Musings about involvement in research…

Almost every research funding application will now have a section asking about involvement, be it "patient and public involvement", "public involvement" or "user, carer, practitioner involvement".

The first response for some will then be *what does the funder want me to write*. For others it'll be *I will have an advisory group with one carer, one user, one practitioner representative and they will meet every 6 months*. Some will slowly drift towards, what I'll call, tokenistic involvement to keep the funder happy (or just to be able to write something in that particular section) and hope it's enough.

That's not necessarily because those completing that research funding application don't care about involvement. They might not feel involvement works for their proposed study and the default fall back is having an advisory group. For others it may just be not knowing what does work.

There are, of course, many conversations and issues around involvement: not least defining it, how to do it well, whether involvement improves the research or the impact from the research. These are, by their nature, complex discussions and to different interest groups raise a number of sensitive issues. For me perhaps the difficulty with entering these discussions is the

current lack of knowledge and evidence on what does work, how and the outcomes for research, impact and on those involved themselves.

Yet, our learning from the SCEiP project suggests research needs to be involve relevant stakeholder's to have an effect on policy or practice. Trying to garner interest in research findings after a three year study is difficult at best. This is something many funders already know, research that involves relevant non-academic groups is more likely to lead to impact. So, we know that... it's nothing new... so why aren't we seeing more of it?

SCEiP activities

Two of the many activities within the SCEiP project included bringing people who use social care services together to discuss involvement in research. This also provided an opportunity for academics, professionals, users and carers to work together to develop their own research proposals for mini project funding.

Becki Meakin from Shaping Our Lives discussed the first activity at our final conference last year (http://socialcareresearchimpact.org.uk/event/creating-an-impact-social-care-research-in-practice/). About 25 people got together, discussed key areas of practice they would like to research, and worked to develop a research funding application. Some of them were (at the time or previously) already involved in research studies; others had academic links or background. The group met twice before submitting their proposal. A number of issues were discussed in the first workshop: some of the discussion focused on what user-led research should be, questions were asked about whether academics had to be involved in proposals for them to be considered robust by funders, and issues

aired around the potential barriers that arise for service users to develop proposals including the perceived lack of organisational/university support for such proposals and complex funding application processes.

An ideas swop shop was also organised providing an opportunity for academics, professionals and others to get together, discuss their research interests and pitch a project application to us. Funding of up to £5,000 was made available for those project applications. One project pitched to us and subsequently developed into a formal proposal involved the Campaign to End Loneliness and the University of Kent. The project – Hidden Citizens (http://www.campaigntoendloneliness.org/hidden-citizens/) – drew together interests around social isolation and led to a successful collaboration which Adrian Adams presented at our final conference.

Our key messages from the project have been set out before (http://socialcareresearchimpact.org.uk/the-sceip-project-and-six-lessons-to-date/). The project wasn't aiming to evaluate involvement or knowledge exchange approaches. We're not able to say involvement through one form or another works best, or that co-production of research proposals is a necessity for impact. However, our aim was to explore ways to improve knowledge exchange between researchers and professionals, and to test out ways methods for doing this. Some thoughts about this follow.

Musings

Co-production may, or may not be, the answer to a more evidence-informed policy and practice environment. To me it still feels as though we need more evidence on this and case study examples to review. In reality, given the nature of funding and of academia,

it's perhaps a way off. But as we've said earlier, knowledge exchange can, and should, take place *throughout* a research study, and research proposals should be developed and undertaken in discussion with key stakeholders to improve their relevance and subsequent impact. Research of value to practice has to have been formulated knowing what is of value to practice (and the same for policy). We've discussed before issues around expectations and contexts, and ideally those need to be discussed and aired before a research question is formulated.

It's probably very easy for me to say there's a lack of evidence around involvement but most funders expect it, and co-production is generally accepted as useful (especially for increasing relevance), so think about that in your future funding proposals.

In a recent meeting a carer spoke about her expectations for a role she may could have in research projects, it was clear that she didn't want to be researcher doing the fieldwork necessarily but felt she had valuable experience and expertise on the question itself, the design, interpreting the findings and so on. There are great examples of service users being involved in research – such as service users as research advisors within a study on homeless women (http://www.inderscience.com/info/inarticle.php?artid=69777) and the QORU Public Involvement Implementation Group (http://www.qoru.ac.uk/about/public-involvement/implementation-group-piig/)– and others of practitioners engaging in research.

We're perhaps in a chicken and egg situation. Someone has to take the lead in identifying a potential research area (inevitably something they are personally interested in) when a call for research proposals comes out. With a short timeframe in some cases to develop proposals, they might invariably look to their

existing relationships to develop a proposal. At the same time we know it takes many months to develop relationships and its difficult to do that without funding and without knowing if funding will follow at some stage in the future.

Perhaps my naïve starting point would be to say involvement should be planned as best for the proposed project, but that implies the project comes first contradicting the idea of co-production. In an ideal world we would have a vibrant research culture in adult social care where such relationships exist to share knowledge and exchange ideas, with practice, policy and research continually learning from each others' expertise.

So what's the answer?

Well I can't honestly say I know… but a few key recommendations come to mind

1. We need to be better at building relationships between research, practice, policy, services users, carers etc without these being tied to a specific research project or funding opportunities. We should be developing approaches that allow us to share knowledge and expertise, and should a funding opportunity arise be well placed to respond to it. There are already a number of networks available and perhaps we need to be better at engaging with those. Such relationships could also build from involvement in earlier studies – relationships don't have to stop when studies finish. In doing so, we need to improve our understanding of each other – our expectations, our requirements and our reasons for being involved in research.

2. A number of funding opportunities are time-limited. But there are also open calls (such as ESRC's open research calls) which allow for proposals to be submitted at any time during the year. We need to try to be better at identifying and developing proposals to such calls to allow us to take as much time as needed to develop relevant relationships or collaborations.

3. Research funders need to make smaller seed fund budgets available to allow people to use these to develop their proposals and collaborations – in much the same way as the NIHR's research proposal development grants work. Funders also need to be more open about what has worked or hasn't in terms of involvement in the projects they are funding.

4. Those involved in research projects need to share their experiences – more critical reflection from both researchers and those involved in studies seems vital.

5. And I couldn't end without saying... we need more research on involvement, co-production, what works and doesn't and – perhaps a more objective evidence-based discussion around this.

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