

NIHR patients and the public

Autumn 2017

Spotlight on dementia research

September is World Alzheimer's month and to celebrate, the NIHR is shining a light on the fantastic research that is happening right now. From studies looking to develop new and better treatments, to research trying to find ways to help people live well with dementia, we're taking a look at some of the different studies hoping to make a difference to people with dementia and their loved ones.

Each week throughout September we will be focusing on a different theme around research.



- Week one: Types of research - it's not all drugs trials
- Week two: The research pathway (and why it takes so long)
- Week three: Developing new dementia treatments
- Week four: Research into rarer dementia types - with a focus on frontotemporal dementia (FTD)
- Week five: Ways to engage in research

My Signals - What research matters to you?

In **My Signals**, health and social care staff and service users tell us which research is important to them and why they feel others need to know about it.

Join the conversation on Twitter and tell us which Signals have interested, excited or surprised you, using **#MySignals**. You can find the latest NIHR Signals on the [Discover Portal](#).



We asked four members of the public who have experience of health research to tell us which NIHR Signals have most interested them, or even prompted them to rethink their care, and explain why they feel the findings are worth sharing.

<http://www.dc.nihr.ac.uk/highlights/my-signals-patients.htm>

PPI group puts clinical trainees through their paces in mock interviews

Patient and public advisors have been putting clinical trainees through their paces with mock interviews on the patient and public involvement elements of their research.

Four members of the Patients and Public Involvement Advisory Group at NIHR Guy's and St Thomas' Biomedical Research Centre (BRC) have carried out informal mock interviews with Clinical Training Fellows.

The advisory group members offered advice on the kinds of questions that a lay person may have about grant applications, to help the trainees improve their applications.



Read more about this initiative on the website of [NIHR Guy's and St Thomas' Biomedical Research Centre](#)

University of Sheffield researchers used Lego to involve children with ADHD and their parents in research!



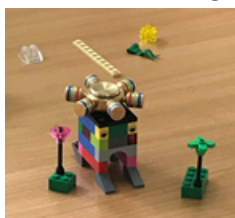
Children and young people with Attention Deficit Hyperactivity Disorder (ADHD) can encounter a number of difficulties including finding it difficult to concentrate at school, finding it difficult to communicate with others, struggling with change and school life, finding it challenging to form and retain friendships with others...the list goes on!

There are also some really great things about having ADHD such as often having a great sense of humour, being very creative, and when managing their condition in the correct way, can go on to lead extremely successful lives. For example, Michael Phelps (the most decorated Olympian to date), Louis Smith (Olympic gymnast, also won Celebrity Strictly Come Dancing!), Richard Branson (hugely successful entrepreneur), Will Smith (actor) and Jim Carey (actor) all have ADHD.



Here at the University of Sheffield, we are interested in how technology can help children and young people manage their ADHD properly so that they can go on to lead successful lives.

In order to do this, Miss Lauren Powell and Dr Jack Parker (School of Health and Related Research, University of Sheffield) held a workshop at Ryegate Children's Centre in Sheffield that involved children with ADHD and their parents using Lego to share their experiences of ADHD and how they think technology could help them manage their ADHD. The method used is called Lego Serious Play (LSP) and can be used to engage members of the public in research. To our knowledge, it has never been used with children and young people with ADHD before. This is a new and exciting way to involve this population in our research – something we find very exciting!



One child made a Lego model of a guard dog. They wanted to feel safe and liked boundaries (there was a structure either side of the dog) in their life.

Continued >>

Another child made a model that represented something that doesn't physically exist, whereby each brick represented a different set of instructions. They found that when they are given more than one instruction at a time at school, they struggle to keep up with the class and to learn. This is a common struggle in children and young people with ADHD.



Another child described how anxiety provoking it is when the teacher gets frustrated with him at school. He said the red brick was used to represent the teacher's anger and the person's hand is raised to represent his anxiety.

It was great to hear that all six children that attended and their parents enjoyed the workshop. One person stated that they had learned about ADHD and now realise that the common myth of "ADHD is just naughty children" is hugely inaccurate.

This work was jointly funded by the Research Design Service Yorkshire and the Humber (RDS YH) and the National Institute for Health Research (NIHR) Telehealth and Care Technologies (TaCT) theme of the Collaboration for Leadership in Applied Health Research and Care Yorkshire Humber (CLAHRC YH).

Written by the University of Sheffield's Miss Lauren Powell (Research Associate) & Dr Jack Parker (Research Fellow)

Patient Led Research Hub: Inverting the Patient Involvement Paradigm



Patients bring crucial insight into research priorities for disease and lifestyle needs, a valuable contribution recognised by a host of involvement initiatives. It is therefore important that patients are involved and enabled from a project's inception, ensuring inclusion of patient centred outcomes and acceptability of study designs. Pioneering work by the Patient Led Research Hub (PLRH) fills this unmet need, as the only UK initiative to allow patients to directly propose, initiate and conduct research. Launched by the Cambridge Clinical Trials Unit in May 2015, the PLRH provides the expertise and infrastructure to support research projects emerging directly from patient organisations, improving research relevance and credibility.

How it works

The driving ethos of the PLRH is to consider any research proposal, irrespective of its focus or disease area. Submissions are invited from any regional or national patient group or patient charity; individuals are encouraged to contact their patient organisation first.

The PLRH will assess each proposal, including background information and current literature, to consider how proposals align with existing knowledge gaps. A trialist will conduct a preliminary feasibility assessment before face-to-face meetings with proposers. Several outcomes are possible: 1) infeasible projects are not pursued, 2) where feasibility is uncertain, further work is undertaken, 3) feasible proposals may be referred to research groups with active and aligned work, or 4) feasible projects are taken forward by the PLRH in partnership with the proposing patient group.

Where the PLRH progresses a feasible project, the proposers are invited to form part of the study team, maintaining co-ownership of the emerging project and intellectual property where relevant. External experts or national research groups are invited to contribute to project development. Equal collaboration by the PLRH and proposers underpins competitive funding applications to public funders, research charities or industry partners. If funding is obtained, projects become autonomous to the extent possible, allowing PLRH resources to become available for new proposals.

Progress

The PLRH has received 23 proposals from 19 different organisations and independent sources. Proposals are wide-ranging from bench to bedside, but with a primary focus on quality of life. Two trials are active:

1. ***DRINK, Polycystic Kidney Disease (PKD) Charity***
Biologically, high water intake in PKD may reduce cyst growth by targeting the hormone vasopressin. Patient surveys and a national Patient Day led to two successful joint funding applications (Addenbrooke's Charitable Trust and the British Renal Society), enabling a randomised feasibility trial of high water intake versus standard care. Directed by lived experience, several features are included to ensure trial participation is easy for patients. PKD Charity has also funded trial technology to later repurpose for general patient use. Recruitment commenced September 2016 and is 70% complete.
2. ***K-MONITOR, Gitelman Syndrome UK***
Gitelman Syndrome is a rare disease that results in dangerously low blood potassium levels. Patients proposed the development of a handheld potassium monitor to inform their daily medication. A joint application to Kidney Research UK has successfully funded the development and miniaturisation of sensing technology. An additional upcoming grant application will aim to support an interventional trial with the completed device.
3. ***Other***
Joint funding applications are underway for projects in chronic pain management in autosomal dominant PKD, and salt loading in Gitelman Syndrome. Four projects proposed by rare disease and mental health patient groups are in early stages of development or feasibility assessment; three projects (Haemolytic Uraemic Syndrome, kidney transplant, pre-eclampsia) have been successfully linked with ongoing trials or aligned with specialist research centres. Five additional proposals regarding Muscular Dystrophy, Dialysis, Lupus, and Lipodystrophy are awaiting further work-up.

Overall, the PLRH has received excellent feedback from patient organisations, affiliated experts and external research groups. Collaboration with INVOLVE, East of England Research Design Service, and local NIHR patient involvement groups allow shared experiences and learning between established programmes and new patient led research. Further investment is now required to increase capacity and infrastructure to efficiently support ongoing and new proposals.

Contact

All feedback and queries are welcomed through email (plrh@hermes.cam.ac.uk) or phone (01223 274570). Follow @PLRH_Cambridge for the latest news, events and study progress.

Patient Experience Survey

Over the last two years the Clinical Research Network has worked on ways to collect and understand patient feedback on their experience of participating in clinical research. A new survey from the NIHR Clinical Research Network shows that nearly 90 per cent of patients asked have had a good experience of participating in clinical research, and 86 per cent would be happy to take part in another research study if it was offered.

<https://www.nihr.ac.uk/news/nihrs-patient-experience-survey-shows-positive-results/6706>

Recruiting study participants?

Whether you're part of the NIHR or a partner research organisation providing data to our systems, using the standardised terminology¹ helps us work better together to inform patient care through research findings more quickly.

Using the same language² when speaking or writing about recruitment across organisations (for example, on our websites, in our reports and in grant award letters) will help us to push the pace of research supported by the NIHR.

For example, using the agreed definition of recruitment and the other terms defined in the NIHR Minimum Data Set³ ensures that we all mean the same thing when referring to recruitment targets. Consistent terminology will also help us to better understand any delays to delivery of research studies to time and target.

(1) From 'push the pace' in para 1: <http://www.nihr.ac.uk/about-us/how-we-are-managed/boards-and-panels/push-the-pace.htm> (2) From 'definition of recruitment' in para 2: <http://www.nihr.ac.uk/funding-and-support/study-support-service/performance-monitoring/recruitment-data/> (3) From Minimum Data Set in para 2: <http://www.nihr.ac.uk/research-and-impact/nhs-research-performance/hra-approvals-and-nihr-metrics.htm>

NIHR key statistics and league table data reveal increase and improvement for 2016/17 research in the NHS

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The National Institute for Health Research (NIHR) has published national data revealing that more people than ever before are being given access to new and better treatments through participation in clinical research. The annual Key Statistics data shows that the number of participants recruited into clinical research studies in 2016-17 exceeded 665,0004, the highest number of clinical research participants in any given year.

<https://www.nihr.ac.uk/news/nihr-nhs-research-activity-league-table-and-annual-key-statistics-data-reveal-encouraging-increase-and-improvement-for-201617/6641>

Who are the NIHR? #WeAreNIHR

A new video has been released to explain who the NIHR is and what it does. The video, which is less than one minute long, describes the NIHR 'in a nutshell' and features people from across the NIHR who are working towards improving the health and wealth of the nation through research.

To watch the video visit: <https://youtu.be/hJI6BEZy5HM>.

Patient Research Ambassadors travel to Florida to promote young peoples involvement in research

Three young Patient Research Ambassadors, accompanied by Jenny Preston from the NIHR took to the sky this month with one common goal; to ensure young people and families have a voice in the healthcare they receive. The team attended the [International Children's Advisory Network \(iCAN\) Research and Advocacy Summit](#): Providing children and families a voice in medicine, research and innovation.

Young Patient Research Ambassadors Sophie Ainsworth, Simon Stones and Robyn Challinor have worked with Jenny on many research projects and together they presented some of their achievements at the Summit, Robyn said:

“The iCAN Summit 2017 has been a week filled with friendships, fun, new ideas, research activities and new connections. Taking part in sessions about industry standards, expectations and the chance for my voice to be heard has motivated me to be more involved in the coming year. Catching up with Young Person's Advisory Groups from around the world only highlights the important work we do in the UK, and how others can learn from us. It is exciting to see what the next year will bring for iCAN, and I look forward to the iCAN Summit 2018 in Edinburgh!”

Sophie will be representing young people's involvement in research at the NIHR INVOLVE at 21 Conference later this year.

INVOLVE Conference 2017



The INVOLVE conference is now fully booked and registration has closed. You can find out about the conference and the work of INVOLVE on our website, www.involve.nihr.ac.uk and will be using the hashtag **#INVOLVEat21** on Twitter for any tweets about the conference.

News from NIHR <http://tinyurl.com/hc2g3jz>
INVOLVE IN: Bulletin issue 1: The AQUA-Trial
<http://www.invo.org.uk/?p=111796>

[Apply to become a public reviewer](#)
<http://tinyurl.com/zxl8hov>

Read the latest NIHR blogs <http://tinyurl.com/zh6bnby>

New Patient Research Ambassador resource
<http://tinyurl.com/zeh8rel>

[Learn Zone](#) <http://tinyurl.com/jjcd9on>

Events <http://tinyurl.com/jpe7zzz>

[Research Changed my life](#) <http://tinyurl.com/zcoj4ax>

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