KING'S College LONDON

# Towards Mental Health

Number 1 2006

## Health Services Research at the Institute of Psychiatry

## Graham Thornicroft, head of Health Services Research, writes:

How do we react to people with mental illness? How can we offer assistance that does in fact help such people? What types of services work? Is the range of treatments available actually based on hard evidence? Which forms of care are acceptable? Which types of treatment are both effective and offer value for money? How can we tailor services according to the age or gender or culture of people in need of help? These are the questions that drive members of the Health Services Research (HSR) group at the Institute of Psychiatry. In this publication, we would like to introduce you to some of our work: to recent findings and to work in progress. We would like to convey to you our excitement in trying to find evidence-based answers to these important questions. Our approach includes a clear and genuine commitment to participation by service users in all stages of research, alongside the highest scientific standards.

Our work takes place within the broad scope of translational research that ranges from the most basic biomedical science to the more applied end of the spectrum, which is our focus. We pay close attention both to contributing to the evidence-base, and then making sure that this knowledge is put into practice. Several HSR staff have led or contributed to writing NICE guidelines, the basic building blocks for good clinical practice nationwide. Alongside papers in scientific journals, we also produce books for a wider readership, such as the new books about the causes of depression[1], on discrimination against people with mental illness[2], and on mental health policy in Europe[3]. At the same time we are determined to increase the capacity and the quality of research on health services, and we run two MSc programmes, and are currently training over 30 PhD students.

Although health care is usually provided within narrow national boundaries, science is multi-disciplinary and international. For this reason much of our work takes place within networks that cross traditional disciplinary and national boundaries. Recently, the HSR group has been greatly strengthened by the arrival of the research group led by Professor Martin Prince, with their focus upon international epidemiology, especially in low income countries. In recognition of the international reach and relevance of our work, the Institute of Psychiatry has recently been designated as the World Health Organisation Lead Research Collaborating Centre in Europe, led by HSR staff.

In short, our expanding HSR group tries to provide practical information, based upon the best possible science, to make mental health care much better in the future than it has been in the past. In this light, I trust that you will find this publication – and future issues – positive, informative and useful.

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# Coping with paranoid thoughts

Martin Canning was given a diagnosis of psychosis when he first became ill in 1998. At the time, he was 25. Now at 32, he is ready to 'rebuild his life' – and gives credit for his recovery to a combination of the right medication and Cognitive Behaviour Therapy (CBT) from PICuP (Psychological Interventions Clinic for outpatients with Psychosis).

PICuP is now a well-established clinical service run by South London and Maudsley NHS Trust. The Maudsley Hospital-based clinic was originally launched as a direct result of research showing this 'talking' therapy could help people with psychosis in addition to medication. A more recent survey showed that users, referrers and therapists are all highly satisfied with the service offered by the clinic.

Martin was referred to PICuP by his GP at a time when 'friends and family were very worried. The illness was recurring on a regular basis, and I seemed resistant to both medication and to therapy,' he said. Since initially becoming ill, he had had three relapses – all to do with stopping or changing medication – and had been off sick from work for some months. After the relapses, he had unsuccesfully tried therapy twice – once with a psychologist and once with a psychotherapist.

Both attempts were with people who didn't specialise in psychosis. 'Clearly they did not have the necessary training to deal with someone who was seriously ill,' he says.

The CBT sessions at PICuP, however, were extremely successful. After the relapses, his diagnosis had been changed from psychosis to paranoid shizophrenia. 'When I started at PICuP, I was quite deluded,' he says. 'I was convinced there was a conspiracy against myself and my girlfriend, that people were trying to kill us. I was convinced there was going to be World War 3. I was living in a fantasy world. I was extremely paranoid and really rather distressed. There was a lot to deal with. I was very negative and my views were very hard to shift.

> 'I was living in a fantasy world. I was extremely paranoid and really rather distressed.'

'The therapists I saw at PICuP were able to break down and challenge those views, to make me search for evidence to support them. They offered a lot of understanding. They were highly motivated people who had my best interests at heart. I felt they could cope with my problems and they wanted my assistance: the therapy involved me. It wasn't someone telling me what to do. They focused my thoughts and they helped me with strategies for coping if I felt paranoid again and if the voices came back. Everything was well explained. They knew my problems, they knew my issues. They had experience of similar cases. The most important thing was that I felt well-handled and cared for.'

Martin went to PICuP for 12 weekly sessions. 'When I started I was very unwell. When I finished, I was an awful lot better,' he says. 'At the same time, I started an increased dose of a medication that agreed with me, and I think it was a combination of the therapy and the medication that worked.'

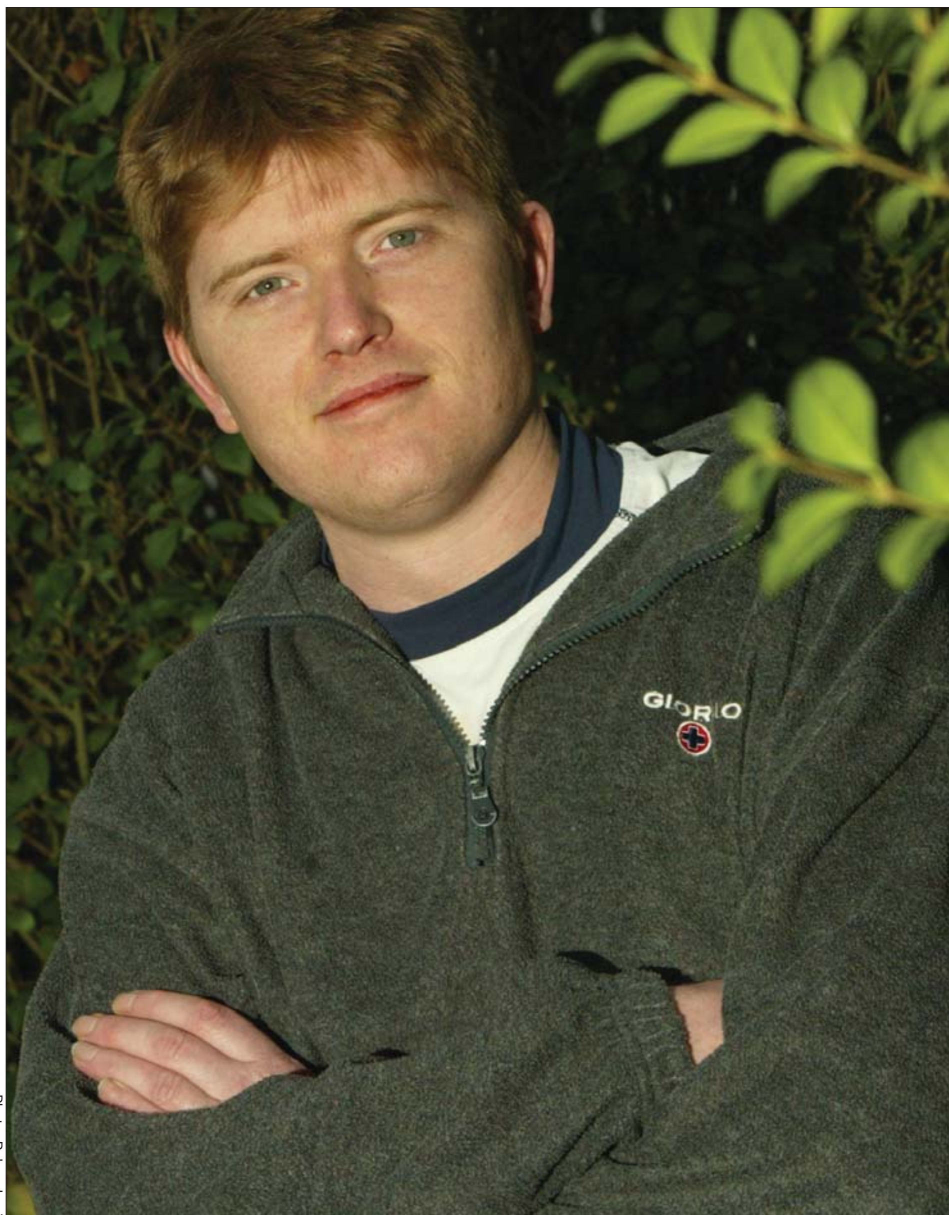


Photo: Rehan Jamil

Martin Canning: 'The therapists at PICuP focussed my thoughts and helped me with strategies for coping if I felt paranoid again and the voices came back.'

After therapy at PICuP, Martin decided he was ready to return to work. Having left York University with a degree in History and Politics, he had worked for the Labour Party, organising events and conferences. Deciding that he needed to consider a different career route, he temporarily took a job in sales, but then quite quickly first fell ill.

After a short period in hospital and now on medication, he took an administrative job in a college, where he was working when he became ill again. 'I was overqualified for the job but was barely able to do it: there were problems with my performance because of my illness.' But feeling well after PICuP and finally getting the right medication, he decided to return to work after a year's sick leave. His employer, however, didn't want him in the same role so Martin accepted a redundancy package.

'The most important thing was that I felt well-handled and cared for by the therapists.'

Searching for new work left him miserable and feeling under-confident. Applications for more than 30 administrative jobs didn't even get to the interview stage. So he went back to PICuP for 'booster sessions' to try to deal with the blow to his self-confidence. 'I wasn't clinically depressed but I was very demotivated and very low. I wasn't thinking psychotically any more, but I wanted advice on how to break the cycle of negative thoughts.'

With the help of the Job Centre, he has now 'widened his horizons' and thinks support work may be an option for him, having been on a course learning about the role of housing officers. A job broker has encouraged him to arrange voluntary work, supporting two advisors who work with people with learning diabilities. He has decided voluntary work is the first step to moving on, with the long term aim of coming off incapacity benefit. 'I want to get up and go out and not sit around. I want to be able to earn money for myself, to be in regular employment and functioning well,' he says.

'I want to be able to earn money for myself, to be in regular employment and functioning well.'

Martin is in the care of his GP and has access to psychiatrists at outpatients clinics and to therapists at PICuP, if he needs them. 'I've been lucky,' he says, 'because I have a partner who is involved in mental health who knows the system, how it works and how to deal with a crisis. I was also lucky to be living in London and within travelling distance of PICuP.'

# PICuP's role...

PICuP won an award from South London and Maudsley NHS Trust in recognition of 'using research to improve treatment for service users'. The number of referrals to the clinic from doctors responsible for prescribing medication has increased dramatically, so much so there is now a three to five month waiting list. A case is being made for expanding the service.

In the last decade, research from the UK, Europe, the USA and Canada has demonstrated that Cognitive Behaviour Therapy (CBT) can help reduce psychotic symptoms. The IoP's work was among research that helped shape guidelines from NICE (National Insitute for Health and Clinical Excellence) recommending CBT for psychosis alongside appropriate medication.

'CBT doesn't necessarily always get rid of symptoms, but it does alleviate the distress caused by them,' said Dr Emmanuelle Peters who co-ordinates PICuP. 'Therapists help people make sense of their unusual thoughts and experiences, and discuss ways of coping with them. It's also about tackling despair, fears, low self-esteem and self-motivation.'

The PICuP team offers supervision to therapists who want to acquire specialist skills in CBT for psychosis. And the team has written *CBT for unusual distressing thoughts and experiences*, a booklet for service users that explains how the therapy can help them change how they think and deal with unusual experiences – like hallucinations and delusions – if they are difficult to cope with. The PICuP team is planning to market the booklet to other mental health trusts where therapists offering CBT could use it to help explain the therapy to service users. There is also an extensive library of booklets, books and recovery articles at PICuP: these resources are available to both therapists and service users.

Team members of PICuP continue to undertake research projects with the help of their service users: about 40 people have signed up to a research register.

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# Radical transformation of Russian mental health care

## A project led by the IoP has helped shift care for mentally ill people in Russia away from long-stay institutions and into the community.

A team of UK-based researchers worked with Russian health professionals and policy-makers in Sverdlovsk Oblast – an administrative region about 2,000 kilometres east of Moscow. The team was co-ordinated by Rachel Jenkins who directs work carried out under the auspices of the World Health Organisation (WHO) Collaborating Centre status which the IoP has had since 1997.

The project in Russia, funded by the Department for International Development in the UK, set out to help make changes in mental health services in a region that embraces six cities including its capital, Ekaterinburg.

'The mental health care system in the Russian Federation is still highly institutionalised,' said Rachel. 'Mental health care has predominantly been provided in hospitals and long stay institutions called "internats" where people stay indefinitely. Our brief was to change that. Events in recent history have led to social upheaval and an increase in mental illness and the government has declared a commitment to reform.'

During the three year project, the team worked in partnership with the authorities that govern both the region and the cities – and with the Federal government. 'In the first instance, it was about presenting evidence-based policies that show community-based care works and then designing and organising training for mental health care professionals,' she said.

'We wanted to develop new organisational structures which could give community alternatives to institutional-based treatment and care. We wanted to create and train specialist multi-disciplinary teams to provide community-based services.'

The project team found training for professionals was outdated – most practitioners lacked the knowledge and skills required to deliver a range of treatments in community-based care. 'There was a lack of contemporary training materials so we adapted and translated *WHO Guidelines for Primary Health Care*,' she said. These have since been distributed to all psychiatrists across Russia.

Ninety-three psychiatrists, nurses and psychologists were given specialist mental health training as part of the project: this has now been incorporated into the Oblast-wide Family Medicine Training Programme. Fifty-three municipal general social workers were trained to support people with mental health problems at home. This training is now to be used throughout the Russian Federation.

To give policy support to the changes, Intersectoral Steering Committees were set up with political backing: the Oblast committee chaired by the health minister, the municipal committees chaired by the mayors. These committees meet regularly and have set up hostels, social housing, sheltered work opportunities and social services for people living in the community. They have also recognised and started to work with a small number or non-government organisations: in the past the charity sector in mental health was practically non-existent, says Rachel. The project included training workshops and a small grants programme for non-government organisations working with service users and carers.

Trained multi-disciplinary teams were set up at four pilot sites to help care for people with mental health problems in the community and avoid hospitalisation. Employment centres now collaborate with mental health services.

'People with mental health problems living in Sverdlovsk now have access to community-based care and staff who have appropriate skills and knowledge,' said Rachel.

'The rates of admission and re-admission to institutions in the region have dropped. This is one step along the road to a radical transformation of a system of care centred around institutions. The attitudes of the health professionals and policy-makers we worked with changed from initial cynicism to explicit enthusiasm and support for practical action.'

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• The World Health Organisation is the United Nations' specialised agency for health. A WHO Collaborating Centre is an institution designated by the director-general to form part of an international collaborative network carrying out activities in support of the WHO programme.

## Complementary medicine: does it help depression?

Can complementary medicines and alternative therapies really make a difference to people who are depressed? According to researchers in HSR's Section of Cultural Psychiatry, there is – as yet – no conclusive evidence that they are better than conventional treatments.

They reviewed research studies about the use of different types of complementary medicine and alternative therapy in depression and found none to be 'unequivocally positive or sufficiently conclusive.' Many of the trials they examined involved only a small number of participants, lasted for a short time and did not meet scientific criteria for 'best evidence'. It is possible, however, says researcher Raj Mohan, that their worth may be proven if larger research projects with more robust designs were carried out – including more pragmatic 'real world' study designs. 'It may be that significant research exists outside of English language journals and western research models,' he said.

About one in every 10 adults in the UK consults a complementary or alternative practitioner every year and the increasing interest in these therapies is reflected across the world. 'Because of the growing popularity of complementary medicines and alternative therapies, service users, planners, GPs and mental health professionals need to be informed about which are effective, which are not and which ones have been adequately evaluated,' says Raj.

Complementary and alternative treatments are particularly popular for use in depression: the research team's review include published studies on the use of St John's Wort, acupuncture, exercise, Saffron (Crocus sativus L), nutritional therapies, homoeopathy, aromatherapy massage, reiki, relaxation, massage therapy, music therapy, yoga, dance and movement therapy and traditional Chinese medicine.

'None were conclusively proven to be better than placebo in depression,' said Raj. 'But all the studies we reviewed had significant methodological limitations when evaluated against the stringent criteria used in evidence-based medicine.

'Depression is under-diagnosed and under-treated.

## Lead mental health research centre in WHO's Europe

The World Health Organisation (WHO) has announced that the IoP is to be the lead research centre for mental health in its European Region. This area stretches from Iceland to Russia and includes 52 countries.

The new status will be launched on 29 August 2006 during the IoP's third International Mental Health Conference for delegates from all over the world.

'There are more than 20 WHO collaborating centres within the European Region. We will work closely with colleagues to enable members of this network to collaborate at the pan-European level,' said Graham Thornicroft, professor of community psychiatry and director of research and development at the IoP and South London and Maudsley NHS Trust (SLaM). 'We will be able to launch collaborative research that will bring real benefits to service users.'

The theme of this year's International Conference is *People on the Move*. There will be speakers and debates focusing on the consequences of displacement due to natural disaster, war, famine, changing land use, changing employment, political oppression and civil conflict.

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Photo: Rehan Jamil

## The pros and cons of nurse prescribing

The views of nurses and doctors working in two NHS mental health trusts will help shape plans for the future provision of specialised training for nurses who want to be prescribers. HSR's Section of Psychiatric Nursing is canvassing the opinions of 300 nurses and 300 doctors employed by both South London and Maudsley and Oxleas NHS Trusts about the Department of Health's decision to allow trained nurses to prescribe any licensed medicine for any medical condition from Spring 2006.

Specially trained nurses are already able to prescribe from a limited formulary. The plans to do away with the limitations have sparked controversy: those in favour argue nurses are more in touch with their patients than doctors, spend more time with them, understand them better and are more willing to talk over the pros and cons of medication. Worries expressed include nurses' lack of experience with drugs and the potential for mistakes.

'We want to find out about doctors' and nurses' attitudes and ideas towards nurse prescribing,' says research nurse Dan Bressington. 'We want to know if people's hopes, fears and aspirations will carry nurse prescribing along or hinder it.

'Many mental health trusts don't have a plan or policy for integrating nurse prescribers into their services so we also want to find out where doctors and nurses think prescribing nurses would best be placed. We're asking how they think new structures would work, how the roles of prescribing nurse and doctor would fit together, who would have overall responsibility for clinical care and what would happen if something went wrong. We also want to take on board nurses' concerns – about new roles and responsibilities and support systems, for example.'

The survey takes the form of a questionnaire mailed to 600 people selected randomly from the two Trust's staff databases.

'There are mixed feelings about nurse prescribing,' said Dan. 'Some nurses are aspiring to it, others are horrified. The reaction of psychiatrists is similarly varied. I think there's a lack of awareness of how other professions feel and how it would all work. We hope our survey will help inform the Trusts' plans for the future and help us in the Section of Psychiatric Nursing plan specialist mental health training on top of the prescribing courses run by King's College London.' To date, only a handful of nurses in both Trusts have completed the training necessary to be able to prescribe from the limited formulary previously operating.

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Given the frequent use of complementary medicines, they warrant the same level of evaluation as conventional treatments,' he said.

In 2001, The Department of Health published an Information Pack about six complementary and alternative therapies – acupuncture, aromatherapy, chiropractic, homoeopathy, hypnotherapy and osteopathy. As a consequence, some are available on the NHS – but the list is based on popularity, not evidence, says Raj.

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## Research results lead to free training

A programme developed by HSR's Richard Gray and funded by pharmaceutical company Janssen-Cilag has given thousands of NHS mental health nurses training to help people with schizophrenia take their medication regularly and as prescribed.

Richard, a senior lecturer in the Section of Psychiatric Nursing, developed the *Concordance Skills* programme following a research trial which showed that people with a diagnosis of schizophrenia are more likely to take medication if mental health nurses involve them in treatment decisions and address their concerns about anti-psychotic drugs.

A team of trained mental health nurses deliver the *Road to Recovery Progamme* which is supported by an educational grant from Janssen-Cilag. The training is available free of charge: since it's launch in 2003, nearly 6,000 NHS nurses have been trained. Janssen-Cilag in Australia and Ireland are now about to launch similar training schemes and Richard is training the trainers in both countries, as he did in the UK.

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to find out more about the *Road to Recovery Programme.*

## Teaching doctors the truth about mental health

Service users and carers say that doctors often display 'the most stigmatising attitudes' towards people with mental health problems. Now the mental health charity Rethink is working with HSR to see if anti-stigma training sessions for medical students and psychiatrists at the start of their career can make a difference.

These sessions will be run by specially trained service users and carers who will be working alongside members of the Rethink training team. The idea is to rid students and psychiatrists of any misconceptions they have about mental illness and present real life stories about how negative attitudes can discriminate and hinder recovery.

The programme will start in the academic year 2006/07 when a sample of randomly selected third year medical students from King's College London School of Medicine at Guy's, King's College and St Thomas' Hospitals will be given the training during their Neurology, Ophthalmology and Psychiatry rotation. Similar training will be given to first year trainee psychiatrists working for South London and Maudsley NHS Trust. The HSR evaluation team – which will include service users and carers – will seek to discover if the training is effective and if it works best for trainee psychiatrists who have already chosen their speciality, or for students who have not yet opted for a specific career route.

'We know from previous work that service user and carer involvement really does help change attitudes,' said Jo Loughran from Rethink. 'Their personal stories and experiences make the most effective difference. We are recruiting a team of six service users and six carers to be co-facilitators of the training and they will be paid an hourly rate.'

The sessions for third year medical students will include role play with the help of actors to measure behaviour and attitudes before and after the training. The sessions for trainee psychiatrists will focus on factual information about stigma and discrimination – the experiences of service users and carers will translate that information into reality.

Changes in attitudes will be measured using a new scale, *Mental Illness: Clinicians' Attitudes (MICA©)*, developed as part of the ASTEC (Anti-Stigma Training and Evaluation Collaboration) by HSR project co-ordinator Aliya Kassam. 'If this works, we would like to see anti-stigma training become an integral and important part of medical students' and/or psychiatrists' training in future,' said Jo.

The long term aim of ASTEC is to produce a training toolkit which could be used around the world. Such a toolkit could not only be incorporated in the curricula of medical schools and for resident psychiatrists, it could also be adapted for use with other groups of professionals, said Aliya.

ASTEC is part of *Mental Health Awareness in Action*, an ongoing programme of work by Rethink and HSR to find out how best to challenge and change stigmatising attitudes about people with mental health problems. Workshops run by service users and carers have already proved successful in secondary schools and for groups of police officers. This latest project is funded by the Guy's and St Thomas' Charity and pharmaceutical company Lundbeck Ltd.

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## Staying mentally well and offering group support

Every other Tuesday, a group of people with learning disabilities meet to talk about strategies for staying mentally well and services available to help them. The group has been meeting in the MENCAP Office in Lewisham, south London, for about five years and is supported by Steve Hardy, Virginia Essam and Peter Woodward from The Estia Centre, part of South London and Maudsley NHS Trust and affiliated to HSR. 'The Group initially started as a ten week course, but when we evaluated it, the people who came on it said: "you professionals always come along and run short courses, what we need is indefinite support",' said Steve.

The Tuesday Group is not a clinical group: it's about information, awareness and self-help. Professionals visit and talk about statutory services available, government policy, new services like an employment agency. Members of the group share their problems and give each other support.

Now the Estia Centre team is producing a *Mental Health Promotion Training Pack* to help other professionals working in the field set up and support similar groups for people with learning disabilities.

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## Helping patients and saving money

Every GP has patients on his or her books who visit regularly, complaining of different symptoms which tests reveal have no organic cause. 'There are a considerable number of patients who go round and round the hospital system, referred by their GPs for more and more tests which always come back negative,' says Andre Tylee, professor of primary care mental health and a GP for 21 years before joining the IoP.

Their problems are really psychological, says Andre, and there is a very sophisticated mental health skill called Re-attribution that can help them come to terms with this. The skill was developed by the HSR's emeritus Professor Sir David Goldberg and Manchester-based Professor Linda Gask – but many GPs do not have the opportunity to take time away from busy practices to attend specialised training in Re-attribution.

Now an experiment seeks to find out if that skill can be taught within a few hours with the help of a video/DVD package developed by Linda Gask, a professor of primary care psychiatry. Andre and his colleagues are giving the package 'cold' to teachers of GP registrars based at three practices in south London: the teachers themselves are given no specific prior training in Re-attribution.

Before showing the video/DVD, actors play the part of patients somatising their emotional distress to allow researchers to assess the trainee GPs' baseline skills. The same GP registrars are being assessed a month later – again with the help of actors – to see if they have picked up and retained the specialised Re-attribution technique.

The video/DVD features real doctors and actor patients and demonstrates 'micro skills' which help patients acknowledge their problem might be emotional within a 10 minute consultation. 'This sort of training would be a much more real option for the NHS than eight one hour sessions or a day long programme,' says Andre.

The cost to the NHS of patients who somatise their distress and present their emotional malaise in the form of somatising symptoms is huge, he said. Every time patients are sent for tests to rule out the possibility of illness when they describe a new symptom, the costs mount. And previous research has shown that about two thirds of patients who have depression initially go to their doctor with somatic symptoms – which means their depression may not be recognised or treated.

'Mostly patients don't even want to consider the fact that it might be an emotional problem and it's a tricky thing to get them to acknowledge it might be stress or worry,' he says. 'If we can find a cost-effective way of teaching Re-attribution skills to large numbers of GPs, it will benefit patients and the NHS. And it seems particularly sensible to give these skills to people who are just about to embark on a life as a GP.'

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Photo: Courtesy Sheffield Newspapers

# Campaigning against discrimination

‘Rejection and avoidance of people with mental illness appears to be a universal phenomenon.’ So writes Graham Thornicroft, author of a new book called *Shunned: Discrimination against people with mental illness* and a report with recommendations for policy-makers for action and real change, published by the Mental Health Foundation.

Both the book and the report ‘represent a major step forward in our thinking,’ says Dr Andrew McCulloch, chief executive of The Mental Health Foundation, the UK charity that campaigns to influence policy, tackle stigma, develop better services and raise public awareness about mental health issues.

The report focuses on practical ways to tackle discrimination and social inequality at home, in personal relationships and at work. But discrimination and prejudice permeate every aspect of the lives of people with mental health problems – their social networks, leisure and recreation opportunities, travel, insurance and financial services. The research Graham quotes, and the real life experiences of people who have allowed their stories to appear in both the book and the report, illustrate that people with mental illness also get a worse deal from all NHS services. Negative and ill-informed stereotypes portrayed in the media exacerbate the ‘stigma’ attached to mental health problems. ‘Without doubt is that widespread discrimination adds to the disability of people with mental illness,’ says Graham, professor of community psychiatry.

Discrimination and prejudice permeate every aspect of the lives of people with mental health problems.

‘There is a mass of evidence from across the world that highlights the impact of discrimination which blights people’s lives.

‘We know, for example, that works helps people recover. Yet rates of unemployment for people with a history of mental illness are very high. This leads to loss of confidence, poverty, lack of social networks and a feeling of having no social value.’

His agenda for change includes evidence-based education programmes to stamp out ignorance and prejudice. ‘Most people have little knowledge about mental illness and what they do have is often factually incorrect. Lay opinions about mental illness are informed more by myth than fact.’ His plan of action includes work in schools, work with health professionals and the introduction of programmes like supported work schemes – as well as better enforcement of existing laws in this country.

‘We should use legal measures intended to support all people with disabilities, like the Disability Discrimination Act,’ he says. ‘Under this law, “reasonable adjustments” at work should be made for people with mental illness, in parallel with modifications made for people with physical disabilities. Employers could provide quieter workplaces for people with concentration problems instead of a noisy open plan office, for example, more frequent supervision to give feedback and guidance about their job, or flexibility in work hours to allow them to attend hospital appointments or travel at times which are less crowded.

‘In every country where it has been examined, people with mental illness are more discriminated against than any other group. We need to take this on board and make it unacceptable, as we have done with other disorders like Aids, with social characteristics like single parents and with racism.’

• *Shunned: Discrimination against people with mental illness* is published by Oxford University Press and will be launched by the IoP, King’s College London and Rethink during summer 2006.
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## Website for carers

Every month, some 30,000 people visit *www.mentalhealthcare.org.uk*, a website for mental health carers created by HSR and South London and Maudsley NHS Trust (SLaM) in partnership with the charity Rethink. The site features information about a variety of mental health conditions and an interactive ‘Ask the Pharmacist’ service. As well as easy-to-understand summaries of research findings from the IoP and SLaM, there are details of current research projects seeking participants.

Mental health carers from across the UK are involved in running the site through a ‘virtual’ advisory group which helps select material to be featured: topics currently include schizophrenia and psychosis, bipolar disorder, autism and young people and mental health. There are also contributions from carers about their personal experiences.

In Great Britain, 1.26 million people are caring for someone with a mental illness. Recent research carried out by Rethink found that more than one in four of these carers say they use the internet to find information.

‘I would like to thank you for providing straightfoward, simple to understand information,’ said one visitor to the site. ‘My son was diagnosed with drug-induced psychosis today and your website has helped me understand the condition and what to expect.’
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# Encouraging men to get treatment for depression

Young men who become depressed often try to cope alone and don't consult a doctor. A study just completed tested whether offering information about depression written for under-35-year-old men by under 35-year-old men would make a difference.

The information booklet was sent out to some 3,000 men with an accompanying letter from their GP offering a confidential consultation with a young graduate worker if they felt they needed it. The results, says Andre Tylee, professor of primary care mental health, are encouraging, and he and his colleagues are currently developing further studies to test other imaginative ways of encouraging young men to seek help before their depression reaches crisis point. 'But there is still a long way to go,' he says.

'Previous research has shown that 18-35-year-old men with depression don't access primary health care and this is worrying because there is a high suicide rate among this group. Previous studies have also shown the difference between the way men and women react to being depressed. Men don't talk about their problems or go for help – or even acknowledge there's something wrong: they tend to play sport or go to the pub. Their depression is often expressed by behavioural and alcohol problems which can lead to trouble with the police and in relationships.'

The booklet mailed out to all 18-35-year-old men registered with two large GP practices in Croydon, south London, was commissioned by the Charlie Waller Memorial Trust, set up in memory of a 28-year-old-man who committed suicide while suffering from depression. Some of his colleagues in the advertising industry produced the booklet to target their peers, re-assure them that depression is an illness and encourage them to seek specialist medical help and advice if they need it. 'Although depression is common, it doesn't take a day off and some Lemsip to cure it,' says the text which includes a dozen 'warning signs' and national contacts for more information and help. The GP practices' accompanying letter included email addresses, text and 'phone numbers for their graduate workers.

The Department of Health-funded study also included interviews with young men who had suffered depression in the past and a group who had never been depressed. These interviews set out to gauge what the target audience thought about the booklet –- called *Depression and how to deal with it* – and their attitudes towards both the concept of depression and seeking medical help.

This research complements a wider programme of work which seeks to find out why young people under 25 often don't go to their GP for help for mental health problems. This project includes listening to young people talking about their experiences in their doctors' surgeries – or saying why they didn't go for help. A 'youth expert panel' has been set up and is in the process of designing 'quality standards' for GP practices: the idea is that GPs could be assessed against the standards and given some sort of kite mark which could potentially re-assure younger patients. 'One of their biggest concerns is confidentiality,' says Andre. 'Many say they would not trust their GP not to tell their family. We want to work out a way for practices to re-assure younger patients that they adhere to a strict code of confidentiality, and that theirs is a safe place to go to talk about problems.' GPs are currently being consulted about the proposed quality standards and a kite marking system.

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**www.** *cwmt.org (The Charlie Waller Memorial Trust)*

## Mental health nurse to strengthen care for people with MS

People with Multiple Sclerosis (MS) often suffer depression and fatigue and may have cognitive problems. But many GPs and psychiatrists have scant experience of helping people who have mental health problems as a result of an underlying medical condition, says Eli Silber, a consultant neurologist at King's College Hospital (KCH).

'There have been a number of studies which have identified the mental health needs of people who have MS but not much has been done to meet those needs,' says Eli who runs a clinic for people with MS at KCH. 'People who have MS and mental health problems are often left out – particularly those with very complex problems who may not benefit from the limited services available from hospital-based psychologists and psychiatrists.'

With funding from the MS Society and Teva Pharmaceuticals, Eli has now teamed up with Professor Kevin Gournay in HSR's Psychiatric Nursing and Professor Tony David in Neuropsychiatry at the IoP to launch a three year project that seeks to offer the help that's needed by supplementing the skills of the experienced nursing team already working with people with MS, both at KCH and in the community.

A community psychiatric nurse joined the MS nurse team from April 2006 to help assess and deal with the mental health needs of people with MS who live in Lambeth, Lewisham and Southwark in south London. Not only will she work directly with patients – referred to her by colleagues on the nursing team and neurologists – but she will also have an educational role, sharing her mental health knowledge and expertise with the MS nurses. 'There is also a need for education about mental health amongst people with MS and their carers as there is still considerable stigma,' says Eli. People in need will receive care in the community but the service will be supported by psychiatrists, if appropriate.

The research will measure the success of having a professional dedicated to mental health needs working as part of the MS team. 'We will be assessing the needs of patients referred to her and the success of the interventions used,' said Eli. 'She will be imparting her skills to other nurses and other professionals: their satisfaction, and the satisfaction of patients, relatives and carers, will also play an important part of the evaluation.'

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## Helping people find and keep paid work

Four employment consultants are trying to help people with the most severe mental health problems find and keep a job. The consultants are part of a research project being carried out by HSR with the help of STATUS Employment, a south London based charity working with people with all sorts of disabilities.

Two of the employment consultants working under the remit of the SWAN (Supported Work And Needs) project are based in the borough of Lambeth: the other two are working in the nearby borough of Croydon.

People recruited to the SWAN trial are randomly offered the experimental intervention – in the shape of extensive support offered by an employment consultant – or regular job-seeking services. The SWAN team is aiming to recruit a total 216 people to the study, funded by the Wellcome Trust, the King's Fund and South London and Maudsley NHS Trust.

'Many people with severe mental health problems have been out of the job market for a long time and even though many desperately want to work, it's not easy to get back in, especially as employers are often reluctant to hire them them because of stereotypes and stigma,' said Dr Louise Howard.

'The employment consultants find out what sort of work people are interested in, give them guidance about their expectations, help them prepare a CV and then help them get ready for both the interview and the job. The consultants meet the employer first of all to try to dispel some of the stigma and will go with their clients not just to the interview, but also on their first day and thereafter to help train them on the job and give them confidence.' One of the measures of success of the scheme will be the amount of time people stay in work, not just the number of people who get jobs.

In the past, it was often assumed that people with severe mental health problems were unable to work, says Louise. 'If they did, they were put in sheltered employment: the idea was that they would eventually be ready for the real world of work. But what happened in reality was they never got there. They stayed in these sheltered employment schemes.' Nowadays, many people with mental health problems are still unemployed: the unemployment rate among people diagnosed with schizophrenia, for example, can exceed 90 per cent.

A new way of thinking which has had promising results in America is that it's much better to get people who want to get back to work started in the real job market. 'Patients are very keen to work and it's good for their well-being. Real employment gives structure to lives and boosts self-esteem.'

Health professionals are sometimes reluctant to refer people towards employment, she said. So as part of the trial, the employment consultants are going along regularly to meetings of community mental health teams. 'It's a bit of a culture shift for health professionals to think about getting some of their clients into work,' said Louise. 'The idea is that the consultants become part of the teams and supported employment then becomes a regular part of a care package.'

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## National guidelines for NHS treatment

Two HSR professors have chaired Guideline Development Groups for NICE (National Institute for Health and Clinical Excellence). NICE guidelines are meant to help health professionals at work: they are recommendations about the appropriate treatment and care of people within the NHS, based on the best available evidence.

Professor Kevin Gournay led the Group responsible for developing *Violence – the short term management of disturbed/violent behaviour in in-patient psychiatric settings and emergency departments*, published in 2005. These guidelines cover how people in the NHS should try to prevent violent situations from happening and what they should do if someone becomes violent.

Emeritus Professor Sir David Goldberg chaired the Group responsible for developing *Depression: Management of depression in primary and secondary care*, published in 2004. These guidelines cover the care people can expect to receive from their GP or other health workers, the information they can expect to receive, the treatment they can expect and the kind of services that can help.

An independent Guideline Development Group is set up to develop every NICE guideline. Each group is made up of people with relevant experience and expertise, including health professionals, service users and carers.

***www.****nice.org.uk*

## Supporting a policy for European Union

The European Commission's first Green Paper about mental health was published at the end of 2005. One of the pieces of evidence it uses to support the proposal for a European Union strategy on mental health is research carried out by HSR about the cost to society of young people with conduct disorders.

Researchers in HSR showed that adults who behaved in a persistently and pervasively anti-social way when they were children cost the public sector ten times more by the time they were 28 than adults who had had no conduct disorder problems in childhood. The greatest cost was due to crime and fell upon the criminal justice system. The next greatest costs were extra educational provision, foster and residential care and state benefits. The research concluded that anti-social behaviour in childhood is a major predictor of how much an individual will cost society in adulthood.

*Improving the mental health of the population: Towards a strategy on mental health for the European Union* lists 'significant losses and burdens to the economic, social, education, criminal and justice systems' as one reason for proposing a strategy that could help build solutions. Another reason is that 'stigmatisation, discrimination and non-respect for the human rights and the dignity of mentally ill and disabled people still exist, challenging core European values.' Mental ill health affects one in four citizens across the European Union: some 58,000 citizens commit suicide each year.

In addition to effective and high quality mental health care and treatment, the Green Paper also calls for promotion of mental well-being and prevention of mental ill health. A European Strategy would offer the scope for exchange and co-operation between Member States and the opportunity to learn from each other.

The purpose of the Green Paper is to launch debate: the consultation period ends on 31 May 2006 and the results will be published at the end of the year.

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## Fate of lone children

Testimonies from asylum-seeking children who arrive by themselves in the UK will help the Refugee Council design services to better meet the needs of those separated from their families and culture, often having witnessed traumatic events.

Researcher Menakshi Sharma is interviewing 150 under-18-year-olds about their experiences when they first arrive in this country. 'They are at a vulnerable age and their needs and aspirations are sometimes poorly understood by service providers and carers,' she said.

HSR's Section of Cultural Psychiatry is carrying out the research jointly with the Refugee Council with the financial backing of the King's Fund. 'We are interested in their health, both physical and emotional, their experiences within the asylum system, the care they receive from social services and the aspirations they have about living in England,' said Menakshi, who will be interviewing 50 of the original sample after a year to ask what it's been like living here.

The number of asylum-seeking children without families in the UK increased from 600 in 1996 to 6,700 in 2003. Many of the children Menakshi has interviewed so far are from Ethiopia and Iran. The study will be complete by the end of 2007.

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## Call for support for social workers

Many mental health social workers throughout the country are stressed, emotionally exhausted and feel undervalued at work. That's the conclusion of research carried out by HSR that recommends employers take action to recognise the demands of the job and better support mental health social workers.

*Mental health, burnout and job satisfaction among mental health social workers in England and Wales* was published in the British Journal of Psychiatry early in 2006. The report of research commissioned originally by health czar Louis Appleby and funded by the Department of Health says: 'Excessive job demands, limited latitude in decision-making and unhappiness about the place of the mental health social worker in modern services contribute to poor job satisfaction and burnout.' It suggests these may be factors contributing to recruitment and retention problems faced by the vast majority of employers in the UK. Staff shortages and resulting huge workloads contribute to the stress felt by those in posts.

A postal questionnaire sent to a randomly selected sample of mental health social workers in England and Wales revealed twice the level of stress at work reported by similar surveys of psychiatrists. 237 questionnaires were analysed: 63 per cent reported having to do extra work to cover for absent colleagues or staff vacancies. Absences were primarily due to sick leave. Many people were unable to take time off in lieu of out-of-hours work because of pressure of work and vacancies. 43 per cent said they felt undervalued at work.

'The most striking findings are the high levels of stress and emotional exhaustion,' said Peter Huxley, professor of social work. 'Mental health social workers are more emotionally exhausted and feel less valued at work than the average mental health worker.'

Employers and central government need to consider how to improve conditions for mental health social workers, make them feel valued, enhance decision latitude and reduce job demands, says the report.

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# The perspective of service users

What does it feel like to be sectioned and compulsorily detained? Is what doctors and therapists believe to be the best treatment path for a patient with mental health problems necessarily good for that patient's self-esteem? Do people who agree to take part in research trials really understand what they're signing up to?

SURE is a research group trying to answer these and other questions to test how effective services, treatments and policies for people with mental problems are from the users' point of view. Of a team of 12 (researchers, administrators and co-ordinators), eight have had first hand experience of psychiatric services and treatments. This experience adds a wealth of understanding and perspective.

SURE stands for Service User Research Enterprise: it is one of the largest units within UK universities that employs people who have both research skills and experience of mental health services. 'In most organisations, service users get involved in research as volunteers,' says Dr Diana Rose, co-director of the unit and Europe's first senior lecturer in user-led research. 'Very few universities hire "user researchers" – people who can make use of their experience to make research more pertinent and meaningful in a field dominated by the point of view of clinicians and academics.'

Every piece of research carried out in the field of mental health is ultimately meant to benefit people with mental health problems. But does it?

Back in 2000, a consultation exercise with people living in Croydon, Lambeth, Lewisham and Southwark who use mental health services run by South London and Maudsley NHS Trust (SLaM) led to the setting up of SURE. It became clear at that time that the priorities of researchers and service users often differed: service users said their top priority was to be involved in all aspects of research. Researchers in academic institutions have historically applied or bid for grants to fund projects without consulting or involving service users in the planning. In SLaM nowadays, researchers have to say how they're involving users in every proposed project when putting their bid together: 'But we know there's still a lot to be done when you look at some of the answers,' says Diana.

Out of the consultation exercise and an ensuing conference was also born a local Consumer Research Advisory Group (CRAG) which is supported by the SURE team. The Group sends two representatives to every meeting of the joint IoP/SLaM Research and Development Steering Group and its views therefore contribute towards shaping the research agenda. The SURE team runs an annual training course for service users in all aspects of research and weekly sessions for researchers at the IoP seeking advice and information about how best to plan projects collaboratively. 'It's not only service users who need training to do collaborative research. Clinical academics need advice on how to involve service users,' says Diana.

Since its launch in 2001, SURE's own research projects have centred on issues important to services users. Its first study – *Consumers' Perspectives on ECT* – was a Department of Health-commissioned systematic review of what patients thought about electroconvulsive therapy and influenced 2003 guidelines about obtaining consent to the treatment from the National Institute for Health and Clinical Excellence (NICE). The guidelines also cover when ECT should be used and advise an accreditation programme to make sure professionals are properly trained and peer-reviewed.

An analysis of research papers, reports by user organisations and first hand testimonies from patients showed that about half the people receiving the treatment felt they had not received enough information about the procedure – involving anaesthesia and an induced fit as a result of an electric current passed through the head – and its common side effect of memory loss. About a third felt they had not freely consented – as they must do by law – even when they had signed a consent form. 'We found patients who felt the procedure was used as a threat, patients who signed the consent when medicated and patients who trusted doctors to do what was best without understanding the procedure fully,' says Diana.

> 'Very few universities hire "user researchers" – people who can make use of their experience to make research more pertinent and meaningful.'

'Researchers without any experience of mental health services argue that patients don't want lots of information and that because ECT causes short

Photo: Science Photo Library

**‘Researchers without any experience of mental health services argue that patients don’t want lots of information and that because ECT causes short term memory loss, many people may forget what they’ve been told. But the testimonies of users reveal feelings of distrust or desperation, and of being powerless when faced by a medical professional who is so confident in the efficacy of the treatment.’**

term memory loss, many people may forget what they’ve been told. But the testimonies of users reveal feelings of distrust or desperation, and of being powerless when faced by a medical professional who is so confident in the efficacy of the treatment.’

SURE’s current work continues to put the views of service users centre stage. One member of the team has been developing a method to measure how service users rate the care they receive. In future, says Diana, SURE wants to develop more measures to test how effective service users think services and treatments are. ‘When academics do trials of treatments for example, they measure things like symptom reduction. To a service user, that’s not necessarily the only important thing.’

A survey to test patients’ satisfaction with Cognitive Remedial Therapy (CRT) – which aims to help people improve their memory, concentration and thinking skills – revealed, for example, a side effect of psychological treatment that Diana reckons professionals with no experience of receiving treatment would not even have considered a possibility. SURE helped a group of treatment-resistant patients with schizophrenia who had received CRT through the IoP/SLaM Centre for Recovery in Severe Psychosis draw up a satisfaction survey. Then two of them used the questionnaire to interview 21 other people at the end of therapy. One of the questions was: ‘If you don’t do well at the CRT tasks, does it make you more aware of your limitations and disability?’ About half the respondents said yes. When SURE researchers analysed and cross-referenced the data with the Centre’s records, those who said yes were mostly the ones who had dropped in self-esteem during the course of the treatment. The two service users who carried out the interviews are named as authors on the research.

While another IoP team based in the Social, Genetic and Developmental Psychiatry Centre is leading an international study that seeks to develop a test to enable anti-depressants to be tailored to an individual’s genetic make-up, SURE is involved in finding out about the ethical, legal and social implications of such a development. This independent study was called for by the European Commission which is funding the ‘GENDEP’ research and is being carried out in collaboration with the London School of Economics. SURE’s job is not only to find out what users think of the possibility of developing such tests – but also to discover if people who are taking part in GENDEP fully understand what they have signed up to. ‘There has been very little research carried out in the field of consent for research, particularly mental health research,’ says Diana. ‘The implications of this could be enormous for all trials.’

There are nine countries participating in the GENDEP study: over three years, 1,000 people with depression are being treated with one of two types of drugs on the market, their response monitored and their genetic make-up analysed. Researchers from SURE are interviewing people who have completed the trial as well as people who have dropped out in the UK, in Germany, in Poland and in Denmark. In the UK, they are also interviewing people who were asked to take part and refused.

> ‘When academics do trials of treatments, they measure things like symptom reduction. To a service user, that’s not necessarily the only important thing.’

Another collaborative study focusing on people who receive services seeks to gather patients’ views and experiences of being sectioned and having compulsory treatment. Members of the SURE team have interviewed 300 people in the south east of England during their first week of detention, then again a month later and once more after another two months. They are currently interviewing them again after a year. What makes this a particularly interesting exercise, says Diana, is that one of a pair of interviewers has experience of mental health services and the other doesn’t. ‘The research will seek to find out if that makes a difference,’ she said.

Feeding back service users’ views and experiences to the professionals who provide the services is also of paramount importance. ‘Service providers often complain they take part in research and then never get any feedback,’ says Diana. ‘Our policy is always to tell the professionals what users say before writing up the paper.’

Has shifting the research perspective made an impact? Recently the CRAG itself successfully applied to a local grants fund to try to find the answer. Members of the CRAG team developed a questionnaire which they will use to interview 20 service users who are actively involved and 20 service users who aren’t to compare their experiences of services provided by SLaM. ‘If this research shows that users think greater involvement in research has made a positive difference to their experiences, then there is a very strong argument for expanding that involvement,’ says Diana.

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# MSc opens new career doors

Martin Webber was a social worker, based in a community mental health team, when he decided he wanted to move into research. Studying for an MSc in Mental Health Services Research has helped him make that career move.

Photo: Rehan Jamil

'I had always wanted to go into research,' he says. 'I've always been curious about studying new things. I was frustrated when doing my social work training because I didn't feel there was enough evidence to back it up: social work is theoretically driven rather than empirically based.'

Martin successfully applied for one of two Department of Health-funded four year Social Science Fellowships in HSR's Section of Social Work and Social Care which he saw advertised in *The Guardian*. For the first year, he studied full-time for his Masters. Now he's reaching the end of his contract, having almost finished his PhD.

'Doing the MSc helped build up my skills in writing research proposals,' he said. 'The main emphasis is thinking about the right methods to use to answer the research question you are asking. It gives you a good grounding to get a proposal sorted out. The dissertation at the end was my PhD proposal.'

Now writing up the early stages of his PhD while still collecting information, Martin says he is again benefiting from the MSc programme. 'As I am analysing the data, I am going back to the statistics teaching. I am also preparing proposals for future work.

'I want to stay in research on mental health social work practice and combine some teaching with it,' he says. 'I like the autonomy of research: you are charged with a task and you get on and do it. I enjoy the flexibility and responsibility of running my own research project.'

Dr Nick Glozier is programme leader for the MSc course in Mental Health Services Research. 'You can study one year full-time or two years part-time,' he says. 'The part-time option is good for people who want to continue working while studying – it is useful for health professionals and people who work for health-related policy and non-government organisations or for charities, people who are meant to interpret research as part of their job. It helps them understand how academics speak and write and gives skills to understand people on 'the other side of the fence.'

'The main emphasis of the MSc is thinking about the right methods to use to answer the research question you are asking.'

The course is also a good grounding for people like Martin who want to switch their career to the direction of full-time research, he says. 'It gives you a sound practical and theoretical knowledge base about the practice and interpretation of research and the context in which in takes place,' he says.

The course is a mixture of classroom teaching, group work and private study. It covers research methodology, statistics and research ethics, study designs and research protocols and ends with a research dissertation. 'It's quite intensive and people are expected to do a lot of study by themselves,' said Nick.

**For more information** about the MSc in Mental Health Services Research starting in September 2006, visit *www.research-msc.iop.kcl.ac.uk*

The MSc in Mental Health Social Work is another taught programme run by HSR. It's designed for qualified social workers who want to specialise in mental health care, for social work managers, lecturers and training officers.

For more information about the MSc in Mental Health Social Work, visit *www.iop.kcl.ac.uk/iopweb/studying/taught*

**To find out more** about doing a PhD with HSR, contact Dr Paul Moran, *p.moran@iop.kcl.ac.uk*

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