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Changing what researchers 'think and do': Is this how involvement impacts on research?

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Abstract

Much has been written about the impact of involvement on research and the people involved, but much less is known about the impact on researchers. Based on previous experience of evaluating involvement, I was aware that researchers often report learning something new from involvement. Patients/the public bring 'new' knowledge to researchers, informed by their lived experience and use of services. I therefore carried out a narrative review of the literature to explore in depth what researchers learn from involvement. The findings confirmed that researchers often gain new knowledge and skills through involvement, which can change their priorities, values and attitudes. Therefore, researchers often directly experience the impact of involvement themselves. This learning then changes their practice. It leads them to change the design, delivery and dissemination of their research. Thus, many of the reported outcomes of involvement might be underpinned by what the researchers learnt through the process. Reframing impacts on *research* as impacts on *researchers' learning* has implications for practice and for motivating researchers to work with patients and the public. Further research and future evaluations of involvement might usefully explore the links between researchers' learning and outcomes.

Keywords: patient and public involvement; user involvement; impact

Key messages

- Researchers learn through involvement. They increase their knowledge and skills and change their priorities, values and attitudes: involvement changes what they 'think'.
- Changing what researchers 'think' often informs their research design and practice – it changes what they 'do'.
- The process of researchers' learning from involvement may therefore underpin many of the reported outcomes. This may merit further investigation to explore how involvement 'works' in different contexts.

Introduction

Many of the impacts of involvement on health and social care research have to date been described in terms of the difference made to the research, to researchers and the involved patients/public as separate entities. In this article, I focus on the impacts on *researchers,* and how these might relate to the reported impacts on *research.*

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Numerous reviews of the literature on the impact of involvement have reached similar conclusions (Brett *et al.*, 2014; Domecq *et al.*, 2014; Shippee *et al.*, 2015; Staley, 2009). In terms of the impact on *research*, involvement is reported to influence the design (Crowe *et al.*, 2015; Rose *et al.*, 2011), delivery (INVOLVE, 2012) and dissemination (Littlechild *et al.*, 2015) of research projects. In terms of the impact on the *patients/public* involved, they report gaining new skills and knowledge, increasing self-confidence and gaining satisfaction from making a difference (Ashcroft *et al.*, 2016). 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, slowing the pace of research. It is also notable that most of the reports describe the outcomes of involvement; far less is written about the process and *how* involvement works (Staley *et al.*, 2014).

The contributions made by patients/the public during the process of involvement are informed by their experiential knowledge. They bring 'new' knowledge, insights and perspectives informed by their experience of life with a health condition and/or use of services. It is 'new' because this knowledge has not been previously accessed or used by researchers (Rose, 2014). Researchers therefore *learn* from their experience of involvement.

Learning can be described as 'the act of acquiring new … knowledge, behaviors, skills, values, or preferences and may involve synthesizing different types of information' (Wikipedia, n.d.). In this article, I discuss the findings from a narrative review of grey and published literature reporting on the impacts of involvement, where I aimed to explore what researchers learned from involvement and how they made use of their 'new' knowledge. The findings suggest that researchers use this learning to change their practice. I conclude that this learning process may be a mechanism by which involvement leads to many of the reported outcomes. By first changing what *researchers* think and do, involvement subsequently has an impact on *research*.

Methods

This narrative review focused on published examples of involvement reporting an impact on research. The intention was not to scope the literature to set out the range of impacts. Instead, the purpose was to review researchers' reports in detail, to explore whether there was evidence of researchers learning from involvement and how this had influenced their work.

The literature was obtained by searching INVOLVE's online Evidence Library (INVOLVE, 2015a). This library and a sister library containing reports of good practice (INVOLVE, 2015b) have been in development since 2009. Together they contain over 450 references. In 2009, references were added from a systematic review of the literature (Staley, 2009). Since then, all new journal articles have been identified through quarterly review of the contents of relevant journals and through citation, sourcing articles from the University of Leeds library. Any article that reports on impact, whether positive or negative, or maps the nature and extent of involvement or reflects on involvement in research is included in the Evidence Library. No bias is introduced via the selection of articles. New publications in the grey literature are identified via INVOLVE's extensive networks.

The Evidence Library was searched in June 2015 to identify all articles that had been categorized as including reports of impact (using the search fields on the database) and had been published between 2010 and 2015. A total of 95 publications were identified. These articles were reviewed and information relating to the reported impacts of involvement was extracted. These data were analysed using inductive thematic analysis, to develop themes from the data through repeated examination and comparison (Braun and Clarke, 2013). The analysis was shaped by the author's standpoint and experiential knowledge gained through many years' experience of conducting evaluations of involvement in research.

Results and discussion

Among the 95 articles identified through the database search, 64 only included reports of the final outcome of involvement, such as enhanced recruitment, an improved information sheet or greater demands on time and resources. The remaining 31 included details of impacts on researchers. However, there were no explicit or direct references to researchers' learning within these reports. The themes developed are therefore based on my interpretation of researchers' reports and how these can be reframed as forms of learning. I looked for descriptions of where involvement had led researchers to 'acquire new knowledge, behaviours, skills, values, or preferences'. Within these selected reports, I looked for further evidence as to whether and how this learning had influenced their research.

The thematic analysis of the researchers' reports identified four ways in which they had learnt from involvement. They had:

(1) acquired new knowledge (or enhanced their existing knowledge)
(2) changed their preferences/priorities
(3) increased their skills in communicating with a lay audience
(4) changed their attitude to involvement.

These will be discussed in turn, at the same time as exploring the ways in which this learning subsequently impacted on the research design, delivery and dissemination.

Acquiring new knowledge (or enhancing existing knowledge)

The knowledge that researchers gain from patients/the public often fills gaps in their own knowledge. It reveals what researchers 'don't know' or would not otherwise have anticipated. This may subsequently have an impact at any stage of their research.

Right at the beginning of a project, researchers report that learning about patient experiences prompts ideas for new research questions that they may not otherwise have considered (Staley, 2013, and see Box 1).

Box 1: New knowledge prompts researchers to ask different questions

Through talking to a carer of a person with a long-term condition, Knowles *et al.* (2015) became aware of a category of 'hidden' carers they had not previously included in their research into support for carers. They carried out a new project to explore these carers' needs.

A study of the effects of medication for Parkinson's disease on patients' memory was prompted by patients' reports that their memory was better before taking their first dose in the morning, when they were 'off' medication (INVOLVE, 2013). The researchers had been previously unaware of this side-effect.

Box 2: New knowledge prompts new areas of enquiry

A researcher working on the development of mental health services reported that through working with service users 'You'll hear some things you weren't expecting. We heard interesting things about the link between what people want from a service and their age, which made us think through that in planning the research' (INVOLVE, 2013: 10).

Similarly, such learning has prompted researchers to develop new areas of enquiry within an existing study (Blackburn *et al*., 2010; Jinks *et al*., 2015, and see Box 2).

During recruitment, researchers may not be aware of the best ways to find people to take part in their study, nor how to encourage participation. They often acquire this knowledge from patients/the public, which is frequently reported to boost recruitment. For example, a study of the accommodation needs of Travellers and Gypsies may not have been successful without the insights provided by members of those communities (Blackburn *et al*., 2010). In another study of the use of health services by teenage black and ethnic minority mothers, community members of a steering committee identified the best times and locations to hold focus groups, as well as when and where to find the participants (Muzik *et al*., 2015). This was new information for the researchers.

Similarly, through involvement researchers often learn how their project design is potentially off-putting to participants, and are then able to make changes to avoid problems that they would not otherwise have foreseen (Williamson *et al*., 2015; Iliffe *et al*., 2013; Caldon *et al*., 2010; Staley, 2013; Cossar and Neil, 2015). As one researcher explained, 'You can sit down and put together a very nice study without them [patients], but your recruitment will be low if the design is not acceptable or practical for the people you want to take part' (INVOLVE, 2013: 20).

Patients'/the public's knowledge also informs researchers during data analysis. For example, in a study of substance misuse among users of forensic mental health services, a service user researcher provided insight into cultural influences on substance use, which helped with the researchers' interpretation of the interview data. The lead researcher explained: 'The service user researcher gave a rationale as to why things were being said or not being said, things that we researchers could only hazard a guess at … he was able to marry what was coming out of the analysis with lessons from his own experience' (Staley, 2013: 25).

In the absence of in-depth knowledge about a condition or use of services, researchers can sometimes make incorrect assumptions, for example, about what matters to patients/the public and what interventions may help. Gaining insight through involvement then provides researchers with a 'reality check' (de Wit *et al*., 2014), in effect correcting any misassumptions. This can occur at different stages of research (see Box 3).

Box 3: Learning from involvement can correct researchers' misassumptions

Researchers working on a project to develop a text-messaging service to support people who self-harm, decided to 'abandon their original thinking' when, during workshops with service users, they learnt that their approach might make it more likely that people would harm themselves (Owens *et al*., 2011: 285). Instead, they developed a new approach based on the workshop participants' recommendations.

Changing priorities/preferences

At the point of identifying research questions, involvement often changes researchers' priorities, which can be based on misassumptions about what topics are most relevant and important to patients (Crowe *et al.*, 2015; de Wit *et al.*, 2014; Broerse *et al.*, 2010). As one social care researcher described, 'With research you might set off with a particular idea in mind about what needs to be done – then talking to other people [patients and the public] you realise that … there are other issues that need to be explored that are equally important' (Blackburn *et al.*, 2010: 18). Another researcher, working with survivors of domestic violence, explained, 'You could do studies on a dozen things … they [the survivors] gave us the reasons to run with this one' (INVOLVE, 2013: 22).

When designing research studies, researchers sometimes make assumptions about what outcomes are important to measure. Involvement can encourage them to change their preferences for outcome measures that matter to the participants (INVOLVE, 2013; Carter *et al.*, 2013; Vale *et al.*, 2012) or change their views on what constitutes a 'good' outcome (see Box 4).

Box 4: Involvement can change researchers' ideas about outcome measures

In a study to improve neonatal care, researchers assumed that parents would be concerned about how long their child had to stay in a specialized care unit far from home. However, parents explained that distant care is acceptable when necessary, and they were more concerned about delays in returning to a local hospital because of lack of transport or an available bed (Pearson *et al.*, 2013). The researchers therefore decided to develop a new measure for their study, the period between a child being ready for transfer and the actual time of transfer.

When reviewing a scale used to measure impact on quality of life, mental health service users challenged the clinician's view that a good outcome would be 'close relations with family members'. Their experience told them that their mental health is sometimes improved by keeping their family at a distance (Rose *et al.*, 2011).

On occasion, hearing what is important from the perspective of patients/the public is what convinces researchers that a project is worth doing. This gives them confidence to pursue a project and the motivation to continue, even in the face of criticism from their peers (see Box 5).

Box 5: Involvement can motivate researchers

Researchers working on a new intervention for mental health service users reported, 'We had a roughish ride with this project, particularly from psychiatry colleagues about why develop this intervention – but the service users said it was absolutely essential and asked why someone hadn't done this before and how much it would help them deal with their condition. This helped to keep us going' (Staley, 2012: 21).

Increasing skills in communication with a lay audience

Researchers often rely on input from patients/the public when writing information for a lay audience, including patient information sheets, summaries of research proposals and the results of a completed project (Blackburn *et al.*, 2010; Carter *et al.*, 2013; Cossar and Neil, 2015; Muzik *et al.*, 2015). When patients provide feedback on material that the researcher has written, in effect they are providing a form of 'training' in writing in plain English. They provide insights into what content is most relevant to a patient/public audience and how to rewrite the information in ways that are easier to understand (Staley *et al.*, 2016). Again, this may challenge researchers' incorrect assumptions as to what information is of value. For example, Littlechild *et al.* (2015) reported that the service users involved in their study selected extracts from the findings to present to service providers and managers, which 'enabled them to highlight issues that were very significant to service users and carers but which could easily be dismissed as trivial by academic researchers' (Littlechild *et al.*, 2015: 24–5).

Changing attitudes

Given that involvement can be a learning process for researchers, filling gaps in their knowledge and challenging their assumptions, it is perhaps not surprising that before talking to patients/the public, researchers may not know that these gaps exist or that their assumptions are wrong. People often 'don't know' what they 'don't know'. However, once researchers experience involvement and become aware of its potential, their attitudes to involvement often change (see Box 6).

Box 6: Experience of involvement can make researchers more aware of its potential

In a study that involved stroke survivors in designing and trialling a device to help people walk, researchers initially assumed that patients would simply choose between the options the researchers had developed. They were 'pleasantly surprised that [the patients] raised the very issues that we wouldn't have anticipated … in refining each of those designs and suggesting other options' (Williamson *et al.*, 2015: 263). The researchers appreciated the value of involvement much more, after directly experiencing its impact.

Conclusion

This narrative review of the involvement literature has shown that what is often described as an impact on *research* appears to be underpinned by *researchers' learning* – enhancing their knowledge and skills, as well as changing their priorities and attitudes. Learning often changes practice, as in this case – changing what researchers 'think' often seems to change what they then 'do'. This may be one important mechanism by which involvement brings about the reported outcomes for research. A more detailed exploration of what researchers learn though involvement may therefore enhance our understanding of how involvement 'works'.

This potential mechanism for the impact of involvement may be particularly important in projects where patients/the public are consulted for their views. A different mechanism may underpin the impact of patients/the public as active partners in research. This difference can be illustrated by considering one example, the impact of involvement on recruitment. In some of the reports reviewed in this article, an impact on recruitment could be traced back to involvement challenging researchers' misassumptions about what is acceptable to potential participants, which caused them to change their research design. In other cases, involvement filled gaps in researchers' knowledge about where to find people to recruit and how to encourage participation, which resulted in the development of successful recruitment strategies. Finally, and most frequently, involvement enhanced the researchers' skills in communicating with a lay audience, improving their patient information sheets, consent processes and publicity material. By way of contrast, if patients/the public had been directly involved in the recruitment process, for example by talking to potential participants themselves, the impact of that involvement may have been on the people being recruited, and may not have directly influenced researchers. The mechanism by which involvement leads to a specific outcome, is therefore likely to be related to the context and precisely how patients/the public are involved.

It is of note that much of the involvement literature does not include details of what researchers learnt or 'did differently' as a consequence of involvement. This information was found in only a third of the reports identified through this review, and even then the concept of 'researchers' learning' was not made explicit. This may reflect the importance given to objectivity in academic reporting. Objectivity in research dictates that researchers should remain distanced from what they study so that the findings depend on the nature of what was studied, rather than on the personality, beliefs, experiences and values of the researcher. This means that the personal journey of the researcher is rarely reported. For example, the thinking behind a project may change profoundly as a result of a researcher presenting their ideas at a conference and receiving feedback from colleagues. Involvement can have the same kind of profound impact, but neither kind of influence on the individual researcher would be routinely included in a report of research findings. It is therefore perhaps unsurprising that the accounts of involvement in academic journals tend to focus on the impacts on the *research*, rather than on the learning experience of *researchers*.

Implications for practice

Based on this review, the ways in which involvement seems to impact on researchers can be summarized as revealing the 'unexpected', the things that researchers 'didn't know'. At the beginning of any research project, researchers 'don't know what they don't know'. They may not become aware of this until they learn from talking to patients/the public – sometimes described by researchers as a 'lightbulb moment'.

This means that the outcome of involvement for any particular project is somewhat unpredictable (Staley, 2015). It will depend on precisely where the researcher starts out – what knowledge, skills, priorities and attitudes they bring to the table. Involvement may not make much difference to recruitment, for example, if the researcher's strategy is one that is already acceptable and practical for potential participants. Therefore, the answer to a researcher who asks 'How will involving patients/the public make a difference in my project?' becomes, 'We don't know precisely, but there may be things you haven't thought about or problems you haven't anticipated that involvement will reveal and then help solve.' Understanding this added value of involvement, and the uncertainties around its outcomes, strengthens the case for involving patients/the public at every stage and in all aspects of research. It is only through involvement that the researchers' 'unknowns' will come to light.

Implications for encouraging researchers to work with patients/the public

It is sometimes assumed that encouraging researchers to involve patients/the public requires explaining the benefits for *research*. Much of the guidance and training for researchers includes a review of the different ways involvement impacts on research projects – for example, boosting recruitment, increasing the readability of written information and making research more relevant and useful. This approach does not make explicit that researchers often directly experience the impact of involvement themselves, and that they will *learn* from their interactions with patients/the public.

This may be important to widen their understanding of the purpose of involvement and how it 'works'.

In a recent interview, a researcher with many years' experience of involvement explained that working with patients had been some of 'the most intellectually-stimulating work' she had ever done (personal and private communication), because it had given her new ideas and challenged her assumptions. She saw this as a personal benefit. Explaining how involvement impacts on researchers *as individuals* (see Box 7) may therefore prove to be an effective motivator, by addressing the all-important question, 'What's in it for me?' With a clearer expectation of what they may learn from involvement, researchers may feel more motivated to involve patients/the public in their work.

Box 7: Answering the researcher's question 'What will involvement do for me?'

Involvement will:

- stimulate new ideas
- fill gaps in your knowledge
- challenge your assumptions and encourage you to reconsider what is important
- help you to identify and avoid problems you would not otherwise have anticipated
- deepen your understanding of the issues of significance to patients/the public
- give you confidence and motivation.

Limitations of this review

The literature included in this review was not obtained through a systematic search of online databases, but through using a readily available sample, drawn from an existing library of involvement publications. Although the library contains reports of both negative and positive impacts, the articles identified through this review only contained descriptions of positive impacts. This may reflect a perceived bias towards reporting the benefits of involvement, rather than any harms (Staley, 2009).

The discussion in this report is not intended to provide a definitive answer to how involvement works, but aims to stimulate further debate and exploration of an alternative framing of impact, one that relates to researchers' learning. This may increase our understanding of how involvement works in certain contexts. The reframing is based on the interpretations of one person, myself as the author, and would greatly benefit from the contributions of others, particularly those with different perspectives. However, the ideas expressed in this article are not solely my own, but are informed by discussions with colleagues with many years' experience of involvement. In this sense, they may be said to be informed by the experiential knowledge of people working in the field, and this article represents an initial investigation of how well these ideas are supported by the existing published evidence.

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Notes on the contributor

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References

Ashcroft, J., Wykes, T., Taylor, J., Crowther, A. and 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.

Blackburn, H., Hanley, B. and Staley, K. (2010) *Turning the Pyramid Upside Down: Examples of public involvement in social care research*. Eastleigh: INVOLVE.

Braun, V. and Clarke, V. (2013) *Successful Qualitative Research: A practical guide for beginners*. London: SAGE.

Brett, J., Staniszewska, S., Mockford, C., Herron-Marx, S., Hughes, J., Tysall, C. and Suleman, R. (2014) 'Mapping the impact of patient and public involvement on health and social care research: A systematic review'. *Health Expectations*, 17 (5), 637–50.

Broerse, J.E., Zweekhorst, M., van Rensen, A. and de Haan, M. (2010) 'Involving burn survivors in agenda setting on burn research: An added value?' *Burns*, 36 (2), 217–31.

Caldon, L., Marshall-Cook, H., Speed, G., Reed, M. and Collins, K. (2010) 'Consumers as researchers – Innovative experiences in UK National Health Service research'. *International Journal of Consumer Studies*, 34 (5), 547–50.

Carter, P., Beech, R., Coxon, D., Thomas, M. and Jinks, C. (2013) 'Mobilising the experiential knowledge of clinicians, patients and carers for applied health-care research'. *Contemporary Social Science*, 8 (3), 307–20.

Cossar, J. and Neil, E. (2015) 'Service user involvement in social work research: Learning from an adoption research project'. *British Journal of Social Work*, 45 (1), 225–40.

Crowe, S., Fenton, M., Hall, M., Cowan, K. and Chalmers I. (2015) 'Patients', clinicians' and the research communities' priorities for treatment research: There is an important mismatch'. *BMC Research Involvement and Engagement*, 1 (2). Online. https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-015-0003-x (accessed 29 September 2016).

de Wit, M., Abma, T.A., Koelewijn-van Loon, M., Collins, S. and Kirwan, J. (2014) 'What has been the effect on trial outcome assessments of a decade of patient participation in OMERACT?' *Journal of Rheumatology*, 41 (1), 177–84.

Domecq, J.P., Prutsky, G., Elraiyah, T. *et al.* (2014) 'Patient engagement in research: A systematic review'. *BMC Health Services Research*, 14 (89). Online. http://bmchealthservres.biomedcentral.com/articles/10.1186/1472-6963-14-89 (accessed 29 September 2016).

Iliffe, S., McGrath, T. and Mitchell D. (2013) 'The impact of patient and public involvement in the work of the Dementias & Neurodegenerative Diseases Research Network (DeNDRoN): Case studies'. *Health Expectations*, 16 (4), 351–61.

INVOLVE (2012) *Public Involvement in Research: Impact on ethical aspects of research*. Eastleigh: INVOLVE.

INVOLVE (2013) *Exploring Public Involvement in Research Funding Applications*. Eastleigh: INVOLVE.

INVOLVE (2015a) *The Evidence Library*. Online. www.invo.org.uk/resource-centre/evidence-library/ (accessed 20 June 2015).

INVOLVE (2015b) *Putting it into Practice*. Online. www.invo.org.uk/resource-centre/putting-it-into-practice-database/ (accessed 20 June 2015).

Jinks, C., Carter, P., Rhodes, C., Beech, R., Dziedzic, K., Hughes, R., Blackburn, S. and Ong, B.N. (2015) 'Sustaining patient and public involvement in research: A case study of a research centre'. *Journal of Care Services Management*, 7 (4), 146–54.

Knowles, S., Combs, R., Kirk, S., Griffiths, M., Patel, N. and Sanders, C. (2015) 'Hidden caring, hidden carers? Exploring the experience of carers for people with long-term conditions'. *Health and Social Care in the Community*, 24 (2), 203–13. Online. http://dx.doi.org/10.1111/hsc.12207 (accessed 29 September 2016).

Littlechild, R., Tanner, D. and Hall, K. (2015) 'Co-research with older people: Perspectives on impact'. *Qualitative Social Work*, 14 (1), 18–35.

Muzik, M., Kirk, R., Alfafara, E., Jonika, J. and Waddell R. (2015) 'Teenage mothers of black and minority ethnic origin want access to a range of mental and physical health support: A participatory research approach'. *Health Expectations*, 19 (2), 403–15. Online. http://dx.doi.org/10.1111/hex.12364 (accessed 29 September 2016).

Owens, C., Farrand, P., Darvill, R., Emmens, T., Hewis, E. and Aitken, P. (2011) 'Involving service users in intervention design: A participatory approach to developing a text-messaging intervention to reduce repetition of self-harm'. *Health Expectations*, 14 (3), 285–95.

Pearson, M., Monks, T., Gibson, A. *et al.* (2013) 'Involving patients and the public in healthcare operational research: The challenges and opportunities'. *Operations Research for Health Care*, 2 (4), 86–9.

Rose, D. (2014) 'Patient and public involvement in health research: Ethical imperative and/or radical challenge?' *Journal of Health Psychology*, 19 (1), 149–58.

Rose, D., Evans, J., Sweeney, A. and Wykes T. (2011) 'A model for developing outcome measures from the perspectives of mental health service users'. *International Review of Psychiatry*, 23 (1), 41–6.

Shippee, N.D., Domecq Garces, J.P., Prutsky Lopez, G.J. *et al.* (2015) 'Patient and service user engagement in research: A systematic review and synthesized framework'. *Health Expectations*, 18 (5), 1,151–66.

Staley, K. (2009) *Exploring Impact: Public involvement in NHS, public health and social care research*. Eastleigh: INVOLVE.

Staley, K. (2012) *An Evaluation of Service User Involvement in Studies Adopted by the Mental Health Research Network*. London: The Mental Health Research Network.

Staley, K. (2013) *A Series of Case Studies Illustrating the Impact of Service User and Care Involvement on Research*. London: The Mental Health Research Network.

Staley, K. (2015) '"Is it worth doing?" Measuring the impact of patient and public involvement in research'. *BMC Research Involvement and Engagement*, 1 (6). Online. https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-015-0008-5 (accessed 29 September 2016).

Staley, K., Ashcroft, J., Doughty, L. and 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.

Staley, K., Buckland, S.A., Hayes, H. and Tarpey, M. (2014) '"The missing links": Understanding how context and mechanism influence the impact of public involvement in research'. *Health Expectations*, 17 (6), 755–64.

Vale, C., Tierney, J., Spera, N., Whelan, A., Nightingale, A. and Hanley, B. (2012) 'Evaluation of patient involvement in a systematic review and meta-analysis of individual patient data in cervical cancer treatment'. *Systematic Reviews*, 1 (23). Online. https://systematicreviewsjournal.biomedcentral.com/articles/10.1186/2046-4053-1-23 (accessed 29 September 2016).

Wikipedia (n.d.) 'Learning'. Online. https://en.m.wikipedia.org/wiki/Learning (accessed 13 December 2016).

Williamson, T., Kenney, L., Barker, A.T. *et al.* (2015) 'Enhancing public involvement in assistive technology design research'. *Disability and Rehabilitation: Assistive Technology*, 10 (3), 258–65.