Learning to get better: Recovery Colleges

From the NIHR CLAHRC Oxford and the Nuffield Department of Primary Care Health Sciences, University of Oxford.

“...they became a partner, really, in actually doing the work.”

Professor Ray Fitzpatrick
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“...I think PPI can be a GPS, a navigator, to keep things on track.”

Antonia Santalova, PPI Contributor
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New Research Centre Tackles Mental Health and Dementia

Oxford’s newest research centre is looking at some big questions:

- **Could the internet bring psychological therapies to thousands more people currently waiting for treatment?**
- **Could drugs normally used to treat heart disease help patients with bipolar disorder?**
- **Is it possible to stave off dementia and keep the brain healthy through old age?**

These are some of the questions being tackled by the new National Institute for Health Research (NIHR) Oxford Health Biomedical Research Centre (BRC), which officially launched on 1st April 2017.

The new NIHR Oxford Health BRC is one of the only two across the country dedicated to mental health and dementia.

The centre will have three main research themes: precision psychological treatments, adult mental health, and ageing and dementia.

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**Better access to psychological therapies**

The group of scientists working on this theme, led by Professor Anke Ehlers from Oxford University’s Department of Experimental Psychology, are developing a new internet-based platform which will enable many more people to receive tried-and-tested psychological therapies on their computer or mobile phone.

“At the moment, there just aren’t enough therapists to provide treatment for the many people who might benefit from psychological therapies,” says Professor Ehlers. “Another problem that people have in accessing treatment is that the only free time they might have is outside of normal working hours.”

Once launched, the platform will allow people to access therapies for conditions such as depression and anxiety, and eating disorders, in their own time, with support from a therapist as needed. “This will allow therapists to treat many more patients,” says Professor Ehlers.

The team will also track and assess the effectiveness of this kind of internet therapy, to make the treatments even better.

**Adult mental health**

The adult mental health research theme is led by Professor Paul Harrison, based at the Oxford University Department of Psychiatry, whose team is unpicking the causes of and new treatments for bipolar disorder and schizophrenia.

They are currently carrying out laboratory studies to find out what molecules in the brain drugs called ‘calcium channel blockers’ might be interacting with.

As part of the new BRC, trials will then be carried out in real-life patients to test whether calcium channel blockers are an effective treatment.

“Our hope is to find the next generation of drugs to treat bipolar disorder,” says Professor Harrison.

**Aging and dementia**

Scientists working within the ageing and dementia research theme, led by Professor Clare Mackay, based at the Oxford Centre for Human Brain Activity (OHBA) at the Warneford Hospital, are attempting to understand the ‘neuroprotective’ effect of easy interventions. These are interventions such as, getting more exercise and better sleep, which appear to prevent the slowing in mental function that usually accompanies ageing.

They’re also working to identify and test new drugs for dementia and Alzheimer’s disease and hope to make brain imaging a routine part of assessing brain health in older adults.

To find out more, or see how you could get involved, visit: [oxfordhealthbrc.nihr.ac.uk](http://oxfordhealthbrc.nihr.ac.uk)
Talking about healthy, happy eating

CLAHRC-funded diet researchers take part in Oxfordshire Science Festival

NIHR CLAHRC Oxford researchers recently contributed to an activity discussing diet and nutrition with Oxford’s local community as part of the annual Oxfordshire Science Festival.

On Sunday 17 June, Oxford’s Town Hall played host to the Festival’s Explorazone, where research-based organisations from across Oxford came together with fun and engaging hands-on activities to inspire people of all ages with science and technology.

Through a colourful suite of activities, researchers from the Nuffield Department of Primary Care Health Sciences talked to passers-by about how much sugar, fat and salt is really in what we eat, and the benefits of making simple food swaps. Activities included guessing how much sugar is in a range of everyday food products, investigating a typical basket of food for it’s potential to create healthy, balanced meals, and colouring activities for small children.

The team were also encouraging adults to sign-up for their patient and public involvement group, and to take part in CLAHRC-funded research on self-weighing.

Read more at: www.clahrc-oxford.nihr.ac.uk/news/talking-about-healthy-happy-eating www.ukctg.nihr.ac.uk

Technology should be used to boost empathy-based medicine

Existing digital technologies must be exploited to enable a shift away from the current ideas in healthcare delivery which focuses on tests, treatments and targets rather than the therapeutic benefits of empathy.

This is the opinion of Oxford University researchers writing in the Journal of the Royal Society of Medicine.

Empathy-based medicine, they write, re-establishes relationships as the heart of healthcare.

Read more at: bit.ly/EmpathyB

Open event lets public learn about local research

The exhibition, at West Oxford Community Centre, gave people the chance to talk to healthcare staff about research taking place over a range of medical conditions.

These include heart disease, mental health, diabetes, eye conditions and stroke and visitors were able to find out what they can do to find a trial that they could participate in.

The event was hosted by the NIHR Clinical Research Network Thames Valley and South Midlands (CRN), an NHS organisation that provides staff and resources to get clinical trials up and running in the health service.

Representing the CLAHRC were PPI coordinator, Lynne Maddocks, and PPI contributor Gillian Skyte who both represented the CLAHRC at the event

who offered information on PPI and how to get involved.

The CRNs encourage patients and members of the public to ask their doctor about research opportunities and view trials seeking volunteers at the UK Clinical Trials Gateway:

www.ukctg.nihr.ac.uk

No more need for sweet little lies?

There is strong evidence that so-called ‘open label’ placebos – treatments such as sugar pills that patients are told contain no medically beneficial component – are more effective in relieving patients symptoms for a wide range of conditions than simply offering no treatment.

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The finding, from researchers at the Nuffield Department of Primary Care Health Sciences, University of Oxford, and published in the Journal of Evidence-Based Medicine, casts doubt on the theory that placebos, typically given to patients under the false belief that they are real treatments, work because patients believe they will.

More importantly, the results imply that it is not necessary for medical professionals to lie to their patients about placebos for them to work – which currently prevents placebos being used in routine healthcare – instead, they can be told up front they are being given a placebo and it can still be effective.

“The problem with placebos is that, because it was generally thought that they only work because a patient believes they will, it was necessary to deceive patients in to believing they were being given a real treatment, which is unethical,” said Dr Jeremy Howick, who led the study.

“What this work shows is that placebos can be effective even when patients know they are not a real treatment, which opens up the possibility for doctors to use them, ethically, in normal clinical practice to help patients.”

While some individual studies have previously shown that non-deceptive use of placebos can be effective, this is the first time the totality of the current evidence has been examined.

By conducting a systematic review, a summary of the best available evidence on a topic, the researchers identified five different randomised trials of open labelled placebos on 260 participants.

The researchers recommend that larger trials are needed to explore the potential benefit of ‘open label’ placebos and the contribution of positive suggestions from doctors and to answer the question, “how can we best use these findings in healthcare to benefit patients?”

Read more at: theconversation.com/placebos-work-even-when-patients-know-what-they-are-77074

However, some questions remain about the effectiveness of ‘open label’ placebos due to the limited number of trials and because most of the examined trials only involved a small number of people. Additionally, the trials were all, necessarily, ‘unblinded’ (patients and doctors knew which type of treatment they were receiving) meaning there may be some bias introduced into the results, such as positive suggestions of benefit from doctors to patients.

Overall, the analysis found that there was likely only a moderate risk of the trials examined being biased.

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Read more at: theconversation.com/placebos-work-even-when-patients-know-what-they-are-77074
All suggestions are put before the scientist. Whether public, patient, or expert, anyone can submit a suggestion, an idea for research. The NIHR wants you to suggest an idea.

You can find it at: www.nihr.ac.uk/research-and-impact/research/suggest-an-idea-for-research

New institute director appointed by panel of experts and lay people.

Professor Andrew Morris, from the Usher Institute of Population Health Sciences and Informatics at the University of Edinburgh, has been appointed Director of the new ‘UK health and biomedical informatics research institute’, which is to be named Health Data Research UK (HDR UK).

In a still rare, but increasing, move for such bodies, Professor Morris was chosen by expert and lay panels following an open international search led by the Medical Research Council (MRC). He is a world leader in the field of health and biomedical informatics. His work on systems biology and data science have been instrumental in the development of data science as a discipline.

The HDR UK aims to harness the power of the NHS and associated health and biomedical data in the UK, to develop and apply cutting edge ‘informatics’ (computer-based) approaches needed to address the most pressing health research challenges facing patients and the public.

This is the second occasion in less than six months that a senior research leader has been appointed by the NIHR as well as their fellow scientists. Professor Bart Strooper, Director of the MRC’s Dementia Research Institute, had been the other.

Find out more at: www.mrc.ac.uk/about/institutes-units-centres/uk-institute-for-health-and-biomedical-informatics-research

Improving PPI in clinical trials

METHODOICAL 🔥🔥🔥🔥

More and more patients and members of the public are getting involved in the design and delivery of clinical trials.

But what is the best way to involve patients and members of the public? And what effect has this had on clinical research?

These are the questions examined in a study that ran between October 2015 and March 2016, called ‘METHODOICAL’.

METHODOICAL has now completed it’s work and published it’s results. The study identified 16 ‘critical research priorities’, including:

- developing strong and productive working relationships between researchers and PPI contributors;
- PPI practices in selecting trial outcomes of importance to patients; and
- conducting a systematic review of PPI activity in improving the accessibility and usefulness of trial leaflets and information sheets for clinical trial participants.

A list of all 16 findings and a plain English summary are available at: www.methodicalstudy.uk

GenerationR: six recommendations

A new report from GenerationR, a national Young persons’ Advisory Group, has examined the information available on how and when young people are involved in research, and what difference their involvement makes to research and the young people involved.

They found that most of the information researchers have been collecting was about the stages of research in which people had been involved, rather than who, how and what impact their involvement had on the research or young people themselves.

GenerationR followed up this finding by talking to professionals who work in public involvement to understand how this information gap could be addressed. Their findings are detailed in a report issued in April 2017.

The report makes six recommendations covering areas including data collection, future and follow up work.

The report can be found online at: generationr.org.uk/?p=1375

You can follow GenerationR on twitter (@genrYPAGS and @NIHR_PRAI) for further information about their work with young people.

What impact do medical research charities actually have?

The UK public invest huge amounts of money into medical research charities, but what’s the outcome, what is the impact of this funding and how it’s being used?

A new report from the Association of Medical Research Charities (AMRC) has examined this question.

The AMRC used charity funding data, as reported by the researchers who were using the funding to do this.

The data covered over 40 different charities (just 29% of AMRC’s membership) over a four year period. The total amount of funding over this time was in excess of £1.6 billion.

The report groups its impact findings into five areas:

1. generating new knowledge;
2. translating research ideas into new products and services;
3. creating evidence that will influence policy or other stakeholders;
4. stimulating further research; and
5. developing human capacity to do research.

It concludes that, ‘...It is clear that all charities regardless of size can demonstrate an impact.’


Help improve national standards for Public Involvement (PI) in research.

Over the past year, the NIHR and Health and Care Research Wales have developed and drafted a set of six ‘core standards and indicators’ for public involvement in research.

They are now seeking contributions from a wide range of interested organisations and individuals to help review and give feedback on these standards ahead of piloting them in sites across England, Scotland and Wales.

For the NIHR, developing PI standards is a commitment made in the Going the Extra Mile report, with implementation mandated and overseen by the NIHR Patient and Public Involvement Senior Leadership Team led by Simon Denegri, the National Director for Patients and the Public.

Find out more or take part at: sites.google.com/nihr.ac.uk/pi-standards/consultation

Suggest an idea for research.

The (NIHR) wants you to suggest an idea for research.

Anyone can submit a suggestion, whether public, patient, or expert scientist.

All suggestions are put before the NIHR's panel of researchers, outside experts and members of the public to decide what research the NIHR should be doing. If selected, the details of the research needed are advertised to researchers who compete to provide the best project to gather the evidence.

To help gather suggestions the NIHR has introduced a short online form where anyone can make research suggestions.

Find out more at: www.nihr.ac.uk/research-and-impact/research/suggest-an-idea-for-research
Recovery colleges: Learning how to get better together

Recovery colleges take an educational rather than a clinical or rehabilitation approach to improving mental health.

Following an interesting and successful workshop at the CLAHRC Oxford Stakeholder Symposium in June, we asked Laura Dennis, Head of the Oxfordshire Recovery College, to give us some insight into how recovery colleges support their students on their recovery journey.

The Oxfordshire Recovery College was established in 2015, but the legacy of educational approaches to mental health recovery, and the college model, significantly pre-date this.

Since 2000 Recovery Colleges have appeared all over Australia, New Zealand, Canada and the US. The UK was fairly late to the movement, with the first UK college opening in London in 2009, but since then over 30 colleges have opened their doors across the country.

Each of these colleges has a strong sense of its own identity, operating slightly differently from its counterpart due to the unique needs and contributions of the community it serves.

However, there are some common factors that ensure that all of these different communities receive the same values-driven, heart-led and forward-thinking service regardless of their location:

1) Co-production

Co-production lies at the core of all Recovery Colleges. It means that everything the college does, from designing courses to taking decisions is done in partnership with professionals, people with lived experience, and carers.

This doesn’t just mean heft consultation, but that all of these different stakeholders have real and meaningful opportunities to shape the work that the college does.

An example of this is in the design and delivery of our courses: for each course we have a minimum of two tutors. One will be an ‘Expert by Training’, someone with a professional background in the subject area, and the other an ‘Expert by Experience’, someone with lived experience of that diagnosis or of using that tool in their own recovery.

These dynamic duos write the courses together, drawing on their collective expertise, and deliver them together as well, so that students can benefit from a rounded and authentic approach.

2) Physical base

All colleges have some sort of physical base.

For us at the Oxfordshire Recovery College, our base is in Cowley, Oxford, at the Elder Stubbs site.

From here, we can operate on a ‘hub and spoke’ model which lets us provide courses to various locations across the county. With an office and a training room in Oxford, we then hire other venues to deliver courses in places such as Banbury, Witney and Abingdon.

This lets us go where there’s demand, so if there’s enough demand to see courses running in your area, we can make that happen.

3) College principles

Recovery Colleges aren’t there to give diagnoses, we don’t take referrals, and we don’t tell people which courses to take.

As with all colleges, students choose to enrol and they pick and choose the courses that interest them or they feel would be of benefit. We believe that students are often best placed to know what will work in their own journey, and which topics and tools they have enough genuine enthusiasm for to be able to continually draw upon over a long-term period.

4) For everyone

Recovery Colleges provide an opportunity to learn alongside and, crucially, from other groups you may not usually share your experience with.

We bring together people experiencing poor mental health, their friends, family and carers, and the professionals that support them, and we create a shared learning environment where individuals can come together to explore issues and identify possible strategies.

This creates a unique opportunity to not only break down some of the barriers that may exist between these groups, but also to access really rich learning from within a supportive and diverse community.

5) Information, advice & guidance

Every student has an opportunity to meet on a 1:1 basis with a tutor to access information and guidance, and to set learning goals.

At Oxfordshire Recovery College, we call this meeting ‘an Individual Learning Plan’, and try to review it around every three months to help students keep a sense of forward motion and momentum in their learning.

6) Does not substitute treatment

We aim to work alongside other treatments and services that a person may be drawing upon, to create holistic support that recognises all aspects of that person.

We would never suggest that someone disengage from treatment they’re finding useful to attend the college instead.

7) Does not substitute mainstream colleges

We also aim to work alongside other adult education settings.

All of our courses are bespoke, and you won’t find them anywhere else (including at other Recovery Colleges). This is firstly so that we can make sure that everything is co-produced, but it’s also to avoid duplicating courses that you can access elsewhere.

We often find that we act as an ‘stepping stone’ for people who may be interested in taking other courses or gaining qualifications but feel uncertain or under-confident in going straight to mainstream colleges.

8) Recovery focused

We make sure that recovery principles are embedded in everything we do – from the language we use, to our team culture, to the focus of our courses.

Our college values are ‘hope, opportunity, and control’, and we try to live these in all of our decisions and actions.

Whilst our college will have these things in common with other Recovery Colleges, we also work hard to be unique – being responsive to what students and tutors tell us would be helpful, and being brave enough to try new things, is something we work hard to do and pride ourselves on.

The Oxfordshire Recovery College creates a unique opportunity to share experiences, learn new tools and strategies to better support ourselves and others, and to perhaps feel a little less alone.

If you’re interested in joining our community, as a student or even as a tutor, please get in touch:

oxfordshirerecoverycollege.org.uk
buckinghamshirerecoverycollege.org.uk

Or email Laura Dennis: laura.dennis@restore.org.uk

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Antonia was born and raised in the little-known country of Kyrgyzstan. She was a teenager during the collapse of the Soviet bloc in 1991 and the birth of Kyrgyzstan as an independent country, living through that period of huge change.

While Antonia witnessed many positive and negative changes during that time, the worst thing, she says, was the collapse of the social services, healthcare and education, especially. Despite the challenges, Antonia says that those times helped make her the person she is today: competitive, caring, and curious.

With a background in working with the government and policy making in Kyrgyzstan and central Asia, Antonia decided to broaden her academic training in these areas. Eleven years ago, she applied for and won funding for a Master's degree in Social Policy at Oxford University. She followed this up with a DPhil, which she is currently preparing for publication, whilst also bringing up her two daughters with her husband.

She has remained a member of the Social Policy and Intervention Department, where she now also teaches undergraduates, and has been a PPI contributor for the past six years. She also runs her private consulting business in education.

I wonder, did your interest in PPI or healthcare stem from what you saw happening to the healthcare system back in Kyrgyzstan during the collapse and its effects?

Yes. I was quite young when the collapse happened, a teenager, and I happened to need to go to hospital.

My parents received a long, long list of items to be brought to the hospital. And that list started with things like a pillow and bed linen, and ended with things like catgut and medication. Doctors had absolutely nothing, and their skills and knowledge appeared useless without the means to provide services.

That was a very upsetting week that I spent in the hospital. The impact was such that I decided not to apply to a medical school and abandoned my dream of becoming a doctor.

How did you get involved in PPI?

By chance.

Here in Oxford my daughter got very ill and I had to take her to an out of hours surgery on a Saturday evening, and I was asked if I'd like to reflect on the experience of a blood test that my daughter had. And I was very happy to help because at that point I was working on my dissertation.

So...glad of the distraction?

No, no, the opposite! I knew from my own work how important it is to find interviewees willing to help and be willing to give some time.

So, I said, ‘yeah, sure happy to help.’ That was already some time ago, about five or six years ago. And the person I spoke to was from the DEC [NIHR Diagnostic Evidence Co-operative], Caroline Croxson, and we’re still in touch now.

So, are there any PPI projects that you’ve been involved in that come to mind that you feel you’ve particularly contributed to?

So, the DEC’s work is fascinating. Led by Gail Hayward and Philip Turner, I’ve been involved in the discussion of plenty of different studies and evaluations.

I can’t tell in detail, as many of those are confidential because there are industries involved, as well as researchers and patients. Most of those are aimed at improving diagnosis and getting it right. And that’s very important, I believe, otherwise all of the money spent on treatments used later is useless.

Recently, I applied and was selected to be part of the CLAHRC Theme 1 Early Intervention & Service Redesign Steering Group. Prof Belinda Lennox found my international professional experience interesting. I was particularly attracted because of the Theme I focus on the mental health of children and young people. As a mother of a teenager and a younger child, young people’s mental health is important to me.

How do you feel researchers have responded to your input or feedback?

Usually they are very grateful when they present their project designs or their implementation phase, and hear from us, from people, potential patients and users of the services.

Some of them say, ‘that’s absolutely incredible how quite simple things never occur to us, being in academia in a specific topic for years.’ So, I think that’s a very wise trend to utilise knowledge and expertise accumulated by people with specific diseases, or people like me who use these services from time to time.

Have you seen the results of changes from your feedback?

I think one problem is that, with health sciences, the output, the results, are usually postponed in time. Usually we only hear the feedback at the design phase of a study, how to apply it and so on, but not very often do we hear about the implementation of the project findings because it takes time.

What I can observe, being in PPI for almost six years now, is that change takes years and years – no matter how good or promising the findings were 10 years ago. But what worries me is that the people who could have benefited at the time these findings were made might already be dead.

Have you also been involved in deciding what research is funded?

Recently, I was asked to appraise some grants for different NHS Trusts in England. I think it’s a good idea to give those kinds of proposals to people like me, not because I’m so bright and smart, but because I have no real conflict of interest.

And I find that in some grant proposals the main impact they’re talking about is the scientific publication, the journal article. And that’s fair enough, but what about us, the users of the service!

We’re the reason for all this research money to be spent. I’m sure they are aiming to improve healthcare, but they might from time-to-time forget about the final beneficiary of the research going on. Publications matter in an academic career, and publications in high impact journals make people’s names, that is great. However, this is not an ultimate goal of the NHS.

I think PPI can be a GPS, a navigator, to keep things on track.

So, what would you say to someone thinking about becoming a PPI contributor but were unsure?

I think it’s fascinating, but time-consuming. And you need to have a quite flexible timetable in order to be able to get involved.

As for me, I genuinely feel grateful to the country that welcomed me and accepted me with my family and now provides my children with healthcare. So, I’m happy to contribute my time and knowledge and whatever experience I have.

I think about all my friends, colleagues here and the NHS is really in the heart of the people living here, British or not.

Is there anything that I’ve not asked you about that you’d like to say about PPI?

Just that it could be really a waste of resource not to utilise the expertise of patients and the public.

I feel that some strategy should be developed to attract younger people to PPI. Though there are documents and policy papers looking at this, at that’s just a matter of implementing and following those now.

What do you do when not volunteering in PPI?

I have been working on publishing my dissertation and as an associate member of the department of social policy, so building my profile as well as teaching undergraduate students social policy. I’m fascinated by the students and the younger generation.

I’ve also started my own consulting company, endorsed by Oxford University, to assist youngsters and their parents in their pursuit of the best possible education.

And outside of work?

Outside of work, it’s about keeping my health! With age it becomes more and more complicated, and since I, personally, still don’t know exactly how to navigate the GP system in this country, I came to the decision I should try to take care of my own health as much as possible!

Swimming, gym, cycling, that kind of thing.

I guess your children keep you moving too?

Oh, they run me around! Sometimes I prefer to stay on the couch, but they say ‘no, come on let’s play basketball, let’s go swim!’ And I’m like, ‘OK, fine...?’
meet a researcher

Ray Fitzpatrick

Professor Ray Fitzpatrick is Professor of Public Health and Primary Care at Oxford University’s Nuffield Department of Population Health, and Fellow and Dean of Nuffield College. Until recently he was NIHR Programme Director for Health Service and Delivery. His group developed patient reported outcome measures for joint replacement surgery that are not mandated for services to NHS patients. He is also assistant director for a Department of Health Research Unit (Jointly with Personal services Research Unit, London School of Economics & Kent University) to assess quality and outcomes of health and social services for long-term conditions. In addition to his other responsibilities, Ray also leads the ‘Patient Experience and Patient Reported Outcomes’ theme of CLAHRC Oxford.

You’ve been involved in health-related research for most of your career, what pulled you into it?
It really started with my PhD which was looking at, what were thought to be, bad referrals by GPs to neurologists.

The work involved talking to the patients and it was very clear that both the neurologists and the GPs who referred patients varied enormously in how skilled or unskilled they were in finding out what was actually bothering their patients.

So, some patients ended up in neurology clinics, not the moment that has some element of PPI?

“...the patients would always ask a really obvious question that none of the specialists had thought of...”

And how have you involved patients in that?
We worked with people with long-term conditions – they became a partner, really, in actually doing the work.

It wasn’t always easy because the work we’re doing is complicated, and so it required patience on both sides.

We had to explain the rationale and processes of what we’re trying to do and how. While the patients had to communicate what was often a lifetime of experience living with a long-term condition than we hadn’t. It wasn’t a simple straightforward conversation.

But, I think, that got us to a more fine-tuned and appropriate research programme in the end. It’s a very iterative process, creating, getting feedback, refining, getting feedback, and so on.

So, did you find that rather than being arms-length anonymous ‘patients’ it felt more like it was actually real people?
Yes, it was very concrete.

Another example is a patient advisory group we set up to work on neurological services for people with MS. Parkinson’s, and so on, and it was quite a moving experience.

We worked with seven or eight patients with a neurological condition or people caring for someone with one. In some cases, people were severely disabled so even finding the right kind of place to meet, that was accessible for everyone, could be hard.

Unfortunately, one of them passed away during the study, which was a very powerful and graphic way to learn what it’s like to live with a neurological condition.

What about refining what research is done?
Well, the other side of my life has been managing research, chairing research committees and so on, helping to decide what research we should do. And PPI has had an increasingly strong role there.

What’s happened in the last 20 years is that members of the public, who started off being invisible in these things, are now sitting on the top table with an equal voice to the scientists.

That has been quite challenging, getting from where we were to the public now having an equal voice. I believe that now, in the areas that I work, we’ve got there. They are an equal voice.

I think it’s been an incredible journey.

What sort of things did people ask on these committees?
The questions they ask are absolutely brilliant.

Recently I was chairing a health service research meeting for the NIHR and the patients would always ask a really obvious question that none of the specialists had thought of: if this study is done, would the NHS ever actually implement the results? Is it feasible?

And very often that was the killer question – not the methodological sophistication of the study design or whatever, but would it ever be actionable?

With that kind of experience how do you feel about how rapidly results from studies are then taken up and actually used?
That’s always a frustration for researchers.

It’s frustrating not just for us, but the PPI people as well. Just as we must learn from them, they then have to learn about the constraints of research – very little ever changes in the light of a single study, it’s an accumulating picture from all the related evidence that, in the end, impacts the real world.

Also, one has to recognise that research is only one input. There are others like politics, resources, stakeholder opinion and so on. It’s often a long story from discovery – rarely less than a dozen years – to it being used more widely. This is incredibly frustrating, but it’s hard to imagine it being otherwise.

So, what gets you out of bed in the morning to come and do this, what’s the motivator, and has it changed over time?
It has changed over time. I started working in this field in the mid-70s when being a social scientist in the context of biomedical research was more challenging. It was a challenge to be taken seriously, and to make people see that anything worthwhile could be learnt.

I think that’s changed now and we all recognise the complexity of the health problems we have to deal with, and public health and social science all have their roles alongside biomedicine.

What gets me out of bed? I suppose, ultimately, the challenge.
I like difficulty. I like to be forced to think and – within limits! – to be challenged to think of solutions. They may be scientific, they may be political, or they may be interpersonal.

I’m at the later stages of my career now and the idea that I wouldn’t wake up and have some interesting challenges is more daunting!

And how about outside of work? What challenges do you put yourself up against there?
Well, I have to say that when I’m not at work I really don’t challenge myself. So, I absolutely do not do ambitious global travelling or impossible risky hobbies.

My main thing, really, when I’m not working is finding time to do things with my wife.
She’s in a similarly challenging job, a senior academic at Oxford Brookes University. So, when we’re not working, the main thing is finding time together, whatever it might be: gardening, listening to music, or going for walks.

Probably not being terribly ambitious, but finding time to enjoy life together.
The ‘Better Conversation, better health’ initiative has introduced a series of resources to help health professionals talk to people in a way that puts them in the driving seat: health coaching.

Health coaching is helping people to gain the knowledge, skills, tools and confidence to become active participants in their care so that they can reach their self-identified health goals.

Evidence has shown that health coaching can address health inequalities, encourage people to follow their treatment plans, and reduce avoidable admissions.

As such, ‘Better Conversation, better health’, have released a collection of resources to enable individuals and organisations to improve their health coaching.

The resources can be viewed and downloaded (for free) at:

www.betterconversation.co.uk/resources.html

The next INVOLVE Conference will be held on 28 November 2017, at Church House, Westminster, London.

The title of the Conference is ‘INVOLVE at 21: Celebrate the progress of public involvement in research and consider the opportunities ahead’.

In direct response to feedback from the last conference, INVOLVE has designed this year’s event to be focused and impactful, with an intimate feel that lends itself to networking and collaboration.

Have your say on the future of physiotherapy

The Chartered Society of Physiotherapy (CSP), in Partnership with the James Lind Alliance (JLA), has launched a new survey giving patients, carers and healthcare professionals the opportunity to influence research about physiotherapy.

The survey will enable patients, carers and clinicians to work together to identify the most important questions for physiotherapy research leading to improved care. It will also ensure that funders of health research will know what really matters to patients.

Ruth ten Hove, head of research and development at Chartered Society of Physiotherapy said, ‘Our role is to ensure that everyone involved in any aspect of physiotherapy can have a real say in shaping its future direction.

‘We would like to hear from you if you are a patient, carer, clinician or have any involvement in physiotherapy, the research questions you would like answered about physiotherapy for any injury, illness, condition or disability. The aim then is to turn these questions into priorities for research funding.’

Katherine Cowan, JLA Adviser and Chair of the Physiotherapy Priority Setting Partnership (PSP) said, ‘The Physiotherapy PSP is an exciting opportunity to find out what matters to the people who benefit from physiotherapy research: people receiving physio, their families and the clinicians working with them. The JLA is really pleased to be working with the CSP on this exciting initiative.’

The UK-survey will be open until the end of July.

For more information and to have your say visit:

www.csp.org.uk/priorities

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In order to showcase some of the strongest public involvement examples there will be 12 parallel sessions and 30 posters available on the day.

Additional opportunities to share good practice will be made available via the INVOLVE website and communications.

For more details and registration visit:

www.profbriefings.co.uk/involve2017

Understanding Research

What do we actually mean by research and how does it help inform our understanding of things?

For the non-specialist – including journalists reporting on research – there are several common pitfalls when making sense of research.

This article offers ten tips to help interpret research:

www.theconversation.com/the-10-stuff-we-are-all-make-when-interpreting-research-38816

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Could you be the new chair of INVOLVE?

- The INVOLVE Advisory Group, a respected source of expertise nationally on public involvement in health and care research, is recruiting for a new Chair.
- Can you champion the role of patients and carers in improving UK health and care research?
- Do you have the skills to help our advisory group become a leading influence in global public involvement?

INVOLVE is a national advisory group whose role is to bring together expertise, insight and experience in the field of public involvement in research, with the aim of advancing it as an essential part of the process by which research is identified, prioritised, designed, conducted and disseminated.

Leading with your public, patient or carer voice, you will work collaboratively to develop and amplify the Group’s standing and their contribution to advancing public involvement, both inside and outside the National Institute for Health Research.

You might be a patient or interested member of the public with relevant professional, voluntary or personal experiences and a passion for developing others. Perhaps you are a Charity Director/CEO with an interest in health or research who would benefit from a secondment with INVOLVE?

Whatever your background or professional experience, if you have the skills and passion INVOLVE would love to hear from you.

The closing date for applications is 31st August 2017. Interviews will take place on the 10th and 11th October 2017.

For more information and to apply visit www.invo.org.uk/about-involve/involve-jobs

Can you turn orange into grapefruit?
Find this out, and much more, on Friday 29 September 2017. Explore the world of research with free activities for all ages and interests across oxford.

Get curious – visit curiositycarnival.org