

Understanding and improving Assessment Processes for Talking Therapies (APTT): A new user-controlled research programme

Abstract: Whilst user involvement in research has increased over recent years, it remains rare to find examples of National Institute for Health Research (NIHR) funded user controlled research. This poster will describe a five-year research programme that is being led and controlled by a service user researcher. It will explore the ways in which the programme differs from standard NIHR research.

The topic of the research programme is understanding and improving Assessment Processes for Talking Therapies (APTT). Experiential evidence from service users suggests that talking therapy assessments are problematic, yet this issue is absent from the research agenda. Three connected studies will explore the enactments and experiences of talking therapy assessments and how these can be improved. Study one will systematically review relevant international literature. In study two, pairs of service users and assessors will be interviewed and the convergence/divergence of accounts explored through thematic analysis. Interpretive Phenomenological Analysis will explore service users' lived experiences in more depth. Finally, study three will use consensus methods to generate full clinical guidelines on talking therapy assessments.

The programme is based at St George's University of London and runs until December 2018. It is guided by a Clinical Advisory Group and a Service User Advisory Group. Each study will be shaped and changed by user involvement and user control, and

the aim of this poster is to explore these impacts.

Developing mobile applications for and with young people with long-term conditions learning to share their health-care with professionals: A young person and family-led approach

Abstract: Although young people are frequent users of mobile devices in day-to-day life, there is little reliable research that actually involves young people with long-term conditions as partners in the development and testing of mobile technology applications to support their health needs. However, the transition from child to adult health services means that young people need to develop their own clinical skills and knowledge so that they can manage their condition in a confident and competent manner. Therefore this area of research is ripe for development.

A group involving a patient with juvenile idiopathic arthritis (JIA), a parent, doctors, nurses, researchers and technologists have established a Manchester-based research and development programme on mobile technologies for young people with long term conditions. We have fostered strong partnerships with other national groups to help us agree on research priorities in this important area, and a plan of work

to help us achieve these.

First we obtained valuable suggestions from a national group of children and young people with JIA on the types of information and tools they would like to see included in a JIA specific mobile application. Next we are reviewing the research evidence to help us in our future work, and working with young people, parents and health professionals to produce a detailed software specification for a prototype application to test with young people. This poster will explore and discuss the progress we have made, with a focus on the central role of young people and their families living with JIA in the project.

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Developing patient and public involvement (PPI) at the Bristol Nutrition Biomedical Research Unit: The challenges of tailoring PPI

Abstract: The National Institute for Health Research (NIHR) Biomedical Research Unit in Nutrition, Diet and Lifestyle at the University of Bristol and the University Hospitals Bristol NHS Foundation Trust was launched in April 2012 and specialises in a diverse range of research areas including: nutrition, physical activity and lifestyle in men with prostate cancer; optimising nutrition in children with chronic disease; pre and post-surgical feeding; and sedentary

behaviour in people with diabetes. The Unit aims to carry out research that is translational – directly translating research findings to benefit clinical populations – and involving patients and the public is an integral part of achieving its aims. Nevertheless the diversity of research areas presented challenges for researchers who were keen to involve patients and the public in their research.

This poster explores the ways that researchers, who had varying levels of experience with patient and public involvement (PPI), went about developing involvement across the Unit's key research themes. The presentation will explore how researchers developed PPI policies and associated documentation, adapted recruitment processes to suit patient groups, and tailored induction and training to meet the requirements of PPI involvement across related, yet distinct, research areas. The difficulties encountered and attempts to overcome these are discussed, and examples of successful PPI contributions into research projects are presented.

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A game of science: The gamification of science literacy for hard-to-reach groups

Abstract: In a long-term project partnership between Manchester Metropolitan University and Parkinson's UK, we are developing a distinct kind of engagement activity. Instead of teaching the public about a research topic, we aim to give the

public the tools they need to understand any area of science or health research they wish to engage with. By giving the public these tools we are approaching our aim – to develop a more informed audience – from a different direction to traditional public engagement projects.

Our workshops have been running for several years and have evolved in response to feedback. The workshop style allows the presenter to encourage participants to pull back a curtain and reveal how science is done. Through activities, participants are given opportunities to uncover the research cycle, understand peer review and the primary literature, and to have a go at designing a study for themselves. The skills learnt in these sessions give the audience confidence to find out more about science and engage with research, and may encourage increased patient and public involvement.

Feedback from participants is now directing this project down a new path. We are developing a table-top game – the Game of Science – to teach how science, particularly medical research, is conducted and communicated. Importantly, the table top format of the game makes it suitable for social support groups and those who do not use a computer.

This poster describes the current game prototype and discusses our philosophy for public engagement with research.

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Kidney Research UK:

Developing better patient engagement in research – a pilot scheme within the dialysis community

Abstract: Kidney Research UK welcomes National Institute for Health Research's (NIHR's) OK to ask campaign and web-based engagement activity. However, discussions with its Lay Advisory Committees, patients and carers from around the UK highlighted the need to understand more about achieving effective engagement, responding to feedback and maintaining successful relationships. A more personalised approach supported by national campaigns was needed. Consequently, a small-scale pilot project was developed to determine aspirations and needs, identify best practice, sustain engagement and promote research.

A three-month dialysis focused community pilot in Mid-Wales and Shropshire involved two volunteer research champions. It identified the need for a flexible 'toolkit' approach including information on research impact and a questionnaire. Ten people were signed-up and subsequently stewarded into various involvement opportunities; three volunteers are now involved in advising on a large clinical study. The learnings have also informed our plans to achieve a pool of 50 research champions by 2015.

This is just the start of the journey; for many patients it will take time to be able to or to be motivated towards finding out about research and how to get involved. Relationship building for the longer-term is key as well as the development of support. A further pilot is planned in Scotland in the 'transplant' community.

This exercise and its replication to other sites has the potential to deliver an incremental pool of patient advocates providing specific advice for projects as reflected in the RAPP0RT (ReseArch with Patient and Public inv0lvement: a RealisT evaluation) study and delivering insightful input to the overall NHS drive for increased patient involvement in research.

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Personal impacts on lay reviewers: A Research Design Service South East Exploration

Abstract: The Research Design Service South East (RDS SE) actively involves 9 lay reviewers in a variety of ways. Our dedicated team of reviewers can provide a lay review of research proposals, assessing the quality and appropriateness of the patient and public involvement (PPI) within them. The lay review service is provided as a standalone service, or as a component part of the RDS SE pre-submission panel (PSP). The PSP comprises members of the RDS SE team and lay reviewers and meets to scrutinise funding applications prior to final submission using similar criteria to National Institute for Health Research (NIHR) funding panels. Our team of lay reviewers is also involved in decision making regarding awarding RDS SE PPI grants. Some of our lay reviewers are also involved with the PPI Working Group (which oversees the work plan of the PPI team as laid out in the RDS SE tender and

annual report), and have also been involved in aspects such as feedback on RDS SE marketing materials.

Given the important and highly valued contributions that they make to the RDS SE, we wanted to evaluate the impact that this work had on them from their personal perspective. A survey was designed and sent to reviewers in summer 2013. One lay reviewer also contributed to survey design. Survey response rate was 88%.

Survey results were very encouraging, and highlighted a few themes for the wider research community and structures, and to a lesser degree the RDS SE. This current work follows up preliminary findings presented at the 2012 INVOLVE conference.

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GRIPP 2: Developing consensus on the reporting of patient and public involvement

Abstract: GRIPP2 (Guidance for Reporting Involvement of Patients and Public) provides consensus-based guidance on reporting patient and public involvement, with the intention of enhancing the quality and transparency of the patient and public involvement (PPI) evidence base. GRIPP 2 has been developed in collaboration with the EQUATOR (Enhancing the QUality and Transparency Of health Research) Network and other collaborators, following the EQUATOR 18 step process. We undertook three rounds of a Delphi survey between September 2013 and February 2014 with 143 participants identified from key PPI networks, including academics, clinicians, public

organisations (eg charities, funding organisations) and patients. A face-to-face consensus meeting was held after the Delphi survey was completed to gain consensus by discussion for items not reaching consensus in the Delphi, to tweak wording of items to improve comprehension, and to discuss dissemination of the GRIPP 2 checklist.

Response rates were high in each round of Delphi, with 86% (123) responding in Round 2 and 78% (112) responding in Round 3. A key outcome of Round 1 was the identification of a need for a long form of GRIPP 2 for papers focusing on PPI, and a short form of GRIPP 2 for papers where PPI is not the main focus, such as clinical trials. Participants were therefore asked to identify which items of importance for a short form version of GRIPP 2 in Round 2.

GRIPP 2 (long form and short form) is the first international guidance for the reporting of PPI. This presentation will describe its development, key components and future development.

**Successfully involving
service users and health care
providers in a Cochrane
systematic review of
physiotherapy for people with**

stroke

Abstract:

A systematic review of physiotherapy for people with stroke

There are several different theoretical approaches to the delivery of physiotherapy after stroke. How these are described and delivered can vary considerably. A Cochrane systematic review summarises the results of clinical trials, providing the best evidence on the effectiveness of healthcare interventions. We wanted to update an existing Cochrane review of physiotherapy for patients with stroke, ensuring that it was clinically relevant and useful. We adopted a novel approach to engage stroke survivors, carers and physiotherapists in this systematic review.

User-involvement in this systematic review

We formed a stakeholder group (SG), comprising 13 purposively selected stroke survivors, carers and physiotherapists. The SG met at three pre-determined time points during the 12-month project. The aims of the group were to ensure the updated review was clinically relevant; to agree on whether to include (or exclude) international evidence arising from different cultures and healthcare systems; and to guide dissemination to ensure that the updated review impacted on practice. Formal group consensus methods, based on nominal group techniques, were used to reach consensus decisions.

Discussion and conclusions

The involvement of key stakeholders impacted on all areas of the review, including; inclusion of international studies, classification of treatments, and comparisons explored within meta-analysis. Local dissemination strategies aiming to translate review evidence into practice were formed. User-involvement significantly influenced decisions around the scope and format of the review, and ensured relevance and accessibility of the output. This approach to user-involvement

has implications for other systematic reviews.

A James Lind Alliance top stroke survivor priority leads to a PhD fellowship exploring the long term consequences of stroke

Abstract:

Background: The shared Top 10 research priorities of stroke survivors, carers and health professionals were identified in a James Lind Alliance priority setting project in 2012. Number 2 in the Top 10 (and the top stroke survivor priority) was “How can we help people come to terms with the long term consequences of stroke?” This led to a successful PhD fellowship application intended to address this question.

What did we do? We aimed to answer this complex question, which clearly could not be answered by one stand-alone research project, through implementing a series of projects to ‘unpack’ this top stroke survivor research priority. To achieve this, stroke survivor involvement would be central to our research. Our programme of work is being informed and advised by an advisory group of five long term stroke survivors, brought together specifically for the purpose of this project.

What was the impact? We have successfully completed the planning stage of this research project including achieving

ethical approval. Stroke survivor involvement has resulted in improved design and content of information sheets, piloted and refined focus groups and advice on the best ways of overcoming those potential barriers to stroke survivor participation that may exist, and how best to overcome them.

Conclusion: Involving stroke survivors in the planning of this PhD fellowship has enhanced and provided credibility to our methods. We are confident that continuing to include the stroke survivors' perspective throughout will be of benefit, and further improve the project as it progresses.

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Mighty oaks from small acorns grow: The development and maturation of public involvement in research in Hertfordshire

Abstract: The Public Involvement in Research (PIRG) at the University of Hertfordshire now forms an integral part of research activities within the institution. Over the last decade, the group has developed into a highly proactive, valued and experienced component of research activity within the Centre for Research in Primary and Community Care (CRIPACC). The PIRG has an expansive role that includes recruitment and teaching as well as its research activities.

We will present the levels of involvement of the group,

reflecting the growing diversity of roles and applications. The poster will utilize the involvement model – consultation, collaboration and user controlled – to explore the journey of the PIRG, its contribution to a wide range of research studies throughout this spectrum, as well as at a strategic level and in regional research initiatives such as the Collaborations for Leadership in Applied Health Research and Care (CLAHRCs).

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Sheffield Motor Neurone Disease Research Advisory Group

Abstract: The presentation will be in the form of a poster and it aims to educate people about the group that is now supporting Motor Neurone Disorders (MND) researchers through Yorkshire and Humber to:

- Enable patient and carer perspectives to be included in research proposals
- Identify and prioritise research topics important to patients and their families
- Improve recruitment to research studies
- Aid researchers to write clear lay summaries and study information sheets
- Help share research findings with a wider audience
- Raise awareness of MND research.

The group has increased its activity substantially since its development in 2009 and would like to share its experiences and ideas with other individuals involved in patient and

public involvement work to encourage the innovative methods they have used.

Research agenda setting from the perspective of a highly diverse patient population with visual impairments or ophthalmological diseases

Abstract:

Background: Patient involvement in research agenda setting has been studied in various initiatives. However, little insight is available on effective involvement strategies for both vulnerable, and for highly diverse and divided patient populations.

Objective: To develop a research agenda for people with visual impairments or ophthalmological diseases, taking into account their specific needs for optimal involvement and the heterogenic nature of the patient population.

Methods: The Dialogue Model was used, comprising the following four phases: exploration, consultation, prioritization and implementation. Eight homogenous focus groups were organized and several additional interviews were conducted during the consultation phase. During the prioritization phase, medical research topics and societal and rehabilitation research topics were ranked in two questionnaires. Several strategies were applied to optimize the involvement of visually impaired

participants.

Results: To unify the diverse patient population, the topics of the research agendas were categorized under general themes (eg regenerative medicine, cause and mechanism of disease, and orientation and mobility). Some topics were formulated for specific ophthalmological diseases; however, during the consultation phase a substantive overlap in research topics was identified between the different patient groups. Additionally, by correlating the results of the data to the ophthalmological disease and severity of the impairment justice was done to the diversity of the needs of the patient groups.

Discussion: This research will provide insight in strategies to set up a shared research agenda from the perspective of a highly diverse and divided patient population.

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