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Making service users' and carers'

voices heard in research



Christine Wilson is a Member of the Service User and Carer Partnership Research Development Group (SUCP RDG) at the Mental Health Research Network Cymru (MHRN-C) and a Senior Consultant at Hafal who facilitates the Hafal Expert Leadership Panel (HELP). Here Christine discusses why it's essential that service users and carers are part of the process of identifying and conducting research - and what the research priorities are for service users and carers in Wales today.

Christine writes:

Research has shown that service users, clinicians and researchers often have different views on priorities for research. Mental health is no exception. That's why we are working so hard in Wales to ensure that mental health research reflects the interests of service users and carers. It's essential that service users and carers' views are taken into account when it comes to deciding on research priorities. After all, service users and carers are the experts: they are the people who use the services which are developed from research. At Hafal – a Member-led charity - we are dedicated to ensuring that our services are led and shaped by the people who use them, which is why we recently set up the Hafal Expert Leadership Panel (HELP).

Any successful research and innovation strategy requires the development of well-informed **research priorities**;

alongside appropriate targets and milestones they should guide the allocation of limited research funding and expenditure. In Wales, a national network ensures that service users and carers have the opportunity to have their say on those priorities.

Established in 2005, the Mental Health Research Network Cymru (MHRN-C) aims to bring together researchers, clinicians, service users and carers to generate proposals for new research studies in order to develop a distinctive portfolio reflecting national needs, the needs of service users, and our research strengths. (We talk to the Head of the MHRN-C, Prof. Keith Lloyd, on p.9.)

A Service User and Carer Partnership Research and Development Group (SUCP RDG) was established at the MHRN-C in 2009 to support mental health service users and carers to input into research undertaken by the network, and to help service users and carers to partner with professionals to raise the standard and impact of health and social care research and practice in Wales, the UK and internationally.

Our overall aim is to significantly increase the opportunities in Wales for service users and carers to be involved in writing research funding applications and undertaking mental health research, whether this is research prioritised by mental health organisations or research that service users and carers themselves see as a priority.

Research in action

In 2013 SUCP RDG held a workshop with people from across Wales who had experience of mental illness along with a group of informal carers. The workshop was a joint venture between Hafal,

Involving People, MHRN-C and the University of South Wales. The aim of the workshop was to assist service users and carers to select research priorities and inform a way forward for mental health research in Wales. A large number of research priorities were generated. Group consensus was reached using hand-held voting technology to rank the research priorities in

terms of importance. The table below summarises what services users and carers saw as the most important areas to investigate in the specific categories.

Participants were asked to engage in a further round of voting and to consider their top two research priorities from the

lafal's HELP panel

list of the 12 research priorities already generated.

In a very close vote the research priority to receive the most votes was:-

 Undertake research in schools and colleges to find out what training they provide to their students regarding mental health. And can this training be improved?

A second vote was then undertaken to find the priority which participants felt could most easily be translated into an immediately 'do-able' research subject/application for research funding by the RDG. After another close vote the research priority to receive the most votes was:-

 How can education provide a 'centre of gravity' to recovery, including support? e.g. mentoring?

What the workshop demonstrates is the importance service users and carers place on education, and how they would like to see research explore the potential of the education environment to promote recovery. In the coming years we hope to see these research priorities taken forward. We'll keep you informed!

Research priorities Category How are carers supported during the Treatment and recovery of the person for whom they care? Recovery And are they supported to embrace their changing role at this time? How do service users develop their own support networks? **Education and** How can education provide a 'centre of gravity' to recovery, including support, e.g. **Higher Education** mentoring? What support goes hand in hand with educational opportunities? Stigma and Undertake research in schools and colleges to find out what training they provide to their **Attitudes** students regarding mental health, and can

- this training be improved?
- How much do the media affect people's attitudes to people with mental health problems?
- Support Services including Crisis Support

Employment

- How are service user mentors involved with support services?
- Why are there Crisis Intervention Teams but not Crisis Prevention Teams?
- How are skills provided to service users so that they can achieve their aims?
- Can people with mental health problems be a benefit to their employer?
- Other (any topic not covered by the other 5 categories)
- Are welfare reforms making people more ill?
- How do service users obtain support to maintain momentum towards recovery?

Wales is internationally recognised for its mental health and social care research, and boasts several centres of research excellence across the country.

In the next few pages we chat to some of the people leading that groundbreaking research about their aims – and what research they would like to see undertaken in the future.





Professor Jeremy Hall, Director, Neuroscience & **Mental Health** Research Institute

How would you summarise the research goals of the **Neuroscience & Mental Health** Research Institute?

We aim to understand more about how different risk factors for mental illnesses impact on the brain. This includes both genetic risks that we may inherit and factors in the environment that we experience. By understanding how these risk factors affect the brain and brain cells we hope to produce better treatments in the future.

Your research looks at the role of both genetic and environmental risk factors. Why is this an



Neuroscience & Mental Health Research Institute Sefydliad Ymchwil y Niwrowyddorau ac lechyd Meddwl

important distinction, and has your research found that one has a greater role than the other?

The brain is a hugely complex organ that is constantly adapting to the world it experiences. This makes the brain vulnerable both to genetic changes and to changes in the environment from the predicted state. All the evidence supports the view that both these processes genetic and environmental - are important in mediating vulnerability to mental health problems, although the exact proportions may differ between disorders. This adaptability of the brain also gives us hope for new treatments as the brain remains remarkably plastic throughout our lives.

How does this research have an impact on treatments for mental illnesses?

We believe that mental health problems have their origin in the brain. We therefore need to understand more about the brain if we are going to treat these conditions better. We can now do amazing things such as growing brain cells simply by taking a sample of a person's hair, or turning on and off brain circuits with light alone; that means we can both understand the brain better and work out how to treat brain conditions. It is for these reasons that I believe we will be able to turn our increased understanding of risk into better treatments in my lifetime.

Which areas do you think are ripe for research in the coming years?

There is a huge current investment in research in dementia and I think there are some real prospects of new treatments for this disabling condition in the coming years. However I also think that difficulties that have their origin early in life, such as autism and related conditions like schizophrenia, are very much amenable to the new research tools we have available and I am very optimistic that we can develop new treatments in these areas too.















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Professor
Jonathan Bisson,
Head of the
National Institute
for Social Care
and Health
Research
(NISCHR)

As Head of NISCHR, how would you summarise its main aims and achievements?

The National Institute for Social Care and Health Research (NISCHR) is a Division of the Welsh Government responsible for strategy, policy, commissioning, funding, contract management and governance of health and social care research and development in Wales. It has established an effective infrastructure, along with a range of funding schemes, to support high-quality research and to increase capacity in health and social care research in Wales.

There are many examples of the benefits of NISCHR investment, in terms of improving health and social care, economic growth and job creation in Wales. Specific examples are the Health Informatics Research Unit (HIRU) at Swansea University and their pioneering work on Secure Anonymised Information Linkage (SAIL), the Welsh School of Primary Care Research's work on antibiotic prescribing and resistance, and the National Centre for Mental Health's



work to find out more about what causes mental illness, improve diagnosis, treatment and support for people affected by it. Our vision is for Wales to be internationally recognised for our excellent health and social care research that has a positive impact on the health, wellbeing and prosperity of the people of Wales.

NISCHR has created a community of health and social care researchers in Wales. Why is this 'linking up' of research so important?

We are passionate about linking up health and social care research, not least as we believe that integrated research is vital to improve integrated care. Creating a community of health and social care researchers is key to this as is collaboration across sectors to facilitate the development of high quality research and to translate it into practice. We have recently funded five Research Centres (including renewing the funding of the National Centre for Mental Health) and three Research Units that will be multi-professional and multidisciplinary, including Public and Patient, NHS, University, Industry and Social Care representation as appropriate.

How does NISCHR work to ensure that research is focused on the needs of patients, and in what ways does NISCHR involve patients in setting the research agenda?

We have recently undertaken a major review of what we fund and are now implementing some changes to what we fund to build on what has been achieved to date. These place the public (including patients, service users and carers) in a central position to facilitate the development of research that is responsive to the needs of Wales, highlights the

benefits that research can offer, effectively translates new discoveries into improved care and has a strong ethos of public/community engagement, co-production and transparency. Public involvement is being integrated into everything we do. We intend to launch a national population study that is owned and directed by the public. All people in Wales will be invited to participate in research, to contribute their information and become part of a national study to better inform new treatments, new services, new products and new processes.

As well as being Head of NISCHR you are a professor in psychiatry at Cardiff University School of Medicine. Which areas of research in mental health should be explored in coming years?

I do think that more research needs to be done in mental health and that several areas are ripe for development, including in my own field of post traumatic stress. We are very fortunate to have such strength in mental health research in Wales: the National Centre for Mental Health's inclusive, integrated approach that covers the lifespan is an excellent one. I believe that an increased focus on moving research discoveries into practice is very important. This should address delays in the implementation of better ways to prevent and treat mental illness, and to organise services, ensuring that new research discoveries impact on individuals' health and wellbeing as quickly as possible.





Professor Marcus Longley, Director, Welsh Institute for Health and Social Care (WIHSC)

What have been WIHSC's biggest challenges and achievements in its first 20 years?

I'm tempted to say, 'Surviving 20 years'! Our team consists of about eight or nine core staff, and several colleagues who work with us in their areas of special interest. In the last 20 years we have completed about 200 projects of various sizes, across a range of health and social care topics, from small communities in Wales to pan-European. The most satisfying have been those where change came as a direct result of our work. More commonly, we can help people to understand better the challenges they face, and to evaluate their options for themselves. This can lead to change, but not necessarily immediately or directly. The most frustrating scenario fortunately quite rare - is when we have laboured for months on a project, and at the end the funder has quite clearly forgotten why they asked the question in the first place, and has no idea what to do next.

The most satisfying piece of work for me is where we give voice to people who previously have been unheard and unseen, where we translate their experiences into helpful and innovative suggestions for improvement, and where we then work with clients and professionals to make that change happen.

How would you summarise your research goals and aims?

There are basically two types of researcher, if you'll forgive me the silly caricature. You can tell the difference between them by how they

react, at the end of their research, to the question 'So what? What I am supposed to do with those results?' One researcher - the 'purist' - will respond with a shrug of the shoulders and say, 'That's your problem. My job was to tell you the truth.' The other - the applied researcher - will regard it as their job to help the questioner to think through the implications, based on a good shared understanding of what is and isn't possible and desirable in their world. Their whole approach to the applied research will have been to understand and appreciate the realities and possibilities throughout. and to have gone looking for practical answers, so at the end they can answer the 'So what?' question helpfully.

The purpose of research we do is to understand the world, in order to change it. So we are the second sort of researcher. Applied health policy research is about proper rigour - collecting meaningful information, and getting the facts to speak for themselves - in order to answer questions which really do affect people's wellbeing and the services which serve them.

Which areas do you think are ripe for research?

The research agenda in mental health is huge, and growing. Just being parochial, I think we have a great opportunity here in Wales to make the virtuous cycle of designapply-evaluate-improve work for us. There is no shortage of innovation in Wales, across all aspects of mental health services and wellbeing, from supportive communities and primary care, to dementia services and longterm care, to crisis intervention and support for veterans... and many more - we are a living laboratory. We need to evaluate these experiments, and be rigorous about learning from them. No service is incapable of improvement; no-one should have to rely on a service whose model or approach is flawed. Research has a crucial role in shining a light on these issues, and helping find ways of improvement.

Why is patient involvement important?



Health services in general have had a problem with their patients for years! For a long time, the health service thought the best patient was the one who did as they were told by their doctor. Gradually, it has come to realise that people's problems are too complex for this. In addition, people's hopes and wishes are also more complex - what the doctor thinks is the best outcome may not be what the patient wants. Also, there are important issues here of shared responsibility and motivation a passive patient, waiting to be cured, is likely to be disappointed. Plus the fact that patients increasingly will question what the doctor says, and will want to understand and make up their own mind...

So the NHS in Wales has coined the term Prudent Healthcare for some of this. Another - rather ugly - term, is 'co-production'. Both point to a sea change in how the NHS relates to its 'patients' - even re-christening them, 'partners'.

Third Sector organisations are essential to this change. In part it's about power - no matter how hard the NHS tries, patients are often vulnerable and in a weak position, and therefore can find it hard to assert themselves. Third Sector organisations can be effective individual advocates; they can also advocate on behalf of whole communities, in a way which NHS professionals never could. In part it's also about imagination and creativity. Third Sector organisations see the world a little differently, they understand different perspectives, they have access to a different range of experience and knowledge. All of these enrich the mix of health planning and service delivery.

The NHS has come a long way in the last 20 years. Not only have services expanded beyond recognition, they have also become more humble. Partnership working can be hard, but it's here to stay.



Professor Catherine
Robinson,
Co-director, Centre
for Mental Health
and Society

As co-Director of the Centre for Mental Health and Society (CFMHAS, established 2012), how would you summarise the aims of the Centre, and what have been its greatest achievements in its first three years?

The Centre was established with support from the Betsi Cadwaladr University Health Board charitable fund and Bangor University School of Social Sciences. It is co-directed by Rob Poole and by myself. I am a social scientist and he is a social psychiatrist. It arose out of our successful research collaboration. We believed that our particular combination of experience and skills would allow us to build a truly multidisciplinary partnership. We are pleased that we have managed to draw together a group of really distinguished practitioners and researchers from social, psychological and bio-medical sciences. It is a really strong team with a lot of ideas and activity.

The work that we do has direct relevance for the well-being of people with mental health problems, their families and carers, and for the general population. The work that we do in India on self-harm and suicide is of international significance. We are lucky to have an exceptionally talented member of CFMHAS in Mysore, Dr Murali Krishna, who will be a central figure in our work in the coming years.

Dr Anne Krayer leads our work on anti-social behaviour and mental

health, which is an example of our commitment to working as equal partners with people with lived experience of mental health problems, and with both the statutory and Third Sector.

In what ways are these partnerships with services - and specifically Third Sector organisations and patients - so important to your research?

Right from the beginning of my research career, working with public and Third sector service organizations has been crucial. Early in my career this was framed as cooperation between the University and the service organisations. As my career progressed, the rhetoric changed to collaboration, and grant funding organisations demanded that service providers should be involved in research development. Now we involve people with lived experience in developing and implementing research.

I am particularly proud that we have been ahead of the rhetoric. We have worked with many patients and carers as partners in our research, usually through Third sector organisations. Dr Diane Seddon and I worked on the Carers Strategy in Wales. This brought me into direct contact with carers and their organizations. The clear message from them was the need to do some research in this area. I led a Welsh national study with a carer organisation as the lead partner. Carers research led directly to another collaborative study on stigma and dual diagnosis. Again, a Third Sector organisation was the key partner. This in turn led to our current work on anti-social behaviour with two Third Sector organisations and two police authorities.

CFMHAS promotes a multidisciplinary approach with the use of mixed methods of research. What do you think are the benefits of this methodology?

We are interested in complex problems. They are often best addressed through combined qualitative and quantitative approaches. We are able to use



different research methods in combination to answer the research questions. This combined approach also applies to sources of data. We are particularly interested in using routinely collected data for research alongside its original purpose. An important example is our research on deaths involving alcohol. By using routinely collected data it has been possible to gain an understanding of the role of alcohol in premature death that cannot come from the operationalised categories used by the Office of National Statistics. This unique insight into everyday deaths was the first project undertaken by the Centre and it is still an important research theme. Narrative approaches to exploring lived experience is a feature of our national and international research.

Which areas of mental health research do you think are priorities in the coming years?

Our recent book Mental Health and Poverty (Poole, Higgo, and Robinson Cambridge University Press, 2013) gives a clear indication of the areas we think are priorities. The book brings together a body of knowledge from biomedical and social science to explore a range of issues, including childhood adversity, stigma, the recovery model and substance misuse. The book highlights how important social factors are as causes of mental illness and as impediments to recovery.

Our new partnership with the National Centre for Mental Health is an excellent opportunity to develop major collaborative research projects which combine the National Centre's world reputation for research on genetic factors in mental illness with the Centre for Mental Health and Society's expertise in understanding on social factors.



Dr Michael Coffey,
Associate Professor
Public Health And
Policy Studies,
Swansea University

How would you summarise your research goals?

My research programme examines the ways in which mental health care is organised, delivered and experienced by people providing and using these services. Enduring mental health problems require longterm responses from a range of sectors. However care is often fragmented leading to poor outcomes, further distress and financial cost. The cost of mental illness in monetary terms is considerable, estimated at £7.2 billion in 2007/08 in Wales alone. Better co-ordination and planning of care may improve outcomes, help to build recovery and enable greater participation in daily life. My research team is focused on understanding how care is planned, how this is experienced by those using their services and workers, and how this relates to ideas such as recovery. Our goal is to do this with the full involvement of people who use services with a clear eye on formulating responses aligned with democratic and anti-oppressive mental health care.

You've conducted a lot of research into recovery-focused care planning: what have you found are the benefits of this approach?

At this early stage it is hard to be clear that recovery-focused care planning is being delivered consistently across all sectors for the benefit of people using mental health care. Our recent research with

community mental health teams in England and Wales (COCAPP study) suggests that people delivering and using services are becoming wary of the notion of recovery and how it is being applied. We cannot even be certain how much involvement people have in their care plans or that these documents are effective currency for getting better recovery focused care. The idea of recovery focused care planning is a powerful one with much potential to deliver improvements but there need to be additional supports for people who worry that it is a cloak for planned withdrawal of support.

You've also explored the relationship between identity and recovery from mental illness. Could you tell us how and why identity is so important to a person's recovery?

Identity is important to everyone in all walks of life. It is dynamic and purposeful. There are at least two forms of this, how we are known to ourselves and how we are known to others. For people who experience mental distress, how they are known to others as someone with a mental health problem can lead to negative experiences. These can be internalised and then affect how the person is known to themselves. An example is that we might believe we can never work because there is a view that work increases stress for people and can trigger recurring mental health problems: if we internalise this then we see ourselves as someone who can never work and perhaps that gets in the way of trying to change things. For recovery to be possible individuals must build new understandings of who they are in the light of their mental ill health experiences. My research has shown that people do this all the time but they need more help with this. Recovery requires these new forms of identity work to be supported and honoured by others in all walks of life.

You promote patient involvement in research. Why is this important, and what role do Third Sector organisations play a part in this?



A key element of my research programme is the engagement and involvement of people using services in determining research priorities and designing and conducting research projects. This is of particular relevance and importance in mental health care where people often experience highly paternalistic care and subsequent lack of control over what evidence should count. Third Sector organisations such as Hafal have a key role to play in this because they provide opportunities for people with experience of mental ill health to inform research ideas, encourage participation and engagement with the research agenda and participate as researchers and study participants so that valuable experiences of services are used to inform new ideas on how these are organised and delivered. Close involvement of people using services leads to research which poses questions of more direct relevance to the experience of mental health care, is likely to recruit to studies more successfully and will lead to increased opportunities for knowledge transfer in mental health settings. One example of this is the two year National Institute for Social Care and Health Research (NISCHR) funded Plan4Recovery study I am leading with a team of academic colleagues, service user researchers and with the help of Hafal. We are investigating involvement in shared decisionmaking and social connections in mental health care in Wales and we should have our findings ready to share later this year.

Which areas do you think are ripe for research in the coming years?

The Welsh Government and the Bevan Commission are promoting the idea of Prudent Healthcare. Research calls in Wales already feature reference to Prudent Healthcare and the challenge for researchers is to engage with this

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agenda. It is less clear however what people who use mental health services understand by prudent mental health care and whether there is an appetite for engaging with this when it could be seen to limit intervention in a field with already sparse resources.

One area of interest we have noticed in our projects examining mental health care co-ordination in England and Wales is related to the communication of risk assessment and management plans. Decisions on risk have far-reaching consequences for individuals using services but there appears to be limited sharing and involvement in decisions on risk. Regardless of the validity of some risk assessment procedures we should begin to ask what are the potential benefits of shared discussions on risk status?

The advent of the Mental Health Measure in Wales has also seen some movement of care for some people from secondary services back to primary care services. We are curious to know how people fare in such circumstances and will be

kicking off a new study soon to learn more about this and develop a measure of outcomes to assess this.

A further area of interest is related to mental health literacy in the wider population. This includes knowledge about mental health conditions, recognising these in yourself and others and the ability to use this information to take steps to protect our mental health. Ultimately better health requires wider engagement by us all in recognising what promotes our mental health.



Professor Keith Lloyd, Director, MHRN-C, reflects on its 10 years of achievement - and its incorporation into NCMH

On behalf of everyone who has been involved with Mental Health Research Network Cymru (MHRN-C), I am very grateful for the support many organisations including Hafal have given us over the last decade in helping deliver the studies that matter for mental health.

Ten years ago, the all Wales Collaboration for Mental Health recognised the need for a Network that would address the need for both the volume and quality of mental health research in Wales. Mental Health was then, and remains, a leading cause of disability worldwide. Historically too, mental health research in Wales had been underfunded.

MHRN-C's aim was to bring together key stakeholders in the field of mental health to try to redress this situation and work collaboratively to deliver the studies that matter for mental health. MHRN-C had a unique co-ordinated model of

Rhwydwaith Ymchwil lechyd MHRNC Meddwl Cymru Mental Health Research Network Cymru

approach at its heart: one that was not top down but was built on a true partnership of all those involved in the issues of mental health - service users, patients and those who cared for them, and the providers of the health services they used. Together, they would have the capacity to identify and prioritise key areas of research, the results of which would serve their

needs best.

The story since 2005 is a good one and there have been huge achievements that are impacting positively on the volume and quality of mental health research in Wales. Significant among so many is the establishment of MHRN-C MRC Centre for neuropsychiatric genetics and genomics at Cardiff University, recognition of world-leading research, and likewise, the formation of the Suicide and Self-harm Satellite Cochrane Depression, Anxiety and Neurosis Group (CCDAN) based at College of Medicine, Swansea University. One of the achievements I am most proud of has been the establishment of the service user and carer research group (see p.2).

Over MHRN-C's relatively short lifespan it has succeeded in attracting investment into mental health research in Wales to fund and support key research studies across its portfolio. In 2005 our nine study areas had a value of £5 million; at the end of 2014 this value had increased

to £31 million across 71 study areas. This is testament to the partnerships we have forged and the research that has already been undertaken.

But the value goes much wider: not only has the funding from NISCHR Welsh Government and other monies from across the world significantly increased the ability of MHRN-C to research the causes and treatments of mental health, but has supported the increase in associated jobs and other types of outputs that contribute to wealth generation in Wales. It is public money well spent.

Though MHRN-C ceases to be in 2015, it is not the end of its story as its 'best bits' and some current activities are being incorporated and carried forward in the new National Centre for Mental Health (NCMH) headquartered at Cardiff. The need to deliver the studies that matter for mental health is not by any means a finished matter and work will continue to ease the main health burden in Wales and across the world.

It has been an exciting and dynamic ten years and the momentum will continue. I trust this review will be seen as a summary of our lasting impact and a celebration of the value of quality of the people that have set things in motion and delivered the studies that can really make a difference to mental health.

NCMH

National Centre for Mental Health



Tell us about the aims of the National Centre for Mental Health

NCMH brings together world-class researchers, health professionals and people with lived experience to learn more about the causes of mental health conditions, so that we can help to develop better ways of treating them. We want to change the culture around research in mental health and social care services in Wales - we would like the opportunity of participating in research to be offered to everyone accessing care.

Your research covers a range of disorders. What are the benefits of this broad approach?

The current diagnoses we use in mental health have their advantages, but are only best guesses. In reality, conditions rarely fit into neat boxes. By working beyond diagnostic and also age groups, we are better placed to spot factors that play a role across a number of conditions or throughout the life span.

At NCMH you promote patient involvement in research. Why is this important, and how can Third Sector organisations play a part in this?

We want NCMH to be a genuine collaboration between researchers, clinicians and patients. The perspective of people with lived experience is vital in making sure we are addressing the right issues. Third Sector organizations play an important part too, by sitting on our advisory board and providing invaluable strategic input.

What is the social impact of NCMH in Wales: for example, in promoting understanding of mental illness and reducing stigma?

NCMH is constantly working to engage with patients and the public to increase understanding of mental health conditions and learning disability, and the need for research in these areas – from the events we run to our website and the information leaflets we produce.

Addressing stigma is key, and I strongly believe that the more we understand mental health conditions, the less they will be stigmatised.

Where are the biggest opportunities for research in the coming years?

There are real opportunities to develop diagnostic classifications more closely linked to the causes of mental health conditions rather than the symptoms. There are also exciting genetic findings emerging for many mental health conditions that could lead to better treatments. Finally, there are opportunities for us to make progress in better understanding the complex interplay between the biological, psychological and social factors that make some people more vulnerable to becoming ill. It's going to be a very exciting time to be involved in mental health research, and the people of Wales can join us in being a part of it.

