

newsletter

Summer 2013

Looking forward to Summer, we begin with a reflection on the evidence base for involvement written by members of the INVOLVE Advisory Group.

What's the evidence for? A critical reflection on the evidence base for public involvement in research

By Rosemary Barber, Louca-Mai Brady, Tina Coldham and Helen Hayes

Introduction

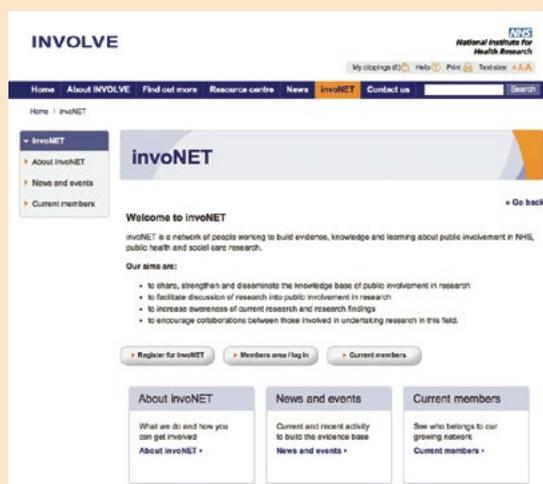
We held an invoNET sponsored workshop at the INVOLVE 2012 Conference to debate the evidence base of public involvement in research and inform the shape of future invoNET events and further work.

invoNET is facilitated by INVOLVE. It is a network of people interested in developing the evidence base on the nature, extent and impact of public involvement in research to increase the awareness of current research and findings, and also to promote shared learning and discussion. It is currently reviewing how best to support those interested in the evidence base and how to broaden awareness of invoNET and the Evidence library.

[Continued>>](#)

In this issue:

What's the evidence for?	1
Public involvement and the REF 'impact' agenda	3
INVOLVE Coordinating Centre news	4
Interesting articles and publications	5
Beyond the usual suspects	6
Public involvement in clinical trials	7
Involving patients and the public in the work of the MRC CTU	7
PPI in research – passing the town hall meeting test	9
Budgeting for involvement	9
STOP Diabetes study	11
Noticeboard	12



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The workshop considered:

1. What do we mean by the 'evidence base'?
2. Who are we trying to influence with this evidence?
3. What are the purposes of the evidence base?
4. What is lacking in the existing evidence base in order to fulfil the purposes identified?
5. How can invoNET help build the evidence base?

The workshop was facilitated by Tina Coldham, Louca-Mai Brady and Rosemary Barber with support from other invoNET members: Jonathan Boote, Jim Elliott, Tara Mistry, Mark Petticrew and Patricia Wilson. Hugh McLaughlin also contributed to the initial development of the workshop.

The workshop was well attended and delegates were very enthusiastic about the discussion topics. There was limited awareness of invoNET and what it could offer.

Questions discussed at the workshop

1. What do we mean by the 'evidence base'?

The nature of the evidence about the impact of public involvement was contested, with different stakeholders valuing different types of evidence. Delegates felt that it was important to clarify the evidence requirements of different stakeholders in order to avoid misunderstandings about the type of acceptable evidence. Not all categories of evidence will be understood or accepted by all researchers. There was felt to be a need for greater specificity about what we mean by an evidence base and for more rigorous evidence.

2. Who are we trying to influence?

Many different types of people could be influenced by evidence of the positive benefits of public involvement in research, including: commissioners of research; NHS providers; influential peers who can provide leadership on public involvement; sceptical researchers as well as researchers in training; and research participants.

3. What are the purposes of the evidence base?

Evidence can be useful to convince sceptics and provide knowledge and learning for people interested in or new to public involvement. We could begin to investigate what works for whom and how, and the importance of the context for public involvement. Different stakeholders are likely to value different aspects of the evidence.

4. What is lacking in the existing evidence base?

We are lacking theoretical frameworks to explain how public involvement can work best and guide evaluations. Information about the impact of public involvement should move from descriptions to testing theories using a strategic approach.

Aspirations are to move towards implementing good practice underpinned by evidence and to build capacity. The links between research findings and the benefits for users of services need to be strengthened. We need to know if the research made a tangible benefit to services. Little information is available about cost effectiveness. If monitoring is set up by research commissioning programmes it could provide information about how public involvement was implemented in research projects and programmes.

Delegates stressed the need to ensure accountability to the public by informing them of the difference public involvement in research has made.

5. How can invoNET help build the evidence base?

Discussions during the workshop confirmed the need to raise awareness and increase the use of invoNET. Delegates suggested invoNET address further questions, including:

- What type of evidence should invoNET provide access to, and for whom?
- How can – and should – invoNET support the development of theoretical frameworks and a more strategic approach to public involvement?
- How can invoNET help to develop approaches to assessing tangible benefits and cost effectiveness of public involvement in research through monitoring and evaluation?

Help us to continue these discussions and find out what others are doing around developing the evidence base for public involvement in research.

Join invoNET

Register on the INVOLVE website
www.invo.org.uk/invoNET/

View the Evidence library

A collection of over 230 references to articles on the impact, nature and extent of public involvement in research www.invo.org.uk/resource-centre/evidence-library/

In the next newsletter we will feature interviews with invoNET members exploring their views on the impact public involvement has on the quality of their research.

Public involvement and the REF 'impact' agenda: squaring the circle?

By Ann-Louise Caress

What is the Research Excellence Framework?

The 'Research Excellence Framework' or 'REF' is a periodic activity undertaken to assess the quality of research in universities in the United Kingdom (see www.ref.ac.uk). It was formerly known as the 'Research Assessment Exercise' (RAE). The REF is very important because it compares research quality across comparable subjects and determines the level of funding available to universities from the four UK higher education funding bodies. The next REF will take place in 2014, so UK universities are well underway towards developing their submissions. These will be assessed through rigorous review by subject-specific panels, which may include lay representation. Submissions are assessed on the type and quality of research publications; volume and source of research funding and quality of the research environment. For the first time, the REF in 2014 will also include assessment of the 'impact' of research.

REF 'impact criteria'

Given that this is the first time that 'impact' has been included in one of these nationwide assessments of research quality in the UK, exactly what constitutes a good example of 'impact' is still evolving. REF guidance defines 'impact' as follows:

'For the purposes of the REF, impact is defined as an effect on, change or benefit to the economy, society, culture, public policy or services, health, the environment or quality of life, beyond academia' (HEFCE et al 2012a)

The emphasis on impact being 'beyond academia' is important. It means that researchers are now required not just to demonstrate ways that their research is highly regarded by fellow researchers, but also how it is 'making a difference' more broadly. In order to do this, each REF submission will have to include several 'impact case studies'.

The broad criteria for assessing these case studies will be the 'reach' and significance' of the impact reported (HEFCE et al 2011). This relates to how widespread the benefit of the 'impact' is and how important or meaningful it is to relevant stakeholders.

Does public involvement have a role in REF 'impact' case studies?

A role for patient and public involvement in, or engagement with research in creating or demonstrating 'impact', as defined by the REF, has been identified:

'Impacts or benefits arising from engaging the public with the submitted unit's research will be included' (HEFCE 2011)

Although this definition refers only to 'engagement', guidance for the REF panel to which much health and social care research will be submitted does make explicit mention of 'involvement' and emphasises that:

'There must be a clear link between the research and the engagement or involvement activity' (HEFCE 2012b)

It further states that:

'The activity should go beyond 'business as usual' engagement or involvement (for example, there was active involvement of service users and/or the public, the activity informed the focus of the research or created widespread interest, was particularly innovative, or created legacy resources)' (HEFCE 2012b)

Challenges

The REF definition of 'impact' (see above) is clear that it cannot be on the research process/research itself, but must have a wider remit. This presents a considerable challenge, given that there is a limited body of evidence regarding the 'impact' of patient and public involvement/engagement on 'outcomes' as opposed to 'process' in research (Staley 2009).

Demonstration of causal links is challenging in many fields, but is especially the case for patient and public involvement in/engagement with research. How is it possible, for example, to 'prove' that such involvement was the 'vital ingredient' that resulted in the 'impact' (and, indeed, should one even strive to demonstrate this)?

All impact case studies must be supported by relevant 'evidence'. This includes, but is not limited to, publications. Other examples of relevant 'evidence' may include demonstrable changes in policy or practice, reports in the mass media or testimonials from relevant stakeholders. Given its novelty in assessment of research quality, many researchers are struggling to provide sound evidence of impact, as this has often not been adequately captured/recorded to date – and patient and public involvement/engagement is by no means immune from this problem!

References

Higher Education Funding Council for England (HEFCE), Scottish Funding Council (SFC), Higher Education Funding Council for Wales (HEFCW) and Department for Employment and Learning Northern Ireland (DELNI) (2011) Decisions on Assessing Research Impact' (REF 01.2011) www.ref.ac.uk/media/ref/content/pub/decisionsonassessingresearchimpact/01_11.pdf

HEFCE, SFC, HEFCW, DELNI (2012a) Assessment framework and guidance on submissions (02.2011 updated version) www.ref.ac.uk/media/ref/content/pub/assessmentframeworkandguidanceonsubmissions/GOS%20including%20addendum.pdf

HEFCE, SFC, HEFCW, DELNI (2012b) Main Panel A Criteria (01.2012) www.ref.ac.uk/media/ref/content/pub/panelcriteriaandworkingmethods/01_12_2A.pdf

Staley K (2009) Exploring Impact: Public involvement in NHS, public health and social care research. INVOLVE, Eastleigh www.invo.org.uk/posttypepublication/exploring-impact-public-involvement-in-nhs-public-health-and-social-care-research/

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INVOLVE Coordinating Centre news

invoDIRECT update

Over 60 groups and organisations have now added their details to invoDIRECT, our searchable online map of networks, groups and organisations that support active public involvement in NHS, public health and social care research. This new resource enables people to be aware of and make contact with others who are carrying out similar work. To add information about your group or organisation, visit www.invo.org.uk/find-out-more/invodirect/ and click on 'Add your organisation' at the bottom of the page.

People in Research

Our People in Research database contains details of over 70 research projects and

research organisations that are currently looking for members of the public to get involved in their work. If you are a researcher or research organisation, visit the website to post opportunities for people to get involved. If you are member of the public, visit the site to find out more about involvement and to search for opportunities in your area. www.peopleinresearch.org/home/

New guidance on payment for involvement

The introduction of Universal Credit has implications for people receiving benefits if they are paid for active involvement in research. We have been supporting Baroness Thomas of Winchester in her work with the Department for Work and Pensions to develop their regulations and guidance for the new benefit. Her commitment to tackling the issue of benefit barriers to involvement has led to some of these barriers being eased. To find out more visit www.invo.org.uk/posttypenews/easing-benefit-barriers-to-involvement/. We will be updating our Payment for involvement guide (www.invo.org.uk/posttypepublication/payment-for-involvement/) later in the year to take account of these benefit changes. In the meantime, we have produced some interim guidance: www.invo.org.uk/wp-content/uploads/2013/05/Benefit-regulations-update-May-2013.pdf

Learning for involvement working group

We have set up a cross-National Institute for Health Research (NIHR) working group to put leadership into how we approach learning for involvement. The group is exploring questions such as: 'What are the essential principles for learning for involvement approaches?' and 'How can we encourage the growth of skills and knowledge for involvement with researchers and members of the public?' You can keep up-to-date with the group's work and find out how you can join in the debate about learning for involvement by visiting www.invo.org.uk/about-involve/current-work/learning/

Deadline for contributions for our next newsletter: **16 September 2013**

If you have any questions on contributing to the newsletter, please contact Paula Davis

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Email: pdavis@invo.org.uk

Interesting articles and publications

Establishing local priorities for a health research agenda

R Whear, J Thompson-Coon, K Boddy, H Papworth, J Frier and K Stein
Health Expectations, December 2012, advance e-publication

This paper describes a two-stage process for prioritising health research topics used by the National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care for the South-West Peninsula (PenCLAHRC). Health research questions were collected from local clinicians, academics and service users. The first stage of the prioritisation included a review of the proposed questions by an Executive Group, which narrowed down the options to research questions that met explicit criteria. The second stage involved a large stakeholder group, including service users, who used a voting system to identify the final 25 projects. Researchers are now bidding for funding to take forward this work.

<http://www.ncbi.nlm.nih.gov/pubmed/23216859>

To see a short video of PenCLAHRC talking about the importance of public involvement in research priority setting, filmed at the INVOLVE 2012 Conference, visit www.invo.org.uk/resource-centre/conference/involve-conference-gallery/

PPI, paradoxes and Plato: who's sailing the ship

Jonathan Ives, Sarah Damery and Sabi Redwood
Journal of Medical Ethics, January 2013, volume 39, issue 3, pages 181-185

In this article the authors unpick a 'paradox' within patient and public involvement (PPI), which highlights a tension between its moral and pragmatic motivations and its implementation. The authors argue that this 'professionalisation paradox' means we need to rethink the practice, and purpose, of PPI in research.

<http://jme.bmj.com/content/39/3/181.abstract>

There is no paradox with PPI in research

Kristina Staley
Journal of Medical Ethics, January 2013, volume 39, issue 3, pages 186-7

This is a response to the previous article. Staley addresses the apparent paradox that training

patients and members of the public prior to involvement in research causes them to lose their lay perspective. She argues that this rarely happens as patients / members of the public are not often trained to the degree of becoming researchers and that they never lose their unique 'lay' perspective.

<http://jme.bmj.com/content/39/3/186.extract>

Mobilising the experiential knowledge of clinicians, patients and carers for applied health-care research

Pam Carter, Roger Beech, Domenica Coxon, Martin J Thomas and Clare Jinks
Contemporary Social Science: Journal of the Academy of Social Science, March 2013, e-publication

This article considers the benefits of combining various types of knowledge for applied health research. It addresses the questions of how patient and public involvement (PPI) impacts on research design and funding, and which patients or members of the public should be involved in which aspects of research. The authors present case studies which demonstrate the advantages of actively involving patients with direct experience of the condition that is to be studied early on in the research process. They conclude that different types of knowledge are required for applied health research: methodological expertise, practice-based expertise, and the experiential expertise of patients or carers.

<http://tinyurl.com/pyfkqkl>

Expectations of new treatment in rheumatoid arthritis: developing a patient-generated questionnaire

Darija Hofmann, Fowzia Ibrahim, Diana Rose, David L Scott, Andrew Cope, Til Wykes and Heidi Lempp
Health Expectations, April 2013, advance e-publication

This article reports on the development of a patient-generated expectancy measure for new treatments in rheumatoid arthritis (RA), using a participatory method. The first stage of the study involved three repeated focus groups and two expert panels with patients with RA conducted by a patient researcher. This generated items for the draft questionnaire which was assessed in the stage two feasibility study. The authors conclude that the participatory research method was useful in involving patients actively in research and to produce collaboratively a feasible, valid and acceptable measure in RA. The scale will be included in a longitudinal observational study with newly diagnosed patients.

www.ncbi.nlm.nih.gov/pubmed/23614783

Living with psychosis: A report on research involving service users

Researching Psychosis Together,
Brunel University, November 2012
ISBN: 978 1 908549 05 1

In this report, the Researching Psychosis Together group explores the experiences of people living with psychosis. Starting from their own personal experiences, the group designed the research to find out what is helpful and to demystify psychosis. They held two focus groups, involving 15 people, who discussed what it is like to experience psychosis. They talked about what to do and the importance of talking to others and not avoiding problems. Many people agreed that finding ongoing skilled help was important, in order to feel safe and more receptive when unwell. The findings suggest that services should give priority to understanding individual experiences of psychosis, so support can be more effective and focused on practical problems in life. Doing this research as a group had benefits for everyone involved. <http://tinyurl.com/ndsckkc>

If you have written or know of any articles or publications relevant to public involvement in research that might be of interest to readers, please contact Helen Hayes at the Coordinating Centre with details: hhayes@invo.org.uk

Beyond the usual suspects, towards inclusive user involvement

Peter Beresford, Shaping Our Lives

The focus of this new report, published by Shaping Our Lives, is to make it possible for everyone who wants to, to be more involved in and have more say over their lives and the services they use to live them. The report draws on findings from a three-year national research and development project supported by the Department of Health, which aimed to find out how inclusive user involvement could be achieved. This user controlled project was particularly interested in looking at why

certain groups of 'seldom-heard' service users experience barriers to involvement and how these barriers can be overcome.

Key findings from the project include:

- Some of the key groups that are often excluded from user involvement are people with alcohol and drug problems, young people, people who communicate differently, people who use residential services, people with learning difficulties, refugees and asylum seekers, people with complex support needs, older people and people from black and minority ethnic groups.
- The best way of involving such service users is reaching out to them and their communities rather than waiting for them to come to you.
- Service users and their user led organisations are especially well placed to build bridges with seldom heard groups.
- Effective and meaningful involvement means exploring, evaluating and monitoring new and creative ways of engaging with and involving these groups.
- There is a need to ensure that the physical, information, communication and cultural access needs of service users are met.
- Sensitive approaches are needed to avoid or overcome the resistance of 'gatekeepers' who can disempower service users, particularly those receiving residential and institutional services.
- Service users are likely to benefit from capacity-building to support their empowerment and involvement.
- The judgmental quality of public discussion about some groups of service users helps create and sustain negative public attitudes, including among other service users.
- There is increasing interest in campaigning for change via social media and social networking sites.

The report is available to download from the Shaping Our Lives website and comprises:

- research report www.shapingourlives.org.uk/documents/BTUSReport.pdf
- findings (a summary of the research report) www.shapingourlives.org.uk/documents/BTUSFINDINGS.pdf
- practical guide www.shapingourlives.org.uk/documents/BTUSGUIDE.pdf

There is also a series of practical resources to download from the Shaping Our Lives website www.shapingourlives.org.uk

Public involvement in clinical trials

International Clinical Trials Day is celebrated around the world on or near 20 May each year. It provides a focal point to raise awareness of the importance of research to healthcare and highlights how partnerships between patients and healthcare practitioners are vital to high-quality, relevant research. Here we reflect on the celebrations by focusing on some recent initiatives and publications about public involvement in clinical trials.

‘OK to ask’ campaign

The National Institute for Health Research (NIHR) is promoting a new campaign aimed at empowering patients to ask their doctor about clinical research and whether it’s right for them. In many cases doctors will approach patients about taking part in research but the NIHR also wants patients and carers to feel empowered to ask about it. If you have a medical condition and are undergoing treatment, the campaign would like you to ask your doctor, nurse or consultant about clinical research and let the NIHR know what happened. Individual researchers and research groups can show their support for the campaign by photographing themselves wearing an ‘OK to ask’ badge. For more information about the campaign visit www.crncc.nihr.ac.uk/oktoask



Public involvement in clinical trials: Supplement to the briefing notes for researchers

This INVOLVE publication provides advice for researchers who design and conduct clinical trials. It was written with members of the Medical Research Council Clinical Trials Unit (see article below) and includes real-life examples of how members of the public have been involved together with resources and references for further information. It is a specialist supplement to support the general information on how to involve members of the public in research which can be found in our Briefing notes for researchers. www.invo.org.uk/posttypepublication/public-involvement-in-clinical-trials/

Involving patients and the public in the work of the Medical Research Council Clinical Trials Unit

By members of the MRC CTU PPI Group*

When INVOLVE published its guidance on public involvement in clinical trials in March 2012 (see above), the Medical Research Council Clinical Trials Unit (MRC CTU) had already done some work to ensure that patients, carers and community members have positive impacts on the quality and usefulness of our research.

Involvement at an organisational level

At an organisational level, we had:

- set up a working group on patient and public involvement (PPI), with input from patient representatives into the terms of reference for the group as well as membership of it
- produced guidance for researchers working on cancer clinical trials about how to actively involve people affected by cancer
- produced an induction pack for people affected by cancer who get actively involved in our trials
- held meetings with patient groups to discuss progress of our trials, results and implications, and future research priorities
- ensured we have PPI in our Protocol Review Committee, which looks at the plans for each of our trials including any written information for people who take part in research
- undertaken and published a survey about PPI in our research.¹

Involvement in individual trials and other studies

Many of our researchers had also worked in partnership with patients, carers and community members to ensure that individual trials and other studies reflected the needs and priorities of patients. For example:

- A lot of our research about HIV and TB takes place in African countries. We have worked in partnership with people in local communities in these countries to make sure that the research works well and is about topics that are important to people.
- Patients and patient representatives have been actively involved in our trial management groups (TMGs), and patient representatives have been involved in writing our guidance notes both for researchers and for PPI representatives on TMGs.²
- We have explored ways to involve patients effectively in a meta-analysis. This type of research does not involve any direct contact with patients – instead it looks at the results of research that has already taken place. That makes involvement more challenging.³

Development of a policy on PPI

Our experience meant that we were asked by INVOLVE to help to write their guidance on public involvement in clinical trials (see above). Working on the guidance enabled us to learn more about PPI in other trials units. We were impressed by the systematic approach to PPI in some clinical trials units – for example the Wales Cancer Trials Unit and the University of Leeds Clinical Trials Research Unit. As a result, and with the support of senior managers, we have been working on an overall policy for PPI for the MRC CTU. We hope this will mean that PPI will become a normal part of how we do our research.

The policy recognises the central role of patients and the public in research at MRC CTU. Our aim is for CTU researchers to build partnerships with patients and the public that help to shape decisions about research, including setting priorities, developing relevant questions and disseminating results. This policy covers all research projects being led by the MRC CTU, with the exception of some methodological research. It commits us to ensuring PPI within individual clinical studies, across programmes of clinical research and at a strategic level.

The policy was developed in partnership with patients and has recently been approved by our senior management team. Our next challenge is to ensure it is implemented!

Please email us for a copy of the policy – contact details are at the end of this article.

Lessons learned

The key lessons we have learned so far are:

- set up a PPI group – it helps to have peer support, share the workload and set deadlines
- ensure you refresh the group every few years - it helps introduce new ideas
- get senior level support – we have had active support from our Unit Director, Max Parmar
- work in partnership with patients and patient organisations
- develop and support relationships between researchers and patients, and between your organisation and patient organisations
- find out what PPI is already happening, and build on that
- remember that trials are complex and have to run according to legal guidelines - people need to understand this before they agree to get involved
- it's helpful to evaluate what you've done, so that you can learn lessons and improve PPI in the future.

*MRC CTU PPI Group: Ben Cromarty, Bec Hanley, Claire Murphy, Ellen Owen-Powell, Karen Scott, Annabelle South, Ben Spittle, Richard Stephens and Claire Vale.

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Email: C.Vale@ctu.mrc.ac.uk

¹ You can download this for free from the Trials open access journal – the link is www.trialsjournal.com/content/13/1/9 and the reference is: Involvement of consumers in studies run by the Medical Research Council Clinical Trials Unit: Results of a survey by Claire L Vale, Lindsay C Thompson, Claire Murphy, Silvia Forcat and Bec Hanley. *Trials* 2012, 13:9

² You can find these on our website www.ctu.mrc.ac.uk/resources/patient_involvement.aspx

³ We wrote about this work in an article which you can access free of charge. The link is www.systematicreviewsjournal.com/content/1/1/23 and the reference is: Evaluation of patient involvement in a systematic review and meta-analysis of individual patient data in cervical cancer treatment by Claire L Vale, Jayne F Tierney, Nicolette Spera, Andrea Whelan, Alison Nightingale and Bec Hanley. *Systematic Reviews* 2012, 1:23 doi:10.1186/2046-4053-1-23

PPI in research – passing the town hall meeting test

By Adam Gordon

Recently I was invited to present some outputs from the Medical Crises in Older People programme (www.nottingham.ac.uk/chs/research/projects/mcop.aspx) to a Comprehensive Local Research Network (CLRN) Meeting in Leicester. It was one of the most mixed audiences I have ever presented to. There were researchers, nurses, care home managers, consultant neurologists and members of the public. Many of the members of the public were older. A couple had hearing impairments. One couldn't see.

I had one hour to present three year's worth of research. Complex research. Nuanced research. Research of which I was very proud ... and suddenly, faced by this audience, I was filled with dread at the prospect of having to do so.

I was nervous because what I had to present included difficult statistics about the health and functional status of care home residents and, more worryingly, qualitative data which described the relationship between primary care, secondary care and care home staff. Presenting this honestly and truthfully, without offending somebody in the room, would have been difficult at the best of times but doing so whilst constantly sense-checking my presentation for lay understanding left me feeling that I would inevitably come up short.

But – to coin a Bushism – it seems I underestimated Joe public.

I carefully chose my words, I avoided three letter acronyms and jargon and hoped that I'd take them with me. Half way through, they started to do the most astonishing thing, interrupting me with the most bright and perceptive questions. They made suggestions about what my research really meant. They told me how services ought to change in response to the findings I was presenting. They even suggested new and interesting ideas for research proposals in the future. The talk shifted from feeling like a lecture to feeling like a collaborative research venture, or a town hall meeting, or a bit of both. At the end, when I put up my slide with the research conclusions and suggestions for future projects, it became clear that everything on there had already been suggested from the floor and mostly by members of the public, rather than my research colleagues.

So what did this do for me? It left me with a warm fuzzy feeling on a Thursday afternoon before Easter ... which was sort of nice. It also presented me, though, with a powerful test of the face validity of my research conclusions. My research has now passed the town hall meeting test – and to a certain extent that beats the international research symposium test hands down.

Patient and public involvement (PPI) can sometimes feel to a researcher like an exercise in political correctness. It can be seen as a need to 'go through the motions'. But the Leicester CLRN meeting taught me it can be something much more powerful than that.

Contact: **Dr Adam Gordon, Consultant and Honorary Associate Professor in Medicine of Older People at Nottingham University Hospitals NHS Trust and Deputy Honorary Secretary of the British Geriatrics Society**
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This article first appeared on the British Geriatrics Society (BGS) blog on 3 April 2013 and is reproduced here by kind permission of the author and the BGS digital media team
<http://britishgeriatricsociety.wordpress.com/>

Budgeting for involvement

By Thomas Kabir and Lucy Simons

"There are some things money can't buy... for everything else there's [...]." This is an advertising slogan for a well-known credit card company.

Involving the public in research costs money.

But there isn't much guidance available about how to budget for the costs of involving people in research.

Both INVOLVE and the Mental Health Research Network (MHRN) have seen what happens when involvement hasn't been properly budgeted for:

- there's a risk the involvement doesn't happen at all
- the involvement goes ahead but financial support is needed from someone else (refer back to the first sentence of this article ...)
- the involvement goes ahead but people are left out of pocket.

The third outcome can be particularly problematic. A carer involved in the MHRN recently said: "[I] would love to be part of the ... group, but the

cost of the travel was equivalent to a bag of food shopping and for someone on benefits or low income the decision was a no brainer.”

INVOLVE and the MHRN have teamed up to produce a new resource that will help researchers, finance managers or anyone else who needs to budget for the costs of involving the public in research studies. It can be used for everything from putting together an involvement budget for an entire study, to working out how much it will cost to run a one-off focus group. This resource is available online at www.invo.org.uk/resource-centre/involvement-cost-calculator/

Payment & Reward				Item Total
Payments and rewards for members of the public in recognition of time, skills and expertise.				
Quantity is the number of each item you need and cost (each) is the cost of a single item.				
+ Fees to individuals	Quantity <input type="text"/>	Cost (each) £ <input type="text"/>	Add Notes <input type="checkbox"/>	£0.00
+ Vouchers or tokens for individuals	Quantity <input type="text"/>	Cost (each) £ <input type="text"/>	Add Notes <input type="checkbox"/>	£0.00
+ Other rewards for individuals, such as prize draw	Quantity <input type="text"/>	Cost (each) £ <input type="text"/>	Add Notes <input type="checkbox"/>	£0.00
+ Fee or donation to a group or network	Quantity <input type="text"/>	Cost (each) £ <input type="text"/>	Add Notes <input type="checkbox"/>	£0.00
+ Funding for additional training and learning	Quantity <input type="text"/>	Cost (each) £ <input type="text"/>	Add Notes <input type="checkbox"/>	£0.00

The first part of the resource is a written guide entitled “Budgeting for involvement: practical advice on budgeting for actively involving the public in research studies”.

The guide:

- provides practical guidance on **what costs** are associated with involvement in research
- includes a step-by-step process for **planning** involvement, identifying the **associated costs** and considering **where** in the research cycle involvement costs might occur
- presents several **examples** of research projects with well-developed budgets for involvement work
- contains tips, and links to useful websites and references.

The second part of the resource is an online ‘involvement cost calculator’. This calculator can be used to work out a budget for involvement work. Costs are grouped into five categories:

- payment and reward
- expenses
- involvement activity costs (that is costs associated with a specific activity such as running a focus group)
- involvement staffing (that is costs of staff who carry out involvement work)
- other costs.

The results can be downloaded so that you can easily ‘cut and paste’ into a document such as a funding application.

So who helped us do this? We asked Julia Cartwright, co-author of the “Public Involvement Toolkit” to write the guide to budgeting for involvement.

We established a project advisory group made up of colleagues from research funders, Involving People, the National Institute for Health Research (NIHR) Research Design Services, the NIHR Clinical Research Networks (of which the MHRN is one), members of the public, and of course researchers to help us with this work. The group provided us with an outstanding level of support and advice throughout. We are deeply thankful to them.

The budgeting resource is just that: **a resource**. The resource won’t give researchers everything that they need to know in order to put together an involvement budget. It can’t as most research studies are unique and hence so are its budgets. But it is a start. And perhaps it will help people to be able to put away their credit cards for good. This has to be good news for everyone.

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STOP Diabetes study

By Alison Dunkley, Mandy Clarkson and Freya Tyrer

The STOP Diabetes study is a population-based study of diabetes among adults with learning disabilities led by Professor Kamlesh Khunti at the Diabetes Research Unit, University of Leicester. The study involves a Leicestershire-wide screening programme and an educational programme for those adults identified as having impaired glucose regulation or at high risk of developing type 2 diabetes. The study is funded by a National Institute for Health Research (NIHR) Programme Grant.

When planning the study, the research team knew the importance and value of involving service users, but we wanted this involvement to be meaningful and to benefit the service users themselves.

Initially, the study was publicised and discussed at local partnership boards, locality groups, and self-advocacy groups. Two local self-advocacy groups expressed an interest in helping us to plan our research. Such groups are a wonderful resource for finding volunteers because they comprise adults who want to express their views and take control of their lives. The service users often want to be more than just a participant in the research process.

The self-advocacy group at Coalville Resource Centre chose the STOP Diabetes acronym and logo and the Speaking up for Health group suggested fridge magnets for advertising the logo. David, from the latter group, took photographs of Tracy (a fellow service user) and himself for the accessible information sheet, flash cards and story cards. Through the research nurse's own contacts we were able to rehearse the clinics, make appropriate changes and organise them in the most efficient way possible.

Probably the team's most innovative idea for involving service users came when we interviewed for research nurses for the study. Research nurses play a crucial role in the study and are responsible for assessing capacity, communicating the study, conducting the health checks and taking blood. At interview and supported by Sue Lyons, a speech and language therapist at Leicestershire Partnership NHS Trust (LPT), Tracy and David

asked the applicants two questions they had devised and afterwards rated the applicants' responses on a scoring card of between 1 and 4 to feed back to the interview panel.

The involvement has not been without challenges. Because the study involves screening an entire population of adults with learning disabilities in Leicestershire, service users who help with the research planning should have the opportunity to be participants in the research. While not normally good practice in research studies, the team feels this is absolutely necessary for such a screening programme. We have, however, had to emphasise to service users that just because they are helping us, they are not obliged to take part in the study.

Our experience shows that researchers can benefit from involving adults with learning disabilities in their research and that service users can benefit from the experience. Sue Lyons expressed her gratitude after the group's first visit to the research offices: "I think we all enjoyed it. Please will you thank the whole team, everyone made us feel so welcome, including your Director." We will continue to work with our service users throughout the project and we look forward to finding more ways of involving adults with learning disabilities in research without resorting to tokenism.

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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 item on our noticeboard please contact the Coordinating Centre.

PURSUN UK **By Delia Muir**

The Pressure Ulcer Research Service User Network (PURSUN UK) is a network of service users, patients and carers with personal experience of living with pressure ulcers or being at risk of developing pressure ulcers. Our network aims are:

- to help provide service users, patients and carers with a voice within pressure ulcer research
- to raise awareness of pressure ulcers and improve patient care
- to develop mechanisms which allow service users, patients and carers to be ethically and meaningfully involved in research
- to recognise and develop the skills and expertise of network members.

The network is supported by the Clinical Trials Research Unit at the University of Leeds. We try to offer a variety of involvement activities which build on the existing skills of our members.

One example of our work is our involvement in interpreting data from the Severe Pressure Ulcer Project. We ran an innovative workshop which utilised theatre techniques and videos to help make the interpretation process inclusive and engaging for everyone involved.

For more information see the videos at <http://youtu.be/bgg6zkbILrg> and www.invo.org.uk/resource-centre/conference/involve-conference-gallery/
www.pursun.org.uk

Friendly disclaimer: The views expressed in this newsletter and in any enclosures are those of the authors and not necessarily those of INVOLVE or the National Institute for Health Research. Articles are selected for the sole purpose of stimulating ideas and debate on public involvement in research.

NIHR launches **Journals Library**

On 20 June 2013 the National Institute for Health Research (NIHR) launched a new online, open access Journals Library providing full publication of studies funded by five of the NIHR research programmes.

Speaking at the launch of the Library, Simon Denegri, Chair of INVOLVE highlighted that all future studies published in the journals will have a plain English summary and authors will be asked to report on patient and public involvement in their study.

For more information link to:
www.journalslibrary.nihr.ac.uk/

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INVOLVE is a national advisory body funded by the National Institute for Health Research to support public involvement in NHS, public health and social care research and development. If you would like to receive a copy of the newsletter or find out more about INVOLVE please do contact us.

