

ppi pulse

Patient and Public Involvement Newsletter

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

Edition 13 – Quarter 4, 2018

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About PPI Pulse

PPI Pulse is produced by the Nuffield Department of Primary Care Health Sciences (NDPCHS), University of Oxford, and the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC) Oxford.

We also produce, with other partners, the 'Involvement Matters' bulletin, filled with current training and other opportunities to get involved in research, health services and commissioning. Involvement Matters is sent out on a roughly monthly basis, depending on the available opportunities.

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Involving patients and the public in the live science of conversation

DPhil student Charlotte Albury writes about her experience taking part in an innovative way of involving patients at New Scientist Live.



I was recently part of New Scientist Live (NSL), where myself and other researchers designed an innovative way of involving patients and the public in the live science of conversation.

We aimed to engage the public in conversation analysis. 'The Conversational Rollercoaster' which was a ground-breaking way of both communicating our results to the public; getting feedback on ongoing work; and uniquely, involving the public in doing analysis and finding results which we then analysed, publicised, and published.

I was part of a wonderful team, where I played a key role in designing and delivering the conversational rollercoaster with the public and was second author on our resulting paper.

One thing we did at NSL was to run a 'ChatLab', which involved a 'Talkaoke' table which was a live chat-show. A host with a microphone sat in the middle of a round table and members of the public were encouraged to sit and talk.

Hosts and members of the public changed, but the conversation carried on flowing with new arrivals and topics organically evolving. The aim was to have a continuous conversation for six hours each day of NSL.

And we did it!

Any member of the public who attended NSL and wanted to participate could, and ages 3-80 all joined in. But this was not the only aim. The Talkaoke table was part of a wider 'ChatLab'. A live video feed filmed the table and showed the events on a big screen. It was hooked up to four computers, each one a different 'analysis station': transcription; collection making; video editing; and photograph generation.

Members of the public who watched the Talkaoke were approached by one of the four of us 'conversation

analysts'. We chatted about our own work, sought feedback on ideas, and explained how conversation analysis works.

I was the only analyst who studies clinical communication, and I spoke with many people about what makes a 'good' conversation with their GP, which was helpful to support my current PhD work. A key aspect was the public led their own involvement, and each interaction was individually designed and tailored.

If someone was interested in what we did, we would show them HOW to do it. To support the public to analyse talk, we would take something easy such as 'How does someone behave when they want to leave the Talkaoke?' and ask a member of the public to observe and describe this. This was then their hypothesis for how 'leaving' works in conversation. If people were interested we'd take them to the analysis stations and support them to use data from the Talkaoke live-feed to confirm or disconfirm their hypothesis.

It was important to us to provide all members of the public with tangible evidence of their involvement, and a resource for further information.

At a real roller coaster you can purchase a photo of yourself screaming at a particularly thrilling point in the ride. We reflected this in our take-home materials, providing everyone with a photo of themselves on the conversational rollercoaster, with a 'waveform' underneath showing their conversation.

Visit the NIHR School for Primary Care website to find out more:

www.spcr.nihr.ac.uk/news/blog/involving-patients-and-the-public-in-the-live-science-of-conversation



local research news

NIHR feedback on CLAHRC Annual Report: Thumbs up for PPI

CLAHRC Oxford recently received feedback from the NIHR on its 2017/18 annual report to the funder.

For this report, PPI took centre stage with PPI training activities listed one of the CLAHRC's top three achievements.

Whilst feedback about all aspects of the report was positive, the NIHR called out specific examples of its PPI activities saying: "The report describes good progress against the CLAHRC's strategic PPIE aims. A strong example of impact is provided on the difference PPI made to recruitment in the OPTiMiSE project." And that, "...it was positive to hear about the focus on PPI training and collaborations with local partners on PPI."

You can read more about how PPI aided the OPTiMiSE study at: www.clahrc-oxford.nihr.ac.uk/i-r/attending-an-existing-group-to-do-PPI

Online sleep help: Sleepio



Thanks to the Oxford Academic Health Science Network (AHSN), Sleepio is now available free to all over-18s in Berkshire, Buckinghamshire, Oxfordshire and Milton Keynes.

There's no need for GP referral or prescription. Sleepio is based on cognitive behavioural therapy, it is a proven alternative to sleeping pills.

This is the first large scale NHS rollout of direct-access digital medicine. The project is led by the Oxford AHSN and funded by Innovate UK.

Sleepio was developed by researchers from the University of Oxford's Nuffield Department of Clinical Neurosciences.

Visit www.sleepio.com/nhs to try it out or find out more

Department researchers scoop medical book awards

The British Medical Association's annual Medical Book Awards, which took place in September, recognises outstanding contributions to medical literature, with prizes awarded in 20 categories judged by around 400 volunteers.

This year's BMA President's Choice Award, chosen by Professor Dinesh Bhugra CBE, goes to Professor Trish Greenhalgh for her book 'How to Implement Evidence-Based Healthcare,' published in 2017 by Wiley-Blackwell.

This book makes sense of the complex and confusing landscape of implementation science, the role of research impact, and how to avoid research waste.

Dr Andrew Papanikitas, also of the department, won an award for his book 'Handbook of Primary Care Ethics'.

You can find out more here:

www.phc.ox.ac.uk/news/department-researchers-scoop-medical-book-awards

Professor Gary Ford: Research Legend



Professor Gary Ford has been identified as one of seven NHS research legends through the NHS 70th birthday celebrations.

Professor Ford is Chief Executive Officer of the Oxford Academic

Health Science Network (AHSN), and also sits on the CLAHRC Oxford Management Board.

Professor Ford's work to develop stroke pathways and establish the FAST public awareness campaign earned him a place alongside such research luminaries as Sir Richard Doll and Sir Magdi Yacoub in the National Institute for Health Research (NIHR) 'I Am Research' campaign.

Professor Christine Roffe said, "Prof Ford has been instrumental in embedding research into almost every stroke unit in the UK ... contributing to better outcomes. Research has changed stroke from an untreatable condition to a time-critical emergency requiring highly organised care systems."

Professor Ford was awarded a CBE for services to research in stroke medicine in 2013.

GP referrals to total diet replacement programmes are effective for the treatment of obesity

New CLAHRC Oxford supported work shows that replacing food with a diet of soups, shakes and bars starting at 810 calories per day alongside regular sessions with a counsellor is a safe and clinically effective way to treat obesity in primary care.

Total diet replacement programmes are not generally funded by the NHS in England but the authors of this study, led by CLAHRC Oxford Theme lead Professor Susan Jebb and published in the BMJ, suggest that there is now enough evidence for these programmes to be one of the treatments recommended for people who are obese.

The work has helped to inform new measures from the NHS to tackle obesity and type 2 diabetes.

The randomised controlled trial involved 278 adults in Oxfordshire who were substantially overweight and interested in losing weight. Participants were either offered a referral to a low energy total diet replacement programme for 24 weeks or were enrolled into their GP practice's weight management programme, including advice

and support to lose weight from a practice nurse.

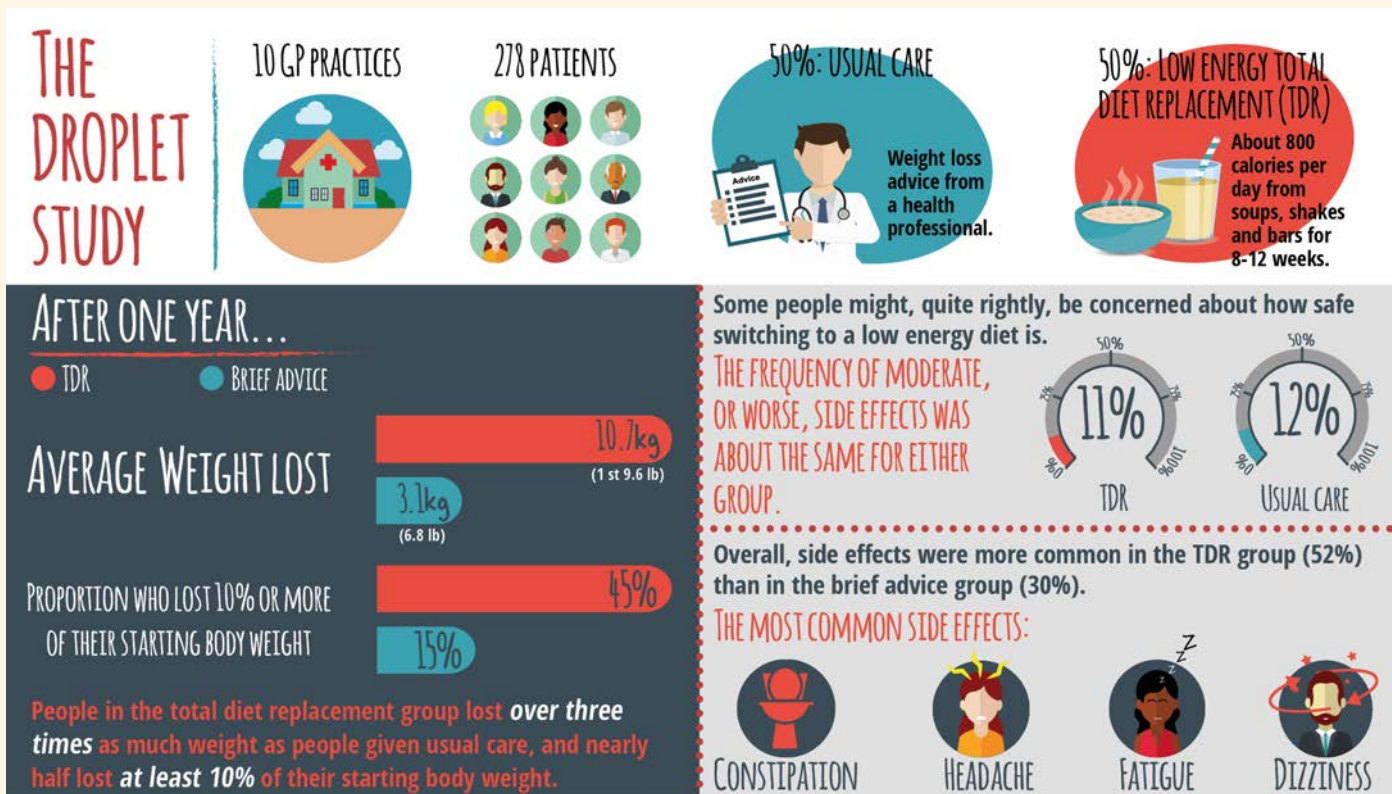
Participants on the total diet replacement programme were asked to reduce their intake to 810 calories a day by replacing all food with specially formulated soups, shakes and bars in addition to milk, water and fibre supplements. These diet replacement products, which are designed to be nutritionally complete, were offered for eight weeks, followed by a gradual re-introduction of conventional food over a further four weeks. Participants were invited to attend regular meetings with a trained counsellor to develop techniques to help them follow the diet and later maintain their weight loss. From 12-24 weeks they were encouraged to continue to use one product a day to replace a usual meal.

After 12 months, these participants had lost on average 10.7kg (1 stone, 9lb) which was 7.2kg (1 stone, 1 lb) more than those enrolled into the GP practice programme. They also showed greater reductions in their risk of developing heart disease, stroke and diabetes.

45% of participants on the low energy programme had achieved a weight loss of 10% or more compared with just 15% in the GP practice programme.

[Read more here:](#)

www.clahrc-oxford.nihr.ac.uk/news/oxford-led-droplet-study-informs-nhs-action-to-tackle-obesity-and-type-2-diabetes



Reference: Doctor Referral of Overweight People to Low Energy total diet replacement Treatment (DROPLET): pragmatic randomised controlled trial. Nerys M Astbury, Paul Aveyard, Alecia Nickless, Kathryn Hood, Kate Corfield, Rebecca Lowe, Susan A Jebb. *BMJ* 2018;362:k3760 <http://dx.doi.org/10.1136/bmj.k3760>

PPI news & resources

PPI – conveniently involving the unusual suspects

How can researchers reach out to people who might not be able to attend PPI meetings during typical office hours?

A team of researchers from the Nuffield Department of Primary Care Health Sciences investigating patients' experience of booking GP appointments online found the best way to reach those who are most likely to use the system was to go to them – rather than relying on people attending a meeting at a University building.

Workshops took place at a workplace or social group during either a scheduled break or at a popular time, including lunchtime workshops for office workers, before the start of a shift for supermarket staff, during a weekday evening for gym members and at a toddler group for busy parents.

Not only did the PPI Contributors not have to fit a meeting into their schedule or travel to the venue, workshops were designed to last just 30 minutes – short enough for most busy schedules.

The researchers published their top tips for anyone else wishing to engage with patients in this way:

- Make the workshops appealing so people want to attend them and ensure the host organisation is supportive. It might even be worth considering an incentive for the host organisation.
- Use tools such as infographics to convey information clearly, Post-It notes for recording ideas to facilitate discussion and worksheets to maximise input from the attendees within a limited timescale.

- Give people the chance to get involved in the long-term if they want to (in this study just over a third of people contributed more time, including one who became a co-applicant on a study).
- Find an individual from within the organisation who is reliable, organised and interested in taking part. For example, a Community Champion for a local supermarket. Use your own contacts where ever possible.
- The Parent and Toddler group in this study did not go well because of interruptions from the children – plan this sort of thing into your programme.

Read more at:

link.springer.com/article/10.1186/s40900-018-0123-1

Female genital mutilation in the UK – where are we, where do we go next?

There is a desire for change to develop from within communities affected by Female Genital Mutilation (FGM), according to new research from Dr Sharon Dixon, a GP and researcher in the Nuffield Department of Primary Care Health Sciences.

To better understand research and health service priorities to support communities affected by FGM, a series of PPI focus groups engaged with community members and professionals involved in their care.

The researchers recommend that any learning and resources need to

be co-created and developed in a way that they can be shared effectively between women, communities and professionals. However, questions remain about how to define community consultation, how to recognise when it was adequate, and how to hear beyond activists in the community so a wider range of voices can be heard.

You can read the full article online at: researchinvolvement.biomedcentral.com

Public Involvement Case studies

The NIHR School for Primary Care Research (SPCR) has published a case study booklet which includes examples of high-quality involvement.

It demonstrates the value placed on providing support for public involvement to SPCR staff and trainees at all levels of project development.

The case studies can be viewed online here:

www.spcr.nihr.ac.uk/PPI/ppi-publications

PPI in Evidence Synthesis for Primary Care

The NIHR School for Primary Care Research (SPCR) Evidence Synthesis Working Group has developed a strategy for patient and public involvement and engagement.

The working group produces high quality reviews, combining all the evidence for what works, in what situations and for whom, for those working in primary care.

“Involving PPI contributors in evidence synthesis is neither an easy nor obvious task,” writes Dr Anne-Marie Boylan, author of the strategy, “as the vast majority of activities undertaken in this type of work are highly specialist and considered most appropriately conducted by trained researchers.”

“Nonetheless, there are ways to involve contributors to maximise the patient and public benefit of evidence synthesis, ensuring outcomes are relevant and important to patients and the public.”

You can view the strategy online at: www.spcr.nihr.ac.uk/files/ppi/eswg-ppi

Young people’s experiences of psychosis

CLAHRC Oxford’s ‘Early Intervention and Service Redesign’ theme has launched a new module Healthtalk.org on young people’s experiences of psychosis .



Psychosis is a mental health problem that causes people to perceive or interpret things differently. This might involve hallucinations or delusions.

Psychosis can be difficult to understand for both young people suffering from it, and the people caring for them.

The new Healthtalk.org resource will help young people, their friends and family, medical and social care professionals, students and trainees to:

- Find out what really matters to young people who experience psychosis;
- See how young people understand and manage their mental health;
- Answer common questions from the viewpoint of people who experience psychosis themselves.

The idea behind the resource

is that seeing and listening to other people talking about their experiences on the Healthtalk.org website will provide young people and their family and friends with additional help, emotional support and practical information.

Young people can read about and hear their peers talk about all aspects of their health experience, including what has helped, or not helped, and why; how they have managed difficult situations; and their plans for the future.

Health and social care professionals, students and trainees who want to understand what it is like for young people with lived experience of psychosis can also gain valuable information and advice from the website and tell young people under their care about the website.

Visit the new moduled online at:

www.healthtalk.org/young-peoples-experiences/psychosis-young-people/topics

A look into the future of children’s research

Meet 16-year old Adam, who introduces VoiceUP, a group of young people who advise researchers like Dr Vibha Sharma on their research to make sure it is suited to young people’s needs.

This film is part of a series, led by Great Ormond Street Hospital, that shines a spotlight on the bright future of children’s research, and highlights how pioneering clinical trials in NIHR Clinical Research Facilities are helping develop new treatments and cures for children with health conditions across the world.



Read and watch more online here:

www.nihr.ac.uk/news-and-events/features/behind-the-research/future-of-childrens-research.htm

British South Asian narratives of diabetes and views on future research

Senior Qualitative Researcher Dr Suman Prinjha, with Project Support Assistant Nasima Miah from the University of Leicester, and Professor of General Practice Andrew Farmer write about a knowledge exchange workshop for patients, public, researchers and health professionals to discuss South Asian narratives of diabetes and what future research should explore. The project was funded by a University of Oxford KE Seed Fund award.

What can health professionals, researchers, patients and the public learn from one another about type 2 diabetes? Patient and public involvement in research, and in setting research priorities, is increasingly important because it can help ensure that research focuses on what matters most to patients. With this in mind, we organised a workshop that would provide the space and opportunity for people with different kinds of diabetes knowledge – academic, clinical and experiential – to share perspectives and ideas.

BACKGROUND: FOCUS GROUPS WITH SOUTH ASIAN COMMUNITIES

In the UK over three million people are thought to be living with type 2 diabetes., Around 11% of whom these people are of South Asian ethnicity, where diabetes is around six times more common than in the general population and people develop the condition about ten years earlier. Despite these statistics, we know relatively little about the lived experiences of South Asians with diabetes, including views of healthcare, self-management and how these intersect with culture, religion, work, family and other

aspects of daily life. We do know that British Asians are less likely to access services than the white British population, that they have worse health outcomes due to diabetes, and that they are underrepresented in research.

We wanted to organise the



workshop because we had recently conducted focus groups with people from various South Asian communities in Leicester, which had aimed to include first, second and third generation people of Indian, Pakistani and Bangladeshi descent. These exploratory focus groups, set up by Nasima Miah from the Centre for Black and Minority Ethnic (BME) Health at the University of Leicester, and facilitated by Suman Prinjha from the University of Oxford, were conducted in English, Punjabi, Hindi, Urdu, Bengali and Sylheti. 67 people talked about their experiences of taking medicines long-term, diet, aging, day-to-day priorities, how travelling to and from South Asia

affected their views on healthcare, and how herbal and complementary approaches were sometimes used alongside diabetes medications.

This preliminary research highlighted several things: how much participants wanted to talk and share their experiences; how little we know

about the best ways to support patients given the diversity in these communities; and how much more we could learn working more collaboratively: patients, public, researchers and health professionals.

To explore the issues raised in the focus groups further – and to share the findings with people who had taken

part in them – we decided to run a workshop in Leicester for research participants, health professionals and other stakeholders in June 2018. The group included people living with type 2 diabetes, community centre managers, faith leaders, researchers, health professionals, and representatives from Diabetes UK and Leicester City Council. Presentations were given by health professionals, researchers and people living with diabetes, and these were followed by a group discussion.

FIRST-HAND ACCOUNTS

The highlight of the day for many workshop participants was hearing first-hand from people living

with diabetes. Four focus group participants talked about the day-to-day challenges they faced and how they dealt with these. Ebrahim, a 47-year-old man who had taken part in the Bangladeshi focus group, was diagnosed with type 2 diabetes when he was 39. He discussed the impact of diabetes on his life, including depression when he was first diagnosed, loss of confidence, anxiety around blood sugar levels, and effects on driving, fatherhood, exercise and insurance premiums. Ebrahim felt that diabetes support should be aimed at the whole family, and stressed the importance of raising awareness of the different ways that a diagnosis can affect a person's life, not just their physical health.

Ravinder, who had originally changed her mind about speaking in public, reconsidered after she had heard other people present and had seen how informal the workshop was. A 49-year-old woman who had taken part in the Punjabi focus group, Ravinder said that one of her biggest challenges over the past 14 years had been 'self-discipline' in terms of diet and exercise. At a recent six-month review with a practice nurse, Ravinder was told that her blood sugar levels had risen and the nurse advised adding another medication. Ravinder said:

All their interest was to add another medication in, and that was it...I'm trying (to lose weight) but I think it would be nice if we could have a little bit more support from practice nurses, GPs. I think all I wanted was for them to say was, you know, maybe on a one-to-one, special case, that "Okay Ravinder, come back in four weeks' time and I'll weigh you and do another blood test." Not every month, you know, just something to support my plan (to lose weight), but it was a total blank.

Shofiqul, a 71-year-old man from the Bangladeshi focus group and a Leicester City Councillor, felt strongly that universities should engage with local communities when conducting research and disseminating the findings.

Stress and a holistic approach

to healthcare was another theme that came up several times during the workshop. Rabia, a 62-year-old woman from the Pakistani focus group, said that she was diagnosed with diabetes at a very stressful time in her life when she was migrating from Germany to England. She believed that most South Asians with diabetes had stressful lives and that a holistic approach, including diet and positive thinking, could help. Rabia felt that a holistic approach had enabled her to reduce her diabetes medication with the support of her GP.

Sonal, like Rabia, also related to a holistic approach, and talked about the Ayurvedic clinic and diabetes support group that she ran in Leicester. She recalled the shock she felt when she was diagnosed with gestational diabetes and, years later, with type 2 diabetes. She found it difficult to manage her diet, including at home where she cooked for her family, none of whom had diabetes. Sonal felt that restricting her diet, including at family and community functions, often made her feel 'outside the community'. In 2012 she set up a diabetes support group, and she stressed the importance of talking about the emotional impacts of diabetes as well as diet and physical activity.

WHAT NEXT?

The workshop provided a valuable opportunity to hear the views and experiences of people from various backgrounds and gave us much to think about, including the different priorities for future research and the gaps in our own knowledge – for example, which lifestyle factors can affect diabetes; what are the main causes of stress in South Asian people; what are the commonalities and differences between Hindu, Muslim and Sikh experiences and what are the effects of age, generation, religion and culture?

There was also a lot of interest in working together and the event enabled us to develop new relationships and consolidate old ones. Seeing our participants again but in a different context helped us

to get to know one another better. Many participants asked how they could continue hearing about our research with British South Asian communities. A lay summary of the workshop was sent to participants one week after the event, and a short article about it was published by the Centre for BME Health.

We also compiled a list of people who said that they would like to work with us in the future, and informed participants of the various ways in which they could contact us to give feedback or get involved in further work. We plan to keep participants updated by letting them know of any papers that we publish on the focus group findings, any grant applications that we write, and any new research that we plan to conduct.

The workshop was our first step in discussing ideas about future research and coproducing a project with British South Asian communities. Increasingly seen as an important approach to designing, conducting and disseminating research, coproduction involves people working together, not in spite of their different kinds of knowledge, experiences and perspectives but because of them – the value of which was striking in this workshop. Our next step is to submit joint applications for funding with patients and the public. These will draw on the ideas generated in the workshop as well as explore new methods of coproducing research with British South Asian communities.

Read more about this work at:

www.phc.ox.ac.uk/news/blog/british-south-asian-narratives-of-diabetes-and-views-on-future-research

meet a PPI contributor / Interview



In 2019 it will be 10 years since Marney Williams had a stroke.

While that event has influenced a large part of her life since, it doesn't define her. Marney, now 58, is a teacher by profession and nature.

Though she hasn't taught in schools full-time since the stroke, she tutors on a one-to-one basis for private clients and for the local authority, helping pupils with problems boost their education. The elements of a good teacher – communication and curiosity – are instead a larger part of what defines her.

Following her stroke, Marney had aphasia – problems understanding or producing speech and/or the ability to read or write. The thing she missed most, she says, was reading. And that was what she decided to tackle first in her rehabilitation, not least because she wanted to find out more about the cause of her stroke.

The cause, she was told, was rare, not well understood but 'statistically unlikely to happen again'.

Since her stroke, Marney, a mother of three, has been keenly involved in the research process and built up extensive experience as a PPI contributor and supports CLAHRC-funded projects on blood pressure.

You've said that you wanted to find out more about the cause of your stroke. That must have been difficult in the early days?

I found it deeply unsatisfactory to be told that my stroke was 'just one of those things and we don't know much, and it's unlikely to happen again'.

So, after six months of rebuilding my ability to read and doing my own poking about I'd built a case for further investigation. I was able to go back to my GP and make a successful case for further testing.

Despite the language disability, I had still managed to persuade a series of doctors of increasing seniority that something was worth looking at. And, in the end, I was right.

The last test I had was a skin biopsy. They found that it looked very much like I had a connective tissue disease, although I had no genetic match to known conditions.

That was the start of being interested in research.

Did you have any medical or scientific background or experience before that do draw upon?

I taught maths, I don't have a biology or chemistry background, so I'm not a scientist, but, the sort of data aspect of research is familiar.

I was told that statistically it won't happen again, but then again, you would never have expected it to happen

in the first place, so that wasn't entirely comforting.

And, from a population statistics point of view you're looking to manage a situation, but from a personal perspective it's an all or nothing situation: you have a stroke or you don't.

So, I think assessment of personal risk and assessment of population risk are rather different things.

When did you first come across PPI as it now is?

Initially no one could give me a clue as to who to contact or how to find where other people with such conditions gathered.

After about 18 months, someone told me about a stroke charity called Connect – now closed. Connect helped people with aphasia, and through that I got involved in a project raising awareness of the needs of people with aphasia in the community.

One of the staff working there had seen an advert asking for lay members to join a committee at the UK Stroke Forum. I thought I might find that interesting and be able to represent people with aphasia. I applied and was asked to join.

That was a really useful interaction with a wide range of stroke professionals, and I helped in planning the programme for a conference in Glasgow. The conference included a presentation that was essentially a conversation between a researcher and a patient

member involved in research by the Stroke Research Network.

I was really interested, and fought my way to the front afterwards to say, 'I'm really interested in this, how can I get involved?'. And that was the start.

What happened from there?

We had regular meetings with researchers and a day of talking and generating ideas for research projects – right at the beginning of the research cycle – putting people with diverse backgrounds in a room to discuss their perspectives.

Researchers and clinicians brought their knowledge while we gave our personal experience, identifying unmet needs and so on.

It was through doing that that I met Professor Richard McManus and Dr James Shepherd, Shepherd,

“I was really interested, and fought my way to the front afterwards to say, ‘I’m really interested in this, how can I get involved?’

And that was the start.”

primary care researchers with Oxford University and CLAHRC Oxford.

What sort of involvement did that bring?

The first project James asked me to be involved in was for the over 80s. I offered to go speak to a group of over-80s and gather their thoughts on some of the issues about the proposed trial – I think the other researchers were sort of surprised about this, but it seemed to me the obvious kind of thing to do, to go talk to the patient groups.

I think they found that useful, though unfortunately that project didn't get funded. However, what I'd done for that has been reworked into other funding bids which have been successful.

James was important in encouraging me, telling me that I had something to offer. He was the first person to ask, as though it was the most natural thing in the world, if I would like to be a co-applicant on a study. He, in particular, encouraged me to keep going. So, I've been grateful for that.

Over time I've become involved in other projects as well. I'm currently a co-applicant on three studies, and I'm on the steering group for two others.

Did you have any anxieties or concerns about dealing with researchers?

There was a degree of anxiety that came from having aphasia. You're always a bit apprehensive about looking stupid, but that wasn't really so much about dealing with the setting as the fact that you have aphasia; you worry people think you're stupid if you're slow.

In many ways if you're in a medical environment it's kinder than 'real life'. The fact that everyone knew I had had a stroke meant I was a bit less hung up on asking

people to repeat or explain things. I never felt that I couldn't ask a question or anything like that.

People with stroke in general tend to suffer quite a lot from fatigue, and I less so than many. In the earlier years, the process of listening and concentrating was very exhausting. I was invariably asleep on the train on the way home.

But mainly, everyone has been really nice and supportive, and the individuals I've met have been universally charming.

Have there been any difficulties with being a contributor?

No, I don't think so really.

In the early stages the ability to read and absorb was a problem, but all the people I've worked with are good with sending out the things we need to read in advance. Which meant that I'd had time to feel I'd prepared appropriately for meetings – sometimes more than other people...

I don't personally have any physical difficulties, and if I want to know something I'll ask. I think I'm sensitive to where the focus of the meeting needs to lie and that I don't want to take more than my fair share of time, or equally not speak up when I want to. But I've definitely settled more into it over time.

If someone was sitting on the fence about being a contributor, what would you say to them?

I would encourage people to participate in something local for an afternoon, something with no big commitment, and see if they liked it and build up from there.

For example, I might suggest where they might find a study in their area of interest and places they could look things up further.

I like the idea of giving people a taster. Every year Imperial College London has a festival where researchers showcase their research activities and there's always a PPI stall where we engage with the public. Last year I pushed for people to be given the chance to do a PPI taster, it was a real success.

meet a researcher / Interview



Dr Rupert McShane is a Consultant Psychiatrist working at Oxford Health NHS Foundation Trust, and Associate Professor in Oxford University's Department of Psychiatry.

His clinical and research interests are in dementia and 'treatment-resistant' depression – depression that has failed to improve in response to standard treatments. He leads the Oxfordshire electroconvulsive therapy (ECT) and ketamine services for treatment resistant depression.

Ketamine, often better known as a 'party drug' of abuse, is also licensed for use medically as an anaesthetic. This allows doctors, such as Rupert, to prescribe it for 'off label' (i.e. non-intended) uses. This is typically given as an intravenous infusion in a hospital setting.

About 6% of adults in England will experience an episode of depression each year, and over half of them will continue to have significant symptoms after taking standard antidepressants for six weeks or more.

How did you come to be involved in ketamine research?

Phil Cowen, a Professor of Psychopharmacology at the Department of Psychiatry, mentioned an exciting development about ketamine, and asked if I would be interested. Together we applied for a grant and did a short study using ketamine in people with resistant depression.

Some of the effects we saw were positive and quite dramatic, so we decided to carry on with the research.

The story since then, really, is one of trying to help patients using what is basically a new treatment, that had only the barest-skinkest of evidence of its benefits.

Through that work we've been able to develop a lot of clinical and research experience quite quickly and come to develop what we think might be a good way of using ketamine for patients.

As a psychiatrist, have you always been involved in the research side of things as well?

I've always been interested in research and involved, yes. I'm an NHS consultant but I have an honorary university post, and I also lectured for a while

How do you find balancing those two different roles?

Oh, I'm having a great time. I really enjoy it.

I think I probably enjoy the what one might call the 'clinical experimentation', which is more about each individual patient, trying to work out what helps them rather than the more 'protocolised' side of research. It's closer to what's really needed in psychiatry; it's closer to the patients.

So, that's why in a sense, I've stayed in an NHS job rather than move to a full research role.

It seems like you're very interested in the human element of your work?

To be honest I've just always loved talking to patients, listening to them, explaining things and helping them. I think there's a sort of teaching element to it, but it works the other way as well.

Fundamentally, one's teachers are the patients themselves. Finding the right paths together and seeing it as a mutual enterprise is, I think, what medicine is really about. And I don't see research as being different in that regard, and that's one way PPI fits in.

What sort of things is PPI helping you with at the moment?

We are hoping a form of ketamine for depression, called esketamine, will be licensed in the near future.

An important issue we're working on is trying to grapple with what the medical, individual and social implications of using ketamine as an antidepressant might be. Especially as it is also known as a drug of abuse.

The problem is not really that it's very addictive. It probably causes no more problems, by way of harms, than benzodiazepines [such as Valium], and probably less harms than alcohol.

Could you tell us a little more how PPI has fit into your ketamine work?

I think there are some really important issues we need to grapple with. I think fundamentally it's a problem that arises through an advance, which I suppose is the right sort of problem to be working on.

It's the size of the issue, I think, which might drive

public perception – there’s potentially a lot of people with treatment resistant depression.

Whilst ketamine looks effective, if it gets licensed – which I think will be a great advance – for long-term use there’s still a lot we don’t know.

I also suspect there will be a group of patients who might find it difficult to manage their use of ketamine. And there is a potential difficulty in how that is going to be perceived.

My biggest worry is that there may be some form of backlash against it as a treatment and that might further stigmatise people with mental health problems and psychiatry in general.

Getting the feedback of public and patients on that early could be invaluable.

And how have you begun to address this?

We recently held a conference with about 40 PPI representatives.

It included people who had either had ketamine as a treatment in the past or currently, people taking it recreationally or to self-medicate, were addicted to it, and people or their carers who had expressed an interest in taking it.

We wanted to get their views on what the issues about using ketamine and similar drugs in the NHS were.

What did you find out from them?

The main concerns were that people felt a degree of monitoring was required. Secondly, people were concerned about access to the drug.

Many said their experience of access to psychiatric services in general hadn’t been terrific, and they were anxious about there being effective drugs which they couldn’t access. That also included practical issues about access, such as travel to hospitals to be given the drug.

Relating to monitoring, people were also worried about what the use of their data would be. For example, in this space, people were worried about the police getting hold of it and using it against them – they were, after all, using a non-approved drug of abuse. So, if they control access to that data it helps.

There’s also a concern about the extent to which extreme views and worries could undermine what we’re trying to do. Worries about things like people ‘pretending’ to be depressed in order to access the drug.

What have you done with this PPI input?

One of the things we’re doing is using an electronic health record where, crucially, the patient can see everything and controls access. So, if they wanted to invite their mother, therapist or friend to see their record, they can. It’s completely transparent, but it’s in their control.

From that, we’re developing the idea of using it as the basis for a registry or a way to facilitate the monitoring that they thought necessary.

It’s an iterative process, we’re getting feedback from patients as we go along. I use it day-in-day-out clinically,

“Fundamentally, one’s teachers are the patients themselves. Finding the right paths together and seeing it as a mutual enterprise is, I think, what medicine is really about.”

and I think it’s a very interesting way of doing things. I think it’s sort of with the zeitgeist as well.

There will obviously be situations and people for whom that’s not a perfect solution, but I think it’s an idea whose time has come.

What gets you out of bed to do this on a day-to-day basis?

It’s very interesting, and I feel like I’m in a very fortunate position to be able to help people, I think this form of treatment is going to help a lot of people in the future.

What keeps you busy outside of work?

Well, family and I play the harp – have done for some time.

In fact, I have a concert with the Radcliffe Orchestra coming up. The orchestra is made up largely of people who work at the local hospitals. It’s on March 9th at Tingewick Hall at the JR.

Do you come from a musical family?

I suppose so, yes.

My father read medicine at university and didn’t pass his exams because he was too busy playing the double bass in a jazz club – or at least that’s his story!

To find out more about the work of the ketamine treatment service at Oxford Health NHS Foundation Service, please visit:

www.oxfordhealth.nhs.uk/ketamine-service

Setting the national research agenda for tobacco control

A consultation involving members of the public with doctors, researchers, healthcare commissions and policymakers has informed the NIHR's latest funding call for research into tobacco control.

The Cochrane Tobacco Addiction Group's priority setting project, led by staff in Oxford University's Nuffield Department of Primary Care Health Sciences, set out to understand the opinions and experiences of a broad group of tobacco addiction stakeholders through a series of national surveys and an Oxford-based workshop in 2016. A clear message emerged – that there are many unanswered research questions in the areas of tobacco use prevention, harm reduction and cessation.

The project highlighted eight tobacco-related priority research categories, with corresponding questions, and four overarching priority themes for tobacco research.



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To develop their commissioning brief for potential research projects across England and Wales, the NIHR cites the Cochrane group's priorities as the basis for their own national research agenda for tobacco control.



8 priority themes for tobacco control research

The Cochrane Tobacco Addiction Group's research prioritisation exercise involving over 300 people identified a total of 183 unanswered questions in tobacco control through two online surveys and an Oxford-based workshop, narrowed down to **24 priority questions across eight research themes:**

- ★ Addressing inequalities in tobacco use
- ★ Delivery of smoking cessation treatments
- ★ Electronic cigarettes
- ★ Quit attempt triggers
- ★ Preventing tobacco use in young people
- ★ Tobacco use in people with mental health problems and/or substance abuse issues
- ★ Interventions targeting whole populations rather than individuals
- ★ Quitting during pregnancy



Welcoming the funding call, the Cochrane Tobacco Addiction Group's Managing Editor and lead investigator for the project, Dr Nicola Lindson, University of Oxford, said: "One of the goals of the exercise was to set our own priorities for coming years; but we were hopeful that we could disseminate the results widely enough that the wider community would also benefit. It is great to see that we achieved this. We really hope that it will drive much needed research and ultimately contribute to public health."

Read the full report: tobacco.cochrane.org/ctag-taps-project



This project was funded by the NIHR School for Primary Care Research.



My involvement as a PPI Contributor in the ALIC4E Clinical Trial



Keith Shankland writes about his involvement in the ALIC4E trial, from the Nuffield Department Of Primary Care Health Sciences, which was set up to look at whether giving people antiviral medication to people with flu made them feel better faster.

I originally became involved with this interesting and comprehensive trial with an invitation from the the Primary Care Clinical Trials Unit at Oxford University to review a number of pieces of patient literature. These were information leaflets, posters and, very importantly, patient diaries that recruited patients would be requested to complete over a period of time - these diaries being essential to the core management and outcome of this very comprehensive trial.

I was particularly concerned to ensure that these materials, including the patient diaries, were structured and written in a consistent manner. It was also important that patients easily understood what was being requested of them and, critically, motivated them to complete these diaries on a daily basis. I made a number of suggested amendments to the structure and language of the literature to the trial management team and was pleased to see them adopted.

Following on from this review I was invited to become the PPI representative on the Trial Steering Committee which is basically the body charged, along with the Data Management Committee, of ensuring the trial is run and managed in conformance to the approved protocol. This was very important to me particularly as there was a high degree of patient participation involved, i.e. diary completion on a daily basis. The consistency of this was a big challenge for the trial management team in order to ensure the integrity of the trial. I was pleased to observe there was a high degree of success on the level of diary returns and subsequent analysis and from my point of view it was a refreshing experience to support the team in this challenge.

PPI contributors really have a positive contribution to make to the planning and management of clinical trials like ALIC4E.

In my participation I always feel a sense of duty to represent the views and needs of the patients who are volunteering to participate in the evolution and establishment of evidence based medicine.

It has been a pleasure to be involved in the ALIC4E trial and I would like to thank Professor Butler and all his trial management team for the courtesy they extended to me and to listening, acknowledging and actioning my suggestions and input.

To find out more about the ALIC4E trial, click here: www.phc.ox.ac.uk/phctrials/trial-portfolio/alic4e

7 steps to the 'Perfect Patient Information Journey'

A seven-step process for health services to improve information for people with long-term conditions is set out in a major new report recently published by the [Patient Information Forum](#).

Using this process, it is hoped services can transform the information experience of patients in a matter of months.

Briefly, the seven steps are:

1. Get the leadership team on board and clarify roles
2. Find out what your patients think
3. Find out what your staff think
4. Map the current patient information journey and identify gaps
5. Identify and make improvements
6. Evaluate the impact of changes made
7. Benchmark, review and maintain patient involvement in implementation of change.

Download the full report (.pdf) from this link:

www.pifonline.org.uk/wp-content/uploads/2014/11/PIF-PPI-Journey-Final-25Jun18-1-website-version.pdf

Big screen launch for Local PPI group

The Oxford Blood Group took over the Ultimate Picture Palace in Oxford for their launch.



Colleagues at the Oxford Blood Group took over the Ultimate Picture Palace in Oxford to show a screening of the play “People are Messy”, launching their new patient engagement group for those with blood conditions.

65 people attended, 25 of whom were patients or members of the public.

People are Messy is the recording of the play by the same name produced by Oxford patients and researchers in collaboration with the Theatre of Debate. The play explores the experience of two young men with a rare inherited anaemia, and their efforts to contribute to clinical research. The play touches on the interests and constraints of all players in patient involvement, from how patients interact with their clinicians (ranging from grateful to questioning) to the time constraints on researchers and their own emotional baggage.

Dr Bethan Psaila, a researcher at the MRC Molecular Haematology Unit (MRC MHU) who attended the event said “It underlined the importance of an open dialogue between clinician scientists and patients on priorities for medical research, and prompted a number of ideas for how the Oxford Blood Group can help us achieve that here in Oxford.”

“This event was a wonderful start to a great conversation. Patients, doctors and scientists, all on an equal footing, sharing viewpoints and listening to each other” said Dr Noémi Roy, Consultant Haematologist and

co-founder of the Oxford Blood Group. “Only by understanding each other will we begin to make a real change in how patients are involved in shaping the research we do. So let’s keep talking. “

As the Oxford Blood Group exists to promote PPI in haematology, it was particularly gratifying to learn that so many of the researchers and health professionals in the audience felt that they had

changed their minds about PPI, and that they would be more proactive in engaging with patients from now on. 15 people stated that it had changed their perspective on PPI.

For more information, visit:

www.imm.ox.ac.uk/about/news/oxford-blood-group-launch

oxfordbrc.nihr.ac.uk/research-themes-overview/haematology-and-stem-cells/oxford-blood-group

