**Shared Learning Group on Involvement in Research**

**Capturing the impact of involvement in research:**

**Some things to consider**

The[Shared Learning Group on Involvement in Research](http://www.slginvolvement.org.uk) is a grouping of national, UK based charities that have an interest in health and a commitment to involving patients, service users and carers in research. The aim of the Group is to provide peer support and opportunities for shared learning to people working in patient and public involvement in research[[1]](#footnote-1). Our members are concerned about how best to capture the impact of involvement. Capturing impact is also one of the new [public involvement standards](https://sites.google.com/nihr.ac.uk/pi-standards/standards).

We have developed a list of things our members should consider if they are thinking about capturing the impact of involvement in research. We hope that this list might be useful to others, so we are sharing it. We welcome your views – an email address for feedback is included at the end of this paper. We will review comments and update this list in summer 2019.

1. **Be clear about purpose**

What can change (or has changed) as a result of involvement? What aspects of involvement are you hoping to capture or monitor? Who are you planning to report this impact to? What will that group/person want to know?

1. **Focus on *im*proving, not on proving**

You might look to capture how involvement has improved the research or how to improve involvement in the future. We should have moved beyond having to prove that involvement adds value.

1. **Think about a range of impacts**

For example, think about impact on one or more (but not necessarily all) of these:

* A research project/s (at any stage, from design to implementation)
* Research strategy
* Research priorities
* Decision making committees (e.g. for funding and for ethics)
* People who get involved
* Patients and carers who are not directly involved
* Researchers and/or staff
* Relationships
* The charity
* Society more broadly

1. **Impact can be positive and negative**

It’s important to be honest about this and to be open to what didn’t work as well as what did, as we can learn from this.

1. **Involvement can lead to impacts that you weren’t anticipating**

For example, by involving people you may not fund a research study you may otherwise have funded, because they advise you that it will be unlikely to recruit to time and target. So it’s helpful to ask some open questions when you are thinking about impact.

1. **Involvement does not have to lead to tangible change to the research for it to have an impact**

For example, involvement may give researchers confidence or reassurance that they are doing the right thing in the right way. It can also help people who get involved to feel empowered, more hopeful, and/or more confident.

1. **Think about diversity**

This might include:

* Gathering the perspectives ofpeople who got involved and of researchers
* Gathering the perspectives of a diverse range of people
* Reflecting on the diversity of the people who have been involved

1. **Think about how you will gather information and when you will do it**

What methods will you use (e.g. surveys, interviews, asking researchers to keep records of changes made as a result of involvement etc.)? Do you need to use more than one method? Would it be helpful to look at what stakeholders hope to achieve through involvement when a project starts? Will you need to wait some months after a project has finished to see the impact of the involvement?

1. **Qualitative data is important**

It can capture the quality and the context of involvement. It can also capture lessons learned. Quantitative data can sometimes be extracted from qualitative data.

1. **Be aware of the context in which the involvement is taking place**

For example, the impact of involvement on a piece of laboratory based research may be very different to the impact of involvement in a qualitative study (see [this paper](https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-015-0008-5) for more discussion of this issue).

1. **Celebrate success**

It helps to motivate everyone and to recognise the value that involvement can add to research.

**Tell us what you think**

Please email ([admin@slginvolvement.org.uk](mailto:admin@slginvolvement.org.uk)) and tell us:

1. What you think about this document
2. Whether you have used it, and if so, how

We’ll review this feedback in June 2019 and make changes in response.

Shared Learning Group on Involvement in Research

June 2018

**You are welcome to use and adapt this paper, but please acknowledge the Shared Learning Group on Involvement in Research if you do so. Thank you.**

1. By involvement in research, we mean research being carried out ‘**with**’ or ‘**by**’ patients and carers, rather than ‘**to**’, ‘**about**’ or ‘**for**’ them. See http://www.invo.org.uk/find-out-more/what-is-public-involvement-in-research-2/ [↑](#footnote-ref-1)