Research Update

For reprint orders, please contact reprints@future-science.com

CLINICAL INVESTIGATION

Developing support for mental health clinical research: the Mental Health Research Network experience

Clin. Invest. (2012) 2(5), 459–463

Research can improve people's health and well-being, and its use to guide the nation's health is written into UK NHS policy. The National Institute of Health Research supports research in the NHS through clinical research networks like the Mental Health Research Network (MHRN). The MHRN supports research working collaboratively with people using services and those providing them. It supports studies that are based within mental-health services, social-care services and within primary-care services, irrespective of methodological approach. The network helps researchers screen participants for eligibility, recruit participants, conduct assessments, collect data and liaise with clinicians to promote the value of research. The MHRN provides online resources about how to involve people using services and their families and friends in research, and on how services can support and engage with research. It also helps private companies recruit participants in the NHS.

Patrick Callaghan*[1], Anthony David[2], Shon Lewis[3], Max Marshall[3], George Szmukler[2], Til Wykes[2], Joanne Ashcroft[3] & Stephanie Burns[2]

[1]School of Nursing, Midwifery & Physiotherapy, University of Nottingham, Queens Medical Center, Nottingham NG7 2HA, UK
[2]Institute of Psychiatry, King's College, London, UK
[3]University of Manchester, Manchester, UK
*Author for correspondence:
E-mail: patrick.callaghan@nottingham.ac.uk

Keywords: advice • engagement • research • resources support

The NHS is the primary provider of healthcare to the UK's population. The NHS Constitution expresses the principles and values of the NHS [101]. The NHS Operating Framework [102] is the annual business plan for the service. The need to promote and conduct research to improve the existing and future health of the population is enshrined in both the Constitution and the Operating Framework. It is through research that health services make discoveries and make these discoveries matter to people's health and wellbeing. The National Institute for Health Research (NIHR) identified that several health topics required specific support and set up six topics, one being in mental health. The Mental Health Research Network (MHRN) supports research conducted in England, working collaboratively with people using services and those providing them. For research to have this impact it requires a high level of engagement from staff working at all levels and from people who use the services. The purpose of this article is to describe the role of the MHRN in supporting clinical research and provide examples of how this support is used in practice.

The NIHR

In 2007, following the publication of Best Research for Best Health [103], the UK Government formed the NIHR with a vision to "improve the health and wealth of the nation through research." The NIHR is the mechanism through which the Department of Health in England funds and supports research in the NHS.

Support for research in the NHS is provided by Clinical Research Networks that support the growth and delivery of well-designed research [1]. There are six disorder-specific networks, one of which is the MHRN.

FUTURE SCIENCE part of fsg

10.4155/CLI.12.40

ISSN 2041-6792

The NIHR MHRN

The MHRN is managed through a partnership between the Institute of Psychiatry, King's College London and the University of Manchester. It has an executive board led by a Director with overall responsibility for its governance and five associate directors who have lead responsibility for a specific area of activity, including NHS engagement, patient and public involvement, information systems, performance and industry engagement. The Network has eight regional hubs that cover the whole of England, capturing approximately 60% of the population. The hubs work with 34 NHS Trusts (hospitals), 40 Primary Care Trusts and approximately 20 university partners with research expertise in primary, secondary and social care. The MHRN also works closely with the devolved countries of the UK [2].

■ The importance of research

Research that impacts people's health and wellbeing, requires a high level of engagement from staff working at all levels of the NHS and from people who use NHS services. The MHRN's Engagement Strategy recognizes that engagement involves highlighting the importance of research to all staff, emphasising this to key decision-makers and people using services, and using engagement champions to influence others. The Strategy shows the MHRN's approach to improve NHS engagement in research in mental-health services with explicit milestones and deliverables around setting a national benchmark for engagement in research, engaging decision-makers by communicating the value of research to senior staff and professional associations, engaging service users and carers to influence Trusts' research activity, improving the visibility of research by showcasing Trusts that are exemplars of research engagement, identifying and developing engagement champions to promote research, working with NHS assessment and improvement bodies to incorporate research engagement into their assessments and increasing the number of industry-sponsored studies.

■ Support in practice

The MHRN enables research projects into mental health to happen within the NHS in England and it does this through working with researchers, mental health professionals, people with experience of mental health problems, their families, and research and development staff based in NHS trusts. The Network supports studies based within mental-health, social- and primary-care services irrespective of methodological approach. Multicenter and multisite projects, and small single-site pilot studies, whether publicly or industry funded, are supported by the MHRN.

The MHRN provides resources to researchers on how to involve people using services and their families and friends in research. It also provides information to R&D Managers on how they can support research within their Trusts. The Network provides health professionals with information on how they can become involved in research and advises researchers on how to make their research a success. The MHRN also helps private companies recruit participants in the NHS. Anyone interested in these resources can access them at the Network's website [104].

■ Support, allocation & advice

Researchers seeking support from the MHRN must first have their study adopted. A noncommercial study is likely to be adopted if the proposed research addresses issues of high scientific quality that are useful to the NHS. The studies are also required to have stringent ethical review and external peer review. The studies are usually funded by NIHR partners who fund high-quality research, but it is also possible for non-NIHR partners to have studies adopted if they comply with all of the requirements. Once the network adopts a study it is allocated to Hubs where recruitment is required for multicenter studies, which will be at several locations.

Support from the Hubs is provided by Clinical Studies Officers (CSOs). CSOs often have a background in a mental health-related subject and will have undergone additional training that the Network provides, such as training in symptom assessments. The CSOs help researchers screen participants for eligibility, recruit participants, conduct assessments, collect data and liaise with clinicians to promote the value of research and enlist their help in participant recruitment [2]. The CSOs are an invaluable source of advice on all aspects of conducting the study.

To date, the MHRN has supported 499 studies; at the time of writing 178 of these studies are currently recruiting. These studies encompass most mental-health conditions and originate from all corners of the country (Figure 1) and recruit across the age range. Figure 2 shows the recruitment to studies in the last 5 years.

■ Good practice examples of how the MHRN supports research

There are many examples of how the MHRN supports research. For instance, a pilot scheme run by the MHRN in East Anglia matched the interests of trainee psychiatrists to research studies being conducted in this region. The trainees were able to assist in reviewing patients for inclusion, gained experience in research and increased their knowledge of the early stages of psychosis.

An important challenge in mental-health research is recruiting sufficient participants to trials of nondrug treatments. A multisite trial comparing collaborative care for people living with depression with care as usual (the CADET study [105]) is supported by the MHRN hubs in the west of England, north-west and north London in partnership with the Primary Care Research Network. This support helped researchers recruit to the target of 550 participants and improve the external validity of the study by recruiting from representative services.

Support from the MHRN helped researchers deliver the TRACK study investigating the transition of mental health care from adolescence into adulthood [3]. TRACK identified a gap in care, showing that 33% of young people receiving mental-health care from child and adolescent mental-health services fell through a gap in care provision once they became working-age adults. TRACK has led the Child and Mental Health Observatory to recommend that all child and adolescent mental-health services have a dedicated transition lead as a solution to closing this gap.

Notwithstanding the differences in the studies cited above, they all have one thing in common. As evidenced from the feedback from the Principal Investigators, without the support from the MHRN it is unlikely that these studies would have succeeded. Thus, important sources of evidence might have been lost to the mental health community.

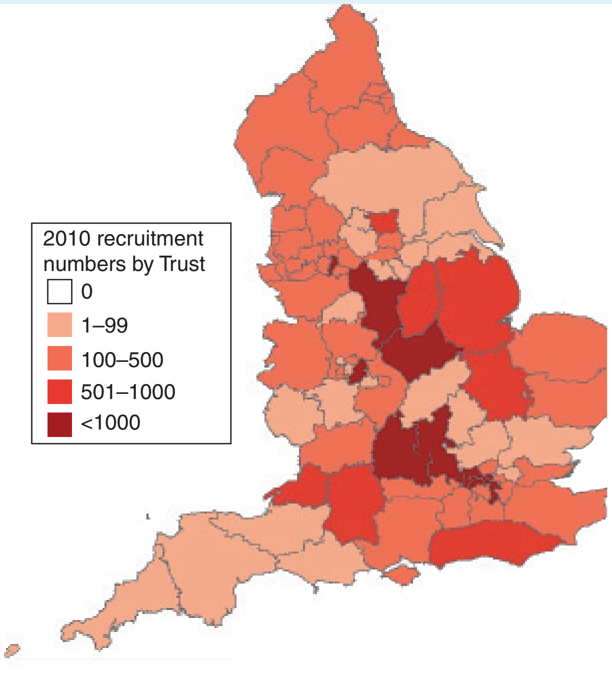

Figure 1. Numbers recruited to studies by Trusts in 2010.

Support to researchers: feasibility & support to timely recruitment for research

Feasibility and support to timely recruitment for research (Fast–R) is a service that the MHRN offers to researchers seeking quick access to specially trained mental-health service users for advice on how to write clear and easily understood participant information sheets, consent forms and recruitment plans. It is hoped that by using Fast-R researchers will secure quicker ethical and research governance approvals and MHRN adoption. Fast-R can be accessed at the MHRN website [106].

Working collaboratively with service users & their families & friends in research

A key concept driving the provision of health services in the UK is patient involvement in decision making, encapsulated by the idea ‘there will be no decision about me without me’. NIHR MHRN recognizes the important role that service users and their families and friends can play in research and actively encourages them to consult, collaborate and work in partnership with researchers, or take the lead on projects. It does this by linking them through hubs to research in their region. To encourage researchers to involve service users and their families and friends in research, the MHRN has published good-practice guidelines and a toolkit against which researchers (and others) can assess how well they are involving such groups. These resources, as well as resources for family members, friends and carers, and the toolkit for involving service users, can be found at the MHRN website [107–109].

While it is still early days in service user involvement in research, an independent evaluation commissioned by MHRN reported that all the studies randomly chosen for examination had service user involvement, but the nature and degree of involvement varied [110]. In total, 40% of studies had service users involved in research steering groups and approximately 60% made an impact on the design of the research through influencing, for example, the questions to be addressed by the study, the choice of outcome measures and practicalities (questionnaire

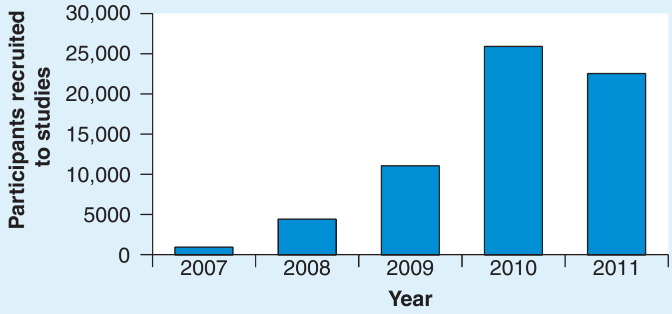

Figure 2. 5-year participant recruitment numbers to Mental Health Research Network adopted studies.

length or time spent undergoing intrusive interventions). Many studies involved service users in writing lay summaries of research. Despite the positive examples of service-user involvement that emerged from this work, researchers reported several obstacles to involvement: a lack of time and resources; a lack of experience on how to involve service users; a lack of clarity about what was expected; difficulty in finding the right service users; managing the employment and human-resource issues; dealing with service users' ill-health and overcoming negative attitudes to involvement among colleagues. NIHR MHRN provides support for involving service users in research that should help researchers overcome these obstacles.

MHRN has also recently provided some important information for researchers on outcomes in a study called 'Making Outcomes Matter' [4]. This study captured service users' views on the use of outcome questionnaires in common use for evaluating the effectiveness and benefits of a mental-health treatment. Such measures can show whether there is an improvement or deterioration in a person's state of mental health. Despite the widespread use of questionnaires, and their potential benefit, many service users questioned their relevance in capturing their experiences. Making Outcomes Matter invited 25 service users to an expert panel review that examined two areas of questionnaire use; measures of depression and social functioning, and measures of psychosis and quality of life. The results revealed that some of the most widely used measures got the lowest rating from service users. The exercise also found that, contrary to popular belief among researchers, service users were prepared to complete long questionnaires; they questioned whether short questionnaires could capture the range and complexity of their experiences. They also concluded that negative, as well as positive, effects of treatment should be considered. It is hoped these findings will be the catalyst for the development of questionnaires that are more meaningful to service users as well as alternative measures of capturing service users' experiences that reduce the bias in using questionnaires.

Working with industry

NIHR MHRN is committed to increasing the number of industry-sponsored studies – mostly clinical trials – in its portfolio; currently it has 21. Such studies are essential if new or improved medications and technologies are to be made available to patients [5]. This is a challenging commitment. Conducting large-scale clinical trials is often costly, the bureaucracy in carrying out these trials is often complex and service users and clinicians sometimes appear unwilling to participate in such studies. In their discussion paper on the partnership between industry and the MHRN, David and Williams report the mental health community's misgivings about the pharmaceutical industry owing to suspicions about the concealment of data on negative outcomes, disproportionate inducements to staff and concerns that the industry seeks to pathologize distress [2]. However, working closely with industry has many potential benefits. It allows the MHRN to help shape studies in order to ensure they are of relevance to the concerns of the NHS, its clinicians, researchers and service users, it provides access to a strong service-user voice that is often receptive to working with industry, it can help industry access expert, experienced and receptive clinicians and helps industry develop incentives that do not compromise professional ethics.

Conclusion

The MHRN offers invaluable services and resources to the research community and those seeking involvement in mental-health research. Future aims of the MHRN include getting all of the mental-health workforce more interested in scientifically cutting-edge research (i.e., including nurses and other health professionals not just doctors) and on the other hand, carrying out quality research into under-represented topics such as the effectiveness of nursing approaches. Increasing the engagement of services in research, in particular industry studies, remains an important MHRN objective.

Future perspective

The MHRN has made a substantial contribution to improving the quality of research and its support to researchers has helped generate evidence that is making a difference to people's mental health and well-being. Despite these successes, challenges remain in increasing the number of industry-sponsored studies, increasing the number of Principal Investigators from nursing and the allied health professions, increasing the level of research engagement in mental-health Trusts and extending the levels of involvement of service users, their families, friends and carers in research. Addressing these challenges forms an important part of the MHRN's objectives in the foreseeable future.

Acknowledgements

T Wykes would like to acknowledge the support provided through the National Institute for Health Research Biomedical Research Center for Mental Health at the South London and Maudsley NHS Foundation Trust and Institute of Psychiatry, King's College London, UK.

The authors acknowledge the help of S Chopra from the Mental Health Research Network in providing statistics for this paper.

Executive summary

- The need to promote and conduct research to improve the existing and future health of the population is enshrined in both the NHS Constitution and the NHS Operating Framework.
- The Mental Health Research Network (MHRN) helps researchers screen participants for eligibility, recruit participants, conduct assessments, collect data and it promotes the value of research.
- Since its inception the MHRN has supported 499 studies, including commercial and noncommercial studies, that in the last 5 years have recruited 64,483 participants of all ages from all NHS Trusts in England.
- A key objective of the MHRN is to increase the number of commercial studies and those led by nurses and allied health professionals.

Financial & competing interests disclosure

The authors are contracted on a paid basis to the National Institute for Health Research Mental Health Research Network as Director (T Wykes), Associate Directors (P Callaghan, A David, S Lewis, M Marshall, G Szmukler), Assistant Director (S Burns) and Deputy Assistant Director (J Ashcroft). The authors have no other relevant affiliations or financial involvement with any organization or entity with a financial interest in or financial conflict with the subject matter or materials discussed in the manuscript apart from those disclosed.

No writing assistance was utilized in the production of this manuscript.

References

Papers of special note have been highlighted as:

■ of interest

■■ of considerable interest

1 Darbyshire J, Sitzia J, Cameron D *et al.* Extending the clinical research network approach to all of healthcare. *Ann. Oncol.* 22(7), 36–43 (2011).

■ **Seminal paper describing the origins of the Clinical Research Networks in England and illustrating how they support research.**

2 David A, Williams B. Industry sponsored clinical trials and the Mental Health Research Network. *Pharmaceutical Physician* 18, 6–10 (2008).

■ **Supporting industry-sponsored research is important and a challenge in mental health. This paper examines the value of such research to people's mental health and well-being.**

3 Singh S, Moli T, Ford T, Kramer T, Weaver T. Transitions of care from child and adolescent mental health services to adult mental health services (TRACK Study): a study of protocols in Greater London. *BMC Health Serv. Res.* 8, 135 (2008).

4 Crawford MJ, Robotham D, Thana L *et al.* Selecting outcome measures in mental health: the views of service users. *J. Ment. Health* 20(4), 336–346 (2011).

■ **Report of a study led by mental-health service users that helps us rethink the use of questionnaires to collect data on the efficacy of treatment on outcomes for service users.**

5 Wykes T, Marshall M. Reshaping mental health practice with evidence: the Mental Health Research Network. *Psychiatrist* 28, 153–155 (2004).

■ **Shows the potential of the Mental Health Research Network to influence the quality of mental-health care.**

■ Websites

101 Department of Health. The NHS constitution (2012). www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_132958.pdf

■■ **An important strategic paper enshrining the importance of research in promoting the nation's health and well-being.**

102 Department of Health. The Operating Framework for the NHS in England (2011). www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_131428.pdf

103 Department of Health. Best Research for Best Health: introducing a new national health research strategy (2006). www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4127153.pdf

104 The National Institute for Health Research, Mental Health Research Network. www.mhrn.info/pages/what-we-do.html

105 The Collaborative Depression Trial. https://penctu.pcmd.ac.uk/cadet/AboutCADET.aspx

106 The National Institute for Health Research, Mental Health Research Network. Fast-R service. www.mhrn.info/pages/fast-r-service.html

107 The National Institute for Health Research, Mental Health Research Network. Resources for people who have personal experience of mental health problems. www.mhrn.info/pages/people-with-experience-of-mental-health-problems.html

108 The National Institute for Health Research, Mental Health Research Network. Resources for family members, friends or carers. www.mhrn.info/pages/family-members-friends-or-carers.html

109 The National Institute for Health Research, Mental Health Research Network. Toolkit for researchers. www.mhrn.info/data/files/FOR_RESEARCHERS/Toolkit/TOOLKIT_COMPLETE.pdf

110 Staley K. An evaluation of service user involvement in studies adopted by the Mental Health Research Network (2012). www.mhrn.info/data/files/MHRN_PUBLICATIONS/REPORTS/Service_user_involvement_evaluation.pdf

■■ **Excellent article providing evidence on how collaborating with service users can make a fundamental difference to the quality of research.**