

# **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.

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# **Forming, storming, norming and performing: Developing an external PPI advisory group**

Abstract: The poster content will include:

- The rationale for and mechanisms of forming an external advisory group supporting patient and public involvement (PPI).
- The issues concerning the recruitment of public contributors.
- The challenges of establishing a group of this type.
- Developing a high functioning group which has become a 'critical friend' to the organisation.

The issues we hope to raise include:

- The transferability of this model to other organisations.
- Group practices and mechanisms and their relative success.

- Impact of the group.

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# The Involvement Portfolio

**Abstract:** The Involvement Portfolio has been developed by the NHS R&D Forum Service User and Carer Working Group. It is a tool for those using health and social care services who are involved in voluntary or involvement activities such as consultation, committee membership, research and development, to record and provide evidence of their activities.

Many people using health and social care services are involved in a range of involvement and voluntary activities such as research, teaching and training. Much of this involvement goes unrecognised although the participants are gaining valuable skills and experience as well as contributing their experience and expertise. This tool allows people to record the skills and experience gained through involvement and voluntary activity as this can help with applications to undertake new activity, for educational or vocational courses, or to find employment.

In the portfolio, the portfolio holder has the opportunity to record their employment or other experiences including those gained through voluntary activity, or life experience such as being a carer or a parent, training events and experience of leading or facilitating training, 'involvement activity' and experience including taking part in committees, in consultation events, in NHS or social care research and development, or in curriculum development for educational courses. The portfolio holder has the opportunity to record the involvement activity they have taken part in, the type and

level of involvement, the skills learnt, and any qualifications gained.

The portfolio was successfully launched some years ago and has now been refreshed and re-launched taking into account the lessons learnt and experience of its use.

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# **Patient identified need as a driver for service and product innovation**

**Abstract:** Securing greater patient and public involvement is a central theme of health policy in many countries (Coulter 2011) and is a growing healthcare phenomenon (Boote et al 2012, Staniszewska et al 2011, WHO 2006). However, the voice of the professional, in general, continues to have a stronger input and impact than that of the patient.

This paper will outline a framework for patient identified need that aims to address this imbalance by moving beyond the concept of 'involvement' at some point, to putting the patient voice first so that it sets the direction in determining research priorities, treatment and product innovations and methods of service provision.

Using a co-production methodology (Gillard et al), we have worked with patients, in different clinical and educational settings to develop this framework and identify some core underpinning principles that need to be present to foster good quality and effective patient and public involvement (PPI) that leads to innovation that is fit for purpose.

We will:

- feedback on the patient experience of using this model when working with health technology industry to inform the development of new products and the NHS and higher education in regards to service innovation and education and research priorities.
- invite discussion on the potential value of the framework from their PPI experiences.

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# **The Citizen Scientist Concept: Building a research active community**

Abstract: Public understanding of health research and access to information about local involvement opportunities is a widely recognised problem yet no simple solution seems to meet the public need.

As the Citizen Scientist Project Public Advisory Group, our goal was to help people find out about health research in our local area and opportunities where they can take part in research studies. The project aims to put the choice with the patient which we believe is a concept that is long overdue in clinical research. The Citizen Scientist Project is pushing a cultural change of encouraging members of the public to enquire about research rather than being approached by a clinician. This is important as the vast majority of patients whose health, care and treatment we are trying to improve live in our communities not in our clinics. We believe that by

making research more accessible in this way we can increase awareness, understanding and acceptance of the research.

The practical implications for the Citizen Scientist project are how we best communicate local research to local people. Improving access to opportunities and understanding of what research is and isn't are key objectives. We helped to determine the design and feel of the project and work closely with the management team to provide sense checks and oversight from a public perspective. We are proud to have helped drive this unique and innovative project forward. This poster is designed and presented by the Citizen Scientist Public Advisory Group (CSAG).

The Citizen Scientist Advisory Group supports the management team for the Citizen Scientist Project. They formed in early 2012 and consist of members of the local population of Salford. They have provided a means to sense check and support decision making for the project from early setup to its current plans for wider roll out.

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**Building a new PPI community  
from a CLAHRC programme:  
Creating lenses to focus  
CLAHRC East of England**

# participation multidimensional perspectives

Abstract: The Collaboration for Leadership in Applied Health Research and Care (CLAHRC) East of England which links universities, NHS Trusts and other regional health and social care organisations and communities, is developing patient and public involvement (PPI) across several dimensions of its programme of research. It has a specialist PPI theme group tasked with developing a PPI research portfolio of PPI-specialist topics as well as with encouraging PPI to be embedded across the whole programme. These will need to recognise and encompass diverse approaches to and ways of recognising 'high quality', relevant and meaningful research. To achieve this will entail identifying and using research and action 'lenses' to focus issues of culture, process and ownership, for a new "PPI community" is to be built which can engage in research collaborations.

A key aim is to learn from and share lessons through case studies and narratives about the dynamics at work here. Current plans include:

- enabling different kinds of PPI representation and experience in our work by building on existing networks including relevant voluntary organisations and regional Healthwatch memberships
- using action research and Normalisation Process Theory approaches to build working knowledge about the implementation experiences of and range and quality of impacts from embedding PPI within a developing programme
- identifying level and type of resources, communication and training needed by all PPI partners (researcher, clinical and lay) for PPI to be effective.

We will actively encourage audience perceptions of our

selection and use of 'lenses' to encourage convergences and collaborations and enhance awareness of potential refractions and divergences.

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# **“Doing PPI at scale”. Exploring the impact of public involvement in the NIHR Greater Manchester Primary Care Patient Safety Translational Research Centre: Interim findings of a formative evaluation**

**Abstract:** The Greater Manchester Primary Care Patient Safety Translational Research Centre, funded by the National Institute for Health Research for five years, undertakes research to improve patient safety in primary care. Approximately 8% of its £6.5million budget is devoted to public involvement and engagement. A key element of the Centre's approach to public involvement is its Research User Group (RUG). The RUG is made up of 12 patients, carers and service users with an interest in patient safety. The RUG works in partnership with the Centre's researchers, advising on, and assisting with, research developments. The Centre is keen to evaluate the impact of the RUG to ensure that RUG



members are involved appropriately and meaningfully, and to ensure that its budget for public involvement and engagement is being spent wisely. As such, an evaluation of the impact of the RUG is currently underway.

This presentation will outline:

- How (if) the RUG works in partnership with the Centre's researchers
- The methods used in the evaluation of the partnership working between the RUG and the Centre's researchers
- How RUG members are actively involved in the evaluation, through their membership of the evaluation advisory group
- Some interim findings, based on interviews with key stakeholders, as well as impact feedback forms completed by both RUG members and Centre researchers

We will provide a number of examples of the impact of RUG members, as well as discussing the challenges of undertaking meaningful public involvement within such a complex organisation.

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