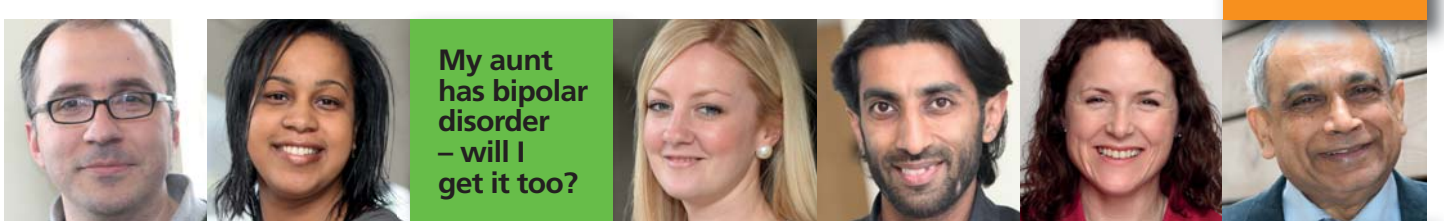
Mental Health Research Network

NHS National Institute for Health Research

Mental health research can help all of us

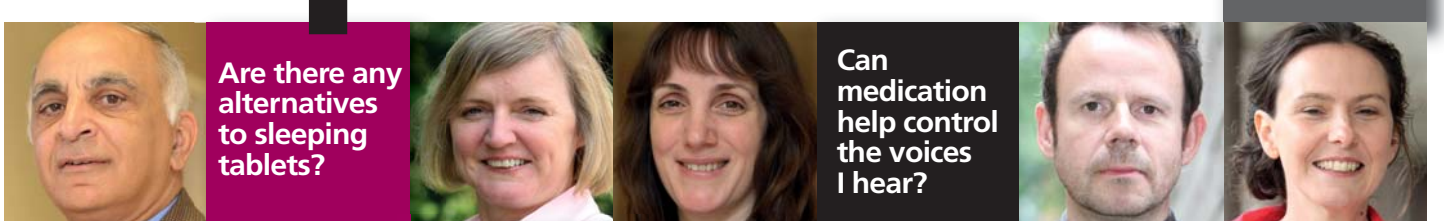
How do I support my child who has ADHD?

Will stress make me mentally unwell?



My aunt has bipolar disorder – will I get it too?

Will drugs make me feel less anxious?



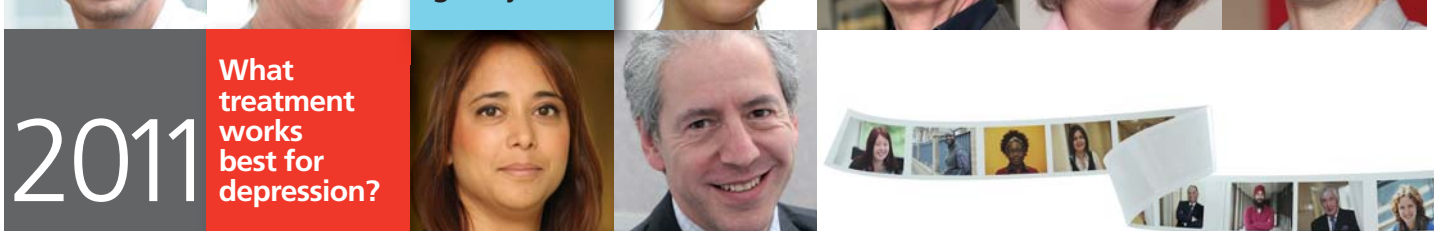
Are there any alternatives to sleeping tablets?

Can medication help control the voices I hear?

How do I help my son who has psychosis get a job?

2011

What treatment works best for depression?



Just as all of us become physically unwell at times, our mental health also sometimes takes a turn for the worse.

One in every six people has a mental health problem: depression and anxiety are among the most common.

That 'one' might be you, or your child, or your brother, your parent, your gran, your neighbour, your work colleague, or your friend.

In the same way that research trials have developed new treatments for physical health problems – from flu to cancer – research projects can lead to new ways of helping people who have mental health problems.

The Mental Health Research Network is a government-funded organisation that helps make research happen.

All the people pictured in this publication are involved in the work of the Mental Health Research Network.

The Mental Health Research Network...

...supports research projects that are carried out in England. That support includes helping university-based research teams set up projects, and finding people who use NHS mental health services who are willing to take part in studies and trials.

We also encourage people who have personal experience of mental health problems to be involved in our work – and in the research studies we support – as advisors and collaborators. Ultimately, it's you (or your child, your brother, your parent, your gran, your neighbour, your work colleague or your friend) who will benefit from the treatments and services that are proven to work in trials and studies, or by the new knowledge and understanding gained as a result of research.

This publication contains examples of the research projects we support.

You can find out more about who we are, what we do, and how to get involved in our work, on page 31.
Or visit our website www.mhrn.info.

The Mental Health Research Network is part of the National Institute for Health Research and is therefore known as the NIHR MHRN.

While most people are happy to chat to family members, friends, neighbours – and even strangers – about their physical health problems, many are reluctant to share news about their mental ill health. Despite the fact that mental health problems are an everyday experience for thousands of people, many still think it's 'bad' or embarrassing to be mentally unwell. Some of the studies we support try to find out the best way of ending discrimination against people with mental health problems and attempt to change attitudes so people don't feel isolated and ashamed.

Scientists and researchers are constantly trying to find out why mental health problems develop and what happens inside people's brains. Knowing more about this means they can work out better ways of treating mental ill health – and ways of keeping people well. Some research projects ask people to give samples of DNA or blood to help researchers look for genes involved in mental health problems or chemicals inside the body that might play a part. Other research teams ask people to have brain scans.

Some research trials test new treatments for mental health problems. These might be talking therapies, drugs, or other sorts of support – like befriending, computer programmes or self-help books.

Enabling mums with postnatal depression to be more active

About 10 per cent of new mums develop postnatal depression after giving birth. Doctors prescribe antidepressants and offer talking therapies, if they are available – but now a Birmingham-based team of researchers wants to find out if encouraging women to exercise regularly can also help.

Two hundred women from across the West Midlands with a diagnosis of postnatal depression are being recruited to a trial with the help of GPs and health visitors. All of them will continue with any treatment suggested by their doctor, but half will also be allocated a 'Physical Activity Facilitator' (PAF) who will visit them in their homes and try to help them to be more active.

'The PAF will talk to each woman about what sort of activities she likes, and find out what is available in her local community – classes with crèches, for example,' said Dr Amanda Daley at the University of Birmingham who is leading the project. 'The PAF will give women information about opportunities to exercise locally. Mostly, we are trying to encourage pram-walking in the local community – something that doesn't cost anything, but is active and gets women out of the house.' Each woman will have the chance to meet and consult with the PAF on two occasions at home, and then stay in touch by phone.

All the women agreeing to take part in the trial will be followed up after six months to see if those who met with the PAF have started to exercise regularly, and whether being more active has made a difference to the symptoms of postnatal depression.

About 80,000 women a year develop postnatal depression in the UK. The figure may be even higher, says Dr Daley, as some women don't seek help because they are scared of being thought a bad mother.

> In the UK, about 80,000 women a year develop postnatal depression.

The symptoms of postnatal depression include low mood, irritability, confusion, fatigue, anxiety, forgetfulness, guilt, an inability to cope and feelings of worthlessness. Occasionally, some women with postnatal depression consider taking their own lives.

'Postnatal depression can have a substantial impact on the mother, the baby and the whole family,' says Dr Daley. 'There is a need to examine

Trying to understand more about bipolar 2 disorder

Thanks to people like Stephen Fry, most of us are much more aware of what a diagnosis of bipolar disorder means. What many people don't know, however, is that there are two types of bipolar disorder – and even though the second kind, bipolar 2, is more common, it is not nearly as well understood by researchers or mental health professionals.

Like people with bipolar 1, people with bipolar 2 experience episodes of depression, and also have periods of time when their mood is extremely high, or 'manic'.

But for people with bipolar 2, the 'highs' are much less severe and the symptoms of 'hypomania' less likely to interfere dramatically with their lives or demand admission to hospital. The depression they experience, however, can be much worse than the depression experienced by people with bipolar 1.

An estimated two in every 100 people have bipolar 2, and women are more likely to be given the diagnosis than men. However, there has been little research about bipolar 2 to inform decisions about treatment, and researchers have scant knowledge about how the illness develops.

'There is a large and growing body of research on bipolar 1 disorder and the best treatment options that may help in both the short term and longer term,' says Professor Nicol Ferrier at Newcastle University. 'Unfortunately, bipolar 2 is hardly ever the main focus of research studies, and so there are gaps in our knowledge of how the problem develops over time. There are no drugs specifically licensed for the treatment of bipolar 2 in the UK, and few evidence-based guidelines to inform treatment plans. We are unclear about the best treatment options.'

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Professor Ferrier is now leading a research project that seeks to shed more light on bipolar 2 disorder. He and his colleagues are recruiting a group of 180 people in the north east of England who have been given the diagnosis and who are willing to tell researchers about their symptoms, and what sort of care they are offered by mental health professionals. People are being found through mental health services and primary care services with the help of the staff employed by the Mental Health Research Network.

'Some women don't seek help because they are scared of being thought a bad mother.'

ways of helping women who experience postnatal depression, and encouraging them to exercise may be one way.

'Encouraging exercise may also have benefits in terms of improving cardiovascular health and reducing weight – this has been identified as a particular concern for new mothers,' she says.

The *Physical Activity for Mums – Promoting Health and Recovery* study finishes in 2012 and is funded by the National Institute for Health Research School for Primary Care Research.

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Initially, those who agree to participate are being asked to complete a daily mood diary for at least three months and meet with researchers regularly to talk to them about what it's like to live with bipolar 2.

Many of the people recruited to the ABC Study *(A Bipolar Cohort Study)* are agreeing to stay involved with research for three years and give information to other teams who are working on other studies. All of the studies will aim to ultimately develop better services and treatment for bipolar 2 – they may test drugs and talking therapies, for example.

The *ABC Study* is funded by the Medical Research Council and the volunteers with bipolar 2 will stay involved until 2012.

Alternatives to sleeping tablets

About a third of us will have problems sleeping each year, and the knock-on effects can be serious. People may find it hard to be productive during the daytime and tiredness increases the risk of accidents. Insomnia and disturbed sleep can contribute to mental health problems like depression and anxiety, and also to physical health problems – obesity, high blood pressure and heart disease.

Yet GPs often have little to offer their patients bar sleeping tablets or advice leaflets – even though surveys have shown both doctors and patients would welcome other options. 'GPs often don't know what to do for the best when someone comes in with sleep problems,' says Professor Niroshan Siriwardena, a Lincolnshire GP and University of Lincoln researcher.

Now a project led by Professor Siriwardena seeks to equip GPs and practice-based nurses with the skills they need to propose alternatives to medication, within a standard 10-minute consultation.

With the help of eight GP practices in Lincolnshire, he and the research team have developed a package of techniques that GPs can use to assess and treat sleep problems in the surgery without using drugs. 'We have gathered together techniques that are proven to be effective, worked out how GPs and practice nurses might use them, and adapted them accordingly,' he says.

The research team has run a small trial to find out if it is possible to train GPs and practice nurses to use the package within two two-hour sessions. And an online e-learning resource is being built so GPs throughout the country can have access to these treatments and techniques.

The package focuses on 'problem-solving' and includes tools to help GPs gauge the causes of a sleep problem and how serious it is – a short questionnaire called an 'insomnia severity index' and 'sleep diaries' where patients log their sleeping patterns and factors that might influence them, like exercise and the consumption of coffee and alcohol. GPs are taught the principles and techniques of cognitive behaviour therapy (CBT) for insomnia – to help people deal with racing thoughts that keep them awake, for example. And they learn about sleep education, sleep hygiene, muscle relaxation techniques and stimulus control, helping people understand how activities and environment can benefit or adversely affect their sleep, as well as other evidence-based methods like sleep restriction to help them advise patients on restoring sleep patterns.

The three-year 'REST' project also included surveys and focus groups that showed health professionals and patients were both keen to have alternatives to sleeping tablets, known as 'hypnotic drugs'. Patients said they wanted GPs to listen more and assess their problems carefully. Some said they felt they had to convince their GPs that their sleep difficulties were serious and impacting on their lives, while GPs sometimes assumed patients wanted a prescription.

'GPs often don't know what to do for the best when someone comes in with sleep problems.'

GP Dr Zubair Qureshi took part in the REST project and says: 'Our team consists of GPs, nurses, a practice manager, a health visitor, district nurses and complex case managers. We have all learned about using sleep assessment tools and we try to spend more time with patients presenting with insomnia and take their presenting problem seriously. Patients are followed up by both doctors and nurses and kept under review. We have noticed greater patient satisfaction and most patients do attend for follow-up. Patients have become more empowered to deal with their insomnia. We are also trying to use CBT techniques in the consultation. There has been a fall in our Z-drug and benzodiazepine drug (sleeping tablets) prescribing as a result.'

The *REST* project was funded by the Health Foundation *Engaging with Quality in Primary Care Initiative*.

Tackling depression in the classroom

More than 5,000 teenagers are taking part in a research study that seeks to find out if school-based group therapy can help them stay mentally healthy during adolescent years.

The research team wants to find out if making a cognitive behaviour therapy-based programme part and parcel of the school timetable can help students learn skills to keep themselves well, stay happy and positive – and in particular, stave off depression.

An estimated one in five young people experience depression before they reach 18, with knock on effects on their school grades, their social lives and development – and a resulting increased risk of experiencing depression and other mental health problems in adulthood.

> One in five young people experience depression before they reach 18.

Eight comprehensive schools in Bath, North East Somerset, Bristol, Nottingham and Wiltshire are taking part in the research project, allowing researchers to run the Resourceful Adolescent Programme (RAP) in some of their PHSE (Personal, Health and Social Education) sessions for pupils in years 8, 9, 10 and 11.

The Programme was developed by Queensland University of Technology in Australia to promote positive mental health in teenagers, and specifically sets out to prevent teenage depression. RAP tackles negative thinking and low self-esteem and encourages students to identify personal strengths, learn how to problem solve, keep calm, and get along with other people. Research in Australia and New Zealand over the past decade has shown the programme to be effective.

The UK-based research team, led by Professor Paul Stallard at Bath University, has 'tweaked' the therapy with the help of young advisors recruited from participating schools to make sure the language and concepts are relevant to teenagers in this country.

Two specially recruited and trained psychological assistants are working with students and alongside teachers in each PHSE session offering RAP. Some of them are psychology graduates and PhD students, some are teachers or

Playground behaviour has important effect on children with ADHD

A culture of bullying and aggression in English schools is making the behaviour of children with ADHD (attention deficit hyperactivity disorder) worse, says Dr Ilina Singh from the London School of Economics and Political Science. 'This sort of environment elicits uncontrolled aggressive behaviour in children who have difficulties with self control – as children with ADHD do,' she says.

Dr Singh led a team of researchers who talked to 150 children in both England and the USA to find out about the reality of living with a diagnosis of ADHD.

That diagnosis can be a controversial one, she says, not least because of a debate about whether it is ethically sound to prescribe drugs that affect the function of the brain to pre-adolescent children who have ADHD. Yet, she says, the opinions and experiences of children are hardly ever considered in that debate.

The VOICES study set out to remedy that omission, and put children firmly centre stage. Through one-to-one interviews, the researchers wanted to find out what a diagnosis of ADHD means to school-age children, whether it changes the way those given the diagnosis see themselves – and alters the way other people relate and respond to them.

The researchers talked to children with ADHD who are taking medication, children with ADHD who are not on medication, and children without a diagnosis of ADHD. All of the children interviewed were aged between nine and 14. What the interviews showed was a significant difference in attitudes between children in the USA and children here. 'In this country, children associated a diagnosis of ADHD with anger and aggression, but in the USA it is seen as a marker of poor academic performance,' says Dr Singh. 'In England, ADHD is associated with children who get into a lot of fights and trouble at school. In the USA, the children with ADHD are the ones that don't get the good marks.'

> In this country, children associate a diagnosis of ADHD with anger and aggression, but in the USA, it is seen as a marker of poor academic performance.

The culture of schools in England has a lot to do with this, she says. In the USA, there is teasing and name calling, but for the most part, physical aggression is deemed unacceptable.

'However, every child we spoke to in England talked about a significant culture in school of aggression and bullying. Most children, diagnosed or undiagnosed, boy or girl, had had direct experience of bullying, fighting, pushing, shoving or ridiculing. Children who have a diagnosis of ADHD said they were targets of a special kind of bullying: other children sometimes intentionally tried to get them angry – "wind them up"– for the fun of watching them lose their temper and fight.'

Much of the research about ADHD has focused on 'cognitive

former teachers, and some are clinical studies officers from the Mental Health Research Network who are working on the study.

In addition to the RAP sessions, some of the PHSE lessons will be run as they normally are, and some of them will be run with the help of two psychological assistants but cover subject matter dictated by the national curriculum rather than the RAP. Regardless of which sort of PHSE they attend, the 5,000 12-16 year olds are all filling in questionnaires in the classroom about their mood and how they feel about themselves, whether they have self-harmed, and whether they have used drugs or alcohol – at the beginning of the research, then after six months, and finally a year later. The information collected in these questionnaires will allow researchers to analyse how effective the RAP has been in comparison with the other types of PHSE sessions. The researchers hope that by offering the RAP universally, it will help young people who have a higher risk of developing depression and might not otherwise seek help because of the stigma attached to mental health problems.

Professor Paul Stallard:

'We hope that by giving young people the tools that can help them build resilience, they can avoid depression becoming a problem in adolescence and later life.'

'We hope that by giving young people the tools that can help them build resilience, they can avoid depression becoming a problem in adolescence and later life,' says Professor Stallard, who also works in child mental health services as a consultant clinical psychologist .'If the trial shows RAP to be successful, we hope to be able to roll out this programme to schools throughout the country.'

Adolescents who experience depression are more likely to experience other mental health problems as adults.

The PROMISE *(Promoting mental health in schools through education)* trial is funded by the National Institute for Health Research *Health Technology Assessment Programme* and is due to report its results at the end of 2011.

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deficits' – problems with thinking processes that make it hard for children to pay attention, concentrate or hold themselves back. But Dr Singh says the environment in which children grow up also has an important part to play. 'You have to take account of an environment which contributes to antisocial and aggressive behaviour, and schools need to think about how they can better support children with ADHD, children who need help with self-control. The children we spoke to said they are not given enough support from teachers – they think teachers either don't believe the diagnosis is real or simply excuse aggressive behaviour because of the child's ADHD diagnosis.'

Dr Ilina Singh:

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Estimates of the numbers of school age children with ADHD vary around the world and range between five in every 100 children and 11 in every 100 children. About 75 per cent of children diagnosed with ADHD are boys. The National Institute for Health and Clinical Excellence (NICE) says that ADHD is probably under-recognised and under-treated in this country.

Between five and 11 per cent of school age children have ADHD. Three quarters of those diagnosed are boys.

Methylphenidate (marketed as Ritalin or Concerta) is the most common form of treatment. Consumption of this drug is rising rapidly in most countries, sparking concern and fuelling the adult debate about the prescription of psychotropic medication for children.

However, the great majority of the children interviewed for the VOICES study who were on Ritalin said that it was making a positive difference to them, and was eliciting a positive response from other people, says Dr Singh.

Children in the USA felt medication helped them perform better at school, while children in England felt that medication helped them have more self-control over aggressive behaviour, and gave them the ability to think and take a decision rather than just act impulsively.

The downside is that children in both countries experience side effects – loss of appetite, headache and problems sleeping. Children in the USA are routinely given another drug to help them sleep, she says.

'The study confirms that medication is mainly viewed as a good thing by children. Medication doesn't solve all the problems, it's not a panacea and shouldn't be used exclusively, but it does help children become more self-aware and have more capacity to take responsibility for their behaviour.'

The VOICES study recruited children via university clinics in the USA and through services run by NHS trusts in England. It was funded by the Wellcome Trust.

studies we support
making a difference

Testing a new type of ward for older, confused people

A new kind of ward has been set up at a hospital in Nottingham to investigate whether combining the know-how of medical and mental health professionals can lead to a better standard of care for older people who are admitted to hospital with medical problems, but are also behaving in a confused way.

Two-thirds of NHS hospital beds are occupied by people who are over 65 – and up to 60 per cent of them have, or will develop, dementia, delirium or depression. Most of them are cared for in mainstream hospital wards, where staff trained in physical health care may not have the expertise to deal with mental health problems. About 10 per cent of older people who are admitted to hospital are agitated or aggressive, or wander and shout, and can be disruptive. Staff without specialist skills often struggle to cope with this behaviour. What's more, inexperience in planning discharge and liaising with appropriate community-based services means older, confused people often stay in hospital for a long time.

Two-thirds of NHS hospital beds are occupied by people who are over 65 – and 60 per cent of them have, or will develop dementia, delirium or depression.

'Older people with mental health problems can have very prolonged stays in hospital, and unfamiliar environments and routines can contribute to disorientation and agitation. The chances of getting an older person who is confused back home diminishes as time goes by,' says Sarah Goldberg. She is a member of a research team that wants to find out whether a new type of hospital ward can better support this group of patients.

The Medical and Mental Health Unit at Queen's Medical Centre (part of Nottingham University Hospital NHS Trust) is at the centre of a research project led by Professor John Gladman, a professor of the medicine of older people at Nottingham University.

Sarah Goldberg:
'Older people with mental health problems can have very prolonged stays in hospital, and unfamiliar environments and routines can contribute to disorientation and agitation.'

The Unit, which opened in June 2009, has 28 beds and has been designed with elderly, frail and confused people in mind. Medical equipment is concealed or locked away, and the ward is signposted and painted in a way that helps patients to orientate themselves. The staff team includes geriatricians and psychiatrists, nurses, occupational therapists and physiotherapists, some of whom are mental health specialists. Those who come from a medical background have been trained in mental health care, focusing on dementia and delirium, and the mental health professionals have been trained in medical care.

Family members are often not very happy with the care offered to their elderly and confused relative.

Over two years, nearly 500 patients and their families will be asked to take part in the TEAM *(Trial of a Medical and Mental Health Unit for Older People)* project. Half of the older people will be cared for on the new Unit, and the other half on general or specialist medical wards to allow the research team to evaluate whether mental health input makes a difference.

Treatment on the Unit is for both physical and mental health problems, and includes daily activities that aim to help maintain people's life skills and their ability to communicate. The staff team is trained to liaise with families and community-based organisations when planning discharge to make sure individuals continue to get the support they need after their time on the Unit.

The research team will measure the success and cost-effectiveness of the new ward by finding out whether, after three months, there is a difference between the physical and mental health, and quality of life, of those cared for on the new Unit and those cared for in general and specialist medical wards. They will be adding up the number of days each person spent 'at home' during that three-month period to give them an idea of the impact of the new Unit. They will compare the time spent in hospital after admission and patients' destination after discharge. Were people discharged to their previous residence, for example, be it a care home or family home, or were they placed in a nursing home which offered more intensive support?

Family members are often not very happy with the care offered when their elderly and confused relative is admitted to medical wards in hospitals, says Sarah Goldberg, so the research team also wants to discover if treatment offered on the Unit can make family members feel less worried, anxious and stressed, and more supported in their caring role. Family members will be recruited to the study to supplement information about their elderly relative, and also to talk about their own health and well-being.

There are only a few specialist medical and mental health wards like this in the UK, and this is the first time that their benefit has been evaluated by research.

The project is part of a National Institute for Health Research-funded research programme called *Medical Crises in Older People*. The specialist unit has been developed by Professor Rowan Harwood, a consultant at Nottingham University Hospitals NHS Trust, who is a member of the research team.

How computer-based therapy might help overcome thinking difficulties

Mental health problems can make people's memory, concentration and planning skills become muddled and less effective than they were before an illness developed. This is particularly true for people who have a diagnosis of schizophrenia.

Cognitive remediation therapy (CRT) sets out to help people become aware of particular thinking difficulties that may hinder them in their everyday lives, then work out and repeatedly practice strategies to help them overcome any problems.

'If you know you are not very good at remembering, and you are aware that there are some situations in which your memory may need particular help, CRT can help you find a strategy to deal with that,' says researcher Dr Vyv Huddy. 'If you are going shopping, and have problems remembering, particularly in busy places, you could, for example, use an acronym made up of the first letter of each item you want to buy. The strategy ultimately depends on a person's thinking style – whether they prefer visual or verbal material, for example.'

> 'CIRCUITS is very different from, but has similarities to, brain training software.'

Dr Huddy is part of a research team based at the Institute of Psychiatry (IoP), King's College London, that is testing CIRCUITS, a brand new computer-based version of CRT designed to make this sort of training more widely accessible to people, and to specifically tackle the thinking problems associated with schizophrenia.

The content of CIRCUITS has been developed by psychologists Dr Clare Reeder and Professor Til Wykes, both based at the IoP, who have teamed up with software and website developers, designers and IT specialists. The development of the programme has been financially supported by the Garfield Weston Foundation and the Medical Research Council.

Now, 60 people with a diagnosis of schizophrenia or schizoaffective disorder will test-drive CIRCUITS and give information at the end of the programme to allow researchers to compare their thinking abilities and daily activities with those of 60 other people recruited to the trial but not undertaking the programme. The research team is hoping that those who have completed CIRCUITS will have a greater ability and more confidence to get on with their lives, go out and potentially seek work, volunteer or study, for example.

Vyv Huddy, who is coordinating the research, says CIRCUITS is very different from, but has similarities to, brain training software. 'The difference is that CRT is about carrying out tasks that help people make links between their thinking problems, strategies they can use to help them, and situations where they can use those strategies,' he says.

CIRCUITS transforms paper and pencil-based CRT into 40 hour-long on-screen sessions, using everyday situations and activities as scenarios for the tasks. The programme encourages people to practise tasks repeatedly, and to try out different strategies to find the one that works best for them. After practising as much as they want at home, people then put the strategies they have learned into practice in real life. CIRCUITS is web-based, but it can also be made available as a programme on a lap top that can be taken to people's homes if they have no computer or internet access.

Dr Vyv Huddy:

'If you know you are not very good at remembering, and you are aware that there are some situations in which your memory may need particular help, cognitive remediation therapy can help you find a strategy to deal with that.'

In traditional CRT, a therapist will work on a one-to-one basis with each individual for every session. For the computerised version, therapists will still be involved, but the amount of time they spend with each individual will vary.

'People with schizophrenia are often socially excluded and may not use computers, let alone have one,' says Dr Huddy. 'So the first step may be for therapists to help people become familiar with a computer and the actions necessary to complete the CIRCUITS sessions. The amount of therapist input will depend on the needs of each individual, and the trial will help us learn how to best enable clients to work independently. Therapists will remain involved until we are confident each individual can work alone.'

> 'CIRCUITS will hopefully give people more confidence to get on with their lives, go out and potentially seek work, volunteer or study.'

People with experience of schizophrenia and schizoaffective disorder have helped make sure CIRCUITS is tailored to their needs, feeding back on the content and advising to ensure the tasks included in the training sessions are relevant to their lives. They also tested the programme to help iron out any hiccoughs before the trial started.

The research team will continue to collect feedback about the content and useability of CIRCUITS as the trial progresses.

The trial, supported by the National Institute for Health Research *Research for Patient Benefit* fund, runs until 2012.

A researcher's perspective...

Peter Tyrer has been a researcher in mental health for four decades, during which time he has also continually offered professional care to people with mental health problems, working mostly in community-based services. 'I think it is very important for researchers to do clinical work,' he says. 'Seeing patients keeps you in touch with the reality of their lives. It also keeps you relatively humble, and helps keep you grounded.'

A psychiatrist and professor of community psychiatry at Imperial College London, Peter leads the North London Hub of the Mental Health Research Network (MHRN). In this role, he promotes the importance of research to mental health professionals working in a dozen NHS trusts, and encourages them to help recruit participants and to get involved in studies to inform their work. 'If there is no evidence, people rely on clinical experience. They extrapolate to ordinary practice – the "I know what works best" mentality. But they could be completely wrong.'

People with experience of mental health problems also play an important part in research, he says, not just as participants, but also as advisors and consultants. 'But given that many people are not keen on treatment, it's not surprising that it can be challenging to get them involved in research in any way.

'The negative view is that participants of research are guinea pigs, but actually good research really benefits them.'

'The negative view is that participants of research are guinea pigs, but actually good research really benefits them. The MHRN adopts a team approach – we encourage researchers to work with people with mental health problems and their families in planning and conducting projects. It works better to organise research in that way, and it can encourage people to feel more confident about taking part in studies.'

He has been a key player in the MHRN from the beginning, and was instrumental in setting up the North London Hub – though the name is deceptive. The hub's geographical boundaries cover north, east and west London, and also stretch north of the capital to include Oxfordshire, Berkshire and Essex: the total area is home to 6.8 million people. One in six of them currently has a mental health problem.

Peter trained as a psychiatrist at the Maudsley Hospital in south London and then went to work as a senior lecturer at the University of Southampton. But the academic-focused role meant he had less contact with patients than he would have liked, so he moved to a clinical post in Nottingham, and then came to west London 22 years ago to combine research and work in community-based teams. He worked in assertive outreach teams in Paddington and in Hammersmith and Fulham until a year ago.

Nowadays, he gives second opinions and sees individual patients – he is an honorary consultant psychiatrist with Central and North West London NHS Foundation Trust and West London Mental Health NHS Trust.

His research has always focused on improving services for people with anxiety, depression and personality disorders – 'common' disorders that, he says, account for 90 per cent of all mental health problems. 'Personality disorder is more hidden than depression or anxiety, but probably even more common,' he says.

'In assertive outreach teams, we classically work with people who are "difficult to engage", but the main reason they do not want to engage is not their main (official) diagnosis but their personality disorder. Our research has shown that 90 per cent of people seen by these teams have a personality disorder.'

Some of his current work involves developing better services for people with personality disorder. He chaired the group responsible for developing the NICE (National Institute for Health and Clinical Excellence) guideline on the treatment and management of borderline personality disorder, published in 2009. He has also been involved in the evaluation of specialist services for people with severe personality disorder who are, or have previously been, considered dangerous.

He is currently chairing a group charged with revising the diagnostic system for personality disorders in the 11th revision of the International Classification of Diseases (ICD) on behalf of the World Health Organisation. This is one of the main classification systems used to make diagnoses by health professionals. The new version of the ICD is due to be complete by 2015, and the updating process involves bringing together experts in particular specialities from across the globe to discuss new knowledge and evidence from recent research.

At Imperial, he is head of the Centre for Mental Health in the Division of Experimental Medicine. Many of his research projects are adopted by the Mental Health Research Network – like the CHAMP study, seeking to find out whether specially-designed cognitive behaviour therapy can help people who worry excessively about their health *(see page 20)*, which has involved recruiting participants from outpatients clinics at five hospitals in London and Nottinghamshire.

'Pragmatic trials conducted with the help of large numbers of ordinary NHS patients give reliable results that inspire confidence and can change things for the better.'

As hub 'lead', he works with a small team of researchers from other universities within North London's boundaries who sit on an executive committee, and liaises closely with hub manager Sandra O'Sullivan, whose job it is to oversee and organise support for studies. 'We are there to help recruit people as participants to studies, but also to encourage researchers, mental health professionals, people with mental health problems and their families to be involved in the research we support,' he says.

Working collaboratively ensures the best possible research results, he adds. 'If you want to get the best people to work on a particular project – be they researchers, professionals or people with experience of mental health problems – you need a wide circle to choose from. The MHRN can help with that – the network's circle extends across England.

'Research is sometimes carried out by people who are particularly enthusiastic about treatments, be they psychological therapies or drugs. By getting lots of people involved who have no vested interest, you are more likely to get accurate and unbiased results. Pragmatic trials conducted with the help of large numbers of ordinary NHS patients give reliable results that inspire confidence and can change things for the better.'

studies we support making a difference

Practical therapy to boost people's mood after a stroke

After a stroke, people may initially feel frustrated by not being able to lead their lives in the way they previously did. Those who have communication problems as a result of the stroke may find it particularly difficult – and may have bouts of low mood that can hinder their recovery.

A research project in Trent seeks to find out if 'behaviour therapy' can lift people's mood by helping them gain confidence and motivation to once again do pastimes that bring them pleasure.

'After a stroke, people who have communication difficulties may not be interacting with other people and may not be able to do lots of activities they previously enjoyed – even watching television or reading a book might be a challenge,' says Dr Shirley Thomas at the University of Nottingham, who is leading the research. 'Behaviour therapy is very practical and can be adapted for people who have communication problems. The theory behind it is if people don't get any reward from the things they do, and how they spend their time, their mood becomes low. When people are busy and doing things they like, their mood is higher.'

An assistant psychologist works with people in their own homes and helps them set realistic goals for increasing the time they spend doing things they enjoy, or helping people come up with similar alternatives. 'One lady used to do a lot of flower arranging, but had lost her confidence and motivation, for example. One man wasn't in a position to play football with his children any longer, but still wanted to play games with them. At the end of therapy, the lady was once again doing flower arrangements, and the man was playing different sorts of games with his children in the house,' says Dr Thomas.

Dr Shirley Thomas:

'After a stroke, people who have communication difficulties may not interact with others or be able to do activities they previously enjoyed – even watching television or reading a book might be a challenge.'

The assistant psychologist works with people for three months and on average meets with them 10 times – about once a week – though will meet more regularly if an individual needs it. Time is also flexible – on average, each session lasts an hour, but can be shorter or longer to suit each individual.

Almost 100 people who have had a stroke and now have communication problems (called 'aphasia' by health professionals) have been recruited to a trial testing the value and effectiveness of the behaviour therapy.

Half of them are meeting with an assistant psychologist on top of their post-stroke treatment, while the other half continue with the treatment alone. All of them are asked about their mood, and how they are spending their time,

Enlisting the help of survivors of childhood brain cancer

Are children who have brain tumours that are diagnosed and treated before their fifth birthday more likely to go on to develop mental health problems in later life?

A team of researchers led by Dr Howard Ring at the University of Cambridge has tracked 117 survivors of childhood brain cancer living in England and enlisted their help to try to start answering this question.

Previous research has shown that adults who have survived brain cancer in childhood are more likely to have an intellectual disability, and to develop epilepsy. Dr Ring and his colleagues want to find out if tumours also increase the risk of mental health problems – and whether different sorts of treatment given for the cancer might play a part in the development of mental ill health in adulthood.

'Ultimately, the results of this study could contribute to making sure people who need help with their mental health after a childhood brain tumour receive appropriate care,' he says.

Brain tumours affect between 122 and 133 children in every million.

Understanding more about the potential links between childhood brain cancer, the treatment given and mental health problems in adulthood could also help inform future choices made by parents of children with brain tumours. 'It is helpful to know about all risk factors – including whether a certain type of treatment might change the risk of a psychiatric problems 20 years down the line, for example.'

The individuals who agreed to give information to researchers were treated for a brain tumour between 1957 and 1981. Mental Health Research Network staff worked with the research team to trace them, using NHS numbers that accompany a record of diagnosed cancers and treatments held in the National Registry of Childhood Tumours, a database held at Oxford University.

Researchers have asked them about their mental health since their tumour was treated, and have also been collecting information about IQ and 'apathy' – a separate syndrome


studies we support making a difference

three months and six months after joining the trial. The research team will then be able to compare their answers and find out if those who received the behaviour therapy are undertaking more activities they enjoy, and whether this has affected their mood.

Every year, more than 130,000 people in England and Wales have a stroke. One third of them have problems with communication as a result.

The research team is also collecting information about symptoms and mood from those volunteering to take part in the trial, and from another 100 people who have communication difficulties following a stroke. Researchers want to understand more about how problems with communication impact on people's mental health to enable them to design better support. 'Previous research has shown that low mood can affect people's quality of life and how they recover from a stroke, but much of it hasn't included people with communication problems,' says Dr Thomas. 'It's harder to do research if people have difficulties understanding other people's speech, or find it hard to get their own message across.'

In this project, the researchers are using questionnaires that have been designed especially for people who have trouble communicating, and are also asking relatives and carers to add to the information they collect.

Every year, more than 130,000 people in England and Wales have a stroke, and about one third of them have difficulties speaking, reading, writing or understanding language as a result.

- The *Communication and Low Mood* (CALM) study ends in 2011 and is funded by the Stroke Association. The study has been given support by the Mental Health Research Network, and its sister Stroke Research Network.

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that Dr Ring says can really interfere with some people's lives.

'This is a specific syndrome where people have extreme difficulties motivating themselves,' he says. 'People can develop apathy after a head injury or when they have a neurodegenerative disease.

Adults who have survived brain cancer in childhood are more likely to have an intellectual disability, and to develop epilepsy.

'I have come across people who have survived brain tumours and have troublesome apathy, so we decided to find out how widespread this is as part of the project – the more information we have, the better we can meet people's needs.'

Brothers and sisters of the childhood brain tumour survivors were also invited to give information about themselves to the research team. 'Genes, environment and individual experience all contribute to psychiatric problems, so collecting the same information from siblings for comparison purposes can help us analyse what part the tumour and treatment has had to play in any mental health problems that people have experienced,' says Dr Ring.

Brain tumours in childhood are rare, affecting between 122 and 133 children in every million.

- This research is funded by the Samantha Dickson Brain Tumour Trust. You can find out more information about childhood brain tumours on the Trust's website, *www.braintumourtrust.co.uk*

Best bipolar drugs

People with bipolar disorder are often prescribed either lithium or valproate as long-term medication to help prevent relapse. The results of the BALANCE trial shows that either a combination regime of both drugs, or lithium alone, is most effective over two years.

Lithium was standard 'maintenance treatment' for more than four decades. In recent years, however, there has been a shift away from lithium because of its potential side effects, and valproate has been more widely used for relapse prevention, particularly in the USA.

The BALANCE trial was led by Professor John Geddes at Oxford University and set out to discover whether prescribing both drugs at the same time would work better than either of the drugs taken by themselves.

330 patients with bipolar disorder 1 took part in the trial and were recruited from across the UK, and in France, Italy and the USA. They were randomly divided into three groups – one group was prescribed lithium only, another valproate only and the third took a combination of both drugs. Researchers followed them for two years to find out if the medications were keeping them well, or whether they had a relapse of either a manic or depressive episode.

Sixty-nine per cent of people on valproate had a relapse during the two-year period, compared to 59 per cent of people who took lithium and 54 per cent of people who took both drugs.

People who are on lithium and have frequent relapses would fare better if they switched to a combination therapy rather than valproate, said the research team.

However, the researchers pointed out than more than half the participants in the trial who took combination therapy did have a relapse and did need extra medication during the two-year period.

- The study was funded by the Stanley Medical Research Institute and the results were published in *The Lancet* in January 2010. BALANCE stands for *Bipolar Affective disorder: Lithium/ Anti-Convulsant Evaluation.*

studies we support making a difference

Will gentle exercise benefit older people's mental health?

Can encouraging elderly people who live in residential and nursing homes to take part in gentle exercise classes, and to walk more, be an effective alternative to antidepressant medication?

Antidepressants are commonly prescribed to residents but may not mix well with other medications frequently taken by older people – residents of homes are typically on between six and eight different kinds of drugs. Some antidepressants may cause unpleasant side effects in older people, and increase the number of falls that can lead to disability and death.

More than 40 per cent of people who live in nursing homes have depression, although their symptoms may not always be spotted. A research team led by Professor Martin Underwood at Warwick University thinks that offering exercise to all residents and helping them be more active may lift the mood of those who are depressed and benefit everyone else in other ways – potentially leading to better mobility, less chronic pain and fewer falls. Those improvements may in themselves help protect people from developing depression in future.

More than 40 per cent of elderly people who live in nursing homes have depression.

The team has designed a programme that involves training staff in residential and nursing homes to help residents to be more physically active every day, and holding twice-weekly exercise classes for residents. These are led by specially-trained physiotherapists who have experience of working with frail, older people. All residents will be encouraged to join the 40-60 minute long classes, whether they are depressed or not.

The programme is being tested in a research trial that involves 77 residential and nursing homes in Coventry, Warwickshire and north east London.

Helping residents be more active on a daily basis in reality means encouraging them to walk more, and physiotherapists

Helping children who have autism or Asperger syndrome overcome anxiety

Children and young people who have autism or Asperger syndrome are four times more likely than their peers to worry so much that it interferes with their everyday life. Researchers at Newcastle University are finding out whether group therapy can teach them strategies to deal with their anxiety within seven once-a-week sessions. Their parents are attending separate group sessions at the same time so they can understand the techniques their children are being taught to deal with and overcome their anxiety, and help them practice at home.

The cognitive behaviour-style group therapy sessions are based on *Exploring Feelings*, a manual written by psychologist Professor Tony Attwood, who runs a clinic in Australia for people with autism and Asperger syndrome. Each group has two leaders and each session lasts for two hours.

The Newcastle-based project is a small pilot trial: if it proves to help the symptoms of anxiety, the team plans to run a larger UK project to test its success. Thirty-three nine-to-13-year olds with Asperger syndrome and their parents are taking part in the first-stage study and have been recruited from child and adolescent mental health services and community child health services in Northumberland, Tyne and Wear.

Initially, half the families took part in the group therapy and were assessed after two to three months. This allows researchers to compare the anxiety of children who joined the sessions with the anxiety of those who did not to find out what difference *Exploring Feelings* may have made. The other half are offered the therapy at a later date. The research team is keeping in touch with the young people and their parents for a year, contacting them every three months to find out if their anxiety has improved.

Around one in 100 young people has an autism spectrum disorder and 40 per cent of them have an anxiety disorder.

Around one in 100 young people has an autism spectrum disorder (ASD) and research suggests that 40 per cent of them have an anxiety disorder, says Professor Helen McConachie who is leading the research.

'We did a survey of anxiety among young people with ASD in Northumberland, Tyne and Wear and asked parents to say if they thought their young person needed professional help. Of those who judged their young person did need help, only 56 per cent were getting it.

'Anxiety waxes and wanes, but it can seriously affect home and school life and can be hard to overcome without professional support. This intervention is short and, if proven to work, could be realistically delivered within existing resources in child and adolescent mental health services,' she says.

Effective therapy for anxiety in young people with autism spectrum disorder is funded by the National Institute for Health Research *Research for Patient Benefit* funding stream and will end in 2011.

are offering staff training and advice on how best to do this, including making sure appropriate and safe walking aids and footwear are available.

All staff in all the homes that are participating in the study are given training about how to recognise and treat the symptoms of depression. Half the homes are running the programme, the design of which has been informed by research about the benefits of exercise and the practical experience of the research team from Warwick University and the Centre for Health Sciences at Barts and the London School of Medicine and Dentistry. Before the trial started, the research team worked in three homes to finalise the details of the programme, taking advice from staff, residents and their family members.

Professor Martin Underwood:

'A group exercise programme that combines a social element and improved exercise tolerance is a promising non-drug approach to depression.'

Researchers will monitor the health of all residents in all the homes to see if those who take part in the programme are less likely to be depressed after a year. They will also measure whether the programme has made a difference to the symptoms of residents who had a diagnosis of depression when they initially joined the study. Through interviews with residents, family members and staff, the research team also wants to find out if the programme has improved people's general health and mobility: they will count the number of falls people have had and measure time they have spent in hospital. The research will include a cost-effective analysis of the programme.

'A group exercise programme that combines a social element and improved exercise tolerance is a promising non-drug approach to managing depression,' says Professor Underwood. 'If this intervention is shown to be effective, it could be implemented as part of routine health and social care.'

The OPERA *(Older People's Exercise intervention in Residential and Nursing Accommodation)* trial is funded by the National Institute for Health Research *Health Technology Assessment Programme* and is due to finish in 2011.

New toolkit to support relatives

People mostly experience a first episode of psychosis when they are in their late teenage years or early 20s – and 60 to 70 per cent are still living at home with their families. 'It can be a frightening time for relatives who often have little knowledge of what is happening, or what to do for the best,' says Fiona Lobban, a psychologist and researcher who works at the Spectrum Centre for Mental Health at Lancaster University.

'Family members of people with a diagnosis of psychosis need information and help to understand the symptoms and better support their relative, but most mental health trusts don't have the resources or trained staff to do that.'

60 to 70 per cent of people who have had a first episode of psychosis still live with their families.

So Dr Lobban is leading a research project that has developed the *Relatives Education and Coping Toolkit* (REACT), a package of support for family members of people experiencing psychosis for the first time. It includes information and guidance for coping, using cognitive behaviour therapy techniques. The research team has worked with family members to make sure the resource – available as a publication or online – meets their needs. And they reviewed previous research to find out what has been proven to be helpful for relatives of people with psychosis.

They are now inviting families and friends living in Lancashire, Cumbria and Greater Manchester to try out the Toolkit and give feedback about how useful it is.

Half of the 100 family members who sign up to the REACT trial will test the Toolkit and be given support by phone, email or Skype. The other half will continue to talk, as they normally do, to the mental health professionals who are caring for their relative. Both groups will give information to the research team so their experiences can be compared after six months to see what difference the Toolkit has made. The Toolkit will then be modified and honed in the light of feedback from family members.

The research is supported by the National Institute for Health Research *Research for Patient Benefit* funding stream and is being carried out in collaboration with the mental health charity Rethink and Manchester University-based researchers.

Families can volunteer to take part: visit *www.reactstudy.co.uk*. Researchers are looking for people who have made initial contact with early intervention services run by Lancashire Care, Greater Manchester West Mental Health and Cumbria Partnership NHS Foundation Trusts over the past two years, and who are continuing to recieve support from one of these teams.

Dr Fiona Lobban:

'Family members need information and help to understand the symptoms of psychosis and better support their relative, but most mental health trusts don't have the resources or trained staff to do that.'

Why personal experience makes research better

'Research need not be an esoteric exercise. You don't need to have a degree to get involved and there is no substitute for experience. Unless you've walked in those shoes, day in and day out, you simply don't have full insight into a particular mental health problem.' So says Tim Rawcliffe whose job it is to encourage people with experience of mental health problems to work with researchers – and vice versa.

Tim is service user development officer for the MHRN regional office covering the north west of England. 'I try to demystify research and promote opportunities to get involved to service users. There are many ways of being involved, regardless of your background, and the experience of having a mental health problem gives you a particular insight that can complement the view of an academic researcher who has no personal experience,' he says. 'I also work with research teams to highlight the benefits I think service user involvement can bring, and help them work out meaningful ways to involve people.'

Nowadays, most funding bodies – and indeed the Mental Health Research Network itself – demand evidence of 'involvement' before support is offered. However, for some research teams, this can still seem to be an ill-thought through, eleventh hour exercise that often feels far from meaningful, he says.

'It's a bit of a mixed picture. Some research teams are very committed to service user involvement and it is one of their first considerations when putting together a research proposal. Some teams specifically employ service user researchers and involvement is embedded in their research design. But other researchers sometimes leave it far too late in the day: all too often involvement appears to be an afterthought, perhaps seen as being necessary only to complete the funding application form. They are not getting people's opinion in a meaningful way because the proposal is largely set in stone. Researchers get less benefit if they come along when all the decisions are cut and dried, and there is also limited benefit for the people who are asked to comment. It's very frustrating when that happens.'

Yet the benefits involvement can bring to research projects are immense, he says. 'The priorities of academic researchers who have no experience of mental health problems are not necessarily the same as the priorities of someone who has used mental health services, so involving service users can make research more relevant.

'The experience of having a mental health problem gives you a particular insight that can complement the view of an academic researcher who has no personal experience.'

'My gut feeling is that service user involvement can also benefit recruitment. By commenting on the design, for example, service users can make sure the tasks asked of individuals who agree to participate are not too arduous.

'An academic with no experience won't necessarily know if the way a study is undertaken and planned is making realistic demands of the individuals who agree to take part in it. In the real world, sitting for two hours and answering very personal questions may be an emotionally-draining task for someone who is unwell and feeling vulnerable. It can leave people feeling pretty raw, and people with no personal experience don't necessarily know that. By getting service users involved with developing, designing and delivering questionnaires, researchers can get advice about the right way to ask things of people, about what is realistic and reasonable.'

Tim has worked at the MHRN's North West Hub as a paid employee since 2006 but before that was involved in its work as a service user representative member of its advisory board.

After a psychology degree followed by a Masters, his personal experience of using mental health services began while he was undertaking a PhD. During time off study

and work, he became involved in service user groups and heard about the Mental Health Research Network at a local event. 'It was when the hub was being set up and they talked about the two things I was interested in – research and user involvement.'

Over the years, he has built up a huge network of contacts with service user groups based in the catchment areas of the nine mental health trusts that work with the hub and is in touch with scores of individuals willing to offer their expertise to research teams.

'To me, involvement is a moral issue – we should involve people who are ultimately recipients of care and services potentially developed by research.'

He is particularly keen too to encourage people who are not members of service user groups to get involved. 'The clinical studies officers tell people they recruit to studies about who I am, and about the chance to get involved in research. I certainly know of one person who is now a paid researcher and whose original route into research was as a participant.'

Tim still sits on the hub's advisory board that meets twice a year. In addition, there is a service user advisory group with representatives from each of the geographical areas covered by the different trusts providing mental health services within the hub's boundaries. The discussions and recommendations of that group feed into the executive committee that runs the hub: Tim is also a member of this committee.

'The requirement to have service users involved in studies is still fairly novel, and some researchers are possibly nervous and apprehensive,' he says. 'But I think things are changing slowly and the MHRN as an organisation has a genuine commitment to make meaningful service user involvement happen.

'To me, involvement is a moral issue – we should involve people who are ultimately recipients of care and services potentially developed by research. It is only right and proper that people are offered the opportunity to be involved.'

Make sure working with us doesn't affect your benefits

People with personal experience of mental health problems and their families who get involved with research projects through the Mental Health Research Network (MHRN) are paid for their work.

Payment can, however, affect benefits: the MHRN therefore subscribes to the Citizens Advice Bureau Involvement Helpline. This means anyone who wants to get involved in the work of the MHRN or the studies it supports can get professional advice about how their benefits and tax credits might be affected.

Details about accessing the confidential, freephone service are available through the MHRN's regional offices *(details on the back page)* or through the centrally-based Service Users in Research (020 7848 0644) or FACTOR – Friends/Families and Carers Together in Research (020 7848 0643), or email mhrnppi@kcl.ac.uk. The remit of both Service Users in Research and FACTOR is to enable people with experience of mental health problems and their families to get involved in research projects supported by the MHRN.

'We strongly advise anyone who is receiving benefits to take advice before they get involved, as each benefit has different rules about the amount of money people are allowed to earn while they are claiming it,' says Service Users in Research coordinator Thomas Kabir.

Supporting people with psychosis who want to work

A diagnosis of psychosis, for the majority of people, leads to long-term unemployment: an estimated 70-80 per cent of people who have had psychosis for some time do not have a job. But almost two-thirds of people experiencing psychosis for the first time are also unemployed, and a team of researchers from across England wants to try to change that.

They are giving people who are recently unwell practical help to find a job, but also attempting to increase their self-esteem, and help them feel more motivated and positive about their ability to work. A research project called ENDEAVOUR *(Improving employment outcomes for young people with first episode psychosis)* aims to find out whether offering extra support in the shape of 'motivational interviewing' will make a difference to people's job prospects.

Professor Tom Craig:

'When people with psychosis are looking for work, they face not only discrimination from employers, but also may struggle with their own low expectations of themselves, often as a result of being unwell and other people's responses to the illness.'

'When people with psychosis are looking for work, they face not only discrimination from employers, but also may struggle with their own low expectations of themselves, often as a result of being unwell and other people's responses to the illness,' says Professor Tom Craig from the Institute of Psychiatry, King's College London, who is leading the research. Most people with psychosis, whether recently diagnosed or living with a diagnosis for some time, want to get back to work, he says, and a job can help people on their road to recovery. 'Work gives people a purpose in life. It makes people feel good about themselves, increasing their self-worth, and enlarges people's social circles.'

But over the past 50 years, unemployment rates for those with chronic psychosis have risen steadily, and it is now also common for people who have experienced a first episode of psychosis to be out of work.

Specialist vocational workers offer Individual Placement and Support (IPS) – this means helping people to get a job, and then continuing to support them in their working lives, and supporting the employer, for as long is necessary. The idea is that everyone is offered IPS, regardless of their symptoms, or their previous participation in work experience schemes, or in schemes designed to prepare them for employment.

Almost two-thirds of people experiencing psychosis for the first time are unemployed.

IPS has been tested in America and proven to help people who need more intensive support return to work, increasing people's chances of getting and

Can online therapy beat stress and depression at work?

If you're stressed or depressed, you're more likely to take time off work – and even if you do go in, you will probably be a lot less productive while you're there.

Now two large private sector employers are taking part in a research trial to find out whether offering their staff therapy online can make a difference to people's mental health – and thus help them work more efficiently and effectively.

The research team, led by Professor Justine Schneider at the University of Nottingham, is recruiting 355 employees who are feeling the effects of stress, anxiety or depression, via their place of work.

Half of those who sign up to the trial are following the MoodGYM programme, an online cognitive behaviour therapy (CBT) package developed by Australia National University. The programme is designed to last for six weeks but can be completed by people at their own pace. The other half are signposted to different websites that include information about depression and stress, and tips for dealing with it.

'This sort of therapy could offer savings to employers on a massive scale.'

Everyone who joins the trial will continue to have access to help that is already available in their workplace, including support from occupational health departments. They are also given telephone support for six weeks from a trained team of freelancers recruited by the Mental Health Research Network's East Midland plus South Yorkshire regional office.

The research team is collecting information about people's symptoms and limitations caused by stress and depression both at work and at home – when they join the study, six weeks later and then again after three months. They will also ask about any professional help people have sought, and

keeping a job. And a report on mental health and employment commissioned by the previous UK government (*Realising ambitions: better employment support for people with a mental health condition, 2009*) recommended introducing IPS in this country.

'The evidence from IPS research is encouraging, but most studies in America have involved highly motivated people who sign up for both employment and to take part in research, and in some studies, have had to demonstrate a commitment before being accepted on the programme,' says Professor Craig. 'The trials show IPS gets 50-60 per cent of people into work, but that still leaves 40-50 per cent who do not find employment. We want to find out what part confidence, readiness for work, and motivation has to play when seeking a job, and whether offering people motivational interviewing as well as IPS can help.'

Motivational interviewing (MI) is a technique used by mental health professionals in many mental health services. The ENDEAVOUR research team thinks that, coupled with IPS, it might boost people's chances of getting and keeping a job by helping them overcome any fears or ambivalence they may have about re-entering the job market or returning to education, and feel motivated by the potential benefits.

An estimated 70-80 per cent of people who have had psychosis for some time do not have a job.

All mental health professionals working in two early intervention teams and offering support to people who have experienced a first episode of psychosis have been trained in MI techniques. The research team is following 50 people recruited to the project from each team to see what happens as a result of combining MI and IPS. They will similarly follow another 100 people recruited from two other early intervention teams. They will be offered IPS only so researchers can see if the addition of MI has had an effect. 'By training all members of an early intervention team, we hope to increase the uptake and success of IPS provided by the employment specialists,' says Professor Craig. 'We hope MI and IPS together will improve the number of people who are in employment and education one year later.'

The research team will find out how long a job, or period of study, has lasted over the 12 month period, and will also collect information from the 200 participants to try to paint a bigger picture of what personal characteristics and attitudes help or hinder people getting back to work.

People are being recruited to the trial from early intervention teams in Lambeth and Wandsworth in London, and in East Birmingham and Worcester.

- The ENDEAVOUR study will finish in late 2011. It is funded by the National Institute for Health Research *Research for Patient Benefit* programme and is being carried out in collaboration with South West London and St George's Mental Health NHS Trust, Warwick Medical School, University of Warwick, Worcestershire Mental Health Partnership Trust, the Centre for Mental Health, and South London and Maudsley NHS Foundation Trust. A cost-effectiveness evaluation will be carried out by the Centre for the Economics of Mental Health at the Institute of Psychiatry, King's College London.

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time taken off work. This will allow comparisons to be made between the two groups, and allow researchers to judge not only whether MoodGYM has made a difference to people's mental health and ability to work well, but also whether it is cost-effective. Much of the information is being collected online at a specially-designed website.

'Research has shown that people who are depressed take three and a half times more sick leave than their colleagues who have no mental health problems – an average 28 days a year compared to eight days a year,' says Professor Schneider. 'People with depression and anxiety may turn up to work, but under-perform and this productivity loss is estimated to be even greater than productivity lost through absenteeism. If the trial shows that computerised CBT can improve performance in the workplace by effectively treating depression and anxiety, and teaching self-management strategies, it could offer savings to employers on a massive scale.'

Professor Justine Schneider:
'The appeal of computerised programmes is that they are low cost and easy to access, and possibly free of the stigma attached to seeking help from mental health services.'

Online or computer-based packages, mostly based on CBT techniques, have already become common within health services as a treatment option for depression and anxiety. Two of these computerised packages are recommended by the National Institute for Health and Clinical Excellence (NICE) – *Fearfighter* for panic and phobia, and *Beating the Blues* for mild and moderate depression. 'The appeal of these computerised programmes is that they are low cost and easy to access, and possibly free of the stigma attached to seeking help from mental health services,' says Professor Schneider.

- This study – *Computerised CBT for common mental disorders: randomised controlled trial of a workplace intervention (cCBT)* – is funded by the British Occupational Health Research Foundation and is due to be complete by August 2011.

Helping to allay people's fears about their health may also save money

People who worry a lot about their health may constantly seek reassurance from their GP – and are often sent for hospital-based tests to put their mind at rest. Some people have endless rounds of expensive tests that all come back negative.

Now a team of researchers, led by Professor Peter Tyrer at Imperial College London, is finding out whether a specially-designed talking therapy may help anxious patients develop ways of coping with their concerns about their health. As a result, they may go to their doctor less often and have fewer referrals to specialist clinics, thus saving money.

'Health anxiety can place a substantial burden on health services,' says Professor Tyrer. 'Its central feature is sufficient fear of having a serious disease to lead to medical consultation, and very commonly, this is followed by further investigations. Between 10-20 per cent of people who attend medical clinics have abnormal health anxiety and patients often rotate between different clinics, depending on the focus of their symptoms.'

'The central feature of health anxiety is sufficient fear of having a serious disease to lead to medical consultation.'

The CHAMP *(Cognitive behaviour therapy for health anxiety in medical patients)* trial is testing a form of cognitive behaviour therapy (CBT) that specifically tackles health anxiety. Researchers have recruited patients who are especially concerned about their health from specialist medical outpatient clinics where they have been referred – gastronenterology and cardiology clinics, for example. Consultants and clinical nurse specialists working in a range of clinics in five hospitals in London and Nottinghamshire have helped to identify people who may worry excessively about their health. Members of the research team then used a simple questionnaire to measure health anxiety: all patients who scored highly were invited to take part in the study, and half of those who said yes were signed up for a maximum 10 one-hour sessions of the specially-adapted CBT. The therapists have, wherever possible, worked in the same hospital outpatients department as the clinic where people were first contacted.

Between 10-20 per cent of people who attend medical clinics have abnormal health anxiety.

In total, 445 patients have agreed to take part in the trial and the research team is keeping in touch with them all for two years to find out if the CBT makes a difference – if the patients who had the CBT are less worried about their health and seeking fewer consultations with doctors than those who didn't see a therapist. Researchers have explained what health anxiety is to everyone recruited to the study: previous research has shown that this information alone, which seeks to put their anxiety into context, may benefit some people and make them less worried.

The research team will also weigh up whether there is a cost benefit in offering CBT to patients with health anxiety.

The Confederation of Health Anxiety Sufferers Supporting Increased Services (CHASSIS) has advised on the CHAMP study, which is funded by the National Institute for Health *Research Health Technology Assessment* programme and will end in 2012.

A treatment that tackles all the symptoms of anorexia

The majority of people with anorexia nervosa exercise compulsively – yet the existing treatments for the life-threatening eating disorder largely ignore this common symptom. Now a team of researchers at Loughborough University Centre for Research into Eating Disorders (LUCRED) has developed a new talking therapy that targets all the symptoms of anorexia, including the compulsion to be excessively physically active.

The cognitive behaviour therapy style treatment is called LEAP. 'It is the only treatment in existence designed to tackle compulsive exercising,' says Dr Jon Arcelus, a consultant psychiatrist at Leicester Eating Disorders Service run by Leicestershire Partnership NHS Trust. He is also a visting fellow at Loughborough University and works closely with LUCRED director Dr Caroline Meyer.

About 80 per cent of people with anorexia nervosa exercise compulsively and they are more likely to spend time in hospital.

'Our new therapy is not meant to make patients stop exercising altogether, but rather to educate them about what constitutes healthy, non-excessive exercise and help them regain control over their behaviour,' he says.

LEAP has already been piloted and now LUCRED has teamed up with the University of Sydney in Australia to embark on a trial to find out how

studies we support making a difference

Brain scans may yield clues as to why antidepressants don't always work

State-of-the-art brain scanning is helping to shed more light on how antidepressants work – and why they only work for some people and not for others.

Doctors in the NHS wrote more than 39 million prescriptions for drugs to tackle depression in England in 2009 – yet antidepressants only help 50 to 70 per cent of people who take them.

Researchers know that different types of antidepressants affect the levels of two brain chemicals – serotonin and noradrenaline – that send messages between brain cells. But they don't yet understand how the drugs work inside the brain to improve some people's mood – and why they don't make a difference to everyone.

NHS doctors in England wrote more than 39 million prescriptions for drugs to tackle depression in 2009.

Now 40 people diagnosed with depression have been recruited to the REMEDi study and have had a brain scan before and after a course of citalopram, an antidepressant commonly prescribed for anxiety and depression.

During the first scan, the volunteers were given a small injection of citalopram so that the research team at the University of Manchester could gauge how their brains respond – and whether that response could predict what sort of difference the drug made to their symptoms after eight weeks. The second scan allowed researchers to look for changes that may have occurred in the brain during treatment, particularly in the brains of people who improved while taking the antidepressant.

Understanding more about the brain processes that are modified by antidepressant medication will help scientists, in the longer term, develop better, new types of drugs that can help everyone who has depression.

Thirty people who have never experienced depression also agreed to have a brain scan to boost the research team's knowledge of the workings of antidepressants. The images of their brains will be compared with images of the brains of people who are depressed so researchers can again look for specific differences.

'In spite of more than 50 years of clinical experience with antidepressants, we still really don't know how they work in the brain.'

The study is funded by the Medical Research Council and is led by Professor Ian Anderson, a professor of psychiatry who chaired the Guideline Development Group for the 2009 NICE (National Institute for Health and Clinical Excellence) guideline for treating depression.

'In spite of more 50 years of clinical experience with antidepressants, we still don't really know how they work in the brain,' he says. 'Our research group is particularly interested in using new brain imaging techniques to study how antidepressants affect the brain and can influence the way it handles emotional information. We think this could be the key to understanding how a physical treatment can help an emotional disorder like depression. We hope that this research will be another step in our understanding that will eventually translate into being able to treat depression more effectively.'

- The REMEDi *(REmission MEchanisms in Depression)* study is due to report its results by the middle of 2011.

effective the new treatment is. Between 150 and 200 people with anorexia will be recruited to take part in the four-year randomised controlled trial: in the UK, people are being recruited through services for eating disorders based in Leicester and Northampton.

The new broad-based therapy, tackling all symptoms, will be compared to an established talking therapy for anorexia nervosa.

Both types of treatment involve weekly sessions with specially trained therapists over a 34-week period.

The research team will analyse which treatment has the most success after a year in terms of helping people to restore their weight and adopt more normal eating habits. 'If the research shows that LEAP is an effective therapy, it will have a significant impact on the lives of people who have anorexia nervosa, and will be huge step forward in the treatment of this severe illness,' says Dr Arcelus.

Dr Jon Arcelus:

'Our new therapy is not meant to make patients stop exercising altogether, but rather to educate them about what constitutes healthy, non-excessive exercise and help them regain control over their behaviour.'

About 80 per cent of people with anorexia nervosa exercise compulsively: previous research has shown they are more likely to spend time in hospital, relapse more frequently and become more unwell.

- The study *(LEAP in the treatment of anorexia nervosa)* is funded by the Australian government's National Health and Medical Research Council.

studies we support making a difference

Facts and personal testimonies could combat prejudice

People with mental health problems often experience discrimination and prejudice in every area of their lives: other people are quick to pre-judge and make assumptions about them, often based on inaccurate stereotypes portrayed in the media.

Researchers at the Institute of Psychiatry, King's College London want to find out if a short training course focusing on the facts about mental health, and presenting people's personal experiences, can make a difference to the attitudes and actions of hundreds of student doctors, trainee teachers, teachers already based in the classroom and other school staff. 'Doctors, other health professionals and teachers are very influential and can have a significant impact on the lives of people with mental health problems,' says researcher Bettina Friedrich.

> The training aims to make a difference to the attitudes and actions of student doctors, trainee teachers and teachers already in the classroom.

The training is run by the mental health charity Rethink as part of *Time to Change*, an across England social marketing campaign trying to challenge myths about mental health problems and so help combat stigma and prejudice.

Third year medical students are being recruited to the training sessions through five medical schools – at King's College London, Nottingham, Derby, Bristol and Leicester. Trainee teachers, undertaking a Post Graduate Certificate of Education, are being recruited at colleges in Leicester, Manchester, Sussex and Birmingham.

The one or two day training sessions differ slightly for each group of trainee professionals – medical students get a lecture and role play session while trainee teachers have a workshop and interactive play about a first episode of psychosis and common reactions of family and friends.

But the core content is the same – facts and figures to combat misinformation and personal testimonies that previous research has shown can help change people's preconceptions.

> Some medical students will be 'assessed' by people with experience of mental health problems and their relatives during mock practical exams.

The research team is evaluating the success of the training by asking all those agreeing to take part in the project to fill in questionnaires about their knowledge and attitudes, and the way they might behave towards someone with mental health problems, before and after the sessions, and by email six months later. Some people are filling in the questionnaires without having had the training to allow researchers to quantify what effect the sessions have had. Some medical students will be 'assessed' by people with experience of mental health problems and family members during mock practical exams called 'OSCEs' (Observed Structured Clinical Examination) where they consult with an actor pretending to be a patient.

The training has grown out of previous work carried out by Rethink in collaboration with the Institute of Psychiatry that showed similar sessions run with police officers, school pupils, medical students and trainee psychiatrists helped to change the way they thought about mental health problems and behaved towards people who experience them.

Bettina Friedrich:

'Doctors, other health professionals and teachers are very influential and can have a significant impact on the lives of people with mental health problems.'

The END *(Education not Discrimination)* study includes training for up to 50 teaching and non-teaching staff already working in schools who have a remit for pastoral care. There will also be training for staff working at GP surgeries.

- *Time to Change* started in 2009, is led by Rethink and MIND, and financially supported by the Big Lottery Fund and Comic Relief. Researchers at the Institute of Psychiatry are evaluating the success of the campaign as well as individual projects launched under its wing. *Time to Change* also includes adverts featuring people with personal experience of mental health problems talking about what it is like to live with a mental illness. The END project finishes in 2011.

Monitoring the side effects of medication

Seroquel is a brand name for the antipsychotic drug quetiapine, prescribed for people who have schizophrenia and bipolar disorder. Manufacturer AstraZeneca has developed a new, 'prolonged-release' formulation of the drug – Seroquel XL tablets are designed to release the quetiapine slowly and continuously over a 24-hour period to provide steady blood levels of the medicine throughout the day.

A four-year study, funded by the pharmaceutical company but carried out by an independent research organisation, is now monitoring short-term side-effects of the new, slow-release tablets, which are taken once a day. 750 people who have been prescribed Seroquel XL to treat schizophrenia or a manic episode of bipolar

Can 'dignity therapy' help older people in care homes?

Can encouraging people to document the issues that matter most to them, and what they most want to be remembered, help bolster their self-esteem and enhance their sense of dignity as they enter the last period of their lives?

'Dignity therapy' gives people the opportunity to create a permanent, written record of important events and people in their lives with the help of a specially-trained nurse, and has been shown to benefit terminally ill patients in Canada, and help their families come to terms with their grief.

'The feeling that nothing of your life will be remembered is associated with loss of dignity.'

Now a team led by Dr Sue Hall from the Department of Palliative Care, Policy and Rehabilitation at King's College London (and including the architect of dignity therapy, palliative care nurse Harvey Chochinov), wants to find out if it could reap the same sorts of benefits for older residents of care and nursing homes in the UK. 'When older people move into nursing and residential homes, many become reliant on staff not just for medical care, but also for help with daily tasks. Some may feel that they are not living the last part of their lives in as dignified a fashion as they would like,' she says.

'Pride, self-respect, quality of life, well-being, hope and self-esteem are all associated with dignity – and research has also shown that the feeling that nothing of your life will be remembered is associated with a loss of dignity.'

Dignity therapy involves interviewing someone about their life, posing standard questions that are given in advance so people have time to think about their answers. The interview includes the chance for people to say what they would like to be remembered for, and to give any messages or advice they have for family members and friends after their death. The interviews are transcribed verbatim and edited – and each individual has the chance to amend or add to the edited version before it is finalised. The interviewee can then choose to give the document to relatives or friends, or keep it for themselves.

Dignity therapy gives people the opportunity to create a permanent, written record of important events and people in their lives.

The research team has worked with residents, their family members and staff in 15 homes for older people in south London to see if the therapy is appropriate for and potentially beneficial to people who are not necessarily terminally ill but are approaching the end of their lives.

They have trialled the therapy with some of the residents to find out if the technique needs adapting to meet the specific needs of older people, and will use the experience to help plan a large research trial to test its effectiveness.

'Older residents may be confused, or deaf, so may find it hard or taxing to be interviewed and remember parts of their lives. They may struggle to recall names of people and places that have been important to them. Some may have no family to leave their document to – so it may be necessary to tailor dignity therapy to their needs,' says Dr Hall.

The study has been funded by the Dunhill Medical Trust. Harvey Chochinov is based at the Palliative Care Research Unit at the University of Manitoba in Winnipeg, Canada.

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disorder are being recruited to take part in the research. They are being signed up with the help of clinical studies officers based at all the Mental Health Research Network's regional offices, and mental health professionals working in mental health trusts throughout England.

With each individual's permission, mental health professionals are reporting any side effects that people experience during the first three months after starting on Seroquel XL. They are also giving information about people's medical history and past medication regimes, and the dose of Seroquel XL that has been prescribed.

Another 750 people prescribed quetiapine in its traditional 'immediate release' format (taken twice a day) are also being recruited and monitored so comparisons of the two types of formulation can be made.

The research project is called the OASIS *(Observational Assessment of Safety in Seroquel)* study and is being carried out by the Drug Safety Research Unit in Southampton. OASIS was prompted by a request from the Medicines and Healthcare Regulatory Authority (MHRA), the organisation that must issue a licence to drugs before they can be used in this country.

AstraZeneca carried out extensive trials of Seroquel XL before it went on the market, and the OASIS research project is part of post-marketing procedures for the new product. The MHRA first gave a licence to Seroquel XL in 2008 for the treatment of schizophrenia and manic episodes associated with bipolar disorder (50, 200, 300 and 400 mg prolonged release tablets). It has since granted a licence (in March 2010) for Seroquel XL 150mg prolonged release tablets that can be prescribed for schizophrenia, bipolar mania, and bipolar depression.

The OASIS study started at the end of 2009 and is being led by Professor Tony Hale, a professor of psychiatry at the University of Kent and Professor Joe Reilly, a professor of mental health at Durham University and deputy lead for the Mental Health Research Network's North East Hub.


Ruth Hennem


Philippa Lowe


Angela Fiori

How the views of family members and friends can help researchers

People who support a relative or friend who has a mental health problem have experience and knowledge that can help researchers plan the practicalities of their projects. FACTOR is a network of people who have that experience and are willing to work with researchers, offering insight that makes research much more relevant and 'real-life'.

'I don't think researchers always realise what carers do and how much we know about services and about our relatives – the people who use services,' says Philippa Lowe, a member of FACTOR, who supports her son who has a diagnosis of schizophrenia.

FACTOR stands for Families/Friends and Carers Together in Research. It was set up by the Mental Health Research Network (MHRN) as a way of involving relatives of people with mental health problems in research studies it supports.

Members of FACTOR can choose how involved they become and how much time they commit. Some go to an occasional focus group, or to one-off consultation meetings. Others go along regularly to committees and steering groups. Some belong to a Carer Reference Group that meets once a month and is visited by researchers seeking input on specific projects. Members of the London-based Carer Reference Group have advised on how to make written information about research easy to understand, for example, and about the best way to recruit people to research studies and keep in touch for follow-up work. A second Carer Reference Group meets in Coventry and is open to carers who live in the West Midlands.

Both Carer Reference Groups were set up by FACTOR coordinator Geraldine Mason, who is based in the MHRN coordinating centre. A locally-based

pychiatrist is also there to help lead the discussion, answer specific questions or explain research techniques and de-mystify procedures.

Matthew Broome is the psychiatrist in Coventry: he works half the time in an early intervention service offering support to young people experiencing their first episode of psychosis (which is run by Coventry and Warwickshire NHS Partnership Trust), and half the time as a researcher at the University of Warwick.

As a researcher, he says, his work is informed by the contact he has with people who have mental health problems through the early intervention service. 'I think you only really know the problems that need to be solved and the questions that need to be answered if you work as a clinician,' he says.

'In early intervention services, the patients are quite young, and quite often come in with their parents or other family members. We therefore also do a lot of work with family members – they are great allies and a good relationship with relatives is invariably an asset.'

Matthew also has personal experience as a carer. He supports a member of his family and says he is only too aware of 'how services sometimes fail to meet expectations, and are sometimes not as therapeutic as they could be.'

'You learn so much over the years, and sometimes it all seems a bit negative, so for me, getting involved in research is about putting what you have learned to some positive use.'

'It can be hard to find out information, and some mental health professionals are less willing or able to talk to the distressed individual or their family members. I have been on inpatient wards visiting a relative where you feel powerless, where staff avoid eye contact and try not to answer questions,' he says.

Finding the answers to questions is one of the reasons why some people joined FACTOR. 'I got involved in research because I wanted to find out what was

Josie Forshaw

going on, about anything new that might be able to help my sister,' says Ruth Hennem. 'One of the reasons I wanted to get involved was to find out more about genes,' says Josie Forshaw. 'I have two grandchildren born to two people with schizophrenia and I want to find out what to expect in future. Being involved in research means we help researchers but we also learn things that might help us.'

Other people have become involved for different reasons. 'My way of coping with everything is to get involved with as much as possible. When I realised my son had this diagnosis, it was good for me to have a lot of relevant occupation,' says Philippa Lowe. 'To keep very busy is good for me, and it's also good for me to do lots of things around schizophrenia.'

Angela Fiori says: 'We see people on a daily basis and you get to become a real expert. You learn so much over the years, and sometimes it all seems a bit negative, so for me, getting involved in research is about putting what you have learned to some positive use.'

Professor Elizabeth Kuipers at the Institute of Psychiatry, King's College London, is one of the researchers who has worked with FACTOR members – and has invited two of them to be co-applicants on a funding bid for a research programme that will develop and evaluate services designed to support family members and friends.

FACTOR sent representatives to one of the Mental Health Research Network's 'Clinical Research Groups' that has been developing research proposals about the needs of carers of people with severe mental illness. The Group is chaired by Professor Kuipers.

'Being involved in research means we help researchers, but we also learn things that might help us.'

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

Become a member of FACTOR

If you would like to become a member of FACTOR, or find out more about its work, contact coordinator Geraldine Mason on 020 7848 0643, geraldine.mason@kcl.ac.uk. Or you can join FACTOR online – visit www.mhrn.info Anyone who does work for FACTOR is paid for the hours they put in.

What care is best for people with learning disabilities and epilepsy?

About 20 in every 100 people with a learning disability have epilepsy – and a research team in Cambridge is trying to find out the best way to offer them treatment and care.

Epilepsy is far more common in people with learning disabilities, particularly those with profound learning disabilities. Yet most research trials carried out to find which medications and treatments are most effective rarely include people with learning disabilities. 'There is therefore little evidence to show what works best for a group of people who are often dependent on others to help and support them,' says Dr Howard Ring, a consultant psychiatrist who works in a community-based team offering support to people with learning disabilities, and carries out research at the University of Cambridge.

Dr Howard Ring:
'There is little evidence to show what works best for a group of people who are often dependent on others to help and support them.'

Epileptic seizures are caused by an unexpected electrical overdrive in the brain, which makes millions of neurons 'fire' simultaneously. People with epilepsy are normally prescribed medication that dampens down electrical activity, but one in five people don't respond to medication and their epilepsy is called 'intractable'.

People with learning disabilities are more likely to have intractable epilepsy, and more likely to be given a combination of drugs instead of just one. The side effects of medication include dizziness, drowsiness, nausea and memory problems. Some people with learning disabilities are also more likely to have mood swings, behaviour problems and increased difficulties with daily living as a result of their epilepsy. 'For people with learning disabilities, epilepsy can have a very negative effect on the quality of their lives,' says Dr Ring.

People with learning disabilities and epilepsy are currently offered treatment either by a consultant psychiatrist based within learning disability services, or by a consultant neurologist based at a hospital. A small number of people are treated by their GP, and

Epilepsy is far more common in people with learning disabilities, particularly those with profound learning disabilities.

Wirral babies help researchers find out more about stress

Scores of children born to first-time mothers during 2007 and 2008 are helping researchers understand more about emotional and behavioural development, with a particular emphasis on the role of stress in family life.

Some 1,200 mothers-to-be who live in The Wirral were first recruited to the *Wirral Child Health and Development Study* when they were four months pregnant. Research midwives talked to them in antenatal clinics at the Wirral Women and Children's Hospital in Arrowe Park (run by Wirral University Teaching Hospital NHS Foundation Trust) to find out about their health and lifestyles, and whether they had experienced, or were currently experiencing, stressful situations.

The research team – led jointly by Helen Sharp at Liverpool University and Jonathan Hill at the University of Manchester – has followed the emotional and behavioural development of the children born to 300 of them when the babies were five weeks, six months and one year old, and researchers were meeting with families again in 2010 and 2011 as the children reach two-and-a-half.

All the original group of 1,200 women and their partners were contacted when their babies were one-year old, and will be asked to give information again as their children turn three: Mental Health Research Network staff are helping the research team find families who have since moved out of the Wirral area.

Research health visitors are meeting them at their homes and talking to both parents and children to find out about the toddlers' emotional and behavioural development and parents' mental health and circumstances.

'We know that humans have many inbuilt mechanisms for dealing with stress, and indeed that stress may be a necessary part of human life,' says Jonathan Hill, a professor of child and adolescent psychiatry. 'So we need to know more about how parents and children adapt to stress and under what circumstances stress makes children vulnerable. The study is trying to understand whether stress in pregnancy, or early in a baby's life, affects the child's development.'

By keeping in touch with families as their children grow older, the research team also wants to find out how children adapt to and cope with stress they experience, or stress experienced by their parents. 'We have already discovered, for example, that the way a six-month-old

Professor Jonathan Hill:
'We have already discovered that the way a six-month-old baby's heart rhythm changes when they face a challenge is related to how anxious their mother was during pregnancy.'


nearly 100 people with a learning disability and epilepsy who live in Cambridgeshire and Norfolk have been interviewed by the research team over the past three years to try to find out which sort of care works best.

Researchers have also interviewed their family members, carers and doctors to try to get a complete picture of different sorts of treatment and support, and their effectiveness.

'The information we have collected will allow us to examine what is working best for which individuals, and why,' says Dr Ring. 'This study is one of the first steps in making sure people with epilepsy and a learning disability get the best possible treatment.'

The results of the study, supported by the National Institute for Health Research *Research for Patient Benefit* funding stream, should be available at the end of 2011.

baby's heart rhythm changes when they face a challenge is related to how anxious their mother was during pregnancy,' says Professor Hill. 'What we don't yet know is whether this shows the baby has developed early on ways of coping with challenges, or whether this is a sign that the baby may need extra support through childhood.

'Previous research has shown that children with emotional and behavioural problems are more likely to develop mental health problems in future, but the origins of this are not yet well understood. Understanding the origins and the processes involved is ultimately important to help us develop early interventions to reduce problems in childhood, and as a result, problems in later life,' he says.

The plan is to continue to follow the children throughout adolescence and into adulthood.

The first two phases of the *Wirral Child Health and Development Study* are funded by the Medical Research Council until 2014.

Telephone treatment for young people with obsessive compulsive disorder

Children and young people from all over England are referred to the Maudsley Hospital's specialist clinic for obsessive compulsive disorder (OCD). The treatment offered there is a specialist form of cognitive behaviour therapy: therapists help children understand OCD and anxiety, learn how to resist the urge to behave in a compulsive way and put distressing obsessions into context. Evidence shows this treatment works – and now staff there are running a research project to find out if they can deliver it by telephone to make it easily available to people who find it difficult to travel.

'Even though we accept referrals from across the country, the symptoms of OCD may preclude young people from leaving home or getting on a train or bus,' says Dr Cynthia Turner who works at the clinic. 'The treatment we offer may not be available in some areas, so the point of our research is to see if it is possible to make our specialist service more widely available to young people and their families.'

Between one and three under-18-year-olds in every 100 experience the symptoms of obsessive compulsive disorder.

The trial is recruiting 80 young people referred to the specialist clinic, which is run by South London and Maudsley NHS Foundation Trust, and comparing telephone therapy, given to half of them, with face-to-face therapy, given to the other half. 'It's exactly the same therapy, using the same material. Young people are given a workbook and do homework tasks in between the 14 sessions they have with an individual therapist. It's just the mode of delivery that is different and we want to find out if delivering by telephone works as well.'

A very small pilot study carried out prior to the trial had promising results, and some of the children who tested the treatment-by-telephone said they preferred to have sessions at home,

Dr Cynthia Turner:

'The point of our research is to see if it is possible to make our specialist service more widely available to young people and their families.'

and at their convenience. The time of the telephone sessions are fixed to suit each family, but within the constraints of a 9am-5pm weekday service.

Parents are involved in both the telephone and clinic-based therapy, and all the young people participating in the trial are being followed for a year to find out if the treatment has helped reduce their symptoms. They are also being interviewed and asked what they think of the different methods of delivery, and there will be a cost-effectiveness analysis.

Between one and three under-18-year-olds in every 100 experience the symptoms of OCD. 'It can stop them going to school and engaging in social activities, and can disrupt family life,' says Dr Turner. 'Young people are often embarrassed by the symptoms and try to keep them secret from family and friends, and this means they may not seek help straightaway.' The paucity of specialist services also means that children with OCD can go untreated for years.

Results of *Evaluation of telephone administered CBT for young people with OCD* are likely to be out in 2012, through post-treatment results will be available earlier. The trial is supported by the National Institute for Health Research *Research for Patient Benefit* funding stream.

Hope and self-esteem are most important for recovery

No-one has a good life if they feel hopeless, says psychologist and researcher Richard Bentall. But for people with a diagnosis of psychosis, a feeling of hopelessness and low self-esteem hinders, more than anything else, their attempts to reclaim and rebuild their lives.

'If you can't imagine a good model of yourself in the future, or see a way of becoming that good model, life is very miserable indeed,' he says. A professor of clinical psychology at Bangor University, he is leading a team of researchers who have completed interviews with nearly 130 people who have experience of psychosis. These interviews reveal that hope for the future, and feeling confident and positive about oneself, are the two most important aids to personal recovery. 'These two factors are much more important in terms of well-being than whether people hear voices or are experiencing other symptoms,' he says.

'The difference between people who feel they are on the road to recovery and those who do not think they are, is how much hope they have, and how much they believe in themselves. This clearly has very obvious implications for the way we run psychiatric services. To support recovery, mental health services need to foster hope for the future and boost people's self-esteem, and in general, at the moment, they aren't very good at doing that.'

The interviews included a batch of questionnaires to gauge people's sense of hope, self-esteem and other potential contributors or confounders to recovery. There were also objective tests to measure memory and people's ability to pay attention and concentrate.

Researchers asked people to say how well they thought they were: the results showed the more hopeless people felt, the more they believed they had problems with thinking, memory and attention, even if they did not. 'Those who believed they had problems with memory and attention were pessimistic about the future. Their cognitive functioning as measured by objective tests was not related to where they thought they were on the road to recovery,' says Professor Bentall.

'The more hopeless people felt, the more they believed they had problems with thinking, memory and attention, even if they did not.'

The research team is busy analysing all the data collected but in the meantime is moving on to a second-stage project. The researchers want to find out to what extent people's feelings about their recovery progress fluctuate over a period of time, and what events and circumstances influence those feelings.

They are asking people with psychosis to keep a daily diary with the help of a watch that prompts them at regular times to make a note of how they are feeling, what they are doing, where

Recovery programme is anchored in personal experience

Jason Price is a member of the RECOVERY programme research team in Manchester. He is working on the STAR (self-help therapy and recovery) trial that, with the help of 120 people, is evaluating a new Recovery Guide.

The Guide, developed jointly by people with experience of psychosis and psychologists, encourages people to think about their illness in different, more positive ways, and explains cognitive behaviour therapy techniques that could help them on their road to recovery. It also includes stories of other people's recovery paths.

The idea is that people work through the Guide at their own pace over a nine-month period. People who are helping to test its success can choose to get extra telephone support from both a psychologist and peer support worker – someone who has personal experience of psychosis themselves. Or they can opt for both telephone and group support at regular meetings led by a psychologist and peer support worker: these encourage people to share both experiences and coping strategies. The research team is also recruiting people to the trial who are managing their own recovery without support from either the Guide, peer support workers or psychologists, but who are prepared nevertheless to give information about themselves and their recovery journey over the same time frame. This will enable researchers to make comparisons about people's recovery progress in order to judge the success of the Guide and different packages of support.

'It is a "participant preference" trial so people can choose which arm they want to join,' says Jason. He is interviewing people when they are first recruited to the research, and will talk to them about their experiences of recovery at the end of the nine-month period. 'Different things work for different people, so I think it's important that people are able to choose what sort of support they get.'

Jason is one of two service user researchers employed by the RECOVERY programme. The other is Liz Pitt, and both of them are also working as peer support workers on the STAR trial.

Jason first became involved with University of Manchester research as part of an advisory committee made up of people with personal experience of psychosis. The committee was set up


they are and who they are with. When the watch 'bleeps', they fill in a two-minute questionnaire to log these details.

'They are simple questions about mood, self-esteem, about whether people feel stressed, if they are feeling confident and on the road to recovery at that time,' says Professor Bentall.

People who have agreed to take part in the project will wear the watch for six days and the results of the short questionnaires they complete will allow the research team to understand more about the process of recovery, and what part fluctuations in mood and confidence have to play.

The method is called 'experience sampling' and the point of the project is to ultimately use the information collected to develop different ways of supporting people over time, and help people regulate, as well as monitor, their own moods. 'Researchers treat people like snapshots – they measure how they are at particular points in time,' he says. 'But in real life, people aren't snapshots, they are movies. One thought leads to another thought, and that new thought can then change your mood.

'Some people are good at controlling their mental states, their feelings and moods, and some people are like yo-yos. We are recruiting people to this project who feel they are on the road to recovery, and also people who believe they are not, and we think the fluctuations will be more extreme in people who do not feel they are moving forward. If this is the case, we could then work out ways of helping people learn how to regulate these fluctuations to support their recovery.

'In addition, we can look for patterns – if it turns out people feel on the road to recovery on a Tuesday, but then on a Thursday they don't, we can examine the data to find out why people had a sudden reduction in well-being. What were they doing?, who were they with?, what stress were they experiencing? Knowing what situations are likely to contribute to a low mood means we can develop ways of supporting people, helping them to watch out for situations or experiences that may hinder their recovery, and prompt them to seek help if appropriate.'

People who have no experience of psychosis are also being asked to take part in the project and keep the daily diary.

'We will be looking for factors common to everyone that affect the stability of self-esteem, and people's ability to regulate their own mood,' he says.

- The two-stage project is part of the five-year RECOVERY programme of research that seeks to develop better ways of supporting people with experience of psychosis who are rebuilding their lives. Funded by the National Institute for Health Research, the programme is led by researchers at the University of Manchester, where Professor Bentall previously worked.
  The five different projects being carried out under its banner include testing a cognitive behaviour therapy-based programme to help people who attempt, or think about, taking their own lives, a project that it is investigating the best way to support the recovery of people with bipolar disorder, and the STAR trial, reported below. To find out more about the RECOVERY programme, contact Heather Law, *Heather.Law@gmw.nhs.uk*

Jason Price:

'A lot of doctors think hearing voices is a bad thing, and yes, sometimes they can be intrusive and disruptive. But they can also be comforting and may be a positive experience for someone.'

for a service user-led study carried out by Liz Pitt and Martina Kilbride, looking at people's experiences of recovery from psychosis, and this project was the precursor and one of the inspirations for the RECOVERY programme.

Since joining the RECOVERY team, Jason has also helped to develop a tool that can be used by researchers to measure the symptoms of psychosis from the point of view of an individual experiencing them. Most questionnaires measuring symptoms are designed by people with no personal experience of psychosis and therefore reflect a professional perspective of mental illness. 'A lot of doctors think hearing voices, for example, is a bad thing, and yes, sometimes they can be intrusive and disruptive. But they can also be comforting, and may be a positive experience for someone,' he says.

The 'Subjective Experience of Psychotic Symptoms Scale' (SEPSS) was developed in consultation with people who have experience of psychosis and can be used by researchers who want to find out if symptoms and their impact on people's daily lives have changed over a period of time. 'We talked to service users about recovery, about what it meant to them, about their hopes and dreams,' says Jason. 'We talked about their experiences and types of symptoms, how they felt about them, how they impacted on their lives and social lives, how they coped.'

The end result is a questionnaire that measures positive, as well as negative, elements of psychosis.

People with personal experience of psychosis have played an integral part in the RECOVERY programme since its inception – Liz and Martina were consulted about the plans for the research and were co-applicants on the successful bid to the National Institute for Health Research for funding, along with a group of academics and psychologists based at the University of Manchester. A Service User Reference Group offers ongoing advice to all studies, and people with experience of psychosis are employed as part of the research team and involved as consultants for individual projects.

- The STAR trial started in March 2010 and will recruit participants over a two-and-a-half year period.

If you are interested in finding out more about how people with personal experience of mental health problems work together with academic researchers on MHRN-supported studies...

Join Service Users in Research

Service Users in Research was set up by the Mental Health Research Network as an expert organisation to advise research teams and encourage people with mental health problems to get involved in studies and trials as advisors, collaborators and consultants.

We keep our members up to date with opportunities for collaboration and share examples of good practice.

To join, visit
mhrn.info/serviceusers
or email
mhrnppi@kcl.ac.uk
or ring
020 7848 0644

All the MHRN's regional offices (hubs) involve people with experience of mental health problems in their work, and you can contact them directly. Their details are on the back page.

Are you interested in working with us?

The day-to-day business of the Mental Health Research Network is carried out by teams of staff based in eight regional offices, called 'hubs'. They work closely with all the people needed to make research happen on their patch – researchers based at universities, mental health professionals working in services run by NHS trusts, people with experience of mental health problems and their families, and research specialists working in NHS organisations.

We help research teams recruit people who volunteer to take part in their studies, and also help them find people who are willing to collaborate with them. This includes mental health professionals and people with experience of mental health problems and their relatives.

If you're a researcher and would like our support for a study or trial, or if you're a mental health professional, or someone with experience of mental health problems who wants to get involved in research, contact your local regional office: details are on the back page. Alternatively, visit our website, **www.mhrn.info**.

If you have personal experience of mental health problems as either a service user or carer, you might like to join Service Users in Research or FACTOR (Families/Friends and Carers Together in Research). If you become a member of either of these two organisations, we will keep you up to date with opportunities to get involved in research projects that we support.

The Mental Health Research Network is part of the National Institute for Health Research (NIHR). Our coordinating centre is based at the Institute of Psychiatry, a school of King's College London. Some of our coordinating centre staff also work at the University of Manchester in Preston.

Research experience for junior psychiatrists

A Mental Health Research Network (MHRN) scheme gives junior psychiatrists in East Anglia the opportunity to get hands-on, practical experience in trials and studies.

'All psychiatrists are encouraged to do some research as part of their training, but it is sometimes difficult for them to find the right opportunities,' said Dr Jesus Perez, a consultant psychiatrist at Cambridgeshire and Peterborough NHS Foundation Trust who leads the MHRN's regional office in East Anglia, known as the East Anglia 'Hub'.

Trainee psychiatrists working in Cambridgeshire, Norfolk, Suffolk and Bedfordshire can apply to get involved in one of the 40 plus studies seeking to recruit participants through the NHS that are supported by the MHRN in the area.

'We are giving up to six young psychiatrists a year the chance to get involved in a study that matches their interests,' said Dr Perez *(pictured left)*. 'The experience we offer will also be tailored to the needs of individual studies.'

Dr Perez says he hopes the East Anglia Hub scheme will get psychiatrists in the region interested in research early on in their careers. 'We want to increase the number of clinicians who are interested in research, increase the number of consultants who are capable of taking part in research. We hope by offering this sort of experience to junior psychiatrists that we can contribute towards creating a culture where clinical work and research sit side by side.'

Trainee psychiatrists can apply to the MHRN East Anglia Hub to gain research experience if they work at Cambridgeshire and Peterborough NHS Foundation Trust; Norfolk and Waveney Mental Health NHS Foundation Trust; Suffolk Mental Health Partnership NHS Trust; or in services based in Bedfordshire that are run by South Essex Partnership NHS Foundation Trust. Contact the MHRN East Anglia Hub on 01223 746 135 or email hub manager Angela Browne, *angela.browne@cpft.nhs.uk*.

'All psychiatrists are encouraged to do some research as part of their training, but it is sometimes difficult for them to find the right opportunities,' says Dr Jesus Perez.

Who decides the definition of a 'good outcome'?

Researchers routinely use a variety of standard questionnaires to assess people's mental health, their symptoms, their quality of life, and side effects of medication. The questionnaires are used in studies to test the success of new treatments and packages of care, and also in evaluations that may determine future funding of NHS services. But a project commissioned by the Mental Health Research Network (MHRN) showed that a professional's view of what constitutes success – a 'good outcome' – doesn't always tally with the opinion of the individual whose life is being assessed. The MHRN asked a team led by Dr Mike Crawford at Imperial College London to find out what people who use services for mood disorders and psychosis think of questionnaires designed to assess their state-of-being, and whether, in their opinion, they do the job they are supposed to do accurately.

In the world of research, the questionnaires are called 'measures' or 'scales' and are either completed by a professional who interviews an individual, or completed by the individual themselves. They are mostly designed by researchers and aim to measure change or improvement, or set out to give an insight into someone's mental health.

Two expert panels of people with experience of mental health problems discussed and analysed a sample of two-dozen questionnaires that are commonly used in research studies, and increasingly by mental health professionals working with people with psychosis and people with mood disorders. All volunteers had personal

People with experience of mental health problems were particularly criticial of questionnaires designed to measure 'social functioning' and challenged the definitions of a 'normal life' contained within them.

Course teaches communication skills – and boosts confidence

A new course has been created to give people with experience of mental health problems the confidence to get involved in research, understand paperwork produced for studies and trials and contribute at meetings.

The Communication Skills course has been designed by Jackie Barrett and David Armes, both of whom have experience of mental health problems and are involved with the work of the Mental Health Research Network's North London Hub.

It combines an introduction to mental health research with an introduction to communication skills. The course is very practical and interactive and sets out to boost people's confidence in both formal and informal meetings about research. It also includes tips for reading and understanding research documents and reports, often written in mental health jargon.

'We think it's important to get service users involved in research, but we also need to think about their training needs, and give them confidence to get more involved,' says hub manager Sandra O'Sullivan *(pictured left)*. 'Going to research meetings can be very intimidating if you're not used to it. You need to be able to read people's body language, know when to speak and when to listen, and to understand the points of action. Many people do have the confidence to take part in meetings associated with research projects, but others don't.'

The course is also suitable for newly-recruited hub staff who will be working with people who use mental health services to both recruit them to, and involve them with Mental Health Research Network-supported studies.

'New members of staff who have been recruited as clinical studies officers may also need a confidence boost as they will be joining meetings to help get research projects off the ground. It is also very useful for them to get a chance to be working with service users straight away,' says Sandra.

The course was launched at the end of October 2010 and is led by Jackie, a qualified English teacher who has worked as a lecturer in various further education colleges in London, and David, who has worked as a researcher.

'We start off by looking at the opportunities available for working with the MHRN and explaining about the research process' says David. 'Service users are already experts by experience, but they need to have confidence in the skills they already have.'

The plan is to make the course available across England via all eight MHRN regional offices (hubs).

David and Jackie are among a team of service users who regularly work with the North London Hub on projects that aim to get people with experience of mental health problems more involved in research. They have also been working on a toolkit for researchers who want to get service users and their relatives involved in their projects, and this includes practical resources like job descriptions. Service users who work with North London Hub also maintain *www.sunlows.org.uk*, a website that contains information about mental health research being carried out in the area.

The Communication Skills course has been designed by Jackie Barrett and David Armes, both of whom have experience of mental health problems and are involved with the work of the Mental Health Research Network's North London Hub.

experience of mood disorders and/or psychosis.

They gave each tool used by professionals a mark out of 10 – and only seven of the 24 questionnaires gained a score of '7' or more. Some of the most widely used outcome measures in mental health received very low scores.

The panels were particularly critical of questionnaires designed to measure 'social functioning' – giving them scores of between '3' and '4.5', and challenged the definitions of a 'normal life' contained within them. People with experience of mental health problems may disagree with professionals about what equates to a 'good outcome' in terms of getting on with their everyday lives, they said.

The panels suggested questionnaires about social functioning should be designed to find out whether people are happy in certain areas of their life, rather than asking specific questions that take no account of individual preferences and are based on a professional's judgment of 'normality'. Some of the questions included in these measures were considered by the panels to be not only irrelevant but also intrusive – questions about people's sex lives, for example.

They also expressed concern that some of the questionnaires were far too long, that others were far too short to be comprehensive, and that there was a focus on mental ill health rather than mental good health. The questionnaires should also ask about the negative effects of treatments and packages of care, instead of just concentrating on potential improvements, they said. Some questionnaires have been developed more recently in collaboration with people who have experience of mental health problems, but these were not included in the project.

For more information about the study, email *l.thana@imperial.ac.uk*.

Promoting the value of research to nurses in East Midlands and South Yorkshire...

Student nurses are given the opportunity to learn about mental health research – and how to locate the evidence they will need to inform decisions they take about treatment and care – during time spent with the MHRN regional office (hub) covering East Midlands and South Yorkshire.

The hub offers experience, generally lasting six weeks, to three students a year who are training to be mental health nurses on courses run by the Division of Nursing at the University of Nottingham.

These placements aim to enthuse students about research, so they become actively involved in projects when they qualify, says hub manager Ann Priddey *(pictured left)*. It's also helpful for student nurses to learn about how the evidence they will use in their working lives is generated, she says.

Nurses-in-training spend about half their time on placements, the majority of them in hospitals or community-based services. The placements offered by the East Midlands plus South Yorkshire MHRN Hub are 'fairly unique,' says Ann. She and her team give students an insight into the way research is undertaken, the various rules and regulations governing projects, and the way people are recruited to participate in research studies.

The hub office is based within the Institute of Mental Health at the University of Nottingham, and students are also encouraged to talk to researchers based there to find out about different projects and ways of getting involved in research. 'We expose them to the complete research process, from "I have an idea" to recruiting on the ground,' she says. The students also learn about what the Mental Health Research Network does, how it works with NHS organisations, and the role of the National Institute for Health Research.

During placements, students need to be supervised by a mentor, and three of the hub's clinical studies officers who are registered mental health nurses undertake this role. Hub manager Ann Priddey is also a trained (but no longer registered) psychiatric nurse.

...and in the Heart of England

Getting involved in research may be a low priority for busy mental health nurses, already carrying a heavy workload. They may not realise that research can help, rather than hinder their working lives, and improve the quality of care that people with mental health problems receive, says Rangeni Zinyama from the MHRN's Heart of England regional office (hub). She is coordinating a project that aims to explain and promote the benefits of research to mental health nurses – and encourage them to collaborate on projects or run their own studies.

The Heart of England Hub has teamed up with Birmingham and Solihull Mental Health NHS Foundation Trust and three universities – Birmingham City, Birmingham and Wolverhampton – to develop learning materials for both student and qualified mental health nurses, and to enthuse nurses already working in mental health services.

The idea is to develop learning materials for student mental health nurses at all three universities. The materials will focus on what research is, methods that are used, how research teams work collaboratively with people with mental health problems and how to plan a project. They will be available online for the 2011 academic year and will include specially made videos of interviews with nurses who have carried out, or been involved with, research projects. Academics from the three universities are involved in preparing the materials, which also include links to useful websites, relevant literature and book references, and information explaining the world of research as well as the process.

A new scheme initiated as part of the project means student nurses from Birmingham City University will be able to spend part of one of their placements learning about research. The arrangement will start in 2011 – students who are undertaking work experience with a community-based service run by Birmingham and Solihull Mental Health NHS Foundation Trust will work with staff in the Trusts' Research Innovation department and in the MHRN Heart of England Hub for one day a week. 'Students will be able to find out about the research projects we support, how research operates and how we recruit to studies,' says Rangeni.

> Mental health nurses may not realise that research can help, rather than hinder their working lives, and improve the quality of care that people with mental health problems receive.

The partner organisations also plan to develop learning materials about research for registered nurses who are continuing their professional development. These too will be accessed online and will be initially be available to nurses working for Birmingham and Solihull Mental Health NHS Foundation Trust and then to nurses working at all the trusts involved in MHRN-supported studies through the Heart of England Hub.

MHRN's work to involve experts by experience is 'shining example of best practice'

The Mental Health Research Network (MHRN) has been praised for the way in which it involves people with experience of mental health problems and their families in its work – and for encouraging and enabling research teams to do the same.

Dr Edvard Beem *(above left)*, director of the Netherlands Organisation for Health Research and Development, and Dr Frederick J Frese *(above right)*, an American psychologist who has personal experience of mental health problems, were invited to review and comment on the MHRN's 'patient and public involvement' (PPI) activities. These focus on encouraging people with experience of mental health problems and their families to become involved in research as consultants, advisors and collaborators. The philosophy of the MHRN is that people who are experts by experience should be an integral part of everything it does, and both its regional offices (hubs) and coordinating centre work to this end.

During a visit to London, Dr Beem and Dr Frese met staff and a range of people involved in the studies and trials supported by the MHRN, including people who have mental health problems, their relatives and researchers.

'I am very much impressed by the way the MHRN has taken up PPI systematically, and I have learned a lot from this approach,' said Dr Beem. His organisation funds health research, including mental health research, in The Netherlands by distributing government money through different programmes.

'Our aspiration is for meaningful participation, and the policy we pursue is for researchers to include patients in their research,' he said. 'We make researchers aware that involving patients can help them with the design of their projects, can help in implementation, and can also help make the results of their research happen.

'We produce guidelines for research teams on how to involve consumers, we run a PPI training programme, and in certain programmes, PPI is a condition of funding. This means we monitor the progress of PPI activities, and there are consequences if people don't deliver – the ultimate consequence would be the withdrawal of funding.

'But the MHRN does more than we do in terms of helping researchers get research done, including introducing them to patients willing to get involved. We have no similar type of support in The Netherlands and we can learn from this.'

Dr Frese said that in America, the focus has been on campaigning against stigma and discrimination, rather than actively encouraging people with personal experience of mental health problems to get involved in research.

'It puts joy in my heart to know something like this is going on,' he said. 'People want to be partnered and respected in a respectable working relationship, and the work being done by the MHRN is a step in the right direction.'

In the States, involvement in research tends to be on an ad hoc basis. 'England is far ahead of the USA in involving consumers in mental health research activities,' he said. 'I am impressed by the way the MHRN has systematically developed involvement in research and in its work.'

Dr Frese – who was diagnosed with schizophrenia when he was a young Marine Corps officer – is coordinator of the Summit County Recovery Project in Ohio. Until his retirement in 1995, he was director of psychology at Western Reserve Psychiatric Hospital, also in Ohio. He is past president of the National Mental Health Consumers' Association and has given more than 2,000 speeches around the world.

After their visit, they said the MHRN does an 'excellent' job involving people with personal experience of mental health problems and their families in its work. 'The MHRN is a shining example of "best practice",' said Dr Beem in a written report.

www.mhrn.info

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Published by the NIHR Mental Health Research Network, February 2011
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The Mental Health Research Network is part of the National Institute for Health Research and supports studies in England.

Written and designed by Inside Out, printed by Calverts