



Mental Health
Research Network



National Institute for
Health Research



PEOPLE
make mental
health research
possible

The Mental Health Research Network is funded by and part of the National Institute for Health Research (NIHR), and is one of the Topic Specific Networks of the NIHR Clinical Research Network.

All sorts of people make mental health research possible.

It's not just researchers, scientists and people with academic backgrounds who are involved with studies seeking to develop better treatments and services for people with mental health problems.

People with experience of mental ill health and their families play a crucial role, as do mental health professionals who work in NHS services that can be developed and improved as a result of research studies.

Many projects could not take place without the participation of people who are unwell – and sometimes people with no experience of mental health problems as well. The information they all give can help researchers find out more about different conditions and illnesses, and try to work out why some people are more at risk of becoming unwell. Information given by people who use services can lead to changes that make those services more effective and more efficient.

The eight people featured here are involved in research through the Mental Health Research Network, an organisation that supports research studies carried out in England with the help of people who use NHS services and people who work in them. The Network is funded by the government's National Institute for Health Research (NIHR) and is known as the NIHR MHRN.

The eight people you will read about have all been given an award by the NIHR MHRN for the significant contribution they have made to research studies supported by the organisation.

There are eight NIHR MHRN offices throughout England known as 'Hubs'. To find out more about the work of the NIHR MHRN, or how to get involved in studies supported by your local Hub, visit www.mhrn.info

JUNE WAINWRIGHT

June Wainwright has experience of mental health services from many different perspectives. She worked as a mental health social worker, supporting people with mental health problems and their families. She worked for a mental health NHS Trust as a project manager charged with getting service users and carers involved in planning services and research studies. And she has been a user of mental health services since her teenage years.

When she retired three years ago, she became involved in mental health research supported by the North East Hub of the NIHR MHRN.

June has completed a PhD that she undertook part-time while working as a mental health

social worker, so knows about the process of

research. She has now suggested that the North East Hub set up a scheme that will offer training in research skills to service users and carers who want to be part of research projects. 'It's important for service users and

carers to get involved in research – they can contribute ideas for studies that will make a difference to them, and they can advise on how to carry out research in a more human way to take account of the particular vulnerability of people who are participating, for example. But service users and carers need to learn how to do research, about ethics, about confidentiality, research methodology, about systems and scientific rigour.'

June volunteered to participate in a study supported by the Hub that is seeking to find out more about bipolar 2 disorder, the diagnosis that she has been given. As well as giving information regularly and keeping a daily mood diary, she is feeding back to the team of researchers the pros and cons of being a participant, and making suggestions for improving the experience. She is acting as an advisor, putting the participants' point of



view, for another study investigating treatment-resistant depression. 'I'm really acting as an advocate for participants,' she says. 'People who are not well can't always speak up and won't necessarily be strong enough to say what they think or ask for help. Generally speaking, the research teams really want to listen to what I have to say. It is not just tokenistic involvement.'

Service Users in Research was set up to involve service users in studies supported by the NIHR MHRN and June is a member of the Committee that plans its activities. There are members from every area covered by the NIHR MHRN. She is also a member of the North East Hub's Executive Committee, which takes the lead and oversees NIHR MHRN activities within the Hub's geographical boundaries.

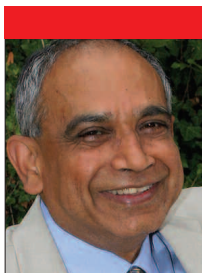
LAWRENCE RATNA

Dr Lawrence Ratna was a psychiatrist for 43 years. For 35 of them, he was based in Barnet in north London, working in the community with people with mental health problems and their families.

Four years ago, he returned to Barnet, Enfield and Haringey NHS Foundation Trust in a changed role, spearheading NIHR MHRN-supported research projects that recruit people from mental health services run by the organisation.

'There is a lot of paperwork and there are many meetings involved in setting up and running research projects. It takes a huge amount of time to steer them through the organisation and get clients and care professionals involved,' he says. 'Research can be a drain on clinicians' time and it is hard to do research on top of the demands made by the services themselves. What I do is to make sure involvement in the projects doesn't add to their workload.'

More importantly for him, his role also involves working closely with people who agree to take part in the research projects. 'In the UK, there is no payment for participation in research. It's a gift relationship – patients and their families



are giving their time, and I think it's very important they have something in return, and that it is an increased amount of attention.

'They are able to ring and meet with me if they have worries or queries about the research, and I make

sure they understand what they are doing and feel comfortable. It is very important that people who take part in research give informed consent, so I spend time with patients, talking to them, and to their families and their significant others, explaining the purpose of the research and what they will do if they agree to participate.'

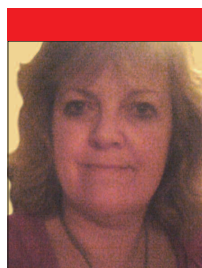
The NIHR MHRN-supported studies recruiting from services run by the Trust are varied – from drug trials to finding out more about the quality of life and quality of relationships that people with schizophrenia have.

Research has featured throughout the whole of Lawrence's career in the NHS. In the 1970s, he was involved in setting up the UK's first 24-hour crisis service. 'At the time there was enormous opposition to community-based care and we needed to validate our work through research,' he said.

For the NIHR MHRN North London Hub, he liaises with commercial organisations keen to recruit research participants through NHS services and is also a member of the central NIHR MHRN Adoption, Advisory and Allocation (3As) Committee that decides which studies the Network should support.

ANGELA HAWKE

Angela Hawke led the team that set up early intervention services for the whole of Cornwall in 2004. One year later, the newly created team was invited to take part in the National EDEN study (NEDEN), a NIHR MHRN-supported research project seeking to gauge the effectiveness of early intervention services for young people experiencing their first episode of psychosis. The Cornwall team was one of five services based at different



sites that agreed to help recruit people with psychosis who were willing to give researchers information about themselves and their mental health. 'Members of the early intervention team recruited 126 clients to the study, explaining the research

to them and asking if they were willing to take part. The NEDEN research team shared our office and worked as part of our team,' said Angela.

The early intervention service is run by Cornwall Partnership NHS Foundation Trust and offers support, advice and treatment to young people aged between 14 and 35 who have experienced a first episode of psychosis. 'We also do a lot of health promotion work and projects aimed at raising awareness of the service,' she says. 'Much of our work is creative and innovative and outside the boundaries of traditional mental health services, trying to reach young people.

'We work in partnership, for example, with a theatre group and our clients were involved in creating a play about psychosis that toured schools. We put on a play in the local jail and are making an underwater film about psychosis that will go on YouTube. All of this work involves our clients and aims to explain what psychosis is to young people, and promote the importance of getting help as early as possible.'

Angela's first experience of mental health services was in an old-style psychiatric hospital where she worked as a nursing assistant. She signed up to train as a mental health nurse and started a career that has involved work both in hospitals and the community.

'The work with the NEDEN study was the first time I had been involved with a research project,' she said. 'NEDEN was the first major National Institute for Health Research-funded mental health study to take place in Cornwall, and involvement in the study has helped to promote a strong research culture within the early intervention service and the whole Trust.'

Services run by Cornwall Partnership NHS Foundation Trust now take part in 10 studies supported by the West Hub of the NIHR MHRN.

TONY MORRISON

Professor Tony Morrison has been hiring people with experience of psychosis to be part of his research teams developing new treatments and support for some years. 'It doesn't matter what interests academics have from a theoretical point of view, or

what interests clinicians have...if the research is of no use, or not relevant to users, it's not good. By employing people with psychosis and saying "this is an essential criterion for the job", we are ensuring studies are relevant to people who have the most vested interest.'



Tony is a professor of clinical psychology at Manchester University and also works at Greater Manchester West Mental Health NHS Foundation Trust where he was charged with setting up early intervention services, and runs a psychosis research unit.

Now a large programme of research funded by the National Institute for Health Research seeks to find out ways of best supporting

service users who are rebuilding their lives, and develops earlier work carried out by two service user researchers he employed. The RECOVERY programme is supported by the NIHR MHRN – as is the recently started ACTION trial testing the effectiveness of cognitive behaviour therapy for people with psychosis who are not taking medication, and the EDIE-2 trial, evaluating specially adapted cognitive behaviour therapy for people who are at risk of experiencing a first episode of psychosis.

Service users are involved in all three of these projects, either hired as consultants, or employed as researchers. 'Most of them have no formal background in research, though some have degrees,' said Tony. 'We offer them regular supervision and they learn on the job.'

In addition, the RECOVERY programme and ACTION trial teams have set up advisory groups of service users who meet regularly to offer advice on how to carry out the research, taking account of the mental health needs of participants. A member of the NIHR MHRN's North West Hub team comes along to these meetings and offers support.

The Network's North West Hub 'provides all sorts of valuable support that makes conducting research less problematic,' said Tony. 'Recruitment is one of the biggest headaches of research. Participants have to be recruited through care co-ordinators or services, and it is not always easy to get your foot in the door and talk to busy teams of mental health professionals about getting involved in a trial. Clinical studies officers employed by the Hub do a lot of work on recruitment and that frees up research staff to spend more time on the project.'

JO GREENWOOD

In 2009, Jo Greenwood organised the nuts and bolts of the NIHR MHRN's annual Scientific Conference where researchers from across England came together to share ideas and progress on different projects. It was a huge feat of event management: the conference lasted for three days and there were 300 delegates, most needing accommodation and transport, all of them needing food. She arranged online booking, travel arrangements for speakers, an opening reception and a gala dinner, and also set up her own system for monitoring income and expenditure to make sure the books balanced.

Jo is administrator at the East Midlands NIHR MHRN Hub, a post she has held since 2004. In the past, she had worked for several different companies



in the private sector in PA and secretarial roles before becoming a full-time mother. After five years at home, she signed up for an IT course to refresh her skills and then went back to work as a part-time PA for Dr Hugh

Middleton, who carries out mental health research at the University of Nottingham. 'It was the first time I had worked for a university, and the first time I had worked in the field of mental health,' she says. Hugh Middleton became involved in the newly launched NIHR MHRN Hub, and so did Jo – she is now a full-time employee there.

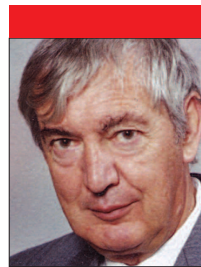
Her job is mostly office-based in the university building that houses the East Midlands Hub. Hub staff and researchers turn to her when they need to know information about bureaucratic procedures and systems that govern the NHS, and she often investigates the best and speediest way of solving particular conundrums. Having been there from the start, she now has an extensive network of contacts to call on for advice. Her role is also to support

staff employed by the Hub, answering their queries, helping them sort out problems and organising pay and travel expenses. She is responsible for monitoring budgets and reporting on the financial state-of-play to the Hub Executive. She organises and supports Hub Executive and other meetings, and helps 'guide and support service users and carers who become involved in Hub business. I attend their meetings and help with the administration of any projects they are undertaking,' she said.

TONY RIVETT

Tony Rivett was a teacher for all his working life. When he retired from his position as deputy head at a large comprehensive school a decade ago, one of the things he did was to sign up as a volunteer in his local hospital's accident and emergency department, where he helped to direct and comfort people. 'I learned a lot about how the NHS operates and found it very rewarding to work with some extremely committed people in the health service,' he says. He was invited to voice a lay person's point of view at different hospital committees overseeing research projects, and from there was asked if he would like to get involved in the work of the NIHR MHRN East Anglia Hub.

Having supported his son for many years, his experience as a member of a family affected by mental health problems brings a



real-life perspective to the table. 'When I was a deputy head, I was seconded to various placements in the private sector,' he said. 'I learned that in the private sector, the customer is king. The companies I worked with made their money by constantly referring to customers, and that dialogue made sure their products sold. They knew that people could always go and buy products elsewhere

– but that’s not the case for most of us in education and in health. In both education and health, there is largely a captive audience, and there is not the same tradition of saying to customers, “how can we change?, how can we make our services better?, how can we involve you?, your views are important to us.”

‘People who use services, and their families, should be consulted about and involved in research projects that can lead to service developments and new treatments. Mental health research ultimately can lead to much more effective services, and it’s important that lay people are involved in that process to make sure the end product is what they would like to see.’

Tony is a member of Experts in Experience, a group of service users and carers in East Anglia who are consulted by different authorities and organisations about projects to do with health and social care. He is also involved in Suffolk Respite, an organisation that offers respite care to people with caring responsibilities.

For the NHR MHRN, Tony is the Carer Representative on the East Anglia Hub Executive, a member of the East Anglia Hub Service User and Carer Group, and a member of the Advisory Board of FACTOR (Families/Friends Together in Research), the NHR MHRN’s national network of carers interested in mental health research.

JACKIE SMART

Jackie Smart introduces potential partners in research: people with experience of mental health problems, academics and mental health professionals.

Jackie is service user development officer for the NIHR MHRN’s Heart of England Hub. ‘I try to encourage service users to be engaged in the research process,’ she says. ‘This could be commenting on, or critiquing literature, or at the other end of the scale, coming up with research ideas and working in collaboration with researchers. I also work with researchers keen to support service user engagement and

I try to match people in terms of their interests, expertise and skills. Some service users who are interested in research are academics who have been ill, there are other people who are re-skilling themselves, others who have a contribution to make because of their experience.’

She took the post a year ago and has spent much of the first 12 months making contact with, and enthusing, service user groups as well as researchers and professionals working in the universities and health services based within the area covered by the Hub. ‘Some service users are understandably cynical after years of tokenistic involvement and we want to change that view,’ she says.

Jackie has knowledge and experience of how the NHS works through her involvement with Sandwell Mental Health and Social Care Foundation NHS Trust where she was appointed as a non-executive director four years ago to represent the voice of service users. She also knows about academia – in 2002 she became involved in Suresearch, a network of service users in research and education, which is supported by the Centre of Excellence in Interdisciplinary Mental Health at the University of Birmingham.

Her association with both the Trust and Suresearch grew out of an involvement with service user groups that started after she became unwell in 2000. ‘Both Sandwell NHS Trust and Suresearch have really helped and supported me,’ she says.

She is passionate about research because it can, she says, really prompt change and make services better. Over the past year, she has organised a series of seminars to bring researchers, clinicians and service users together and from those meetings have come the seeds of 10 collaborative research projects. ‘My next task is to move those ideas forward,’ she says.

MARK HAYWARD

Mark Hayward is director of research for Sussex Partnership NHS Foundation Trust, an organisation that runs mental health services for people living in the county. In this post, he is encouraging mental health professionals employed by the Trust and people who use services and their families to take part in research projects supported by the NIHR MHRN.

Taking part in studies supported by the NIHR MHRN can benefit service users and their families in the longer term in two ways, he says. Firstly, the results of the individual studies can add to greater understanding and lead to better services and treatments. Secondly, their participation can help reap more research studies in future as the Trust builds up contacts, expertise and financial support for research. 'The South London and South East Hub of the NIHR MHRN helps us understand the landscape of research funding,' he said. 'The Hub



helps broker our relationship with researchers who hold grants for NIHR MHRN-supported studies and helps us learn about funding opportunities. Ultimately, we want to apply for grants to carry out our own research studies that address local needs, research that can make a difference to services and people's lives.'

The Hub funds two research nurses who work in the Trust's services full-time, helping to recruit participants to NIHR MHRN-supported studies and explaining to mental health professionals why taking part in research is important.

Mark trained as a clinical psychologist and used to work in community-based services for people with mental health problems, while carrying out research to try to understand more about the voice-hearing experiences that are associated with psychosis, and find ways of alleviating some of the distress this can cause. He worked with people with psychosis to help them have a more balanced relationship with the voices they hear, rather than be abused or frightened by them.

Nowadays he works half the week at Sussex Partnership NHS Foundation Trust and the rest of the time at the University of Surrey as a tutor on the postgraduate Doctorate in Clinical Psychology course, training clinical psychologists of the future.