**A link between learning and impact in public involvement in research: implications for evaluation and practice?**

**K Staley**

**June 2017**

****

**Introduction**

The impact of public involvement in research is often described in terms of the difference made to the research, the researchers and the people involved [1-4]. Involvement impacts on *research* by influencing the research question [5], the project design [6], the way the research is carried out [7], and the dissemination of the findings [8]. Patients/ members of the public report gaining new skills and knowledge, increasing in self-confidence, and gaining satisfaction from making a difference[9]. By way of contrast, there are far fewer reports of the impacts on *researchers*. The most commonly reported impact is a requirement for more resources and for more of the researchers’ time, sometimes slowing the pace of research [1,3].

The contributions made by patients/ the public during their involvement are informed by their experiential knowledge, i.e. what they have learnt from living with a health condition and/ or using services. Patients/ the public’s knowledge, insights, values and perspectives will often be ‘new’ to researchers[10]. Researchers therefore *learn* from their conversations with patients/ the public. What researchers learn subsequently changes their thinking and practice, to bring about the commonly reported impacts on research [11]. With this focus on the exchange between researchers and patients/ the public, ‘who’ is involved, ‘what’ gets exchanged and ‘what’ researchers learn all have an important influence on outcomes.

This discussion paper reflects on how researchers’ learning is linked to the reported impacts of public involvement on research. It makes use of a logic model [12] to describe the relationship between the inputs, activities, outcomes and impacts of public involvement in research. Logic models make explicit the difference between short-term outcomes (defined as learning, i.e. changes in awareness, knowledge, attitudes, skills, opinions, aspirations and motivations), medium-term outcomes, (defined as behaviour change i.e. changes in practice, policy and decision-making) and long-term changes, (changing culture and conditions). I have selected three published examples of public involvement in research and created a logic model for each one, drawing on the information available within the published reports. These examples were selected to highlight some of the issues that emerge from analysing outcomes and impacts in this way, in particular the implications for evaluating involvement and describing good practice.

**Analysis and discussion**

The three examples that are reviewed in this paper are projects where:

1. People with carpal tunnel syndrome were involved in developing a funding bid [13]
2. Gypsies and Travellers were involved in the design and delivery of a study of their accommodation needs [14]
3. Young care leavers were involved in a systematic review [15]

A logic model has been used to describe the link between researchers’ learning and impacts in each one and the implications for evaluation and practice are discussed.

**Example 1: Involvement of people with carpal tunnel syndrome in developing a funding bid**

In this example, the impact of the involvement was reported as follows:

“*A new research proposal on carpal tunnel syndrome was presented to the RUG* [Research User Group] *and a discussion ensued about the key questions that the research should address. A RUG member explained that she lost her job as a phlebotomist because the condition stopped her from doing fine finger movements. The researchers realised that they had not considered the importance of remaining in work and being economically active within their proposal. Thus, the one story raised awareness of a major area of investigation that was therefore included in the (successful) bid*”. [Reference 13, page 151]

When this example is used to create a logic model [see Fig 1], it becomes clear that hearing about a patient’s experience filled a gap in the researchers’ knowledge or understanding and gave them ‘new’ insights and ideas (**learning**). This led the researchers to change their project design (**change in behaviour**), which may have contributed to their success in securing funding (**impact**) for a project that better reflected the reality of patients’ lives.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Input** | **Activity** |  | **Short-term outcome**  **Learning** | **Medium-term**  **outcome**  **Behaviour** | **Long-term**  **Impact**  **Culture & conditions** |
| Development of a research user group of people with musculoskeletal conditions | Researchers consult the group about a carpal tunnel syndrome research proposal |  | Researchers learn about patient’s experience of losing a job | Change to  research design | Funding application successful – research more relevant to patients? |

**Fig 1. A logic model developed from Example 1.**

An initial response to this example may be surprise that the researchers had not considered the impact of a health condition on work life, when this is a common experience of many patients. Perhaps the researchers had been aware of this issue, but had discounted its importance. Perhaps they were junior researchers who were inexperienced and therefore had to learn this fact about patients’ lives. Perhaps the researchers were new to the field of musculoskeletal conditions and had made assumptions that the condition and its treatment would not result in job loss. In some ways, this doesn’t matter. In all cases, the researchers would have learnt something useful and relevant that impacted on their thinking and behaviour. What this example therefore highlights is that each researcher may be in a very different place in terms of what they might need to learn from patients/ the public. This will make a significant difference to whether and how involvement influences outcomes. Clearly, if the researchers in this example had been more aware and already included this aspect of work-life in their proposal, then the involvement wouldn’t have led to the same outcomes and impact.

Another issue this example raises is the potential for such insights to be missed if the ‘right’ people aren’t in the room. What if this RUG had not included anyone who had needed to give up work? It can sometimes seem that the researchers’ learning almost happened by luck rather than design, which raises the question of how can it be made more intentional? How do we make sure people with the necessary experience are in the room? One way is to work with groups rather than individuals, to ensure researchers receive a wide range of inputs and insights. This is one of the reasons for increasing diversity within groups. However, diversity is often described in terms of demographics (age, gender, ethnicity, geographical region) which may or may not be significant in terms of researchers’ learning in different contexts. In this example, if the group had been formed entirely of people who were post-retirement age, the relevant knowledge might not have been shared. However, the emphasis might need to be on involving people with a diversity of *experience*, rather than achieving some kind of representativeness of a given population.

This distinction becomes clearer with other types of project. For example, in a project that involved people with Parkinson’s in reviewing a proposal for a trial of a new medications management device, the stage of a person’s condition made a significant difference to their views [16]. People with advanced Parkinson’s were more in favour of the device, while people at earlier stages thought it of little value. A group of patients reviewing the trial proposal were diverse in terms of gender, age, ethnicity and geography, but were biased towards people the earlier stages of Parkinson’s, because everyone there had been able to travel to the meeting. The crucial insight of people at later stages would have been missed, if the researcher hadn’t also consulted other patients using the device in her local area. In conclusion, it is essential to involve patients/ people with the most relevant experiential knowledge for the specific context, as well as thinking about increasing diversity amongst the people involved.

**Example 2: Involvement of Gypsies and Travellers in the design of a study of their accommodation needs**

In this project the researchers worked with a steering group of Gypsies and Travellers to develop the design of their project. One of the Travellers described how he helped to shape the questions that the researchers asked, as well as their overall approach, in order to make the research acceptable to his community:

*“We were eliminating questions that we thought would be offensive or inappropriate. Things that you couldn’t ask – that you wouldn’t know if you were outside the community. For instance, you couldn’t have a male interviewer going and asking a Travelling woman if she was going to have a child. That was one of them that stood out.”* [Reference 14, page 11]

The researcher described how she thought the steering group’s input and the subsequent changes she made to her approach, meant that she avoided potential barriers to conducting her research:

*“The more I worked with the people on this project, the more I realised how little I knew. I would have got it wrong otherwise, and might have had the door slammed in my face for asking the wrong questions*!” [Reference 14, page 11]

Both concluded that the study had been very successful, because it had managed to gather the views of large numbers of local Gypsies and Travellers about their health and accommodation needs. Similar projects in other parts of the country did not succeed in capturing this information.

Again using this example to develop a logic model (see Fig. 2), while collaborating with community members on research design (**activity**), the researcher heard about the interests and concerns of Travellers (**learning**) that led her to rephrase her interview questions and include female interviewers i.e. to change her research design (**changed behaviour**) which appears to have contributed to obtaining high quality data and therefore an improved understanding of accommodation needs by the local council (**impact**).

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Input** | **Activity** |  | **Short-term outcome**  **Learning** | **Medium-term**  **outcome**  **Behaviour** | **Long-term**  **impact**  **Culture & conditions** |
| Gypsies and Travellers invited and supported to join a project Steering Group | Discussing the project design |  | Researcher learns about the community’s needs and concerns in relation to interviews on this topic | Change to research design | High quality data -led to a better understanding of the community’s accommodation needs |

**Fig. 2. A logic model developed using Example 2.**

An important lesson here is that the researcher had no idea beforehand that this is what she would learn from working with Travellers. This was an ‘*unknown* unknown’ before she started. So while a researcher might expect involvement to address their ‘*known* unknowns’, for example they might start with questions such as ‘Is it reasonable to ask people to answer all these questions? What’s an acceptable length of time for an interview?’, on occasion what they learn is unexpected [17]. Researchers sometimes don’t know, what they don’t know. The assumptions they make in the absence of knowledge about patients’/ the public’s experiences, are only revealed and then corrected through a conversation with patients/ the pubic. Researchers often describe this unexpected learning experience as a ‘lightbulb’ moment.

Since ‘unknown unknowns’ are precisely that – unknown – the outcome of involvement is somewhat unpredictable. No one can anticipate which assumptions will be corrected through involvement and this could potentially happen at any stage in the research. For example, there would be no way of knowing there was a flaw in a researcher’s recruitment strategy until patients pointed this out. Therefore, while it is possible to generalise about what involvement typically does, i.e. it can help with recruitment, we cannot be certain that it will always do this in every case. We cannot predict what it is that any particular researcher will learn. The implications for practice are then that involvement should happen at *every* stage of a project, as there is potential for learning to lead to positive impacts throughout.

This example also highlights how the knowledge that the Travellers on the Steering Group provided was unique to their community. No one else would have been able to provide this insight. This again emphasises the importance of involving people with the experiential knowledge that is most relevant to the context, which usually means involving people with direct experience and knowledge of the topic under investigation [18]. This requires some form of matchmaking between people and involvement roles, beyond their individual skills and preferences for involvement.

**Example 3: Involvement of young care leavers in a systematic review**

One of the impacts reported in this example, was the influence of the young care leavers on the selection of the topic for the review. This was described as follows:

“*My funding application stated that the review would be relevant to looked after children’s health. Through fierce debates across three meetings, the group* [of young care leavers] *discussed various topics, most of which were topics often associated with looked after children in a negative way* [e.g. drug use]. *Included in these debates were therefore concerns about avoiding stigmatising language or angles to the review. At the third meeting, the group decided to focus the review on education, arguing that education is the most important thing in a person’s life, and that it is imperative to health. The young people also decided that the review would focus on solutions or support interventions rather than understanding the nature of the problem. This resulted in a final review title ‘Interventions to support looked after children to stay in school’. This was based on young people’s decisions that the review would focus on: education, how to solve a problem, ‘support’ and ‘staying in’ rather than ‘dropping out’.*” [Reference 15, page 9]

Again developing a logic model for this example, (Fig. 3.), through working in partnership with young care leavers on a systematic review (**activity**), the researcher heard what young care leavers believe to be most important for their health, their concerns about stigmatising language (**learning**) as well as the strength of their feeling on these issues. This in turn informed the chosen topic and the focus of the evaluation of the published research findings i.e. influenced the design of the review (**behaviour**) and its findings (**impact**).

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Input** | **Activity** |  | **Short-term outcome**  **Learning** | **Medium-term**  **outcome**  **Behaviour** | **Long-term**  **impact**  **Culture & conditions** |
| Setting up a group of young care leavers to be involved throughout the project | Consultation on the scope of the review |  | Researcher learns what’s most important to young care leavers in terms of their health and desired research outcomes | Selection of topic and focus of review | Findings of the review addressed the issues of most interest to young care leavers |

**Fig. 3. A logic model created using Example 3.**

While there was an immediate, tangible outcome for the research - the changed topic and scope - the researcher also reported how this experience increased her awareness of the bias in language used by researchers in this field. For example, the young people objected to including young offenders within the definition of looked after children, when many of the previous research studies had not made this distinction. Similarly many studies were focused on describing the ‘problems’ of looked after children, rather than seeking interventions to promote positive change in their lives.

Importantly the face-to-face interactions between the researcher and the young care leavers, and the reported ‘fierce’ debate, ensured that not only information was exchanged, but also the young people’s values and emotions. Such an exchange led to a significant change in the researcher’s perception of the professionals’ perspectives and values informing this field of research. This would not have happened if the researcher had worked solely with other professionals, as they could have continued to use their common language and frameworks without challenge. Nor is it likely that such a shift in outlook would have happened in the same way if the researcher had limited her contact with young care leavers to an exchange of documents by email, a mechanism sometimes to support involvement. The nature and the quality of the personal interaction were highly significant.

It is these kinds of shifts in researchers’ awareness and attitudes that could lead to a culture change within research, by ensuring researchers avoid (often unintended) marginalisation and stigma through their work. It is these kinds of less tangible impacts on researchers’ perceptions and values (also forms of learning) that are most likely to result in a change in the research agenda, to ensure that research genuinely addresses the interests and concerns of those it intends to help. A focus on what researchers’ learn through involvement, (rather than focusing on the practical outcomes for research), could therefore help to identify the ways in which involvement can bring about the desired shift in ‘what gets researched’, rather than simply changing how researchers carry out their own research ideas.

**Conclusion**

This approach of using a logic model to describe the link between researchers’ learning and the short- to medium outcomes/ longer term impacts, helps to identify some of the contextual factors that might make a significant difference. One of these factors is ‘what the individual researcher needs to learn’, which will vary from individual to individual, and change for the same individual over time. This is a factor that makes impact highly context specific and somewhat unpredictable in any given circumstance. It is only through providing a ‘reality check’ [19] that involvement is able to challenge researchers’ assumptions and reveal the *unknown* unknowns.

Importantly, if researchers do not realise or recognise that there might be gaps in their knowledge or that they might be making incorrect assumptions, they might not see any need for involvement in their work. If they don’t perceive they have a problem, why would they need the ‘solution’ of involvement? Much effort has been invested in persuading researchers to involve people by providing the evidence of the benefits for research. It might also be helpful to make researchers more aware of how they will learn from patients/ the public’s experiential knowledge – and that this learning is constructive, intellectually stimulating and offers a personal benefit as well as a professional one [16]. Providing a learning experience for researchers, one in which they perceive the direct influence on their own knowledge, skills, awareness and motivation maybe a more effective means to change their behaviour, than simply informing them with data from research on involvement.

*Implications for practice*

Focusing on researchers’ learning opens up different ways of thinking about ‘good practice’. Greater emphasis is then placed on the exchange of knowledge/values/perspectives between researchers and patients/ the public – in essence, a learning conversation – rather than on the circumstances in which the conversation takes place. Good practice might then be about ensuring a good quality conversation, rather than selecting the best ‘method’ of involvement. A ‘good’ quality conversation can take place in very different circumstances; in one example of very effective involvement, this conversation took place in a pub, which provided a more relaxed environment in which to talk than a University meeting room [20].

By way of contrast, even when following all the good practice guidelines, the perfect conditions may not always result in a meaningful exchange supporting genuine learning. Enabling high quality involvement might then need to be about finding ways to prepare researchers to become ‘a listening researcher’ (one who is ready to hear, learn from and respond to patients’/ the public) [21], as well as encouraging patients/ members of the public to become to feel confident in challenging assumptions, and sharing the most relevant aspects of their experiential knowledge. The input of a skilled facilitator, acting as translator, relationship builder and ‘honest broker’ is also an important, and often overlooked, means of supporting an effective and meaningful exchange [21]. This role would benefit from further research.

*Implications for evaluation*

‘Learning’ is defined as ‘the act of acquiring new knowledge, behaviours, skills, values, or preferences’ [22]. What researchers learn through involvement is much more than new information that they can use to make tangible, practical changes to their research design and conduct. Sometimes the input from patients/ the public can challenge researchers’ beliefs and attitudes, to change their values and preferences, with profound consequences for their outlook and actions. It is these kinds of changes that will be important in bringing about the required culture change to ensure research genuinely helps the end-users i.e. to shift the research agenda to be focused on patients’/ the public’s interests and needs. It is of note that much evaluation and reports of impact are focused on the tangible benefits for research. Changing the focus to ask *researchers* to report on what they have *learnt* through their personal experience of involvement, offers one way in which to capture a much broader range of outcomes, and to link this learning to the desired longer-term cultural impacts.

*Limitations of this work*

This paper is exploratory and the start of a more detailed analysis of how researchers’ learning links to outcomes and impacts. In drawing on published examples, the analysis has been limited by the way in which outcomes and impacts have been reported to date in the literature and therefore have not been able to complete all the aspects of the logic model in full. Further development of such logic models could be used to design evaluations to test these links and capture the required evidence e.g. through a more direct investigation of what researchers’ learn from involvement and through longer-term follow up.

It is of note that there is also considerable evidence that learning is mutual, the exchange of knowledge is a two-way process, and involved patients/ members of the public also learn from involvement, which may be linked to the impacts that they report for themselves. Future logic models may benefit from incorporating these other kinds of outcomes/impacts and exploring how these are linked to inputs and involvement activities.

**Acknowledgments**

Thanks to Rosemary Davies, Caroline Doherty, Andy Gibson and Kristin Liabo for their helpful contributions to this discussion paper.

Thanks to Rachel Matthews for her comments on an early draft.

**References**

1. Brett J, Staniszewska S, Mockford C, Herron-Marx S, Hughes J, Tysall C *et al*. (2014) Mapping the impact of patient and public involvement on health and social care research: a systematic review. *Health Expectations* 17: 637-650.
2. Shippee N, Domecq Garces J, Prutsky Lopez G, Wang Z, Elraiyah T, Nabhan M *et al*. (2013) Patient and service user engagement in research: a systematic review and synthesized framework. *Health Expectations* 18(5):1151-66
3. Staley K. (2009) [*Exploring impact:Public involvement in NHS, public health and social care research*](http://www.invo.org.uk/posttypepublication/exploring-impact-public-involvement-in-nhs-public-health-and-social-care-research). Eastleigh: INVOLVE.
4. Domecq JP, Prutsky G, Elraiyah T, Wang Z, Nabhan M, Shippee N *et al*. (2014) Patient engagement in research: a systematic review. *BMC Health Service Research* 14: 89.
5. Crowe S, Fenton M, Hall M, Cowan K, Chalmers I. (2015) Patients', clinicians and the research communities' priorities for treatment research: there is an important mismatch. *Research Involvement Engagement* 1: 2.
6. Rose D, Evans J, Sweeney A, Wykes T. (2011) A model for developing outcome measures from the perspectives of mental health service users. *International Review of Psychiatry* 23: 41-46.
7. INVOLVE. (2012) [*Briefing notes for researchers: Involving the public in NHS, public health and social care research*](http://www.invo.org.uk/wp-content/uploads/2014/11/9938_INVOLVE_Briefing_Notes_WEB.pdf). Eastleigh: INVOLVE.
8. Littlechild R, Tanner D, Hall K. (2015) Co-research with older people: Perspectives on impact. *Qualitative Social Work* 14: 18-35.
9. Ashcroft J, Wykes T, Crowther A, Szmukler G. (2016) Impact on the individual: what do patients and carers gain, lose and expect from being involved in research? *Journal of Mental Health* 25(1): 28-35.
10. Rose D (2014) Patient and public involvement in health research: ethical imperative and/or radical challenge? *Journal of Health Psychology* 19: 149-158.
11. Staley K (2017) Changing what researchers 'think and do': Is this how involvement impacts on research? *Research for All* 1: 158-167.
12. Millar A , Simeone R, Carnevale J. (2001). Logic models: a systems tool for performance management. *Evaluation and Program Planning*. 24:73-81.
13. Jinks C, Carter P, Rhodes C, Beech R, Dziedzic K, Hughes R, Blackburn S and Ong B. (2013) Sustaining patient and public involvement in research: A case study of a research centre. *Journal of Care Services Management* 7(4): 146-154
14. Blackburn H, Hanley B, Staley K. (2010) [Turning the pyramid upside down](http://www.invo.org.uk/wp-content/uploads/2011/06/INVOLVETurningthe-pyramidOct2010.pdf). 2010. Eastleigh, INVOLVE.
15. Liabo K. (2017) Care leavers’ involvement in research: An ethnographic case study on impact*. Qualitative Social Work* (in press) doi: 10.1177/1473325016649255
16. Staley K. (2016) [*An evaluation of a pilot project of patient and public involvement at Parkinsons’s UK*](file:///C:\Users\Kristina\Desktop\16.%09https:\www.parkinsons.org.uk\sites\default\files\cs2442_ppi_evaluation_pilot.pdf). London: Parkinson’s UK.
17. Cossar J, Neil E. (2015) Service user involvement in social work research: learning from an adoption research project. *British Journal of Social Work* 45(3): 225–40.
18. Staley K, Ashcroft J, Doughty L, Szmukler G. (2016) Making it clear and relevant: patients and carers add value to studies through research document reviews. *Mental Health and Social Inclusion* 20(1):36 – 43
19. de Wit M, Abma TA, Koelewijn-van Loon M, Collins S, Kirwan J (2014) What has been the Effect on Trial Outcome Assessments of a Decade of patient participation on OMERACT. *Journal of Rheumatology* 41: 177-184.
20. INVOLVE (2013) [*Examples of public involvement in research funding applications: Bridging the gap between memory decline and memory loss in Parkinson’s Disease* (PD)](http://www.invo.org.uk/wp-content/uploads/2013/10/Example1-publicinvolvement-in-funding-app2013-2.pdf). Eastleigh: INVOLVE.
21. Li K, Abelson J, Giacomini M, Contandriopoulos D. (2015) Conceptualising the use of public involvement in health policy decision-making. *Social Science & Medicine* 138: 14-21.
22. Richard Gross, Psychology: The Science of Mind and Behaviour. London: Hachette UK.