

Explaining the benefits of Public Contribution to health research



Written by Peter Bates

Contents

Introduction	1
Research can be better	1
Service improvement can be faster	2
Communication can be stronger.....	2
Personal Development can be more powerful	3
Referencing the claims.....	3
The Down Side	6

Introduction

There are a wide range of benefits that have been claimed for involving Public Contributors in coproducing health research. Some people are driven by particular values that support involvement, perhaps underlining shared ownership and accountability for public funds, active citizenship or the potential for gaining valuable new insights from people of diverse backgrounds. Others look for evidence of benefit – in better decisions, improved services, targeted communication or more relevant research. A third group want to see a stronger focus on patients across the whole health system, so that patient views and priorities feature more strongly in clinical practice and service design, with Public Contribution to research playing a part in this wider picture¹.

Public Involvement may be considered to deliver benefits in the following four areas – research, service improvement, communication and service development. You can find more details below.

Research can be better

- Research can be of higher quality, as the design and methods can be tested by people with a wide variety of perspectives –the public help to ensure that the right questions are asked in the right way.

- Research topics and processes can be selected which are more relevant to the public's perception of need and priority and so would be more acceptable to the public
- Participants in clinical trials may be more likely to give consent, engage and stay engaged if they receive good quality, relevant information and stay involved in the research process.
- Researchers may be more likely to obtain funding if the public are involved.

Service improvement can be faster

- Involvement in research can augment and strengthen involvement in a range of other aspects of healthcare including the following: clinical care; service design and delivery; and implementation of innovation. When this happens, the role of healthcare professionals is changed. These benefits accrue to charities too when they involve people with lived experience.
- Involving people from the beginning can keep the research work focused on the impact on patient care and potential for service improvement. They inject a sense of urgency to use research findings to improve people's lives.
- When commissioners and managers have to explain their plans and their actions to the public, the quality, pace and delivery of their planning can improve, along with the effective use of limited resources.
- Services can be held to account for their implementation of the improvements if the public understand what should be going on. In addition, public involvement in quality monitoring can check that so-called improvements actually deliver benefits.
- Applying audit tools² to check whether the whole organisation is engaging with the public may provide fresh insights and a stimulus to whole-system improvements.

Communication can be stronger

- Messages reach audiences best when those audiences have been listened to first.
- Messages are presented in a more appropriate format for diverse audiences and people without academic or clinical skills, and this helps the professionals to focus on the main messages too.
- Dissemination can be more effective if the findings are disseminated by the public working alongside researchers and clinicians, especially where these

presenters focus on the key messages and explain things in an accessible manner

- A wider audience can be reached if a variety of presenters are engaged in taking the messages out.
- Effective listening to the public can provide an early alert about anything that might be going wrong.

Personal Development can be more powerful

- It can empower members of the public, helping them get what they want and helping them to feel valued, potentially reducing Exchequer costs in the long run through improvements in physical and mental health, social capital and self-care.
- Researchers and clinical staff can learn new skills in involving people, which will enhance their effectiveness and strengthen their CV.
- It helps to create a personal and organisational culture of candour, accountability and local ownership of local services.

Referencing the claims

The following references are largely drawn from the reviews by [Staley \(2009\)](#), augmented by NIHR & HRA (2016) *Impact of public involvement on the ethical aspects of research*, the 2018 report on impact published by the Alzheimer's Society [here](#) and the review by [Ball et al \(2019\)](#). There are several academic centres specialising in research into public involvement³. Finally here, readers will need to make their own judgement on whether the evidence that is cited is sufficiently persuasive to prove that these benefits do accrue or have the potential to accrue given the right conditions.

When involving patients and public...	Evidence
A wider set of research topics are considered	Bryant & Beckett 2006 ; Crowe et al 2016 ; Hewlett et al. 2006 ; Lindenmeyer et al. 2007 ; Rhodes et al. 2002 .
New research questions arise.	Wykes 2003 ⁴ , Caron-Flinterman et al. 2005
The work has a closer alignment with the public's interests.	Carter et al 2013 ; Evans et al 2011 ; McCormick et al. 2004 ; Staley 2016 , Hahn 2017 .

When involving patients and public...	Evidence
Assumptions, goals and relevance becomes clearer	Barnard et al. 2005⁵ ; Dickson & Green 2001 ; Hewlett et al. 2006 ; Lindenmeyer et al. 2007 ; Rhodes et al. 2002 .
Problems can be helpfully reframed	Fisher 2002 ;
Study design is improved	Wykes 2014 ⁶
Processes for obtaining consent are better	Morris 2004 .
The energy is created to get started	Ross et al. 2005 p.273, McCormick et al. 2004 , p.636
Plans that are too burdensome on patients are abandoned	Cossar and Neil 2015 ; Evans et al 2011 ; Iiffe et al 2013 .
The research is more fundable	Lindenmeyer et al. 2007 ; Lidewij et al 2019
Outcomes are clearer and measures are more suitable	Ennis and Wykes 2013 ; Hanley et al. 2001 ; Hewlett et al. 2006 ; Prinsen et al 2016 .
Specific communities can be reached	Barnard op cit; Blackburn et al 2010 ⁷ ; Burrus et al. 1998 ; McLaughlin 2006 ; Minkler et al. 2002 ; Rhodes et al. 2002 ; Salway et al 2015 ; Schulz et al. 2001 ; Stockdale et al. 2006 .
Survey questions and information sheets are improved.	Broad & Saunders 1998 ⁸ ; Burrus et al. 1998 ; Butcher 2005 ⁹ ; Faulkner 2004 ¹⁰ ; Faulkner 2006 ¹¹ ; Jenner et al 2015 ; Krieger et al. 2002 ; Lammers & Happell 2004 ; Langston et al 2005 ; Miller et al. 2006 ; Minkler et al. 2002 ; Petrie et al. 2006 ; Rowe 2006 ; Smith et al. 2008 ; Stiffman et al. 2005 ; Viswanathan et al. 2004 ; Wright et al. 2006 ; Wyatt et al. 2008 .
Reliability of surveys improves	Schulz et al. 2001 ; Viswanathan et al. 2004
Response rates improve, especially when collecting sensitive invitation	Carter et al 2013 ; Nuffield Council on Bioethics 2015 ; Smith et al. 2008
Research methods become more 'workable'	Boote et al 2011 ; Edwards et al 2011 ; Ennis and Wykes 2013 ; Hanley et al. 2001 ; Jenner et al 2015 ; Nuffield Council on Bioethics 2015 ; Smith et al. 2008 ; Staley 2016 ; Truman & Raine 2001 .

When involving patients and public...	Evidence
Recruitment and participation increased with fewer people dropping out	Bailey et al 2015 , Carter et al 2013 ; Crocker et al 2018 ; Domecq et al 2014 , Fudge et al 2007 , Plumb et al. 2004 ¹² ; Viswanathan et al. 2004 .
Interviews go deeper – especially with peer interviewers	Abma 2005 ; Broad & Saunders 1998 p.11 ¹³ ; Elliott et al. 2002 ; Faulkner 2006 op cit
Interpretation of data is more valid	Barnard et al. op cit; Beer et al 2005 ¹⁴ ; Faulkner 2006 op cit; Minkler et al. 2002 ; Rose ¹⁵ ; Ross et al. 2005 ; Rhodes et al. 2002
Public contributors gain new knowledge and skills	Beer et al 2005 op cit; Cotterell et al. 2007 ¹⁶ ; Cotterell et al. 2008 ; Lammers & Happell 2004 ; Leamy & Clough 2006 ; McCormick et al. 2004 ; Meyer et al. 2003 ; Minogue et al. 2005 ¹⁷ ; Ramon 2000 ¹⁸ ; Ross et al. 2005 ; Rowe 2006 p.469; Wood 2003
Participation in well-designed research is a more valid use of time	Blackburn et al 2010 op cit; Cossar and Neil 2015 ; Staley 2016
Research staff gain benefits	Staley et al 2017 , Manafa et al 2018
Co-authors make dissemination efforts more accessible, persuasive and hard-hitting	Evans et al 2011 ; Littlechild et al 2015 ; McLaughlin 2006 ; Prinsen et al 2016 , Supple et al 2015 ; Sutton & Weiss 2008
Ethical issues are identified and resolved with fewer protocol revisions	Caldon et al 2010 ; Carter et al 2013 ; FDA 2019 , Hanley et al. 2001 ; Littlechild et al 2015 ; Smith et al. 2008 ; Staley & Elliott 2017 .
Increased satisfaction correlates with better health outcomes	Minemyer 2017
Policy formulation improves	Degeling et al 2015
Healthcare improvements are more likely to be implemented	Ali, Altenhofer, Gloinson & Marjanovic 2020 Charities benefit - Harvey, Piercy & Hanley 2020
The role of healthcare professionals is changed	Andreassen 2018

The Downside

Kathryn Oliver and colleagues have catalogued the potential pitfalls, hazards and costs of coproduction¹⁹. Others have found a bias towards certain kinds of impact and have questioned whether a preoccupation with measurement is helpful²⁰. Some complain that the requirement to ‘prove’ the value of Public Contributors is unwarranted unless the contribution of other team members is similarly evaluated. For example, Piroasca and colleagues found widespread risk of bias in research trials yet called for more statisticians and methodologists rather than fewer²¹.

A group of nine research studies²² on the use of patient feedback in the NHS found significant shortfalls in the present system:

- Data collection efforts focus on the Friends and Family test and neglect other kinds of feedback
- Attention is focused on complaints, not other kinds of data
- Data is processed to submit to benchmarking systems, not analysed to derive improvement ideas
- Patient feedback systems are often remote from quality improvement drivers and so have little impact.
- Messages rarely include practical proposals for how to improve things and are passed to people who are not in a position to do so anyway.

¹ Sacristán, J.A. Patient-centered medicine and patient-oriented research: improving health outcomes for individual patients. *BMC Med Inform Decis Mak* **13**, 6 (2013). <https://doi.org/10.1186/1472-6947-13-6>

² Such as the NCCPE Public Engagement [Watermark](#).

³ See for example, the [Patient Experience Research Centre](#) at Imperial.

⁴ Wykes T (2003) Blue skies in the journal of mental health? Consumers in research. *Journal of Mental Health*. 2003;12(1):1–6.

⁵ Barnard A, Carter M, Britten N, Purtell R, Wyatt K, Ellis A (2005) *The PC11 Report. An evaluation of consumer involvement in the London Primary Care Studies Programme*. Exeter UK: Peninsula Medical School.

⁶ Wykes T (2014) Great expectations for participatory research: what have we achieved in the last ten years? *World Psychiatry* 13(1):24–7

⁷ Blackburn H, Hanley B & Staley K (2010) *Turning the pyramid upside down: examples of public involvement in social care research*. Eastleigh: INVOLVE.

⁸ Broad B, Saunders L (1998) Involving young people leaving care as peer researchers in a health research project: a learning experience. *Research Policy and Planning*.16:1-9.

⁹ Butcher, L. (2005) No home, no job. *CareandHealth*, May 10 - May 16, pp. 30.

¹⁰ Faulkner A (2004) *Capturing the experiences of those involved in the TRUE Project: a story of colliding worlds*. Eastleigh: INVOLVE.

-
- ¹¹ Faulkner A (2006) *Beyond our expectations: a report of the experiences of involving service users in forensic mental health research*. London: National Programme on Forensic Mental Health R&D, Department of Health.
- ¹² Plumb, M., Price, W. & Kavanaugh-Lynch, M. (2004) Funding community-based participatory research: Lessons learned. *Journal of Interprofessional Care*, vol. 18, no. 4, pp. 428-439.
- ¹³ Broad B & Saunders L (1998) Involving young people leaving care as peer researchers in a health research project: a learning experience. *Research Policy and Planning*. 16:1-9.
- ¹⁴ Beer D, Keeble P, MacInnes D, Rees D & Reid L (2005) *Development of a Questionnaire to Measure Service User Satisfaction within Inpatient Forensic Services. The Forensic Satisfaction Scale*. Liverpool: National Programme on Forensic Mental Health Research and Development (R&D).
- ¹⁵ Rose D (2004) Telling different stories: user involvement in mental health research. *Research and Policy Planning*. 22(2):23-30.
- ¹⁶ Cotterell P, Clarke P, Cawdrey D, Kapp J, Paine M & Wynn R (2007) Becoming involved in research: A service user research advisory group. In Jarrett L (ed) *Creative engagement in palliative care: New perspectives on user involvement*. Radcliffe Publishing, Oxford, pp. 101-115.
- ¹⁷ Minogue V, Boness J, Brown A. & Girdlestone, J. (2005) The impact of service user involvement in research, *International Journal of Health Care Quality Assurance incorporating Leadership in Health Services*, vol. 18, no. 2-3, pp. 103-112.
- ¹⁸ Ramon S & Lifecraft HC (2000) Participative mental health research: users and professional researchers working together. *Mental Health and Learning Disabilities Care*. 3:224-8.
- ¹⁹ See Oliver K, Kothari A & Mays N (2019) The dark side of coproduction: do the costs outweigh the benefits for health research? *Health Research Policy and Systems* 17:33. <https://doi.org/10.1186/s12961-019-0432-3>. See also See also [Lidewij et al 2019](#).
- ²⁰ Russell J, Fudge N & Greenhalgh T (2020) The impact of public involvement in health research: what are we measuring? Why are we measuring it? Should we stop measuring it? *Research Involvement and Engagement* 6, 63. <https://doi.org/10.1186/s40900-020-00239-w>
- ²¹ Piroasca's team checked the study design of 1659 randomised trials that took place in 84 countries and found only 8% carried a low risk of bias. See Piroasca, S., Shiely, F., Clarke, M. *et al*. Tolerating bad health research: the continuing scandal. *Trials* 23, 458 (2022). <https://doi.org/10.1186/s13063-022-06415-5>. This paper recommends that funding is provided on the condition that research teams include a statistician and a methodologist. However, Shaun Treweek (who is co-author dealing with correspondence), acknowledges that there is not yet evidence to indicate whether the poor studies lack these professionals while the well-designed studies include them, or the problem is due to the incompetence of these team members. Treweek agreed that parallel arguments can be applied to Public Contributors and considered that evaluating the effectiveness of the statisticians and methodologists was much easier than doing so for Public Contribution (personal correspondence, June 2022).
- ²² See <https://content.nihr.ac.uk/nihrdc/themedreview-04327-PE/Patient-Feedback-WEB.pdf>