



Mental Health
Research Network

NHS

National Institute for
Health Research

People make mental health research possible



The Mental Health Research Network is part of the National Institute for Health Research and supports studies in England.



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 have experience of mental health problems – and sometimes people with no experience as well. The information they all give can help researchers find out more about different mental health problems, and try to work out why some people are more at risk of becoming unwell. Information given by people who have treatment and use services can lead to changes that make those treatments and services more effective and more efficient.

The eight people featured here are involved in research projects through the Mental Health Research Network (MHRN), an organisation that helps make studies and trials happen in England – with the support 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 officially called the NIHR MHRN.

The eight people you will read about have all been given an award by the MHRN in 2011 for the significant contribution they have made to research studies supported by the organisation.

They have been nominated by the eight MHRN regional offices (known as 'hubs') to receive a 2011 MHRN Associate Award.

To find out more about the work of the MHRN, visit www.mhrn.info or contact your local hub. The addresses are listed at the back of this leaflet.



Jon Wilson

Jon Wilson's first taste of research was at the beginning of his career as a psychiatrist, and it was a 'lonely and isolating experience'. After a year as a forensic research fellow at Edinburgh, he had collected his data, but then secured a clinical job in Cambridge. He took his research with him and ended up analysing the information and writing up the results on his own, with no formal support. 'I hated it: it was soul-destroying,' he says. 'All my academic aspirations went out of the window: I thought I am never going to do that again.'

Nowadays, however, his view of research has completely changed – he has become an extremely enthusiastic advocate and encourages other psychiatrists working at Norfolk and Waveney Mental Health NHS Foundation Trust to get involved with studies and trials. He has played a key role in setting up and supporting a research department within the Trust, and so much progress has been made, he says, that 'we are now beginning to run our own research projects.'

His change of heart came after staff at the Mental Health Research Network East Anglia Hub speculatively contacted him a couple of years ago: they were in search of psychiatrists in Norfolk who were willing to collaborate on a research project the Hub was supporting. Jon initially said no, but was persuaded otherwise by promises of support and help if there

were problems. Since then, Jon has been involved in many of the MHRN-supported studies recruiting participants through services run by the Trust.

When the MHRN first got in touch, Norfolk and Waveney Mental Health NHS Foundation Trust had 'limited research activities,' says Jon. 'The MHRN East Anglia Hub said it would support us, and we set up a fledgling research department at the Trust. That led to the formation of a research governance committee, and now we have the infrastructure in place to support projects.'

Jon works in an early intervention team in central Norfolk. 'The service is for anyone aged 14 to 35 who is experiencing the symptoms of psychosis, or what might be the symptoms of psychosis,' he says. 'People can self-refer – we want people to get in touch if they are at all worried. We are looking to help people as early as possible.'

So smitten has he become with research and its power to help deliver the best possible service, he successfully applied for a one year 'CLAHRC Fellowship' – an award given by Cambridgeshire & Peterborough Collaborations for Leadership in Applied Health Research and Care. The CLAHRC brings together the University of Cambridge, NHS organisations providing mental

health services in Cambridgeshire and East Anglia, and research organisations like the MHRN East Anglia Hub. With the help of government funding, the CLAHRC aims to test new treatments and ways of working, and then incorporate them into everyday practice in the area.

Jon will spend one day a week throughout 2011 working on a plan to launch a new evidence-based Youth Mental Health service for young people who are worried about their mental health but may not be experiencing the early signs of psychosis. There has been much research to show that early intervention services for psychosis make a real difference – and Jon now wants to offer the same sort of youth-friendly, one-stop service that young people with a range of mental health problems can contact directly without the need for a referral from their GP. 'The CLAHRC Fellowship is allowing me to spend one day week on developing and implementing this new service,' he says. 'We're planning to do it alongside early intervention services, using a similar model and similar approach. We will set the new service up as a platform for research and then evaluate its effectiveness.'

'Getting involved in research can really help mental health professionals focus their minds on what works and what doesn't work. I think if you are involved in research, you are willing to change your opinion and your way of working as a result of the evidence and so offer the best possible service.'

'The difference between the research I previously did and the research I'm involved in now is that then I felt I was completely on my own. The advantage of working with a network is that there are always people willing to support you, people to help you and advise you. With the MHRN, it's not just me versus Goliath.' ■



Liz Pitt

Liz Pitt has been a service user researcher in Manchester for eight years. She first joined a team led by clinical psychologist Professor Tony Morrison in 2003, and the work she undertook with her colleague Martina Kilbride – collecting people’s personal experiences of recovery – helped to lay the foundations for a five-year programme of research funded by the National Institute for Health Research. The RECOVERY programme started in January 2008 and aims to develop better ways of supporting people with experience of psychosis who are rebuilding their lives.

Liz works for Greater Manchester West Mental Health NHS Foundation Trust (formerly Bolton, Salford and Trafford Mental Health NHS Trust) and her role on the RECOVERY programme is twofold: she is a researcher on a trial that is evaluating a new Recovery

Guide (some people are also offered telephone support to find out if that is more effective than the Guide alone) and she also coordinates service user involvement across all five projects launched under the programme’s wing. A Service User Reference Group meets bi-monthly to advise and ensure the experience of participation and involvement in each of the projects is ‘as valuable and easy as possible,’ she says.

The Group is facilitated by Tim Rawcliffe, service user development officer for the North West Hub of the Mental Health Research Network: the work of Liz, Martina, other service user researchers and people who have advised and collaborated on RECOVERY projects has been inspirational to involvement work in the area.

When Liz first entered the world of research back in 2003, she had been unemployed for a while. ‘I had lost two jobs because of my experience of psychosis and at times I felt I would never get a job again. I started to do voluntary work and my plan was to get some references and start looking for, and applying for jobs. I was doing permitted work for Mind in Manchester when I saw an advert for someone who was interested in research.’ The advert had been placed by Tony Morrison’s team and the job was to develop service user research: the experience of psychosis was listed as essential.

‘The post was a job-share with Martina,’ says Liz. ‘Having been out of work for so long, I had lost confidence, so working together with Martina was crucial. We supported each other. Tony Morrison and the other researchers in the team are also very egalitarian in the way they work.’

‘It was up to us to decide how to develop user-led research, and how to carry out the research. We wanted it to be a collective process, so we advertised for people who were interested in

being involved in a steering committee. Martina and I discussed areas we were interested in and asked the committee to make a decision, and they chose personal experience of recovery.’ The steering committee continued to meet and advise on a second piece of qualitative research carried out by Liz and Martina, this time focusing on the impact of diagnosis.

Martina sadly died in 2009, but Liz says her legacy lives on. Both of them were co-applicants on the RECOVERY programme, and the results of their initial research have been used to help inform the development of the Recovery Guide.

The methods, procedures and jargon of research were all new to Liz in the beginning: she had previously worked in funding administration for voluntary sector organisations, local authorities and colleges. When she joined the research team, she initially signed up for a short course in qualitative research at Lancaster University, and the Trust later supported her Masters in Research at the University of Manchester.

Recently, Liz has been reviewing the activities of the RECOVERY programme’s Service User Reference Group – a task she has particularly enjoyed because people have been ‘very motivated and creative’.

‘I think there is a growing response and recognition amongst researchers that it is valuable to involve people who have personal experience of mental health problems, and there are more and more opportunities for that involvement to happen. That’s partly because of the emphasis on involvement from funding bodies, but also because of a growing interest. As there are more examples of good practice about how involving service users in research can be beneficial, I think it will happen more.’ ■



Domingo Gonzalez

Domingo Gonzalez became involved in trials helping to develop new medication a decade ago, before the Mental Health Research Network was set up. A consultant psychiatrist working for Birmingham and Solihul Mental Health NHS Foundation Trust, he is now 'industry lead' for the Heart of England MHRN Hub, and is about to take a key role in a new mentoring scheme, set up to encourage junior psychiatrists and other consultants to become locally-based investigators for pharmaceutical studies.

'Some consultants, however, are reluctant to get involved in research because they think it will be a lot of extra work and paperwork,' he says. 'That certainly used to be the case. But the MHRN makes everything very easy and do-able: the Trust would not be able to take part in as many industry-led studies as we do without the support of the Heart of England Hub, and the recruitment work carried

out by the clinical studies officers. I have done trials without the MHRN and, without a shadow of a doubt, would be reluctant to do trials without them again.'

Domingo's specialist area is psychosis, and he works for a community-based assertive outreach team: he originally came to Birmingham from his native Spain for part of his training 15 years ago, and has been there ever since. For the MHRN, his role is to promote both the Trust's services and the support the Heart of England Hub can offer to pharmaceutical industry research projects.

The new mentoring scheme will be launched in 2011 and has the support of mental health NHS trusts in the area covered by the Hub and pharmaceutical companies keen to find clinicians who will act as principal investigators and take responsibility for projects. Domingo and experienced colleagues already taking part in

industry-led trials will work with junior psychiatrists and consultants new to research, and training and support will be available via the Heart of England Hub.

The mentoring scheme will hopefully lead to more industry-led studies being run within locally-based trusts – which in turn will create more income, some of which can be re-invested in research, he says.

Over the years, Domingo has built up a network of contacts within the pharmaceutical industry. 'The companies are keen to use people who have experience with them. I have been chief investigator or principal investigator on a number of successful studies and I am often approached about new studies and need to find people who have the right expertise. When the new scheme launches, I will be able to mentor people to take the role of principal investigator instead of doing it myself.'

Birmingham and Solihul Mental Health NHS Foundation Trust, he says, has a very positive philosophy about supporting industry-led trials. Domingo sits on a dedicated committee within the Trust that considers each request from industry: 'We look at each proposal holistically – are there people willing to be principal investigators who have the right experience? what are the ethical issues? The pharmacy department has to be on board to deliver medicine, and we have introduced procedures to speed up the historically slow process of getting research off the ground.' ■

Anna Massey started working with the Mental Health Research Network (MHRN) in the north east of England in 2005, when the regional office there was first set up. She is the longest-serving clinical studies officer within the MHRN and has good working relationships with many doctors and other mental health professionals working in services run by Northumberland, Tyne and Wear NHS Foundation Trust. Part of her job is to introduce research studies to them, and ask them to recruit participants through their services.

Her other role is to develop the involvement of people with experience of mental health problems in the research projects supported by the North East Hub. There is a 'groundswell of interest', she says – and she is hoping to get an accredited training course off the ground that can give service users and carers confidence and skills to become advisors or collaborators on studies and trials. 'We want to organise a basic introduction to research and research methods. The idea is to demystify research, so that people who want to get involved can come to the table on more equal terms.'

Anna has been working in research for nearly two decades. After training as a nurse and a few years on medical wards, she joined a team at the Freeman Hospital in Newcastle who were collaborating on industry-sponsored studies investigating new drugs for people who had had a stroke. Her job was to work with patients, help explain the trials to them, help recruit them as participants and keep in touch with them as the studies progressed, gathering information to judge the effectiveness of the medication. The team was led by academic clinician Professor Gary Ford, who went on to become



Anna Massey

director of the National Institute for Health Research Stroke Network, a sister organisation of the MHRN.

Through her work with people who had had a stroke, she became interested in the concept of 'quality of life' – something she was measuring in her work on the research studies. 'I felt that some of the research measures I was using included quite barbaric questions – asking about leisure and recreation activities, for example, when this had no relevance or meaning for people who had had a serious stroke.' When she signed up for an MSc at Northumbria University, she analysed data collected for a Newcastle University-led project – and this ultimately led to the development of a stroke-specific quality of life measure, devised in consultation with patients.

Many of the people who had had a stroke were experiencing depression, and this prompted her interest in mental health. She successfully applied for a research nurse post in the Department of Academic Psychiatry at Newcastle University, initially working with a study team on a three-year research project about depression, and then moving on to a long-term study looking at the causes and treatment of bipolar disorder. She made good contacts and since joining the MHRN, has specialised in supporting studies investigating different aspects of bipolar disorder.

Anna is personally committed to involving people with experience of mental health problems in decisions about research that affect their lives: developing service user involvement in research is therefore very satisfying, she says, and keeps her in touch with people who live in the world outside of academia.

'There is evidence that involvement of service users makes research better, and opportunities for involvement are now becoming more varied and more rewarding,' she says.

'Researchers can't get away with a tokenistic "we talked to a service user in the clinic today and they said it was alright" anymore when planning their projects. Funding organisations want decent evidence of proper involvement, and local researchers are recognising they need to be more inclusive in research design.'

In March 2011, the North East Hub hosted an event held to showcase research projects that have already involved people with experience of mental health problems and their family members, and to highlight future opportunities to become involved with research teams. Anna worked with a steering group of service users and carers who came together to design and run the event: that group now plans to continue to meet to act as an advisory group to all members of the hub team. ■

Paul Stokes has been principal investigator on several industry-sponsored MHRN-supported clinical trials testing the efficacy of medications for mental health problems. This means he leads each research team, takes responsibility for a study, makes sure it is carried out in an ethical way, and helps identify potential participants.

'It's very worthwhile working on these studies,' he says, 'because the results can lead to treatments that can make a real difference to people's lives.' He is involved with a trial, for example, that is testing a compound that might help people who take antipsychotics control their weight gain. 'One of the major problems of antipsychotic medication is that weight gain is a side effect and this is very hard for people. It would be great if this compound helped with this.'

Another study is trialling a new 'depot' antipsychotic – medication given as an injection rather than a tablet. 'The drug is licensed for use in the States but not yet here,' says Paul. 'The injection is given monthly rather than every two weeks, so we hope that this may improve service users' experience of depot medication.'

Paul is an academic clinician – he works three days a week as a researcher with the Neuropsychopharmacology Group at Imperial College London and two days a week as a consultant psychiatrist in a community mental health team in Ealing, run by West London Mental Health NHS Trust. He first started working as a researcher using brain imaging techniques in 2004 while he was training.



Paul Stokes

At Imperial, his research uses PET (positron emission tomography) and fMRI (functional Magnetic Resonance Imaging) scanning techniques – and has focused in previous years on the effects of cannabis on the brain, particularly looking at whether the ingredient that gives people a 'high' – THC (delta-9-tetrahydrocannabinol) – affects the levels of the neurotransmitter dopamine. Dopamine is thought to be instrumental in the development of psychosis. For his current imaging research, the spotlight is on another, less investigated neurotransmitter – GABA. 'GABA is associated with

impulsivity and addictive behaviour and is one of the main neurotransmitters in the brain,' he says. 'We are scanning healthy volunteers to determine the levels of GABA in the living brain, and, if successful, this may then allow us to find out what happens to GABA in people who have addictions or other mental health problems,' he says.

Paul became involved with industry-led trials recruiting participants through services run by West London Mental Health NHS Trust when he met colleagues there already working on clinical trials: 'I was interested in broadening my portfolio of research interest.'

The brain imaging research, he says, is complementary to the clinical trials, and he is now planning studies that will combine both strands of work. 'If people who join a trial testing medication have a scan at the beginning, and then at other times throughout the trial, we may be able to find out how the medication has impacted on neurotransmitters in the brain.'

Paul says the clinical studies officers employed by the MHRN North London Hub have offered invaluable support. 'They are very professional and responsive.'

'As principal investigator on a trial, I work with colleagues within the Trust who help with different aspects of the research and hopefully enthuse them to get involved, and help cultivate the research ethos among nurses, psychologists and other mental health professionals as well as other psychiatrists.' ■



Jennifer Bostock

Jennifer Bostock has been instrumental in setting up FAST-R, a new Mental Health Research Network service that will help researchers gain advice about their studies from service users.

FAST-R will give research teams fast access to people with experience of mental health problems who are willing to comment on and offer expert advice about proposed patient information sheets, consent forms and recruitment strategies. This documentation is among the paperwork that needs to be submitted and agreed by ethics committees before projects can start. The idea is that the service will help speed up ethical and regulatory approval for projects, and in turn help speed recruitment to studies and trials.

Jennifer was first hired by the MHRN's South London and South East Hub in 2010 as a freelance consultant. Her remit was to boost the number of people with experience of mental health problems who are willing to act as advisors or collaborators on MHRN-supported research projects – and also identify studies and trials looking for input from people who are experts by experience.

She ran a recruitment campaign in the area and is organising training for all those who came forward to prepare them for potential opportunities ahead. 'I'm getting researchers and service users involved in designing and delivering the training,' she says, 'to help break down some of the barriers

to involvement. Meeting service users in a training session is not the same as meeting them in a clinical environment, and the idea is to meet on an equal level, as peers.'

Jennifer has worked on the FAST-R (Feasibility and Support to Timely recruitment for Research) service in collaboration with hub staff and more than a dozen people who have experience of mental health problems who will comprise the FAST-R team.

She understands very well the demands of research ethics committees: she is a member of the Institute of Psychiatry/South London and Maudsley NHS Foundation Trust committee and says: 'We frown upon people who have not involved service users in their proposals. All ethics committees, and also funding organisations, now want to see evidence of genuine service user involvement. By using the FAST-R service, research teams will be able to say they have involved service users from an early stage.

'Researchers are primarily concerned with methodology: service users are more concerned with the practicalities of doing the research. They can flag up problems with proposed recruitment plans, or say whether what is written on paper will work in real life. The FAST-R group will advise on information sheets, consent forms and the entire protocol before they go to the ethics committee, and be able to spot any practical problems early on that researchers may not have thought about.'

The training she is organising specifically for FAST-R will focus on 'how to navigate a way through the mountain of research papers without feeling too daunted', as well as appraisal and advisory skills. 'The training will cover the technicalities of research, but I also want to dispel some of the fears, and include some of the philosophy behind ethical concerns in psychiatry,' she says. 'A side effect of the training and experience, and being part of FAST-R, is that it may also enable the team of service users to join ethics committees or other committees to do with research governance in future.'

Jennifer's freelance job for South London and South East Hub is one of several in a very diverse portfolio of work. A true renaissance woman, she has a finger in many pies: she is a Mental Health Act Commissioner for the Care Quality Commission (responsible for protecting the interests of people detained under the Mental Health Act) and a Mental Health Act Manager for Oxleas NHS Foundation Trust (part of a statutory committee that hears appeals from people who have been compulsorily admitted to hospital). She is a Royal College of General Practitioners Quality Practice Award lay assessor, a GP performance assessor, and a peer reviewer and committee member for the National Institute for Health Research.

She is a trainer in mental health promotion and also runs training in critical psychiatry, philosophy/ethics and communication. She delivers group-based cognitive behaviour therapy courses for the mental health charity Mind, writes for academic books and journals and the broadsheet press, and sits on various committees – including the Invention 4 Innovation Panel, which Jennifer says is 'the government's answer to Dragon's Den'. She is also a National Research Ethics Service trainer, designing and delivering courses in mental health ethics to academics and mental health professionals.

Her interest in mental health and academia started after she went to university as a mature student to study psychology and philosophy. She was awarded an Economic and Social Research Council scholarship to do an MA in Philosophical and Social Psychiatry.

She then won a Wellcome Trust Biomedical Ethics Prize to study for a PhD in ethics, genetics and forensic psychiatry.

Of the job she was commissioned to do for the MHRN, she says: 'I think service user involvement is going to explode over the next few years, so

we need new people to come forward. Service user involvement benefits research, benefits service users, and benefits mental health itself. The question for researchers should not be "why involve service users?" – it should be "why NOT involve service users?"' ■

EAST MIDLANDS PLUS SOUTH YORKSHIRE ■



Ronnie Browne

He has advised on the feasibility of proposed studies about pharmaceutical products and acted as principal investigator or co-investigator on a number of different projects. And he encourages colleagues new to research to get involved as investigators on drug trials and other MHRN-supported studies.

'Feasibility involves looking at each study proposal that comes via the MHRN East Midlands plus South Yorkshire Hub – are we able to help recruit participants? Do we have the clinicians who have an interest in the area? Is it feasible for us as a trust to help out on this study? I take a look and discuss each proposal with colleagues,' he says.

'Being a principal investigator involves taking responsibility, but in reality, the leg-work is done by the Research and Development department within the Trust, and the clinical studies officers who are part of the MHRN. They facilitate the work – you can't underestimate what they do.'

His work has contributed to an increase in the amount of research carried out at LPFT, but he stresses that he is just one of a team of people involved in the endeavour. 'The Trust's chief executive Chris Slavin, the medical director Mostafa Mohanna and the clinical director and research lead at LPFT, Brian Ferguson, were all keen to build up research and encouraged me, and others, to get involved.'

Ronnie wasn't new to research: earlier in his career, which started in Dublin, he had previously been involved in industry-led trials. 'The requirements of pharmaceutical trials are stringent and it is a lengthy process before any new medicines come on the market. There is a time commitment involved for both NHS trusts and individual clinicians,' he says.

'People are very busy, and taking part in research is an additional commitment on top of their everyday work. Their greatest reward is the satisfaction of making a difference. It's a big ask, especially when you are working on a lot of different studies and working in a clinic at the same time. But LPFT is very supportive of clinicians involved in research, and there are many here who are very committed.'

'I think supporting research is essential in order to get the best available treatment. New, improved drugs would never come to the market unless we supported industry-led studies, and psychological therapies wouldn't be developed properly unless clinicians supported research. The contribution of service users is paramount to this type of research to ensure the availability of appropriate new pharmaceutical products. Clearly no progress could take place without their invaluable input.' ■

● At LPFT, the MHRN clinical studies officers are part of the research team led by Dianne Tetley, assistant director of research and effectiveness.

Ronnie Browne has been a consultant psychiatrist for about 26 years: for the last six of them, he has been working in a community-based assertive outreach/crisis resolution and home treatment team run by Lincolnshire Partnership NHS Foundation Trust (LPFT). He is also one of a number of mental health professionals within the organisation who has helped industry-led MHRN-supported research studies recruit participants through the Trust's services.



Kate Brooks

Kate Brooks is senior clinical studies officer at the Mental Health Research Network West Hub. She is Bristol-based and her role is to help manage all the administration involved in supporting the 65 research projects that are either being set up or recruiting through NHS services in the huge geographical area covered by the hub – and to support the 18 clinical studies officers (CSOs) who help find participants for studies.

She has a working knowledge of all of those studies and helps the CSOs solve any recruitment problems, or think of new ways of finding potential participants. Some of the CSOs are based far away – the West Hub works with services provided by mental health trusts stretching from Bristol down to Cornwall and embracing Devon, Hampshire, Gloucestershire, Somerset and Dorset – and she keeps in touch by regular teleconferences and emails. ‘Being a clinical studies officer is very hard work,’ she says. ‘You have to win people over – you are basically “selling” something to people who are incredibly busy and have huge workloads.’

Kate joined the West Hub in September 2009 and within a month, she was holding the fort when manager Chantal Sunter went on maternity leave. She acted up again during a two-month period in 2010 before Chantal returned to work.

She cut her teeth on supporting research projects while working for the MHRN’s sister organisation in Wales – MHRN Cymru. She had been living in Cardiff and working in Newport as a psychiatric nurse in a substance misuse service for a couple of years when, by chance, she heard about MHRN Cymru, then in its infancy, from a colleague. Kate became one of the first clinical studies officers employed by the new organisation. She was based at Heath Hospital in Cardiff and for two years, worked almost exclusively on a research project run by a team at Cardiff University, recruiting people with a diagnosis of bipolar disorder. The aim of the study, which is still continuing, is to find out more about bipolar disorder and includes an analysis of people’s DNA. ‘I spent my time making friends with all the nurses working in services for people with bipolar disorder, talking

to service users’ and carers’ groups, giving presentations and promoting the study to people with bipolar disorder and the mental health professionals who were supporting them,’ she says.

When she joined MHRN Cymru, Kate was completely new to research. After studying for an English degree straight from school, she had worked in a care home for people with learning disabilities and then decided to train as a psychiatric nurse. She worked in London for four years – on wards and in the community – before moving to Wales. ‘As a nurse, you were encouraged to always follow the evidence-based NICE (National Institute for Health and Clinical Excellence) guidelines, but you were too busy working to read anything else or find out about research.

‘At MHRN Cymru, I was more or less thrown in at the deep end. There was a lot to learn – all the procedures involved in research, all the different overseeing bodies, all the acronyms, which organisation was responsible for what.’

When she moved to Bristol, the West Hub of the English MHRN was already well-established and by now Kate understood the machinations of the world of research. ‘The senior clinical studies officer post was a new one and it is a massively different job. I try to be supportive to the CSOs and also supportive to the academics we work with. Because I am coordinating and overseeing all the studies, it means I spend less time out and about meeting people ... and I do sometimes miss that.’ ■

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