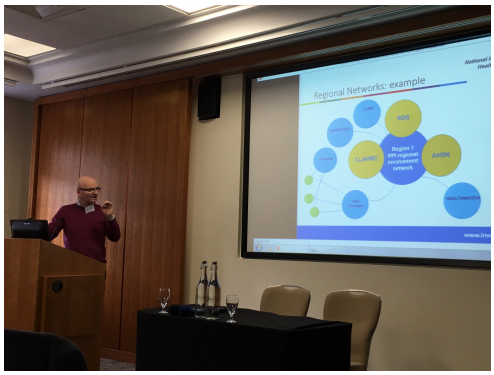
INVOLVE

NHS
National Institute for Health Research

newsletter

Autumn 2016



Welcome to the Autumn 2016 edition of the INVOLVE newsletter.

These are exciting times for INVOLVE with work focusing on three "Community Priority Areas" (Learning and Development, Diversity and Inclusion, Community & Partnerships), where INVOLVE will provide coordination and leadership and work with stakeholders to identify and prioritise key objectives for the next three years.

Also, our new partnership with the Research Design Services is starting to take shape and through that partnership working we are now working collaboratively to support the development and co-ordination of effective regional patient and public involvement (PPI) networks which make best use of effort and resources increasing regional to local connectivity to extend and deepen PPI.

To find out more about our work visit the current work page on the INVOLVE website. http://www.involve.nihr.ac.uk/current-work/

Also in this issue:

The Sharebank - working together to support public involvement in research

Author: Adele Horobin on behalf of the Sharebank team (Adele Horobin, Jane Flewitt, Raksha Pandya-Wood, Jane Stewart, Kirsty Widdowson, Andy Wragg, Paula Wray)

In 2014, the Chief Medical Officer and Director General of Research and Development ordered a review of patient and public involvement in the National Institute for Health Research. The report on this review, entitled 'Going the Extra Mile' was published in March, 2015. It laid out the goal to grow public awareness of research and increase the number and variety of people taking part and getting involved in research. The report listed a number of recommendations to achieve this goal, which included offering better support for the public and researchers to do public involvement. The report also urged local organisations to find ways to work together, so that ideas and resources can be pooled and shared for the benefit of all.

Guided by this report, we developed the public involvement training Sharebank. The Sharebank was set up in 2015 to create a solid platform for delivering support for public involvement in the East Midlands[1]. It was formed in the East Midlands by organisations of the National Institute for Health Research and a local NHS trust working together. These are the Nottingham Hearing Biomedical Research Unit, Nottingham Digestive Diseases Biomedical Research Unit, East Midlands Collaboration for Leadership in Applied Health Research and Care, East Midlands Research Design Service and the Nottingham University Hospitals NHS Trust Research and Innovation team. The principle behind the Sharebank is that individual organisations all have something of value to offer in terms of support for public involvement. That is, to help inform researchers on how to design and carry out research with or by members of the public; also to support the public to contribute to the design and running of research. Organisations share the skills that they have in a reciprocal, or give-and-take relationship, without the need to pay each other for training.

A programme of training events was delivered from October 2015 to March 2016. All organisations which took part ran at least one training event. These ranged from two hour or half day sessions right through to two full days. Training introduced the basics of public involvement in research, provided an overview of what research is and the role of the National Institute for Health Research. More detailed training on particular roles in public involvement, such as lay assessing was also covered. Throughout, training was designed to build in open discussions and group work, so that those attending the events contributed to everyone's learning. Events were open and made known to researchers and members of the public linked to the organisations in the Sharebank. Over 70 people, research staff and members of the public, attended events and the feedback has been very encouraging. People who came to events valued the chance to share their experiences. Indeed, both researchers and public gained useful insights by sharing their views with each other. As professionals in public involvement who delivered the training, we found the experience rewarding and gained new perspectives from listening to and joining in with the discussions.
We look forward to involving the public in growing our programme of support and would welcome enquiries from other research organisations in the East Midlands to get involved.

[1] Horobin A. Going the extra mile – creating a cooperative model for supporting patient and public involvement in research. Research Involv Engagem 2016;2:9

INVOLVE Coordinating Centre News

Welcome

We are delighted to welcome our new Senior Public Involvement Manager, **Kate Sonpal**

Working with the public has always been important to me. After several years as a nurse I became the Patient and Public Involvement Officer at the Southampton NIHR Clinical Research Facility, Biomedical Research Centre, and Biomedical Research Unit. As part of this role I established core public involvement groups for both adults and children, as well as a young adults group in collaboration with the South Central Research Design Service. Outreach work allowed me to help researchers facilitate condition specific groups, as well as reach out to the local community and ensure that opportunities for involvement were offered to a diverse range of people. I ensured that education on public involvement was a priority, both to the public and the research community. I am passionate about the involvement of people in research, especially children and young people.

Interesting magazine and media articles

Social Networking for patients

BMJ, 20-27 August, Cite this as: BMJ 2016;354:i4201

Is social media saving lives? Or is it spreading poor information and damaging private confidentiality? The rapid rise of patient support groups on social media is putting some fundamental ethical questions into the spotlight

http://www.bmj.com/content/354/bmj.i4201

I'm Engaged

The Researcher (NIHR publication)
Dr Cristina Vasilica, July 2016
https://www.cocreatedesign.com/clientarea/NHS/TheResearcherMagazine/mobile/index.html#p=18

Angela Coulter: At last some better news on shared decision making

BMJ, 16 July 2016
http://blogs.bmj.com/bmj/2016/07/01/angela-coulter-at-last-some-better-news-on-shared-decision-making/

Big health data: the need to earn public trust

Failures in implementation of data sharing projects have eroded public trust. In the wake of NHS England's decision to close down its care.data programme, Tjeerd-Pieter van Staa and colleagues examine how we can do better

Cite this as: BMJ 2016;354:i3636
http://www.bmj.com/content/354/bmj.i3636

A Study SHARED

Carole Mockford and Sue Boex

Our study, **SHARED**, is an acronym for **S**ervices after **H**ospital: **A**ction to develop **RE**commen**D**ations. This name also reflects the joint participation of lay and academic researchers, study participants and professionals in our health research study. It was funded by the National Institute for Health Research (NIHR): Research for Patient Benefit (RfPB) stream (PB-PG-1112-29064).

In this study, we aimed to develop recommendations for health and social care service professionals when supporting older people living with memory loss and their family carers in the first few weeks after leaving hospital and returning home. The study idea was initially discussed with carers of people living with dementia at an event held in London in 2011. This event was organised by the Alzheimer's Society and the NIHR for researchers to discuss their project ideas and get some feedback from those who had experienced living with dementia. We felt that talking to carers made our study much more focused on what was important to families.

We had a team of seven, including two lay members, professionals and academics, who were involved from the beginning in shaping the study and they helped to make sure the study progressed well. Once we were awarded funding, we advertised in established Patient and Public Involvement groups for lay members to join a separate Project Advisory Group or to become lay co-researchers. We asked that they had experience of dementia or memory loss particularly as a carer or as someone who lived with the condition. Members of the Project Advisory Group met regularly along with other professionals and academics to discuss the ongoing study and to advise on any problems we were encountering. Those who were co-applicants and those on the Project Advisory Group worked with the lead researcher to make sure the study went as smoothly as possible and finished on time.

We had 12 lay co-researchers at the beginning of the study. Everyone had to obtain some official documentation to enable them to interview people in their homes and they had some basic research training. When out interviewing they were accompanied by the lead researcher who supported them when it was needed. The lay co-researchers were involved as much as they wanted to be and no-one felt they were over-burdened. As well as interviewing, some were also involved in analysing the information we had collected after all identifying details had been removed. We met as a group on three occasions to discuss what we were finding out. We also conducted focus groups together with some of the study participants to see what they thought about what we had found out, and to help to co-develop the recommendations.

By this time we had five lay co-researchers who were actively involved, and they attended local events and international conferences, including the Dementia UK Congress annual research conference in Telford and the Royal College of Nursing annual international research conference in Edinburgh. They told audiences what we had done and what they felt they had added to the study. They also co-authored papers on how we started the study (Mockford et al 2016a) and one on the study itself (Mockford et al 2016b). We hope to write more papers together.

We found that we had a great deal of support from our funders and from the Research Ethics Committee (we had to get their approval on how we planned to undertake the study). We also had a lot of enthusiasm from all members of the research team. However, we did have some administrative problems which were challenging at the start of the study, such as how to pay the honorarium to the lay co-researchers, and in getting permission for them to interview staff on NHS premises in one of the two NHS Trusts in our study. We overcame these challenges, but do feel that there needs to be a discussion to clarify and simplify the administrative processes for lay co-researchers to participate in health research studies. Once over those hurdles the SHARED study progressed very well.

When presenting our study we have had to answer many questions about lay involvement, as there is a great deal of interest from professional and academic audiences about this.

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Sue Boex is a lay co-researcher from the SHARED study. She writes that because of their lived experiences, lay co-researchers were able to empathise and be aware of the participant's problems. Some had been in a similar situation and understood how the participants and carers are dependent on the care system. This understanding was especially useful during the interviews which were sometimes very emotional. Sue feels that, *'it was sometimes difficult not to reflect on one's own personal experiences but we were able to talk to the lead researcher about this'.* Sue added that it was a grounding but worthwhile experience, and one that shows the value of patient and public involvement. The study demonstrated the benefits of lay and academic researchers working together as a team, growing in confidence, able to question each other and looking at the research questions from both sides. *'We hope that this study will encourage other lay people to be involved in research such as this, which has real relevance to improve or make a difference to service users' lives'.*

References

a. Mockford C, Murray M, Seers K, Oyebode J, Grant R, Boex S, Staniszewska S, Diment Y, Leach J, Sharma U, Clarke R, Suleman R (2016) A SHARED study-the benefits and costs of setting up a health research study involving lay co-researchers and how we overcame the challenges. Research Involvement and Engagement (2016) 2:8. DOI 10.1186/s40900-016-0021-3

b. Mockford C, Seers K, Murray M, Oyebode J, Clarke R, Staniszewska S, Suleman R, Boex S, Diment Y, Grant R, Leach J, Sharma U (2016) The Development of Service User led Recommendations for Health and Social Care Services on Leaving Hospital with Memory Loss or Dementia – the SHARED study. (in press) Health Expectations.

Involving parents and adolescents in research: the Kids FIRST study

By Emma Haycraft and Natalie Pearson

The Kids FIRST study is a population-based study of sedentary screen-time (i.e. sitting down to use electronic media, such as televisions, tablets or game consoles) in young adolescents, led by Dr Emma Haycraft from Loughborough University's School of Sport, Exercise and Health Sciences. Kids FIRST is a Leicestershire-wide, family-and school-based educational and behavioural programme to reduce and manage the amount of time that young adolescents (9-11 years old) spend using electronic media during their leisure time. We wanted to do the study because sedentary screen-time has been linked to unfavourable outcomes, such as obesity, metabolic diseases (e.g. diabetes), psychological wellbeing, and poor educational achievement.

Involvement in the Kids FIRST programme required sign-up from families with a young adolescent. We were keen to obtain the views of families to determine, first and foremost, whether they thought our study was a good idea and, if we established this, the best way to recruit them into our study. We also wanted to find out how long our intervention should last and the kinds of resources families would want to engage with.

Involvement involved input from 102 parents and 42 young adolescents who took part in discussions and answered questions online or on paper.

The parents that took part in the discussions said that our topic was a priority for them and their family (or that it was a challenge that they were dealing with at home). Most parents said that they would be interested in such a project because they were keen to find out ways to either reduce or manage the amount of time that their child spent using certain items of electronic media at home. They were very aware of the increased popularity of electronic screen media and noted the increased demand from their child to have the latest screen or to be allowed to spend significant periods of time using screens. We also gained insight into some of the rules and strategies that parents have in place at home, which helped us to inform elements of the intervention.

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All parents felt that receiving a detailed letter from school was an acceptable way of signing up to a study like Kids FIRST. Parents felt that they were likely to engage with paper-based materials, with some stating a preference for these over web-based or e-mail resources. However, no one indicated that web-based or e-mailed materials would be a problem, with half of the parents stating that they would use a website to access information.

Determining the length of an intervention is always challenging. We had to balance having a duration that was long enough to see an effect with the need to avoid participants withdrawing or losing interest. Most parents said that 13-weeks was acceptable.

Interventions require participants to be engaged. We had initially planned several face-to-face sessions as part of the intervention but the views of parents indicated that they would find this challenging and a barrier to participation. As such, we reduced these to just one, non-mandatory face-to-face session at the start of the programme.

We also obtained the views of young adolescents. All of the adolescents had access at home to either their own tablet or a shared, family tablet. They spent most of the time using screens after school and at weekends, which supported the need for an intervention to target out of school screen use.

Interestingly, young adolescents realised that too much time spent sitting was unhealthy but, in many cases, didn't associate spending long periods engaged with screens as being unhealthy.

As Kids FIRST was planned to be a multi-component intervention, including a school-based element, teachers' views were also important. Teachers were keen for lessons to be delivered around the topic of sedentary behaviour and screen use, and found them to be very useful and informative.

Our experience suggests that parents perceive too much screen use in their children to be a problem and that they would welcome a programme that would help them to change this. Young adolescents are aware that prolonged sitting is unhealthy but do not always equate screen use with unhealthy sitting behaviour. Teachers would also welcome lessons about sedentary behaviour.

We found our involvement work extremely beneficial and we would like to thank all of the parents and adolescents who helped us with shaping and refining the Kids FIRST study. We are now designing a pilot study for the Kids FIRST intervention based on what they told us and we look forward to continued involvement in the future.

Contact: Dr Emma Haycraft • E.Haycraft@lboro.ac.uk • 01509 228160

Patient Led Research Hub – a New Initiative to Foster Patient Led Research

Patients can bring crucial insight into research priorities for disease and lifestyle needs. A new initiative launched by the Cambridge Clinical Trials Unit in May 2015 ensures patients are involved from the outset. The Patient Led Research Hub (PLRH) provides the expertise and infrastructure to support research projects emerging directly from, and proposed by, patients or patient organisations, improving research relevance and credibility.

How it works

The activities of the PLRH are supported by trialists, statisticians, a health economist and administrative staff. As research ideas are received, an initial feasibility assessment is conducted within the PLRH. Proposers are invited to discuss their idea in person and, where feasible, a management group including the proposers initiate study design and external funding applications. Strategy and governance are reviewed by the Cambridge Biomedical Research Centre (BRC) and the Cambridge University Health Partners' Patient and Public Involvement Research Oversight Group; seed funding was provided by the Cambridge BRC.

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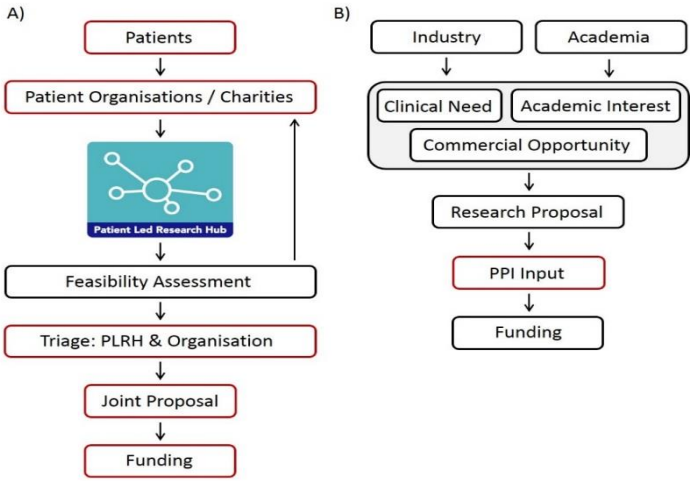
Focus

The PLRH is largely focused on clinical trials, although all projects are considered. The first two fully supported projects are now active: DRINK Randomised Feasibility Trial (see below), and the development of a hand-held home monitor for patients with low or high blood potassium levels. Additional proposals from a range of organisations are at earlier stages of progression. Importantly, the PLRH does not have a specific research: our ethos is to support every proposal, from any organisation, that is technically feasible.



A case study: the DRINK Randomised Feasibility Trial of water intake in polycystic kidney disease

Background

Autosomal Dominant Polycystic Kidney Disease (ADPKD) is the most common inherited renal disease, affecting 12.5 million people worldwide. It is characterised by the relentless growth of cysts throughout the kidneys and liver, ultimately leading to discomfort, pain, and kidney failure. Recent research has shown that vasopressin, a hormone regulating the body's water balance, may quicken kidney deterioration. Blocking vasopressin's effect with the drug tolvaptan can slow the progression to kidney failure; however, this medicine is expensive and has side effects.

Interestingly, drinking beyond the point of thirst stops the body from releasing vasopressin. In theory, this means high water intake (2-4L/day) could have the same benefit as tolvaptan without its negative side effects. This simple, free intervention would have enormous global implications for ADPKD patients. Currently doctors advise patients to drink large volumes, but one small study has suggested the kidneys may actually worsen with associated increase in water consumption.

Against this background, PKD Charity contacted the PLRH, proposing a trial to study the effect of high water intake in ADPKD. From June 2015, PKD Charity and PLRH have been equal partners in addressing this important question.

Study Design

DRINK asks whether it would be acceptable to patients, and technically possible, to perform a large water intake trial in patients with ADPKD. It is a 'feasibility' trial: shorter and smaller than a clinical trial, designed to evaluate study methods and assess the ability of patients to drink a sufficient amount of water to have an effect on vasopressin, and hence kidney function. The trial will run for 12 weeks.

Directed by lived experience within the PKD Charity, several features have been included to ensure trial participation is easy for patients. Home urine tests and smartphone applications allowing patients to enter information and complete questionnaires means that frequent clinic visits and cumbersome fluid diaries are not required. Ideally PKD Charity will be able to repurpose this smartphone technology for all patients to easily monitor their health status and fluid intake.

Progress

PLRH and PKD Charity continue to closely collaborate on trial progression. Funding has been provided by the British Renal Society, British Kidney Patient Association, and Addenbrooke's Charitable Trust. All approvals are in place, and the study should commence in September.

PKD Charity Collaboration

PKD Charity was established in 2000 to support individuals and families affected by PKD, raise awareness, and fund research into treatments. Despite the commonality of PKD, there are currently no clinical studies in the UK. Tess Harris, CEO of PKD Charity, has been heavily involved with DRINK from conception:

> "We started talking with the PLRH in spring 2015 and they showed genuine interest in meaningful research. Early discussions highlighted two potential therapy areas to study: water intake and improved management of chronic pain. Rapidly these topics have developed into: 1) DRINK feasibility study; 2) initial planning of a pain intervention study. The charity has been involved with DRINK from early stages, including co-producing a pilot survey and facilitating patient-researcher engagement.
>
> We are delighted to be involved with PLRH. Our input is valued and we regard our collaboration as a true research partnership."

Contact

PLRH welcomes all queries and research ideas through email (plrh@hermes.cam.ac.uk) or telephone (01223-274570). Follow @PLRH_Cambridge on Twitter for the latest news, events and study progress.

noticeboard

This is a regular column which can be used to advertise events, initiatives and publications about public involvement in Research and Development. If you would like to put an article on our noticeboard please contact the Coordinating Centre.

NHS Digital Introduction

From the beginning of August 2016, the Health & Social Care Information Centre has changed it's name to NHS Digital., along with the strapline 'information and technology for better health and care' which has been developed with the input of patient-led research. The new name, NHS Digital, provides an opportunity to relaunch capabilities to help people understand better the services they provide and to support the triple aim of better health, better healthcare and lower cost. A new website will also be launched, **digital.nhs.uk** which will provide advice and information on the statistics, services and support the NHS provide.

INVOLVE Newsletter

Exciting things are happening with the NIHR website and it's communications over the next few months. The new NIHR website has been launched and has information from across the NIHR.

In January 2017 the NIHR will be launching a new set of newsletters that cover all of it's functions.

One of these will be a new Patient and Public Involvement newsletter for the NIHR. By Summer 2017 the INVOLVE newsletter will become part of this new NIHR PPI newsletter.

If you want to continue to receive INVOLVE news and content in the new PPI newsletter, you will need to sign up to receive it. We will let you know how to do this nearer to the time.
You will also be able to choose to receive other NIHR newsletters if you want to.

We are always interested to hear about your experiences of active public involvement in research, whether you are a member of the public, a researcher or from a research organisation.

If you would like to contribute an article, news item or event notice please contact us.
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