

Expert review: NIHR Mental Health Research Network (MHRN) and its Patient and Public Involvement (PPI) activities

Reviewers:
Dr Frederick
Frese and
Dr Edvard
Beem.
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2010, London.

Purpose of the review: to provide an expert opinion on MHRN PPI activities to date and to find out how these activities compare with involvement work undertaken by research organisations within the USA and The Netherlands; to provide suggestions on how the MHRN might improve involvement activities.

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Executive summary

On 4th & 5th November 2010 an independent review of NIHR MHRN PPI was undertaken by expert international reviews (Dr Frederick Frese and Dr Edvard Beem). Over 2 days the reviewers met and interviewed a variety of people involved with MHRN PPI activities. Relevant MHRN PPI documents were also reviewed. MHRN PPI activity was rated as excellent and an example of best practice. In relation to PPI activity in the USA and The Netherlands the MHRN compares well. The practical support at project level is ahead of The Netherlands. It was noted that without MHRN PPI there would be a considerable loss of empowerment of both patients and carers. Compared to the degree of involvement of users and carers in mental health research in the U.S.A., England is far ahead and activity in England is systematically developed and implemented.

Recommendations include: increased dissemination of involvement work; increasing “public” input and interaction with user groups throughout the UK; increasing training provision; consideration of staff workload and more use of the dispersed network for national work; a more integrated approach for service user and carer involvement and increasing feedback on good practice to the centre from the local networks.

Background

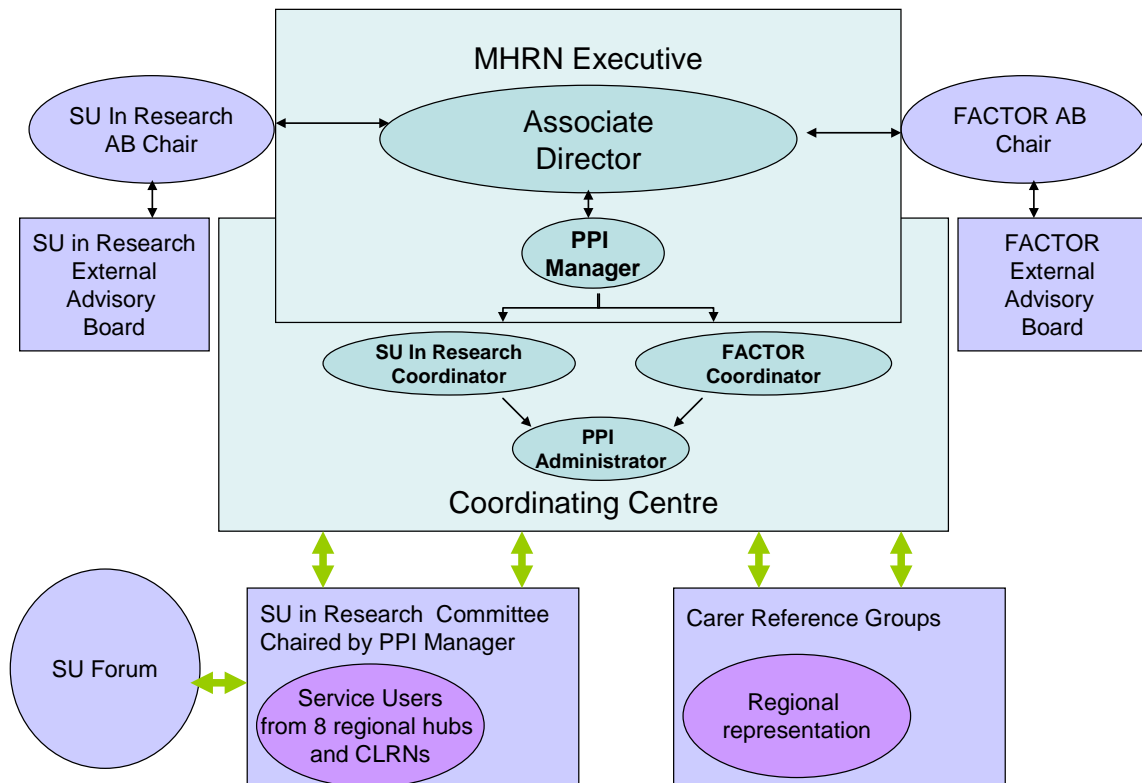
The NIHR MHRN was established in 2003 and is an organisation that makes trials/studies within the National Health Service (NHS) happen in England. The MHRN supports but does not fund research projects and involves people who are experts by experience as an integral part of everyday work. The support offered includes helping research teams to recruit participants, introducing researchers to people with personal experience of mental health problems who can act as advisors or collaborators; matching research teams with mental health professionals who are willing to act as co-investigators or help recruit; and helping smooth the bureaucracy necessary to set up research projects. The network currently provides support to over 300 projects recruiting participants through mental health services run by more than 60 NHS organisations.

The MHRN is one of a number of clinical networks in England that are part of the Department of Health's National Institute for Health Research (NIHR). The MHRN is led by the Institute of Psychiatry, King's College London and the University of Manchester. The network supports both publicly-funded research studies and projects sponsored by industry. The day-to-day business is carried out through 8 regional offices (hubs) that geographically cover the majority of England. Hubs work closely with NHS trusts providing mental health services and university-based research teams within their geographical boundaries. Each hub employs a team of clinical studies officers (CSOs) who help recruit participants to projects.

The MHRN makes contact with people who have experience of mental health problems and their families to encourage them to get involved with mental health research projects. Involving people in research is one of the network's top priorities. Support for involvement is provided at different levels through each hub and from 2 organisations within the NIHR MHRN Coordinating Centre – Service Users in Research and FACTOR (Families/Friends Together in Research). The majority of hubs have a dedicated member of staff to work and support people with mental health problems and their family members who want to get involved in the work of the regional office or in studies locally. At the Coordinating Centre there is a PPI manager and coordinators for Service Users in Research and FACTOR.

PPI Structures

In 2008 FACTOR and Service Users in Research were brought into the MHRN Coordinating Centre. Structures were put in place to ensure connectivity between the centre and the regional hubs to ensure national and local PPI activities complemented each other. The resulting structures for PPI are shown in the diagram below.



Introduction to the review

Two independent international reviewers; Dr Frederick Frese and Dr Edvard Beem, were invited to conduct an expert review of MHRN PPI activity.

Frederick J. Frese III, Ph.D. is a psychologist with over forty years experience in public mental health care and is presently coordinator of the Summit County Recovery Project, serving recovering consumers in the Akron area. For fifteen years, until his retirement in 1995, Fred was Director of Psychology at Western Reserve Psychiatric Hospital.

He is also a consumer, diagnosed with schizophrenia as a young Marine Corps officer. Despite his disability, he was able to gain a degree from the American Graduate School of International Management in Phoenix, AZ; and a doctorate in psychology from Ohio University.

Fred founded the Community and State Hospital Section of the American Psychological Association and is past president of the National Mental Health Consumers' Association. He currently holds a clinical faculty appointment in psychiatry at Case Western Reserve University and is an associate professor of psychology in psychiatry at the Northeastern Ohio Universities College of Medicine (NEOUCOM). He has recently been serving as vice president of the National Alliance on Mental Illness, having left the national board in 2009. He is on the Board of Scientific Advisors for Schizophrenia Bulletin.

He has authored many articles and book chapters and has lectured widely on the subject of schizophrenia. He is also a strong advocate for the involvement of people with mental health problems in all aspects of research.

Dr. **Edvard BEEM is the Director** of the Netherlands Organisation for Health Research and Development (ZonMw). The Netherlands Organisation for Health Research and Development is a national organisation that promotes quality and innovation in the field of health research and health care, initiating and fostering new developments. ZonMw also actively promotes knowledge transfer and implementation, ensuring knowledge is exchanged between all relevant stakeholders (health researchers, health professionals, patients/consumers and the general public). This in turn facilitates the structured implementation of newly developed knowledge in the health care system and guarantees a place for emerging health care issues on the research agenda. In short, one of ZonMw's key challenges is to facilitate innovation and inspiration among the various stakeholders along a single 'knowledge continuum': from basic, strategic and applied research to daily health care services. ZonMw acts as an intermediary between policy, research and practice. The majority of ZonMw's commissions come from the Ministry of Health, Welfare and Sport (VWS) and the Netherlands Organisation for Scientific Research (NWO). The Ministry's main concern is to contribute to public health, including prevention and health care services. NWO is a non-governmental organisation concerned with fundamental and strategic research. As the national research council, it plays a key role in the development of science, technology and culture in the Netherlands.

After 5 years of operation the MHRN underwent a review by the Department of Health. The aims for PPI in the 5 year renewal report were as follows.

- To broaden the scope and capacity of research in mental health, including the full involvement of service users and carers as well as frontline staff.
- Consistently promote a positive image of mental health research via a range of PPI initiatives.

This expert review by Dr Frederick Frese and Dr Edvard Beem examined MHRN PPI activities to date to evaluate MHRN progress towards the above aims. The MHRN PPI work stream has not been independently reviewed previously or benchmarked against other international research organisations. The main aim of the review was to obtain an international benchmark, to evaluate value for money and make recommendations for future improvement. The reviewers compared MHRN PPI activities with involvement activities within the U.S. and The Netherlands. Reviewer recommendations are made to help the MHRN build on current work and develop future PPI plans.

The reviewers were provided with background information on MHRN PPI activities. Additional documents related to MHRN PPI activities were provided during the review [see appendix 1]. Over 2 days, 4th and 5th November 2010, the reviewers met and interviewed a variety of people involved with the MHRN [see appendix 2]. These included representatives from study teams, hubs, clinical research groups etc., from different areas of England.

Remit of the review

- To provide an expert opinion of MHRN 'Patient and Public Involvement' activities to date and compare these activities with involvement work undertaken by research organisations in the USA and The Netherlands.
- To suggest how activities involving people with experience of mental health problems; their families and the general public can be improved and particularly in both commercial and non-commercial studies.

Comparison to PPI activities within the USA – Dr Frederick Frese

Compared to the degree of involvement of users and carers in mental health research in the USA, my meetings with the MHRN personnel, examination of the excellent MHRN website and review of printed materials provided, led me to conclude that England is far ahead of the USA in involving carers and users in mental health research activities. Furthermore this activity in England is considerably more systematically developed and implemented than it is in the USA. This may, in part, be due to England's Health and Social Care Act of 2012 and other regulations requiring the NHS to involve and consult patients.

Although the U.S.A. does not have a similar national mandate, the U.S. Federal Public Health Services Act does have a requirement that states include consumers' and family members' involvement in planning, implementation and evaluation of mental health services. However, according to the 'Grading of the States' report by the National Alliance on Mental Illness, (Honberg, R., et al, 2006. *Grading the States: A report on America's health care system for serious mental illness*), in practice "involvement of consumers and families in various aspects of the mental health system (planning, implementation, and evaluation) is token at best" (p. 20).

Regarding staffing the MHRN, having full-time, doctoral-level, coordinators for both the service user (Dr. Kabir) and Carer (Dr. Mason) research activities is exemplary. Having oversight of the country's mental health research activities organized by dividing England into eight geographical "hubs" is an effective approach to assuring that users and carers are increasingly involved in research activities. I was particularly impressed by the degree of dedication and enthusiasm shown by the MHRN Director (Professor Wykes) and the Associate Director (Professor Szmukler) as well that shown by the users, carers and indeed virtually all the MHRN personnel interviewed.

Regarding mechanisms for providing information to the public and dissemination of results, I was very impressed with the high quality of the MHRN web-site. Particularly noteworthy is the constant focus on the importance of communicating the results of research findings "in plain English".

Comparison to PPI activities within The Netherlands – Dr Edvard Beem

ZonMw is the Netherlands Organisation of Health Research and Development, including health care innovation. In its core business ZonMw is a funding organisation, managing about 80 national programmes. Those programmes vary in size, mode (responsive or managed), approach (open or thematic) and nature (scientific or applied). Funding decisions in all programmes are based upon peer review methods. Both quality and relevance (to the objectives of the programme) are the main criteria for funding projects.

Patient/consumer participation is one of ZonMw's cross-cutting issues, in principle applicable to all programmes. ZonMw considers active commitment by patients/consumers as necessary for any research and development. Making use of the personal expert patient experience is a prerequisite; the overall aim to promote the implementation of research results into health care practice. However, realising this vision in our practice raises a lot of important issues to address, such as developing open minded researchers, empowering patients, and the consideration of the role of patient organisations. ZonMw acts mainly on programme level meaning participation of patient/consumers is limited to participation in our programme committees. Each programme committee is responsible for the design, execution and evaluation of one programme or a set of interrelated programmes.

In our programme committees we categorise patient involvement into six different levels. Patients/consumers might be asked (1) to inform; (2) to be consulted; (3) to give advice; (4) to act as co-producer; (5) to co-decide in the funding of projects (6) to self-govern (parts of) the programme.

ZonMw supports patient/consumer participation by various means. First we developed and published guidelines for patient participation in scientific research. We also published guidelines and a good practice toolkit for grant applicants on how to involve patients in the design of the projects. We run two programmes dedicated to patient participation in research, quality and policy. Finally, we support a community of personal experience experts.

The main differences with the MHRN are obvious. Besides the special focus on mental health MHRN is not a funding organisation, but supports research projects that are carried out with the help of people who use NHS mental health services. The support that is offered includes helping research teams to recruit participants, introducing researchers to people with personal experience of mental health problems either as patients or carers who can act as advisors or collaborators, matching research teams with mental health professionals, and helping to smooth the bureaucracy necessary to set up research teams, sometimes also on ethical approval.

Overall, MHRN offers practical services on a project level, while ZonMw acts on a strategic programme level to allow the patients perspective to be considered. The MHRN is geographically distributed over eight local hubs across England and has a small coordinating centre; this enables the MHRN to offer practical support and services at both local and national level.

Based on the material that was provided to us and the many interviews with the various stakeholders the overall conclusion is that the MHRN is doing an excellent job with its PPI activities. Being involved at the project level on the 'working floor' they are ahead of The Netherlands, where such practical services are not provided. The enthusiasm and commitment of the various groups of stakeholders is striking, and in many cases even very touching. Without MHRN-PPI there would be a considerable loss in the empowerment of many patients and carers, in many cases giving sense to their lives. It is hard to quantify, but on a qualitative basis one might not be surprised if the support of PPI did not prevent a lot of health care costs which would otherwise be spent on "lost souls".

The broad and warm support by all stakeholder groups is striking. Qualitatively, there appears to be an excellent return-on-investment. Regarding the six different stages of patient involvement mentioned above, in most cases MHRN participation is at level three or four, in some cases the highest level is achieved. ZonMw considers the PPI activities as an urgent and essential element in patient participation, thereby facilitating implementation of research results into health care delivery. MHRN is a shining example of a "best practice".

Initial feedback

Following the 2 review days the reviewers met with the core MHRN PPI team to provide initial feedback. The reviewers concluded that they were very impressed with the work of the MHRN and that the Network had taken user and carer involvement in research further than in the Netherlands, and much further than the USA (where there is no system for involvement). They were moved by some of the accounts by users and carers of the acceptance of their involvement.

The reviewers noted that in such a large organisation there is a risk that a high burden of work will fall on a few and care must be taken to ensure people are not overloaded with work. Initial suggestions for overcoming this included more involvement by the hubs with the coordinating centre. It was noted that carer involvement is different from service user involvement; the MHRN should focus on a more integrated approach. The need to disseminate information about the excellent involvement work was highlighted. Informing people about the work of the MHRN will ensure good PPI practice proliferates.

Recommendations

The overall view is the MHRN appears to be making substantial inroads into having users and carers involved in research activities. There were areas that could be improved such as information giving and workload structures.

Provision of information

- Increase use of the MHRN website is encouraged through expansion of the content. Practical content such as a map of MHRN hub boundaries would assist those outside the network.
- Consider use of video content. Videos such as impressive YouTube one of Mr Hindle would help members of the public to better understand the nature of these, often episodic, emotional conditions.
- Good practice should be highlighted and more use made of case-studies and reports which outline how users and carers have been involved. A particularly good and impactful example of this work is the report entitled "Who decides the definition of a good outcome?" Increasing such reporting could have a subtle effect of encouraging researchers to increasingly involve users/carers in their projects.
- Awareness by MHRN staff of the activities of more radical groups of users in the UK needs to be raised. These groups can sometimes be influential in the political arena, and listening to their concerns could be a valuable form of receiving "public" input.
- The value of MHRN-PPI for policy and politicians might be more intensified, emphasizing the great value as an indispensable link in (mental) health care innovation.
- A more systematic selling of the MHRN unique selling points might help to reach out more into researcher communities. For this purpose, a feedback loop of successes and best practices from the hubs back to central offices might be intensified.
- Funders of the research projects are encouraged to develop funds for the implementation of research results into daily health care services.

Workload and structures

- A risk factor in the organisation is the heavy workload of the small central office, being dependent on only a few highly dedicated members of PPI staff. Opportunities to devolve some national work to local hubs should be explored.
- The programme for carer involvement is separate from service users. Carer involvement is not managed through the hubs and is possibly a cause for the under-contribution of carers in research. A more integrated approach is recommended.

Other

- Conducting training for users about research is important. But universities should be encouraged to accept persons in recovery from mental illnesses into formal degree programs, so that users can increasingly have opportunities to become research professionals. For too long many of these educational programs have discriminated against persons with these conditions.

In addition to reviewer recommendations individual comments and recommendations from interviewees were recorded by the expert panel. Interviewee recommendations are in appendix 3.

Concluding statement

The involvement in this external review panel has been a very fruitful and learning experience. The transparent, open and sincere way in which the external panel could work is very much acknowledged. This way of working resulted in this review being really independent and free of any outside pressure.

Appendix 1 – NIHR MHRN documentation provided to the reviewers

- Background document prepared for the reviewers and provided in advance of the review.
- NIHR MHRN PPI workplan Jan 2010 – Jan 2011
- NIHR MHRN Payment policy
- NIHR MHRN Researchers Toolkit
- Working Together, A PPI Framework for the NIHR MHRN
- FACTOR INVOLVE conference poster
- NIHR MHRN Good Practice Guidance for involving service users
- Leaflet: Who decides the definition of a good outcome
- Leaflet: FACTORing the views of caregivers
- Leaflet: People make research possible
- Leaflet: mental health problems affect all of us
- Leaflet: BBC rarely covers depression research

Appendix 2 – Interviewees

Over 2 days the reviewers met and interviewed a variety of people involved with MHRN PPI activities to gain different perspectives on MHRN work.

Interviewee	Role
Joanne Ashcroft	MHRN PPI manager
Jackie Barrett	Service user hub representative
Toby Brandon	Researcher
Stephanie Burns	MHRN assistant director
Marta Buszewicz	MHRN primary care lead and researcher
Sue Collinson	Service Users in Research advisory board chair
Simone Farrelly	CRIMSON trial manager
Josie Forshaw	Carer
Mary Grant	Carer
David Hindle	Service user hub representative
Thomas Kabir	MHRN Service Users in Research coordinator
Helen Killaspy	Researcher
Elizabeth Kuipers	Professor at Institute of Psychiatry and convenor of the carer research group
Philippa Lowe	Carer
Geraldine Mason	MHRN FACTOR coordinator
Rosemary McCabe	Researcher
Joy McPherson	Carer
Jessica Nagar	MHRN north London Hub deputy manager
Tony Rivett	MHRN east Anglia hub based carer
Jackie Smart	MHRN heart of England hub development worker
Jane Smith	Freelance journalist
Poonam Sood	IMPACT trial manager
George Szmukler	MHRN associate director for service user and carer involvement
Til Wykes	MHRN director

Appendix 3 – Individual recommendations

The following comments and recommendations are made by individual stakeholders in the interviews – see below. These were noted by the expert panel

- The relation between the coordinating centre and the hubs needs careful consideration; communication appears to occur on the basis of persuasion, lacking any type of authority powers; no sanctions are in place in case the hubs do not respond to the central messages.
- Researchers seem poorly engaged in the services of the coordinating centre, one mail per month by researchers requesting for help seems modest; apparently most of the service is being delivered to the researchers through the hubs.
- The involvement and engagement of researchers and service users can be improved; to reach out to the research community a more systematic communication of successes, break-throughs and best practices might be helpful; researchers might be encouraged to better communicate their needs for a useful service user involvement. Also, more attention might be given to the feedback of experiences, in order to organise a kind of “learning mode” for researchers and service users.
- Although not a responsibility of MHRN-PPI, one feels the lack of the funding for the implementation of research outcomes into care practice.
- One claims that the access to interesting carers might be increased, by creating a pool of people that stimulate each other’s engagement.
- The positive outcome of the emancipatory training of service users to become “researchers” might be followed up more intensively.
- The support of MHRN in obtaining ethic approval by ethic committees is highly appreciated.