put in.



**Philippa Lowe**

**'I don't think researchers always realise what carers do and how much we know about services and about our relatives – the people who use services.'**

'We are experts by experience in two ways – we support a relative, usually a child, and have personal knowledge about coping practically and emotionally. But we also all have expertise from our professional jobs or from other roles in our lives. I'm retired now, but I was previously a forensic psychologist in the prison service.'



**Ruth Hennem**

**'As carers, we have so much knowledge about the difficulties and problems people face on a daily basis. We can contribute a lot to research projects.'**

We know basic simple things – when researchers talk about getting people to a clinic for a simple blood test, for example, they don't realise the potential problems involved in organising that. I got involved in research because I wanted to find out what was going on, about anything new that might be able to help my sister. It's hard to find out about research unless you are involved.'



**Diana Orr**

**'I joined FACTOR because I was very interested in getting involved in the practical side of research. I think there is so much to learn about mental illness, and that drugs are not the only answer. I'm a retired nurse and because of my background, I don't find what the researchers say hard to follow. I find it all very interesting, and would like to get more involved. I think if psychiatrists and researchers always involved carers, they would get a much better picture.'**

**Angela Fiori**

**'We probably know an awful lot more than many psychiatrists because we see people on a daily basis and you get to become a real expert.'**

You learn so much over the years, and sometimes it all seems a bit negative, so for me, getting involved in research is about putting what you have learned to some positive use. It makes you feel as if you are doing something useful with all that knowledge you have.'



**Josie Forshaw**

**'Psychiatrists don't have a clue: they don't know what it's like to live with an illness. As carers, we often know far more than they do. Being involved in research means we help them, but we also learn things that might help us. One of the reasons I wanted to get involved was to find out more about genes. I have two grandchildren born to two people with schizophrenia, and I want to find out what to expect in future.'**



**Mary Grant**

**'It's important for carers to get involved in research because a lot of what researchers write doesn't always make sense, it sometimes reads as gobbledy-gook. Researchers don't always understand the nitty-gritty of life. We are straight talking, with a lot of common sense. We use normal language and we know what will work and what won't work. Our role is to make things relevant, to make their proposals practical so they get good results.'**

If you would like to join FACTOR, or want to find out more about how we can help research teams, contact our coordinator Geraldine Mason, geraldine.mason@kcl.ac.uk or 020 7848 0643.

**Dr Stefania Bonaccorso** is a psychiatrist and researcher at the Institute of Psychiatry, King's College London. She regularly attends the FACTOR Carer Reference Group in London as its co-facilitator.

'Being part of the Carer Reference Group is incredibly valuable to me as a researcher,' she says. 'Although a research question might be a good idea, it may turn out not to be do-able for very practical reasons that we as researchers may not have thought of because we are coming from a different perspective.'

'I've previously worked with families in a clinical setting but here the interaction and the balance is completely different. In clinical work, I was counselling, advising and directing. At the FACTOR meetings, we are there to work together. The meetings are a safe and stimulating working environment. I've learned a lot by working with this Group. I think carers are an immense resource that we as researchers often do not use.'



**REFOCUS**

REFOCUS is a five-year research programme about personal recovery, looking at how mental health services in England might change. Funded by the NHS National Institute for Health Research, REFOCUS has several strands, and the research team is developing ways of helping mental health professionals extend their knowledge and skills to better support the personal recovery of people with mental health problems.

REFOCUS has set up a 'Lived Experience Advisory Panel' (LEAP) made up of people who have direct personal experience of mental health problems and carers. A member of FACTOR sits on this group, which meets every

six months or so and is chaired by John Larsen, who works for the mental health charity Rethink.

**John Larsen says:** 'I think it's really important to have carers involved in research. People with serious mental health problems are often dependent on other people during their day-to-day lives, and we need to see this side of the picture and acknowledge the importance of that perspective.'

'LEAP is a group where service users and carers can input on the research. At all the meetings so far, researchers have been present – everyone wanted to meet directly, to discuss and comment. They wanted to hear from the horse's mouth rather than have cold comments.'

'The research team gives a very considered and meaningful response to the suggestions made by members of the group. There was a suggestion to supplement the data collection with focus groups of carers, for example, but it was decided not to do that because of the particular focus of the study, and a lack of resource to expand this accordingly. But the discussion in itself was helpful because there was reflection on what can and can't be done, and also a raising of awareness among researchers of the need to consider carers' role in future studies.'

• To find out more about the REFOCUS programme, visit [www.researchintorecovery.com](http://www.researchintorecovery.com)

**MHRN Clinical Research Group**

Two members of FACTOR are part of one of the Mental Health Research Network's 'Clinical Research Groups' (CRGs), funded to develop research on the needs of carers of people with severe mental illness. The CRGs bring together academics, clinicians, people with experience of mental health problems and their family members from all over England to discuss ideas for research in a specific area, and produce proposals. Each CRG works together for two years.

This Group is chaired by Professor Elizabeth Kuipers, who works at the Institute of Psychiatry, King's College London.

Professor Kuipers and colleagues are currently preparing an application for funding for a research programme that will develop and evaluate services designed to support family members who offer support to people

with psychosis, and the two FACTOR members are co-applicants on the bid.

**Professor Kuipers says:** 'I've asked them to be co-applicants after working with them through the CRG.'

'On the CRG, their personal experience has helped formulate ideas that can be turned into research projects that are relevant to them and carers like them. Researchers might be able to do this by themselves, but it's much better to check out ideas from the beginning with people who are experiencing problems, and to develop ideas together with people who know what the realities are. They can also help to prioritise which ideas might be really useful, and stop you going down blind alleys. They help shape our thinking. I think my understanding of carers' problems is quite good, but it's not the same as personal experience.'

• Read more about Clinical Research Groups at [www.mhrn.info/pages/clinical-research-groups.html](http://www.mhrn.info/pages/clinical-research-groups.html)



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**IMPACT**

The five-year IMPACT programme focuses on the physical health needs of people with mental health problems. One of the studies in the programme is a trial testing a support package designed to help people with psychosis take better care of their physical health and cut down on cannabis and alcohol.

A group of FACTOR carers met every two months for a year to discuss the practicalities of that specific trial, focusing particularly on motivation and sharing their first hand knowledge of the potential difficulties. As a result, the research team decided to enlist the help of family members and friends who are supporting

participants on a daily basis: carers of people recruited to the trial are now invited to small group meetings where they are given information about the study and can discuss what they can do to encourage the person they support to change to healthier lifestyles.

FACTOR carers also helped edit parts of a training manual for care coordinators, and information for people recruited to the trial. They advised the research team about language, advocating printed material that was jargon-free and easily understandable for both participants and the care coordinators who would be working with them. They

felt it was important for the material used by mental health professionals to be written in plain English to encourage them to speak in the same way.

Two members of FACTOR continue to regularly attend IMPACT research team meetings.

**Dr Fiona Gaughran says:** 'We wanted to have very active carer comment on our research, about how realistic the proposals were, about issues that are barn-door obvious to carers but that researchers may not have thought of. We wanted to listen and adapt protocols and plans in the light of carers' insights.'

• Read more at [www.mentalhealthcare.org.uk/schizophrenia](http://www.mentalhealthcare.org.uk/schizophrenia)

