

NIHR patients and the public

May 2018



This work uses data provided by patients and collected by the NHS as part of their care and support.

#datasaveslives

Why Patient Data Matters

Patient data is central to the research funded and supported by the NIHR and we have many examples of how we use it. We are encouraging researchers to acknowledge their use of patient data with this citation developed by use My data - do encourage its use if you can.

We have also led or been part of a number of activities to help us better understand people's attitudes to sharing their data for research and other purposes.

Information about why patient data matters is also available on the NHS website. Much of the time, anonymised data is used but this site also explains how the NHS is managing the choice for individuals to opt out of confidential patient information being used.

Another good resource is Understanding Patient Data and Twitter users can use #datasaveslives.

**I AM
RESEARCH**

Be part of the solution

NHS70 I Am Research

The annual I Am Research campaign to encourage patients, carers and the public to get involved in research is underway. For 2018, the campaign also celebrates the NHS' 70th birthday (NHS70).

Every year, more than half a million people help the NHS to improve

healthcare and develop life-saving treatments by taking part in health research.

As part of the national NHS70 celebrations, people are being asked to get involved in research and help shape the next 70 years of the NHS.

If you would like to participate in health research, you can visit the UK Clinical Trials Gateway to find out about studies of interest to you. There's not always a research study to suit everyone, but there are other ways to be involved or stay in touch. This could be as a Patient Research Ambassador, advising researchers on improving patient experiences, signing up for mailings, or simply talking about research.

Events are being held up and down the country to mark I Am Research and International Clinical Trials day. You can also help us spread the word and show support for the campaign, by sharing the posts across Twitter and Facebook and keeping an eye on the campaign page for any updates.

PPI - What researchers can do to improve feedback

At the INVOLVE conference in November 2017 Graham Rhodes (PPI contributor) acted out a well received playlet to demonstrate a common frustration amongst PPI contributors – the lack of feedback from researchers. Graham referred to never hearing if his comments had reached the researcher, not knowing if he was “on the right lines” and not knowing if his comments had made a difference.

To answer some of these questions, six PPI groups in the East of England came together to be involved in a pioneering research study investigating the frequency, variation, importance and satisfaction with feedback about lay colleagues contributions. Together we shaped, planned and carried out a survey and interviews: the results have been published in Health Expectations (<https://doi.org/10.1111/hex.12684>). Throughout, Elspeth Mathie and Helena Wythe (researchers at the University of Hertfordshire), co-operated closely with PPI contributors Graham, Diane Munday, Nick Roberts, Paul Millac and other PPI contributors on the study which was funded by the Collaboration for Leadership in Applied Health Research and Care (CLAHRC) East of England. We found that roughly one in five PPI contributors never had any feedback - despite the word ‘feedback’ having many meanings and different PPI activities requiring different feedback.

Together the PPI contributors, PPI group leads and researchers in the East of England, used the information obtained to co-design feedback forms which could facilitate the embedding of feedback whenever PPI contributors were asked for help.

Having gained experience of using the forms the six groups went on working together to co-design a booklet Guidance for Researchers incorporating into it the knowledge that feedback can keep PPI contributors motivated, support learning and development and make researchers reflect on the impact of PPI within their research.

The Guidance can be found here http://www.clahrc-eoe.nihr.ac.uk/wp-content/uploads/2016/05/Guidance-for-Researchers-PPI-Feedback_2018.pdf

Diane Munday, who is a member of the Public Involvement In Research group (PIRg, University of Hertfordshire) and co-author on the paper remarked; *“I have been a public involvement in research contributor for around 15 years and throughout that time have really valued receiving feedback on my contributions: sadly this has not always been forthcoming so the results of this piece of research are important because they not only provide guidance to help researchers but also detail and underline the advantages that routine feedback can bring to both researchers and to lay members as well as improving research outcomes”*

We are not suggesting that forms or processes can replace on-going dialogue or face to face communication but we hope the Guidance can be used as an informed starting point for discussions around PPI feedback and about expectations at the start of a research project.

We would be interested to hear from anyone who would like to use our forms or Guidance and we can supply paper copies. Please get in touch: Elspeth Mathie (E.J.Mathie@herts.ac.uk)

Twitter: Elspeth_Mathie

AnDy - Research Advisors Group



The Research Advisors' Group (RAG) is a PPI group in the AnDY (Anxiety and Depression in Young people) Research Unit at the University of Reading. AnDY carries out research into the development and treatment of anxiety and depression in children and adolescents. Since 2017, there is also an on-site research clinic offering assessment and treatments alongside research opportunities.

The RAG is made up of young people and parents/carers, who all have personal experience of anxiety or depression or caring for someone who has. Two researchers in AnDY, Dr Polly Waite and Professor Cathy Creswell, set the group up in 2015, initially in collaboration with the Berkshire NHS CAMHS Anxiety and Depression pathway.

We meet once every half term. The date is chosen by a poll so that as many people as possible can get involved. We generally have 6 – 10 Research Advisors at each meeting, including some people who come almost every time and others who come less often.

There is a consistent group of staff at each meeting, so that the Research Advisors know who to expect, and we send out an agenda in advance so that everybody knows what's going to happen. The group developed their own ground rules, such as "it's okay to just sit" and "respect people's privacy" as well.

Our meetings are fairly informal and we split into separate groups for parents and young people. This allows everyone to speak more freely about their experiences. The Research Advisors give ideas and feedback on both the research and clinical sides of AnDY.

"Participation from the research advisors is fundamental to what we do; ensuring that both our research and clinical work is driven by the people that are directly affected," explains postdoctoral researcher Dr Faith Orchard, "I have worked with the RAG group on my research around sleep disturbances in adolescent depression. This feedback has been fundamental in designing the programme of study. The initial ideas shaped up the research design, and I was able to use quotes from the group in my application."

The Research Advisors worked with doctoral researcher Emily Hards on her research on self-concept in adolescent depression, looking at phrases which participants had used to describe themselves. Emily says the Research Advisors' feedback "was so important, especially given how my research is all about better understanding how adolescents describe themselves (their self-concept), so, who better to inform the research than the adolescents themselves?"

Tessa Reardon, who recently conducted a survey of parental help seeking for anxiety difficulties in children, says "the parents in the RAG had a massive input in the planning stages for this study. I worked with them to design the information leaflets about the study and they helped with writing questions to include in the survey. Every time I meet with the group I always come away thinking 'I can't believe we didn't think of that before' - they always bring a new, invaluable perspective."

Some of the other things the group has done recently include planning a video about the AnDY research clinic to show to new patients, discussing different types of diagnostic measures, and even trying out virtual reality headsets and talking about ideas for a virtual reality based treatment.

We have had a specific feedback-based meeting facilitated by someone from the charity Young Minds. During this meeting, we came up with ways to make our group accessible to more people, and make sure those who come get the best possible experience. We have now improved the directions we send out for finding the clinic, so that potential members will have less anxiety about finding us for the first time, and we finish every meeting with a "positive go-round" to end on a high note.

One parent told us “it’s really interesting to hear about what research is being done and great to be able to make a small contribution to this. When my daughter was ill I also appreciated meeting other parents with similar experiences”. Other reasons why people come to the group include being able to share their views and learn about psychology. Since September 2017, alongside being a RAG member, I have been employed to work in AnDY one day a week during my gap year. The team set up this post to ensure that PPI is embedded in everything that is done across AnDy. I attend research, clinic and business meetings as well as 1:1 meetings with researchers and giving presentations about the RAG, for example during our new starter training week and to others thinking about setting up similar groups (including in video form for researchers in Australia!).

Find Out More

If you’d like to find out more about the AnDY RAG, please visit research.reading.ac.uk/andy/andy-rag or find us on Twitter @AnDY_RAG

Kings College - Mental and Physical Pain in art and medicine

As part of the new undergraduate medical curriculum 2020 at King’s College London, medical students have an opportunity to select a module of their own interest during the second year. One of these explores the representation of long term mental and physical pain in medicine and art. A group of six Year 2 students, who enrolled for this course, had the opportunity to gain a deeper insight on patients’ experiences of pain.

Three of us decided to explore Phantom Limb Pain and Agoraphobia. This was achieved through research by visiting exhibitions, poetry, music and films. Each art form provided a different way how physical and mental pain is expressed across a range of long-term conditions. As medical students we found it interesting how physical pain intertwined with emotional and mental distress, is depicted in art, translated and expressed. Many people living with the same condition represent their pain in a very different way.

We each collaborated with one patient we had met during our clinical placements in primary care to co-produce a piece of artwork that mirrored their physical and mental pain. This approach taught us that pain is personal and very specific to each person, their lifestyle, culture and social context that allowed us to view patients with a broader spectacle. Reading between the lines for example we learnt that some daily activities that we find ourselves easily capable of doing, are some of the hardest tasks for some patients. Specifically, we were impressed that in the midst of what seems so daunting, patients continue to be determined and stay positive to overcome their physical and emotional obstacles.

To end this journey, we each co-produced a piece of art to represent the pain of our patients, using their feedback and guidance to create art that speaks for the way they feel. This close collaboration has been helpful to us as medical students to gain a deep insight into the patients’ lives and how the long-term conditions directly affect them and their family and friends. This dialogue over weeks provided us with knowledge about the importance of time, trust, sensitivity and empathy towards patients when communicating about pain and how art provided space to find their voice to express their lives, worries, limitations and hope.

Taking patient and public involvement online

Brighton *et al. Research Involvement and Engagement* (2018) 4:14

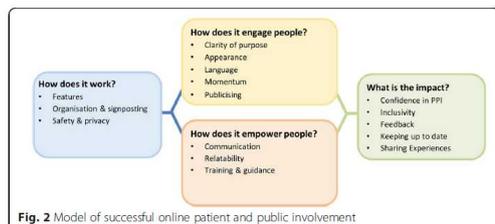


Fig. 2 Model of successful online patient and public involvement

New research explores what it takes for online patient and public involvement to work:

A recent study from the Cicely Saunders Institute, King's College London, published in *BMC Research Involvement and Engagement*, explores the use of an online platform for patient and public involvement (PPI) in palliative care and rehabilitation research.

Using focus groups with PPI members and researchers who had used their forum so far, they explored how well the online forum worked, whether it was a suitable method for PPI, and how PPI members and researchers reacted to using it. To ensure comprehensiveness, Data collection was underpinned by DeLone and Mclean's (2003) model of information systems success, and PPI members helped with the focus group questions, analysis, and write up.

From the results of the focus groups, the team identified four key questions to consider when developing online methods for PPI: (1) How does the forum work? (2) How does it engage people? (3) How does it empower people? and (4) What is the impact?

The main message from their work is that to develop online methods of PPI, a functioning forum is not enough: it also needs to be engaging and empowering to have an impact. Overall, the online forum team felt that the forum showed good promise as a method of PPI in palliative care and rehabilitation research, alongside other methods of involvement. Future work on their online forum will be carried out to address the comments from the evaluation.

To find out more, read the full paper here (open access): Brighton LJ, Pask S, Benalia H, et al. (2018). Taking patient and public involvement online: qualitative evaluation of an online forum for palliative care and rehabilitation research. *Research Involvement and Engagement*. 4 (1): 14.

<https://doi.org/10.1186/s40900-018-0097-z>

Or get in touch via email: csi.ppi@kcl.ac.uk

A Vision for Healthy Publics

Society faces tough health challenges: growing levels of obesity, concerns about antibiotic resistance, the needs of an ageing population, social isolation and more. These are complex problems that arise from the interplay of many factors, such as who we are, where we live, the work we do, the people we know and the environment around us.

The Wellcome Centre for Cultures and Environments of Health, based at the University of Exeter, is dedicated to researching innovative approaches to create and sustain cultures that enable health and well-being across the life course. This new research centre hosts historians, literary scholars, social scientists and medical experts, working together to tackle some of the world's most pressing public health issues.

However, research expertise is not enough on its own; the vision of the Wellcome Centre is of engaged research. Our rationale for focusing on this approach is our conviction that engaged research is fundamental to enabling transformative research. We want our research to be influenced, created, and conducted by and with people whose lives are affected by the research and its outcomes, because we believe difficult issues can only be tackled effectively if we draw on people's skills, experiences and insights of health and wellbeing, and their understanding of the questions and issues that matter to them and their communities. We know there isn't one perfect way to undertake engaged research. The Centre is something of an experiment, funded to be ambitious in researching and engaging in new ways. Our Engaged Research seminars and workshops are open to all; we are committed to ensuring that no one is excluded from participating in engaged research. In the autumn, we will welcome our first group of PhD students. In their proposals, we asked all applicants to show how they proposed to engage with people, groups and organisations throughout their research.

We actively encouraged applications from people who had not taken a traditional route through study, offering support to develop the best possible proposals. We'll begin the second round of studentships later in the year; again, we'll encourage non-traditional applicants and this time around, we're planning workshops to support the delivery of engaged research.

It will be vital for us to show that the Centre's structures and processes can respond to the needs of everyone who engages in our research and that we have supported the development of a truly engaged research community, whose relationships have been transformative for our research. Reflecting on how, why, when and where engaged research has been successful will be key to the Centre being recognised as a world leader in this approach.

Core Outcome Sets



As a public contributor involved in research you are probably familiar with outcomes – the items that researchers use in their research to measure the effect of a new treatment or intervention. For example, in testing the effectiveness of a new treatment for low back pain researchers might be looking at whether or not a new treatment reduced pain or improved mobility.

However, different researchers often use different outcomes in trials investigating the same condition, meaning that studies cannot be compared or combined to see how effective treatments are. Also patients are not always asked what outcomes are important to them. This is why Core Outcome Sets are needed.

The COMET Initiative (Core Outcome Measures in Effectiveness Trials) aims to encourage researchers to develop and use agreed standardised sets of outcomes, known as core outcome sets (COS). These are the minimum set of outcomes that should be measured in all trials of a specific condition. That does NOT mean that researchers cannot include other outcomes in their research, just that they should include the COS as a minimum.

Most COS developers are now including patients in their work to produce COS for particular conditions. This may mean patients or carers with experience of the condition taking part in a survey and a 'consensus meeting' alongside clinicians to identify and agree the items that should go into the COS.

PoPPIE (People and Patient Participation, Involvement and Engagement) is the PPI working group within COMET. PoPPIE recognised the need to develop a plain language video about core outcome sets and successfully applied for funding to do this. A COS video development group was set up and included patients and COS developers working in partnership to produce an animated video explaining COS to the public. The video follows the journey of Laura, a patient with asthma, who is frustrated by the different trial outcomes in (fictitious!) asthma research. She explains how this situation can be improved by the use of COS designed with patient input. The video is called *What are Core Outcome Sets?* and is available here:

<http://www.comet-initiative.org/resources/PlainLanguageSummary>

To find out more, why not watch the video and have a look around the COMET website

<http://www.comet-initiative.org/>.

COMET would really appreciate your feedback on the video. If you watch the video to the very end, an evaluation question will appear. We would be very grateful if viewers could answer the question to help us evaluate the video.

If you have any questions about Core Outcome Sets or the COMET Initiative please contact Heather Bagley, Patient and Public Involvement Co-ordinator: heather.bagley@liverpool.ac.uk
Members of the COS Video Development Group: Rosemary Humphreys; Christine Vial; Rebecca Craven; Liz Gargon; Nicola Harman; Paula Williamson; Sarah Gorst; Bridget Young & Heather Bagley
The video was funded by The University of Liverpool Wellcome Trust Institutional Strategic Support Fund.



The People's Forum: celebrates 16 years of mental health service user involvement

Leicestershire's People's Forum was set up in 2002 to provide an opportunity for service users and carers with lived experience of mental ill-health to share their views with commissioners and service providers.

The forum is run by service users and carers who meet informally (with tea and biscuits) monthly on a Wednesday. Guest speakers, including researchers, are invited for more formal structured discussions. The group has a number of purposes. First, it allows service users and carers to engage with one another in a friendly non-judgemental environment. In this way, people gain confidence, feel more supported, and learn from other people's stories and experiences. Secondly, the forum acts as a resource to inform and influence the planning and delivery of mental health services across the region. As well as making their own contributions, groups and inpatient wards are visited to gather a range of perspectives that are fed back to mental health service providers. Individuals contribute generously to these peer discussions. The forum has collaborated on a number of reports over the years, helping to shape mental health service provision throughout the region [1–3]. Finally, the forum gives advice on mental health research carried out at both regional and national levels. A notable achievement is the support they provided for the most recent Adult Psychiatric Morbidity Survey [4].

The group has also been a particular support to local researchers in the area. For example, in 2016, Alison Drewett, a local speech and language therapist, was awarded a HEE/CLAHRC PhD studentship after visiting the forum to discuss her study. She observed that the group helped her to 'identify clearly research questions' and learn about their 'relationship with other patients' [in inpatient wards]. Having been unsuccessful in a previous application attempt, she also perceived that the additional support received benefitted her 'hugely in terms of being successful second time around'. As a result of funding changes, the forum will be closing in October 2018. We would like to take this opportunity to thank them for their contribution to research and mental health services over the last 16 years. For more information about the People's Forum, please contact: peoplesforum@btconnect.com
To contact RDS East Midlands: rds.em@nihr.ac.uk

New Intervention for Individuals who have Deliberately Set Fires Shows Positive Impact

Until recently, very little research had been carried out into understanding people who have deliberately set fires and even less attention had been paid to understanding their treatment needs and how to reduce their risk of repeating this behaviour. A new intervention for men and women who have set deliberate fires was developed as part of a collaboration between Professor Theresa Gannon and Dr Lona Lockerbie at the University of Kent and Kent and Medway NHS and Social Care Partnership Trust (The FIP-MO; Gannon & Lockerbie, 2011; 2012; 2014). The FIP-MO is a 28 week cognitive behavioural group treatment programme designed to target key psychological factors that the research literature suggests are related to deliberate firesetting (e.g., problematic interest, beliefs and attitudes about fire, offence supportive attitudes, social competency, self-management/coping skills, and safety planning for the future). Patients referred to the intervention attend both weekly group and individual sessions and engage in reflective work to help them understand the factors associated with their firesetting as well developing skills to manage these factors in the future.

A steering group was established for the study which met on a bi-monthly basis throughout the duration of the project; comprising of members from the study team, members of the local Experts by Experience Group, and a service user who had experience of receiving treatment for deliberate firesetting and forensic mental health services. Those with lived experience of mental health and forensic issues provided valuable input and insight into the steering group meetings, enabling the researchers to reflect on the research process, service users' perspective of attending treatment, and also consider ways to disseminate the research upon its completion. We are currently in the process of developing an animated video of the key results for the research to be disseminated to service users at participating sites. This will involve us collaborating with our local Experts by Experience group on the content of the video to ensure that it is accessible for individuals in forensic mental health services.

The FIP-MO was initially developed to meet the clinical need of patients in the Kent region. However, due to a lot of interest, it was decided that a national multi-site research evaluation was needed. This was led by Dr Nichola Tyler and colleagues from the University of Kent and Kent and Medway NHS and Social Care Partnership Trust (KMPT). To evaluate the effectiveness of the FIP-MO treatment, patients at hospitals who had been trained to offer the programme were assessed before and after attending the FIP-MO treatment using a set of standardised questionnaires, which were selected to tap into each of the core areas targeted as part of treatment. At hospitals where treatment was not available, patients with a history of setting fires were recruited to take part in the research as a comparison group and completed the same set of questionnaires at similar time points to those who attended the FIP-MO treatment.

Twenty-six secure forensic mental health services across England participated in the research, eleven as treatment sites and fourteen as comparison sites. The final sample consisted of fifty-two participants in the FIP-MO treatment group and forty in the comparison group. The results of the research showed that patients who completed the FIP-MO treatment programme showed greater improvements following treatment on their problematic interest, beliefs and attitudes about fire, and in their ability to express anger, relative to the comparison group who did not receive the FIP-MO treatment. Further, effect size calculations showed that those who completed the FIP-MO treatment made larger improvements following treatment on the majority of questionnaire measures compared to the comparison group. Patients who completed the FIP-MO treatment also reported feeling that they had benefitted from attending the programme. In particular they felt they had benefitted from, learning about fires and how they spread, learning about the potential effects of fire on others, understanding their triggers and risk factors for firesetting, and learning about how to create a more satisfying life for themselves. This study is the largest evaluation to date of specialist group treatment for men and women with a mental illness who have engaged in deliberate firesetting. The findings from the research suggest that the FIP-MO treatment is effective for reducing some of the key factors associated with deliberate firesetting and support the development and delivery of specialist interventions for men and women with a mental illness who have set deliberate fires. To read the full article by Tyler, Gannon, Lockerbie and Ó Ciardha (2017) please go to <http://rdcu.be/DYyz>

The FIP-MO evaluation was part of a body of work which won the Economic and Social Research Council's Outstanding Impact in Society award in 2016. As part of this a video was prepared with service users and practitioners discussing how the new treatment had benefitted them <https://youtu.be/Y6VW4ISh-HU>

John Braun - Patient Research Ambassador (Case Study)

Please tell us a little bit about yourself

I am a 66 year old administrator at a company in South London manufacturing neonatal ventilators. I am also a prostate cancer patient at the Royal Marsden Hospital (RMH). I was treated in October 2014 as part of a trial using the High intensity focused ultrasound (HIFU) process. I am currently on active surveillance after a recent biopsy revealed some cancerous activity. I still remain confident for the future.

How did you first hear about Patient Research Ambassadors? Through my current involvement as a patient representative on a NIHR funded project, Invention for Innovation (i4i) at the RMH. My role in this project is to provide a patient viewpoint on research needs; I have acted as a volunteer in setting up a whole body MRI scan protocol and as a result I was able to use my experience to improve the patient information sheet for the project. Shortly after commencing work on the project it was suggested by the team that I become an Ambassador.

What made you decide to become a Patient Research Ambassador?

After my treatment I attended an open evening at The Royal Marsden Clinical Research Facility where I learnt about how patients can become involved in research. My offer of help afterwards led to joining the Patient and Carer Research Review Panel which meets quarterly, followed closely by my first invitation to work with researchers on a grant application. During the next couple of years I became acutely aware that both patients and researchers needed educating in the role played by patients in research. Becoming an Ambassador offers the opportunity to take the patient involvement theme out to the public at large.

Why do you think NHS research is important?

The only way that the treatment of patients with clinically challenging conditions will improve is through research. There are too many unknowns that need answers.

To ensure you continue receiving this newsletter please update your preferences here
<https://tinyurl.com/ydh2u8xd>

Taking PPI online

<https://tinyurl.com/y9ouo5rs>

Vision for Healthy Publics

<https://tinyurl.com/ydxo8zb9>

Core Outcome Sets

<https://tinyurl.com/yd3ezz6b>

The Peoples Forum

<https://tinyurl.com/yba4l9vt>

John Braun Case Study

<https://tinyurl.com/y87krwxl>

Why Patient Data Matters

<https://tinyurl.com/ydc4sku8>

NHS70 I Am Research

<https://tinyurl.com/ycvm5mle>

PPI

<https://tinyurl.com/ybzsuslb>

AnDy Research Advisors Group

<https://tinyurl.com/y9gvh6jh>

Mental and Physical Pain in Art & Medicine

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Mailing address: INVOLVE Coordinating Centre, Alpha House, University of Southampton Science Park, Chilworth, Southampton SO16 7NS United Kingdom