Database – Methods and tools to assess impacts: Signposting resource to published case examples of methods and tools

Summary

About:	*This resource provides a database of examples of previous research that has assessed different kinds of public involvement impact*
What:	*The resource uses the typology of impacts identified from our evidence review and identifies methods and tools from published studies that have been used to assess those impacts.*
Who:	*For people who would like to find out how particular public involvement impacts have been assessed in published studies*
How:	*The resource provides a brief introduction to each of the impact types, a matrix showing the studies that have assessed its impact. Information about the methods or tools that have been used to assess impact is provided as well as a full reference for the study.*

Introduction to the resource

The purpose of this resource is to provide references for examples of tools, methods and measures that have been used to assess the impact of public involvement on research in health and social care that could inform the development of an impact assessment plan.

As part of our evidence review we collated public involvement impacts identified by Brett et al. (2010) and Staley (2009) in their systematic reviews and developed a typology of impacts of public involvement on health and social care research. This typology distinguished between impacts on research (see figure 1 on page 3) and on people (see figure 2 on page 75)

This resource provides an overview of and commentary upon published studies that have described their use of a method or tool for assessing the impact of public involvement on research. These studies were identified in an informal review of a number of sources including a time-limited search of Psychinfo, Academic Complete and Medline databases and the following reviews: Boote (2011); Nilsen et al. (2010); Barber et al. (2012) and Brett et al. (2010).

Instructions

In order to use this resource…

- You could start by looking at The Impacts on Research overview on page 3 or The Impacts on People overview on page 75 and identify which impact(s) you are interested in:

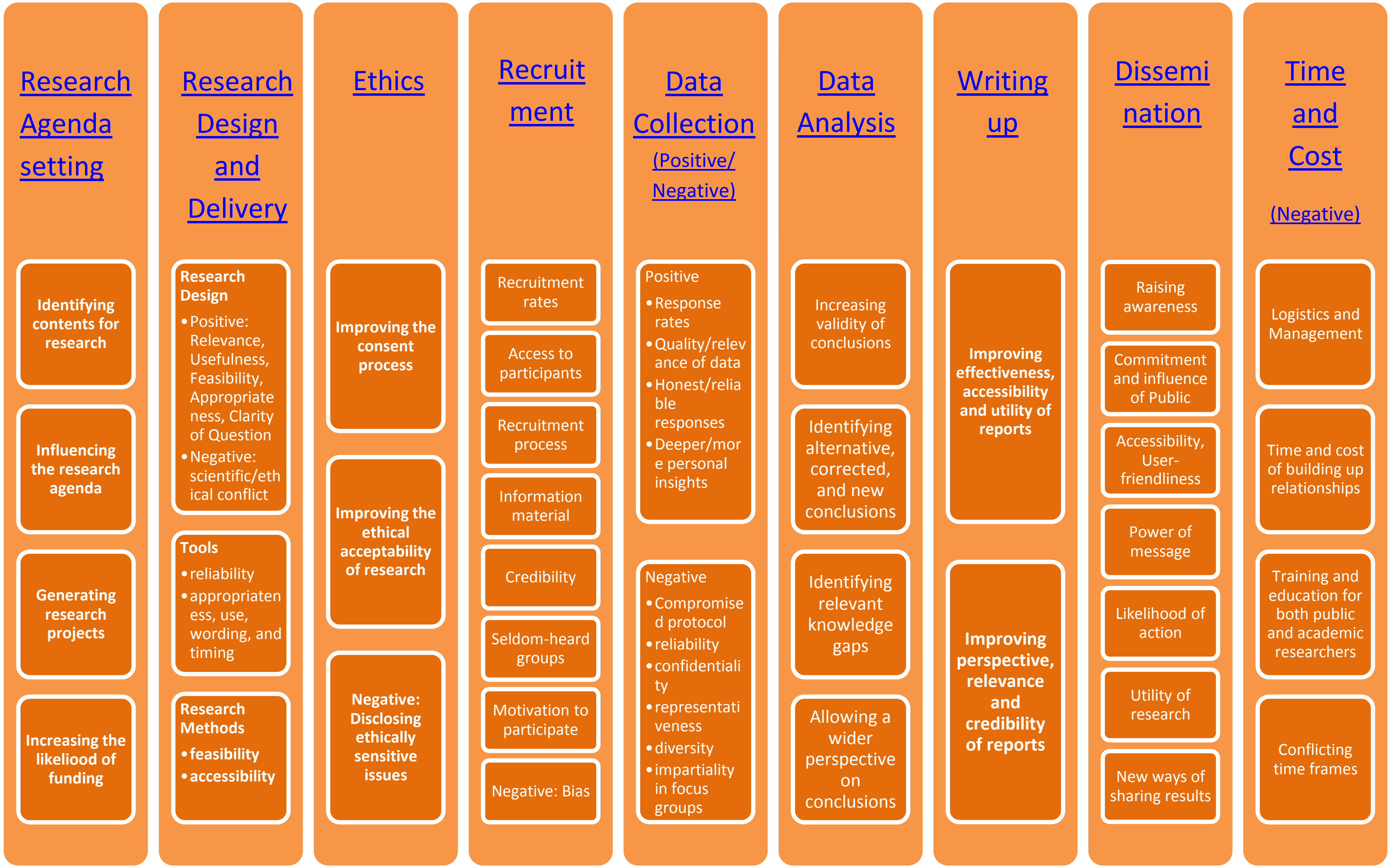
  - Research Agenda Setting; Research Design & Delivery; Ethics; Recruitment; Data Collection; Analysis of Data; Writing Up; Dissemination; Time and Cost
  - On Public-involved; Academic researchers; Research participants; Wider community and community organisations; Funders and on Policy-makers

- This resource uses hyper-links. Click on the impact in which you are interested to be taken to the pages associated with that impact. For each impact you will find 4 different types of information:
  - An overview provides a brief textual review of findings associated with each impact from existing reviews
  - A diagram provides a visual summary of the different types of impact found for each impact heading
  - A table contains the methods and tools that have been used to assess the impact: click on the appropriate method or tool to be taken to a more detailed commentary on it
  - A commentary on each method or tool that identifies: indicators of impact; the extent of public involvement in the main study and in the assessment of public involvement impact and a description of the method or tool. We have also included a limited quality appraisal. It should be noted however that this quality appraisal is based on each paper's own assessments of the steps they took to ensure the quality, validity or reliability of their work. In some cases we have indicated where these steps have not been made clear

- This resource directs readers to relevant studies that have used and described tools, methods and measures of specific impacts. We have deliberately not provided links to or facsimiles of the methods, measures and tools described in the database because we hope that readers will engage with and cite the original papers as part of a process of strengthening the evidence base on public involvement impact assessment. Given the focus within the Public Involvement Impact Assessment Framework on the importance and specificity of research context it would also be inappropriate for the methods, tools or measures to be used without thinking about how they might need to be adapted to the needs of your own research project

- It is intended that this resource should be built upon and added to as more studies that adopt formal approaches to assess the impact of public involvement become available

Figure 1: Typology of impacts on research



Impacts on Research

Research Agenda setting

- Identifying contents for research
- Influencing the research agenda
- Generating research projects
- Increasing the likeliood of funding

Research Design and Delivery

- **Research Design**
  - Positive: Relevance, Usefulness, Feasibility, Appropriateness, Clarity of Question
  - Negative: scientific/ethical conflict
- **Tools**
  - reliability
  - appropriateness, use, wording, and timing
- **Research Methods**
  - **feasibility**
  - **accessibility**

Ethics

- Improving the consent process
- Improving the ethical acceptability of research
- Negative: Disclosing ethically sensitive issues

Recruitment

- Recruitment rates
- Access to participants
- Recruitment process
- Information material
- Credibility
- Seldom-heard groups
- Motivation to participate
- Negative: Bias

Data Collection (Positive/ Negative)

- Positive
  - Response rates
  - Quality/relevance of data
  - Honest/reliable responses
  - Deeper/more personal insights
- Negative
  - Compromised protocol
  - reliability
  - confidentiality
  - representativeness
  - diversity
  - impartiality in focus groups

Data Analysis

- Increasing validity of conclusions
- Identifying alternative, corrected, and new conclusions
- Identifying relevant knowledge gaps
- Allowing a wider perspective on conclusions

Writing up

- Improving effectiveness, accessibility and utility of reports
- Improving perspective, relevance and credibility of reports

Dissemination

- Raising awareness
- Commitment and influence of Public
- Accessibility, User-friendliness
- Power of message
- Likelihood of action
- Utility of research
- New ways of sharing results

Time and Cost (Negative)

- Logistics and Management
- Time and cost of building up relationships
- Training and education for both public and academic researchers
- Conflicting time frames

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Tools and methods for assessing the impact of public involvement in health and social care research: Research Agenda Setting

Overview

The importance of public involvement in setting the research agenda should not be under-estimated:

> *...because it helps researchers to ask the right questions in the right way and thus ensures that research is relevant, widely accessible and influential in terms of both policy and practice.(Owens, Ley, & Aitken, 2008, p. 419)*

However the extent to which its value can be formally recognised depends upon the quality of the impact assessment that is carried out. This resource will highlight examples of measures and tools that have been used in published studies to produce an assessment of the impact of public involvement in research agenda setting. The impacts covered in this resource (and displayed in Table 1) range from the relatively implicit impacts associated with the identification of differences (and similarities) in research priorities between public and academics/professionals to the more explicit and complex impacts that consider process as well as outcome issues. Furthermore it was observed that the more complex the impact to be assessed, the more complex the method and tools used in its assessment.

A range of stakeholders who had experience or knowledge of public involvement in research agreed that it was feasible to assess the impact of public involvement in identifying and prioritising research projects (Barber et al. 2012). Reviews of existing evidence on public involvement impacts carried out by Brett et al. (2010) and Staley (2009) identified a range of impacts on research agenda setting in different types of research, with different kinds of members of the public and involvement happening in a variety of ways. Although Staley noted that much research into the impact on the research agenda appears to be about demonstrating that public-involved can identify and prioritise research questions or topics, there were also a number of attempts to document the wider societal impact of public involvement on prioritising and funding research projects.

Return to Impacts on Research Overview

Research Agenda Setting: Impacts

Impact Research
(Benefits & Challenges)

- Agenda
- Design and Delivery
- Ethics
- Recruitment
- Data Collection
- Analysis of Data
- Writing Up
- Dissemination
- Time and Cost

Overview of Impacts on Research Agenda:

Identifying topics for research

- Considered a wider set of topic than academics working alone
- Opened up new research areas
- Assisted in prioritising topics for the research agenda

Shaping the research agenda

- Shifted focus of research more in line with the public's interests and concerns
- Forced researchers to be clearer about why they wanted to conduct their research and how it would be relevant to the public

Initiating research projects

- Provided motivation or momentum for researchers to initiate and conduct research
- Helped to speed up research process

Impact on funding decisions

- Made research more fundable – e.g. increased credibility; improved feasibility
- Public can have direct influence on funding decisions through peer review

Methods and tools that have been used in published studies to assess the impact of public involvement on research agenda setting

Impacts	**Context**	**Tool**	**Source**	**Page No.**
Identifying topics for research		Dialogue Model	Broerse, J. E. W., M. B. M. Zweekhorst, et al. (2010). "Involving burn survivors in agenda setting on burn research: An added value?" *Burns 36*(2): 217-231.	8
	Comparison of homeless veterans' and service providers' preferences for research	Questionnaire to identify differences in research priorities between stakeholder groups	Cohen, C. I., D'Onofrio, A., Larkin, L., Berkholder, P., & Fishman, H. (1999). A comparison of consumer and provider preferences for research on homeless veterans. *Community Mental Health Journal, 35*(3), 273-280	9
	Exploration of priorities for mental health research in Australia		Griffiths, K. M., Jorm, A. F., Christensen, H., Medway, J., & Dear, K. B. (2002). Research priorities in mental health, Part 2: an evaluation of the current research effort against stakeholders' priorities. *Australian & New Zealand Journal of Psychiatry, 36*(3), 327-339.	10
	Exploration of the priorities for mental health research held by different stakeholder groups	Delphi survey to identify similarities and differences in research priorities held by different stakeholders	Owens, C., Ley, A., & Aitken, P. (2008). Do different stakeholder groups share mental health research priorities? A four-arm Delphi study. *Health Expectations, 11*(4), 418-431.	11
	Priorities assigned to healthcare by users and providers in Greece	Delphi survey to identify the healthcare priorities of providers and users	Efstathiou, N., Coll, A., Amen, J. & Daly, W. (2011). Do Greek healthcare users and healthcare providers share cancer care priorities? Analysing the results from two Delphi studies. *European Journal of Cancer Care 20*(2): 179-186	12
	Research to explore the research	Focus group to obtain public-involved	Brown, K., Dyas, J., Chahal, P., Khalil, Y., Riaz,	14

	priorities of people with diabetes in a multi-cultural, inner-city community	research priorities and compare with existing priorities	P., & Cummings-Jones, J. (2006). Discovering the research priorities of people with diabetes in a multicultural community: a focus group study. *The British Journal Of General Practice: The Journal Of The Royal College Of General Practitioners, 56*(524), 206-213	
Shaping the research agenda	Impact assessment of breast cancer survivors voting on breast cancer research proposals as part of a scientific review panel	Quantitative comparison of academic and lay scores assigned to research proposals	Andejeski, Y., Bisceglio, I., Dickersin, K., Johnson, J., Robinson, S., Smith, H., Visco,l F. & Rich, I. (2002). Quantitative impact of including consumers in the scientific review of breast cancer research proposals. *Journal of women's health & gender-based medicine 11* (4) 379-388.	15
		Questionnaire on participant perceptions of public influence on the review panel		16
	New participation methodology to develop a shared research agenda for asthma and COP	Evaluation framework to assess the effectiveness of public involvement in the research agenda setting process	Caron-Flinterman, J. F., Broerse, J. E. W., Teerling, J., Van Alst, M. L. Y., Klaasen, S., Swart, L. E., & Bunders, J. F. G. (2006). Stakeholder participation in health research agenda setting: the case of asthma and COPD research in the Netherlands. *Science & Public Policy (SPP), 33*(4), 291-304.	17
Impact on funding decisions	Exploration of the impact of public involvement in NHS HTA Programme agenda setting	Mixed methods evaluation of public influence on decisions about priorities for commissioning research	Oliver, S., Armes, D. G., & Gyte, G. (2009). Public involvement in setting a national research agenda: A mixed methods evaluation. *The Patient: Patient-Centered Outcomes Research, 2*(3), 179-190.	18

Research Agenda Setting

Tool or method:

The Dialogue Model

Source:

Broerse, J. E. W., M. B. M. Zweekhorst, et al. (2010). "Involving burn survivors in agenda setting on burn research: An added value?" *Burns* 36(2): 217-231.

Type of tool or method:

Qualitative

Indicators of impact:

Differences in the research priorities held by public-involved and health professionals

Quality appraisal:

The authors state that the Dialogue Model has been validated by its use in previous case studies.

The authors drew upon Guba & Lincoln's criteria to ensure the quality of the research they conducted using the Dialogue Model. They:

- Used member checking and triangulation to ensure *credibility*
- Took steps to address potential asymmetries in power relations between the burns survivors and the physicians to ensure *fairness*
- Regularly checked the participants' satisfaction with both the process and the intermediate outcomes of the research to ensure *satisfaction*

The approach to public involvement in the main study:

Members of the public are included in the author listing, they are also reported to be actively involved in data collection, analysis and decision-making. Members of the public were also involved as participants.

Public involvement in assessment of impact:

Public actively involved in data collection, analysis and decision-making.

Summary:

The Dialogue Model was developed as a way of facilitating public involvement by promoting a dialogic relationship between academics and public-involved. It was also used to identify and integrate the research priorities of public and academics in order to facilitate the development of a shared research program. Different methods for obtaining research priorities from the stakeholder groups were used at each stage, including focus groups, documentary analysis, interviews and questionnaires.

Return to Methods and Tools table

Research Agenda Setting

Tool or method:

Questionnaire to compare priorities for research

Source:

Cohen, C. I., D'Onofrio, A., Larkin, L., Berkholder, P., & Fishman, H. (1999). A comparison of consumer and provider preferences for research on homeless veterans. *Community Mental Health Journal, 35*(3), 273-280

Type of tool or method:

Mostly quantitative

Indicators of impact:

Differences in research priorities were identified by staff and clients of a centre for homeless veterans

Quality appraisal:

Unclear

The approach to public involvement in the main study:

Members of the public took part as participants

Public involvement in assessment of impact:

Unclear – infer that academics undertook data collection and analysis

Summary:

The questionnaire contained 2 sections:

- Open-ended questions to obtain respondent suggestions for preferences
- List of potential research topics from which respondents were asked to identify the five most and the five least important

Chi-square analysis was used to compare staff and client preferences. Qualitative data from the open questions were ‘reviewed’.

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Research Agenda Setting

Tool or method:

Questionnaire to compare priorities for research

Source:

Griffiths, K. M., Jorm, A. F., Christensen, H., Medway, J., & Dear, K. B. (2002). Research priorities in mental health, Part 2: an evaluation of the current research effort against stakeholders' priorities. *Australian & New Zealand Journal of Psychiatry, 36*(3), 327-339.

Type of tool or method:

Quantitative

Indicators of impact:

Differences in research priorities held by different stakeholders

Quality appraisal:

The questionnaire was devised by the project team. The authors reported that they counterbalanced presentation of the questionnaire items by having items displayed either in alphabetical or reverse alphabetical order and sent questionnaires out randomly to participants. Some concern about possible response bias was acknowledged.

The approach to public involvement in the main study:

Members of the public took part as participants

Public involvement in assessment of impact:

Data collection and analysis was carried out by the authors who are academics

Summary:

The questionnaire contained 3 sections:

- List of research topics of which respondents asked to rate all of them in terms of their priority from 1 (low) to 5 (very high) – covering areas such as category of mental disorder, research setting, research topic and population sub-groups
- List of factors that affect how research priorities are decided –rated from 1 to 5
- Lists of sources of information about mental health research that is being conducted –rated from 1 to 5

Stakeholders included mental health consumer and carer advocates; research panel members, GPs, psychiatrists, clinical psychologists and mental health nurses. Statistical analyses including one-way ANOVA were used to compare groups.

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Research Agenda Setting

Tool or method:

Delphi survey to identify differences in cancer care priorities

Source:

Owens, C., Ley, A., & Aitken, P. (2008). Do different stakeholder groups share mental health research priorities? A four-arm Delphi study. [Article]. *Health Expectations, 11*(4), 418-431.

Type of tool:

Quantitative

Indicator of impact:

Differences and similarities in mental health research topics prioritised by different stakeholders

Quality appraisal:

2 members of the project team coded the first-round responses in order to develop round 2 questionnaires. The round 2 questionnaire was piloted on members of the Trust's R&D team.

The approach to public involvement in the main study:

Members of the public took part as participants

Public involvement in assessment of impact:

Data analysis and collection carried out by authors who hold senior academic research positions

Summary:

3-round Delphi survey carried out with 4 different stakeholder groups (service users, carers, healthcare professionals and service managers):

- 1st round participants were invited to identify research areas,
- 2nd round participants rated the priority of each topic using a 5-point Likert scale
- 3rd round participants reviewed previous priority ratings and re-rated the items. The typical values assigned to priorities were indicated by medians and the level of consensus was obtained from the Inter-Quartile Range.

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Research Agenda Setting

Tool or method:

Delphi survey to identify the healthcare priorities of providers and users

Source:

Efstathiou, N., Coll, A., Amen, J. & Daly, W. (2011). Do Greek healthcare users and healthcare providers share cancer care priorities? Analysing the results from two Delphi studies. *European Journal of Cancer Care 20*(2): 179-186

See also:

Efstathiou, N., Ameen, J. & Coll, A. (2007). Healthcare providers' priorities for cancer care: A Delphi study in Greece. *European Journal Of Oncology Nursing: The Official Journal Of European Oncology Nursing Society 11*(2): 141-150

Efstathiou, N., Ameen, J. & Coll A. (2008). "A Delphi study to identify healthcare users' priorities for cancer care in Greece." European Journal Of Oncology Nursing: The Official Journal Of European Oncology Nursing Society 12(4): 362-371.

Type of tool:

Quantitative

Indicator of impact:

Differences and similarities in the healthcare priorities identified by providers and users

Quality appraisal:

The first round of the Delphi survey of healthcare providers was piloted with a small number of nurses who were not members of the Delphi panel.

The authors note a number of issues of validity and reliability associated with Delphi surveys and over three papers show how they addressed them. They note that the validity of Delphi studies is usually assessed in terms of receiving high response rates and show that their surveys received high response rates at each round. They also argue that trustworthiness rather than reliability is usually addressed and draws on 3 criteria: clear formulation of the question, careful transcription of individual responses and documentation of response rates for each round (Crisp et al., 1997).

The approach to public involvement in the main study:

Public were involved as participants taking part in the Delphi survey.

Public involvement in assessment of impact:

Data analysis and collection were carried out by authors who hold academic research positions.

Summary:

2 separate Delphi survey studies were carried out, one with healthcare users (Efstathiou et al., 2008) and the other with healthcare providers (Efstathiou et al., 2007). The priorities were organised into themes and the prioritisation of users and providers compared (Efstathiou et al., 2011). Descriptive statistics were used for the demographics and response rates. An independent t-test was conducted

to examine whether there was a difference between the mean scores assigned to the priorities by the users and providers.

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Research Agenda Setting

Tool or method:

Focus group to obtain public-involved research priorities and compare them with existing priorities

Source:

Brown, K., Dyas, J., Chahal, P., Khalil, Y., Riaz, P., & Cummings-Jones, J. (2006). Discovering the research priorities of people with diabetes in a multicultural community: a focus group study. *The British Journal Of General Practice: The Journal Of The Royal College Of General Practitioners, 56*(524), 206-213.

Type of tool or method:

Qualitative

Indicators of impact:

Contribution of the lived experience of people with diabetes to the development of research themes

Differences in the nature or type of themes generated from focus groups compared with Research Advisory Committees

Quality appraisal:

The focus group topic guide was piloted on one group of participants, but as no alterations were made, data from this group formed part of the analysis.

The approach to public involvement in the main study:

A participatory approach to public involvement was adopted. Some members of the public were involved in identifying the aim of the study. The research team included two participants from the focus group study.

Public involvement in assessment of impact:

The research team included public representatives as well as healthcare professionals

The analysis was carried out by the research team and 2 focus group participants were involved in interpreting the findings

Summary:

The researchers undertook qualitative coding of the priorities generated by focus groups of representatives of people with diabetes and compared them with those of the Research Advisory Committee of the Department of Health and the Medical Research Council.

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Research Agenda Setting

Tool or method:

Comparison of academic and lay scores assigned to research proposals

Source:

Andejeski, Y., Bisceglio, I., Dickersin, K., Johnson, J., Robinson, S., Smith, H., Visco,l F. & Rich, I. (2002). Quantitative impact of including consumers in the scientific review of breast cancer research proposals. *Journal of women's health & gender-based medicine 11* (4) 379-388.

Type of tool or method:

Quantitative

Indicators of impact:

Differences between the scores that lay reviewers and academic reviewers assign to the same research proposals.

Quality appraisal:

Identifies a potential response bias in relation to the academics who were on the review panel and who by extension took part in the study. For example review panel members may have known about and had positive attitudes towards the public involvement on the review panel whilst those with negative views may not have signed up to be part of the review panel.

The approach to public involvement in the main study:

Public were involved in a consultative capacity on the review boards

Public involvement in assessment of impact:

A representative from a patient organisation was listed as an author. We infer that the authors were involved in collecting and analysing data.

Summary:

Scores between 1.0 and 5.0 were assigned to breast cancer research proposals by academic and lay reviewers during anonymous balloting. The scores of academics alone were compared with the scores of academics including lay reviewer scores. Standard deviations of scores and correlation co-efficients for academic and lay reviewer scores were compared. Lay reviewers were found to have similar patterns of voting to academic reviewers.

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Research Agenda Setting

Tool or method:

Questionnaire on perceptions of lay influence on the review panel

Source:

Andejeski, Y., Bisceglio, I., Dickersin, K., Johnson, J., Robinson, S., Smith, H., Visco,l F. & Rich, I. (2002). Quantitative impact of including consumers in the scientific review of breast cancer research proposals. *Journal of women's health & gender-based medicine, 11* (4) 379-388.

Type of tool:

Quantitative

Indicators of impact:

Perceptions of lay reviewer influence on the process and the scientific rigour of the review panel meeting as well as its outcomes.

Changes in participants' perceptions of the impact of lay reviewers before and after taking part in the panel.

Quality appraisal:

Authors report that the questionnaire received face and content validation but no pilot testing.

Identifies a potential response bias in relation to the academics who were on the review panel and who by extension took part in the study. For example review panel members may have known about and had positive attitudes towards the public involvement on the review panel whilst those with negative views may not have signed up to be part of the review panel.

The approach to public involvement in the main study:

Public involved in a consultative capacity on the review boards

Public involvement in assessment of impact:

A representative from a patient organisation was listed as an author. We infer that the authors were involved in collecting and analysing data.

Summary:

An anonymous questionnaire consisting of open and closed response questions on prior experience of review panels and expectations of the current review panel process was administered to panel members prior to and 4 weeks after participation in the review panel. The pre and post panel questionnaires were matched by the participant's self-assigned code. Chi-square tests were used to analyse responses.

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Research Agenda Setting

Tool or method:

Evaluation framework to assess the influence of public involvement in the research agenda setting process

Source:

Caron-Flinterman, J. F., Broerse, J. E. W., Teerling, J., Van Alst, M. L. Y., Klaasen, S., Swart, L. E., & Bunders, J. F. G. (2006). Stakeholder participation in health research agenda setting: the case of asthma and COPD research in the Netherlands. *Science & Public Policy (SPP), 33*(4), 291-304.

Type of tool or method:

Qualitative

Indicators of impact:

Patients able to recognise their own views or priorities in the final shared research agenda

Specific and identifiable contributions of patients to the research agenda (Caron-Flinterman et al. note that patient contributions were identifiable in the shared societal research agenda but not in the prioritised research agenda because many of the patients' priorities were the same as the professionals' priorities)

Change to professionals' priorities after exposure to patients' priorities between the consultation and prioritisation stages of the process

Quality appraisal:

Interviewees were invited to check interview transcripts.

Public involvement in assessment of impact:

Members of the public were involved as participants.

Summary:

The process and outcomes of the participation methodology were assessed with reference to a framework based on Rowe & Frewer (2004) and on the objectives of participation:

- Enhanced legitimacy and rationality of the agenda-setting process
- Enhanced quality (usefulness and relevance) of the research agenda
- Demonstrate knowledge sharing between the stakeholders

A 'triangulated approach' to data collection was adopted and used documentary analysis, observation, analysis of audio and visual materials and interviews with 3 different groups of stakeholders (patients, healthcare professionals and scientists) in asthma and COPD treatment/research.

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Research Agenda Setting

Tool or method:

Mixed methods evaluation of public influence on decisions about priorities for commissioning research

Source:

Oliver, S., Armes, D. G., & Gyte, G. (2009). Public involvement in setting a national research agenda: A mixed methods evaluation. *The Patient: Patient-Centered Outcomes Research, 2*(3), 179-190.

See also: Oliver et al. (2009) *Public involvement in setting a national research agenda(http://eprints.ioe.ac.uk/5147/1/Oliver2009Public179.pdf)*

Type of tool or method:

Mixed methods

Indicator of impact:

The number of research topics suggested by the public as % of total number of suggestions made.

The number of suggestions by the public that led to a commissioned research project.

The number of vignettes the public were involved in creating as a % of all vignettes.

The number of vignettes with public involvement that led to commissioned research projects.

Identification of changes made as a result of public contributions made (increasing patient/carer perspective, identification of different outcomes)

Panel members' views on the impact of public involvement on panel meetings

The number of points raised by public-involved in panel meetings that were recorded in the minutes

Quality appraisal:

Two researchers were involved in the development of a coding frame and in the subsequent coding of interview transcripts.

Public involvement in assessment of impact:

The contribution of the Public Involvement Steering Group is acknowledged in the paper. The authors coded the data, developed the analytic framework, and we infer that the researchers carried out the data collection. Members of the public took part in the advisory research panels.

Summary:

Used mixed methods to identify the extent of public influence over research agenda setting decisions – including structured observations of meetings, documentary analysis and interviews with key informants.

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Tools and methods for assessing the impact of public involvement in health and social care research: Research Design and Delivery

Overview

A number of positive impacts of public involvement on the design and delivery of research were identified in the reviews carried out by Staley (2009) and Brett et al. (2009). Public-involved were found to have influenced the focus, framing or construction of the research question (Staley, 2009). Impacts on the study design were also identified and included:

- Changes to outcome measures and their measurement
- Identification of appropriate end-points
- Timing of recruitment to the trial (Brett et al., 2009).

In most cases, the changes suggested by the public-involved were felt to improve the acceptability or relevance of the study to the participants or other stakeholders. Staley (2009) however noted that in one case the changes to the design of the study suggested by the public-involved were felt to have led to the study's inconclusive findings.

In Barber et al.'s (2012) study a range of stakeholders considered that it was not feasible to assess the impact of public involvement on research design or on managing the research process. There was a perception that public influence was less likely to have an impact on some types of research design (e.g. laboratory-based research) as well as a concern about the costs of an impact assessment.

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Impacts of public involvement on design & delivery

Impact Research
(Benefits & Challenges)

- Agenda
- Design and Delivery
- Ethics
- Recruitment
- Data Collection
- Analysis of Data
- Writing Up
- Dissemination
- Time and Cost

Overview of impacts on Design & Delivery:

Design Positive

- Research findings have been made more relevant and useful to the end-users
- Early involvement of the public helped to re-shape and clarify the research question
- Influence on what outcomes are measured, as well as how they are measured
- Provided views on whether the research is relevant or appropriate to users

Design Negative

- Can lead to scientific and ethical conflict in protocol design
- Can lead to tokenistic nature of public involvement
- Can cause power struggles between researchers and users

Tools

- Improvements in e.g. questionnaires, interview schedules and questions
- Field-testing tools with public improved their reliability
- Helped assess the appropriateness and timing of instruments to the community
- Helped adapt language of the instruments and information to suit the public audience
-

Methods

- Ensured that research methods have worked in practice
- Ensured studies are conducted in a way that makes it easy for people to participate

Methods and tools used in published studies to assess the impact of public involvement on design & delivery

Impacts	**Context**	**Tool/Method**	**Source**	**Page No.**
Improving research design	Community participation - generic	Decision trail	Burns, D. & Taylor, M. (2000). *Auditing community participation: an assessment handbook*. The Policy Press for the Joseph Rowntree Foundation.	22
	Public involvement in an Aboriginal health project focused upon alcohol and pregnancy	Questionnaire to assess the process, context and impact of public involvement	Payne, J., D'Antoine, H., France, F., McKenzie, A., Henley, N., Bartu, A., Elliott, E. & Bower, C. (2011). "Collaborating with consumer and community representatives in health and medical research in Australia: results from an evaluation." *Health Research Policy & Systems 9*(1): 18-31.	23
	Public involvement through advisory committees to a large NIHR funded 5-year programme grant to examine a recovery focus for adult mental health services in England	Typology of recommendations made by advisory committees	Slade, M., Bird, V., Chandler, R., Fox, J., Larsen, J., Tew, J. & Leamy, M. (2010). "The contribution of advisory committees and public involvement to large studies: case study." *BMC Health Services Research 10*: 323-331.	24
	Public involvement in the design of a randomised controlled trial to assess the effectiveness of an intervention for children with cerebral palsy	Case study	Edwards, V., Wyatt, K., Logan, S. & Britten, N. (2011). "Consulting parents about the design of a randomized controlled trial of osteopathy for children with cerebral palsy." *Health Expectations 14*(4): 429-438.	25

Research Design & Delivery

Tool or method:
Decision Trail

Source:
Burns, D. & Taylor, M. (2000). *Auditing community participation: an assessment handbook*. The Policy Press for the Joseph Rowntree Foundation.

Type of tool or method:
Qualitative

Indicators of impact:
Public-involved issues form part of the agenda for meetings or discussions

Decisions made by public-involved are implemented or discussed

Quality appraisal:
Not applicable – the document provides examples of suggestions of activities for impact assessment.

The approach to public involvement in the main study:
Not applicable

Public involvement in assessment of impact:
Not applicable

Summary:
The decision trail provides a way of summarising the contribution of the public-involved to the decision-making process and covers the following:

- How and whether items raised by public-involved gets onto the decision-making agenda
- How the decisions were made and by whom
- How the decision was reported back to relevant stakeholders
- What happened to the decision on its route to implementation
- If and how it was implemented and by whom
- If and how it was blocked and by whom

Return to Methods and Tools table

Research Design & Delivery

Tool or method:
Questionnaire to assess the context, process and impact of public involvement

Source:
Payne, J., D'Antoine, H., France, F., McKenzie, A., Henley, N., Bartu, A., Elliott, E. & Bower, C. (2011). "Collaborating with consumer and community representatives in health and medical research in Australia: results from an evaluation." *Health Research Policy & Systems 9*(1): 18-31.

Type of tool or method:
Qualitative

Indicators of impact:
Context: Telford's principles for successful consumer involvement
Process: Compliance with the project's terms of reference
Impact: Hanley's et al. (2003) briefing notes on public involvement

Quality appraisal:
The authors noted the small number of returned questionnaires and suggested that their findings might not be generalizable. The questionnaire was not formally validated, nor did it undergo piloting but was based on existing and established standards for public involvement.

The approach to public involvement in the main study:
Public involvement took place in different ways:

- Some members of the Aboriginal community were researchers
- Two community reference groups were established, one consisted of Aboriginal community members and the other non-Aboriginal community members
- The project steering committee had one representative from the Aboriginal research network (The community reference groups also became part of the steering committee during the final year of the project)

Public involvement in assessment of impact:
Unclear. All the authors were members of university departments. Two authors coded the open responses and the project manager analysed the data.

Summary:
The authors were unable to find an existing validated instrument to evaluate the public involvement in their project so they developed their own questionnaire to examine the context, process and impact of public involvement. The questionnaire contained 22 items inviting both open and closed responses. A summary of responses to the closed questions was reported using descriptive statistics. Open response questions were analysed using the method of constant comparison. Although the questionnaire focused upon the quality of the involvement, public involvement was reported to have enhanced the research processes, outcomes and outputs and members of the public influenced decisions about the research.

Return to Methods and Tools table

Research Design & Delivery

Tool or method:

Typology of recommendations made by advisory committees

Source:

Slade, M., Bird, V., Chandler, R., Fox, J., Larsen, J., Tew, J. & Leamy, M. (2010). "The contribution of advisory committees and public involvement to large studies: case study." *BMC Health Services Research, 10*: 323-331.

Type of tool or method:

Qualitative and quantitative

Indicators of impact:

Type of recommendations made

Whether decisions were implemented

Quality appraisal:

The authors acknowledged difficulties in coding recommendations, in particular distinguishing between recommendations and comments.

The authors called for more rigorous approaches to collecting data, for example audio recording meetings and conducting a content analysis to identify and quantify themes.

No reliability or validity testing of the coding was reported

The approach to public involvement in the main study:

Public-involved were members of all three committees advising the study, but had the highest level of representation on the Lived Experience Advisory Panel. The committees provided advice to the project but had no formal responsibility for oversight of the project.

Public involvement in assessment of impact:

The authors included a service user and carer co-ordinator from an NHS trust and a member of *Rethink Mental Iillness*, both of whom contributed to the design of the study and the interpretation of the findings as well as commenting on and approving the manuscript.

Summary:

Recommendations from the advisory panels were recorded for the first seven months of the study. Each recommendation was discussed by the research team and decisions about implementation were recorded as ‘Implemented’, ’Not implemented’ or ‘Undecided’. The rationale for each implementation decision was also recorded. Descriptive statistics were used to report types of decisions and the implementation of decisions. Types of decisions were reported by type of advisory board.

A typology of recommendation was generated: Scientific, pragmatic, resources, committee and collaboration

Return to Methods and Tools table

Research Design & Delivery

Tool or method:

Case study

Source:

Edwards, V., Wyatt, K., Logan, S. & Britten, N. (2011). "Consulting parents about the design of a randomized controlled trial of osteopathy for children with cerebral palsy." *Health Expectations 14*(4): 429-438.

Type of tool or method:

Qualitative and quantitative

Indicators of impact:

Take-up of parental preferences for trial design in the rct

Take-up of parental preferences for outcome measures in the rct

Quality appraisal:

Unclear

The approach to public involvement in the main study:

The study was prompted by a request from a charity to examine the effectiveness of an intervention for children with cerebral palsy

Parents were involved in the interviews which formed part of the consultation on the design of the rct

Public involvement in assessment of impact:

Unclear. The authors worked in a university Medical School.

Summary:

Qualitative interviews were carried out with parents to understand their preferences for the design of a randomised controlled trial and its outcome measures. The authors showed that parents preferred a waiting list trial design and that this went on to be used. The authors created a table that showed whether the measures that parents suggested had or had not been used in the final trial.

The authors suggested that high recruitment rates to the trial and the acceptance of the trial by the ethics committee were a result of the public involvement at an early stage of the design process.

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Tools and methods for assessing the impact of public involvement in health and social care research: Ethics

Impact Research
(Benefits & Challenges)

- Agenda
- Design and Delivery
- Ethics
- Recruitment
- Data Collection
- Analysis of Data
- Writing Up
- Dissemination
- Time and Cost

Overview

Findings from our evidence review suggest that public involvement can lead to in improvements to the consent process and to an increase in the ethical acceptability of the research. Reviews carried out by Staley (2009) and Brett et al. (2009) found that public involvement led to the provision of more useful information (Staley, 2009) that was worded in a more appropriate manner for potential participants (Brett et al., 2009) and this had an impact on peoples' ability to provide informed consent.

Neutral or negative impacts of public involvement on ethical processes were also identified. One study found that involvement of the public in reviewing an information sheet for potential participants had little impact on increasing participants' understanding – although problems with the study were noted (Staley, 2009). Public involvement was also associated with potential breaches of confidentiality by a number of studies (Brett et al., 2009). However public involvement at an early stage of the research design process is more likely to mean that potential ethical issues are identified and addressed (Staley, 2009).

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Impacts of public involvement on ethics

Impact
Research
(Benefits & Challenges)

- Agenda
- Design and Delivery
- Ethics
- Recruitment
- Data Collection
- Analysis of Data
- Writing Up
- Dissemination
- Time and Cost

Overview of impacts on Ethics:

Improving the consent process

- Patient information sheets and information were clearer and more accessible

Improving the ethical acceptability of research

- Early public involvement led to the identification of potential ethical concerns as well as solutions to these ethical problems

Negative: Issues of confidentiality

- Potential issues around disclosing confidential issues was associated with PI

Methods and tools used in published studies to assess the impact of public involvement on ethics

Impacts	**Context**	**Tool/Method**	**Source**	**Page No.**
Improving the consent process	Comparison of information sheets on Patient Controlled Analgesia for surgery patients in a hospital setting	Questionnaire designed to obtain participant understanding of Patient-Controlled Analgesia obtained from consent documents	Chumbley, G., Hall, G. & Salmon, P. (2002). "Patient-controlled analgesia: what information does the patient want?" *Journal of Advanced Nursing 39*(5): 459-471	30
	Comparison of information sheets for a study on the effects of cognitive behavioural therapy and exercise for the treatment of Gulf War Veterans' illnesses	Informed Consent Questionnaire (ICQ) Validated scale to measure participant understanding of the study	Guarino, P., Elbourne, D., Carpenter, J. & Peduzzi, P. (2006). "Consumer involvement in consent document development: a multicenter cluster randomized trial to assess study participants' understanding." *Clinical Trials 3*(1): 19-30.	31
		Client Satisfaction Questionnaire (Nguyen, Attkison & Segner, 1983)		32
		Reading levels		33
	An examination of the interpretation of study information in the context of prostate cancer testing and treatment	Qualitative study	Donovan, J., Mills, N., Smith, M., Brindle, L., Jacoby, A., Peters, T., Frankel, S., Neal, D., Hamdy, F for the Protect Study group (2002). "Quality improvement report: Improving design and conduct of randomised trials by embedding them in qualitative research: ProtecT (prostate testing for cancer and treatment) study. Commentary: presenting unbiased information to patients can be difficult." *BMJ (Clinical Research Ed.)* 325(7367): 766-770	34
	Generic development of framework in healthcare	Framework to evaluate patient information leaflets	Garner, M., Ning, Z., & Francis, J. (2012). A framework for the evaluation of patient	35

	settings		information leaflets. *Health Expectations, 15,* 283-294	

Ethics

Tool or method:

Questionnaire designed to ascertain participant understanding of Patient-Controlled Analgesia (PCA) obtained from consent documents derived from focus group consultations

Source:

Chumbley, G., Hall, G. & Salmon, P. (2002). "Patient-controlled analgesia: what information does the patient want?" *Journal of Advanced Nursing 39*(5): 459-471.

Type of tool or method:

Quantitative

Indicators of impact:

Participant views of PCA

Participant knowledge of PCA

Quality appraisal:

The authors argued that the use of questions derived from the focus group increased the content validity of the questionnaire.

The questionnaire was piloted on 10 patients for comprehensibility.

The approach to public involvement in the main study:

Surgical patients who had used PCA in the previous week were consulted through focus groups. They were asked to comment upon the existing patient information leaflet for PCA. New drafts of the patient information leaflet were developed in response to focus group comments.

Public involvement in assessment of impact:

All of the authors were academics/health professionals – it is unclear whether beyond participation in the focus groups that there was public involvement in the assessment of impact.

Summary:

Participants were randomly allocated to receive either an existing patient information leaflet on PCA or to receive the focus group-revised leaflet. An 18-item questionnaire was developed (using some responses from the focus groups) to examine participants' views on and knowledge about PCA after having read the leaflet. 12 of the questions examining participant views of PCA had either yes/no or 5-point Likert scale response options. Comparison of the responses between the two conditions was conducted using Chi-square for the yes/no and Mantel-Haenszel test of linear association for the Likert scale responses. 6 questions tested participant understanding of PCA using multiple response items with 5-7 response options and were analysed using Chi-Square analysis.

Return to Methods and Tools table

Ethics

Tool or method:

Informed Consent Questionnaire (ICQ), a validated scale to measure participant understanding of the study

Source:

Guarino, P., Elbourne, D., Carpenter, J. & Peduzzi, P. (2006). "Consumer involvement in consent document development: a multicenter cluster randomized trial to assess study participants' understanding." *Clinical Trials* *3*(1): 19-30.

Type of tool or method:

Quantitative

Indicators of impact:

Participant understanding of the study

Quality appraisal:

The authors advised that data obtained during the trial were used to assess the psychometric properties of the 10-item ICQ scale. An ICQ-4 scale was developed from the original 10-item scale to assess participant self-reported understanding of the study. This was described as having been validated.

The approach to public involvement in the main study:

Unclear – public involvement not likely to have taken place

Public involvement in assessment of impact:

Unclear – public involvement not likely to have taken place

Summary:

This study was embedded within a larger randomised controlled trial to evaluate the use of cognitive behaviour therapy and exercise to treat Gulf War Veterans' illnesses. For the assessment of public involvement impact, participants were cluster-randomised to receive either a public-involved or a researcher developed information sheet.

The ICQ-4 scale to assess participants' self-reported understanding of the study was administered four times (at baseline and up to 12 months' follow-up). Chi-square analysis was conducted to identify associations between scores on the ICQ-4 and the type of consent document received.

Return to Methods and Tools table

Ethics

Tool or method:

Client Satisfaction Questionnaire (Nguyen, Attkison & Segner, 1983)

Source:

Guarino, P., Elbourne, D., Carpenter, J. & Peduzzi, P. (2006). "Consumer involvement in consent document development: a multicenter cluster randomized trial to assess study participants' understanding." *Clinical Trials 3*(1): 19-30.

Type of tool or method:

Quantitative

Indicators of impact:

Participant satisfaction with the study

Quality appraisal:

The questionnaire was an existing scale that the authors describe as validated.

The approach to public involvement in the main study:

Unclear – public involvement not likely to have taken place

Public involvement in assessment of impact:

Unclear – public involvement not likely to have taken place

Summary:

This study was embedded within a larger randomised controlled trial to evaluate the use of cognitive behaviour therapy and exercise to treat Gulf War Veterans' illnesses. For the assessment of public involvement impact, participants were cluster-randomised to receive either a public-involved or a researcher developed information sheet.

The 8-item Client Satisfaction Questionnaire was administered four times (at baseline and then up to 12 months follow-up). Hierarchical mixed effects models were used to analyse the Client Satisfaction Questionnaire scores.

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Ethics

Tool or method:

Reading levels

Source:

Guarino, P., Elbourne, D., Carpenter, J. & Peduzzi, P. (2006). "Consumer involvement in consent document development: a multicenter cluster randomized trial to assess study participants' understanding." *Clinical Trials 3*(1): 19-30.

Type of tool or method:

Quantitative

Indicators of impact:

Reading level of consent form

Quality appraisal:

For a review of the use of readability levels in healthcare see Ley & Florio (1996)[1] and for a critique of the use of readability levels alone see Garner, Ning & Francis (2012)[2].

The approach to public involvement in the main study:

Unclear – public involvement not likely to have taken place

Public involvement in assessment of impact:

Unclear – public involvement not likely to have taken place

Summary:

This study was embedded within a larger randomised controlled trial to evaluate the use of cognitive behaviour therapy and exercise to treat Gulf War Veterans' illnesses. For the assessment of public involvement impact, participants were cluster-randomised to receive either a public-involved or a researcher developed information sheet.

The reading levels of the consent forms were assessed using the Flesch-Kincaid reading level scores by Guarino et al. (2006). Many on-line Flesch-Kincaid readability level calculators exist[3], but this is just one measure of readability. NIACE (2009) have produced guidance on how to improve the readability of written materials which also contains a SMOG (Simple Measure of Gobbledegook) Index[4] and formula. Alternatively there is an on-line SMOG calculator[5].

Return to Methods and Tools table

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[1] Ley, P. & Florio, T. (1996). The use of readability formulas in health care. *Psychology, Health & Medicine, 1*, 7-28.

[2] Garner, M., Ning, Z., & Francis, J. (2012). A framework for the evaluation of patient information leaflets. *Health Expectations, 15,* 283-294

[3] For example: http://www.standards-schmandards.com/exhibits/rix/index.php

[4] NIACE (2009). Readability: how to produce clear written materials for a range of readers. Accessed from: http://shop.niace.org.uk/media/catalog/product/R/e/Readability.pdf on September 13th 2012.

[5] http://www.niace.org.uk/misc/SMOG-calculator/smogcalc.php

Ethics

Tool or method:

Qualitative study

Source:

Donovan, J., Mills, N., Smith, M., Brindle, L., Jacoby, A., Peters, T., Frankel, S., Neal, D., Hamdy, F for the Protect Study group (2002). "Quality improvement report: Improving design and conduct of randomised trials by embedding them in qualitative research: ProtecT (prostate testing for cancer and treatment) study. Commentary: presenting unbiased information to patients can be difficult." *BMJ (Clinical Research Ed.*) 325(7367): 766-770

Type of tool or method:

Qualitative

Indicators of impact:

Changes to study information and its presentation

Quality appraisal:

Unclear

The approach to public involvement in the main study:

Unclear – public involvement not likely to have taken place

Public involvement in assessment of impact:

Unclear – public involvement not likely to have taken place

Summary:

A prostate testing and cancer treatment randomised controlled trial was embedded within qualitative research in order to improve understanding of and increase trial recruitment rates.

In-depth interviews with potential participants were carried out along with audio recordings of recruitment interviews. The findings informed changes to the nature and presentation of study information to potential participants.

Return to Methods and Tools table

Ethics

Tool or method:

Framework for evaluating patient information leaflets

Source:

Garner, M., Ning, Z., & Francis, J. (2012). A framework for the evaluation of patient information leaflets. *Health Expectations, 15,* 283-294

Type of tool or method:

Mostly quantitative

Indicators of impact:

Changes to the readability and comprehensibility of patient information leaflets

Quality appraisal:

The authors acknowledged that although the study has been used in small-scale and preliminary studies it needs further empirical validation before it could be recommended for use in the patient information leaflet-related research and development.

The approach to public involvement in the main study:

Not applicable

Public involvement in assessment of impact:

Unclear whether public involvement took place in developing the framework – unlikely.

Summary:

The authors proposed a theoretical framework based on a linguistic model of inter-personal communication for assessing public information leaflets that contains 3 elements:

- Readability: Used well-established procedures to assess the extent to which readers can assign meaning
- Comprehensibility: Multiple choice questions based on the lexical and semantic features of the text
- Communicative effectiveness: Explored the readers' emotional, behavioural and affective responses to the patient information leaflets

Although the framework was not developed specifically with a public involvement focus, it could be used to assess the effectiveness of assessing public involvement impact on designing patient information or research study leaflets. The authors hoped that the framework would allow comparisons to be made between different versions of the same leaflet and to explain why some leaflets are more effective than others.

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Tools and methods for assessing the impact of public involvement in health and social care research: Recruitment

Impact
Research
(Benefits & Challenges)

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Recruitment
Data Collection
Analysis of Data
Writing Up
Dissemination
Time and Cost

Overview

In their reviews, Brett et al. (2010) and Staley (2009) point to the mostly positive impacts of public involvement on recruitment that have been identified in the existing literature. For example, Staley (2009) suggests that improved participation rates resulting from public-involvement arise from:

- Members of the public knowing the best way to contact potential participants
- Minimisation of language and cultural barriers
- Better quality and more sensitive information and recruitment processes
- Enhanced legitimacy of the research

As well as improved rates of participation, Brett et al. (2010) note that public involvement may also lead to increased levels of recruitment from a wider range of people including those that are seldom heard.

Public involvement might impact upon recruitment in complex ways. In two studies where interviews were conducted by service-users or peers no effect on or reduced recruitment levels were found (Bryant & Beckett, 2006; Hamilton et al, 2010). However increased recruitment rates were reported in studies where public involvement influenced recruitment strategies (Angell et al., 2006; Edwards, et al., 2011; Iliffe et al., 2011). This suggests that the way in which public involvement shapes recruitment might be more important in determining the level of impact rather than whether public involvement has happened or not.

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Impacts of public involvement on recruitment

Impact Research
(Benefits & Challenges)

- Agenda
- Design and Delivery
- Ethics
- Recruitment
- Data Collection
- Analysis of Data
- Writing Up
- Dissemination
- Time and Cost

Overview of impacts on Recruitment:

- Increased participation rates
- Improved access to potential participants
- Ensured recruitment procedures were sensitive to the needs of the participants
- Improved the information provided to potential participants
- Enhanced to the credibility of the research project and researchers
- Helped to engage seldom heard groups
- Provided commitment, energy and enthusiasm
- Encouraged and motivated people to take part
- Improved response rates

Methods and tools used in published studies to assess the impact of public involvement on recruitment

Impacts	**Context**	**Tool/Method**	**Source**	**Page No.**
Increased participation rates	Public involvement in a network promoting research in dementia and neurodegenerative diseases	Quantitative comparison of recruitment levels before and after the involvement of the public	Iliffe, S., McGrath, T. & Mitchell, D. (2011). "The impact of patient and public involvement in the work of the Dementias & Neurodegenerative Diseases Research Network (DeNDRoN): case studies." Health Expectations. Date of electronic publication Sept. 2011. doi: 10.1111/j.1369-7625.2011.00728.x	40
	Public involvement with a randomised controlled trial centre investigating Paget's Disease	Quantitative comparison of recruitment levels in areas where there is an active public-involvement group compared with areas where there is no active public involvement group	Langston, A., McCallum, M., Campbell, M., Robertson, C. & Ralston S. (2005). "An integrated approach to consumer representation and involvement in a multicentre randomized controlled trial." *Clinical Trials 2*(1): 80-87	41
	Comparison of the effects of different information sheets on recruitment levels for a study on the effects of cognitive behavioural therapy and exercise for the treatment of Gulf War Veterans' illnesses	Quantitative comparison of recruitment levels where the information sheet was developed by the researchers or revised in light of comments by a public-involved focus group	Guarino, P., Elbourne, D., Carpenter, J. & Peduzzi, P. (2006). "Consumer involvement in consent document development: a multicenter cluster randomized trial to assess study participants' understanding." *Clinical Trials 3*(1): 19-30.	42

	Randomised study using structured interviews about mental health service users' experiences of discrimination	Quantitative comparison of recruitment levels where peer status is disclosed, peer status is not disclosed and where non-peers will conduct the interviews	Hamilton, S., Pinfold, V., Rose, D., Henderson, C., Lewis-Holmes, E., Flack, C. & Thornicroft, G. (2011) The effect of disclosure of mental illness by interviewers on reports of discrimination experienced by service users: A randomized study. *International Review of Psychiatry 23*(1): *47-54.*	43
Ensured recruitment process were sensitive to the needs of participants	Public involvement in a network promoting research in dementia and neurodegenerative diseases	Case study	Iliffe, S., McGrath, T. & Mitchell, D. (2011). "The impact of patient and public involvement in the work of the Dementias & Neurodegenerative Diseases Research Network (DeNDRoN): case studies." Health Expectations. Date of electronic publication Sept. 2011. doi: 10.1111/j.1369-7625.2011.00728.x	45

Recruitment

Tool or method:
Quantitative comparison of recruitment levels

Source:
Iliffe, S., McGrath, T. & Mitchell, D. (2011). "The impact of patient and public involvement in the work of the Dementias & Neurodegenerative Diseases Research Network (DeNDRoN): case studies." *Health Expectations*. Date of electronic publication Sept. 2011. doi: 10.1111/j.1369-7625.2011.00728.x

Type of tool or method:
Quantitative

Indicators of impact:
Recruitment levels to studies after the user group was consulted about recruitment.

Quality appraisal:
Unclear

The approach to public involvement in the main study:
Public involvement took place through a variety of structures and mechanisms and was organised at both a central and a local level. Members of the public were involved in both strategic oversight of public involvement in the research programme and practical support was provided to individual research projects.

Public involvement in assessment of impact:
In addition to academic researchers, the PPI co-ordinator of DeNDRoN was included as an author. The authors acknowledged the contribution of public-involved in discussing the ideas contained within the paper.

Summary:
Recruitment levels over time were recorded before and after public involvement took place. In addition a comparison of recruitment levels to the study in geographical areas where public involvement did and did not happen was undertaken.

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Recruitment

Tool or method:

Quantitative comparison of recruitment levels

Source:

Langston, A., McCallum, M., Campbell, M., Robertson, C. & Ralston S. (2005). "An integrated approach to consumer representation and involvement in a multicentre randomized controlled trial." *Clinical Trials 2*(1): 80-87

Type of tool or method:

Quantitative

Indicators of impact:

Levels of recruitment to a trial in areas where user groups are active compared with areas where they are not active

Quality appraisal:

Using this method for comparing recruitment rates was problematic according to the authors because it was difficult to be sure that increases were due to public involvement alone. An alternative explanation for higher recruitment rates could be increased levels of enthusiasm for research and interest in the study topic in areas where user groups were active.

The approach to public involvement in the main study:

According to the authors, the project as a whole used consultation, collaboration and a certain amount of ‘user control’. Consultation was used in order to design the information sheets.

Public involvement in assessment of impact:

A member of the user group was included in the list of authors. All authors were credited with making substantial contributions to the paper and of approving the final version.

Summary:

This method for assessing impact was drawn from a case study on an ‘integrated partnership’ between a user group for Paget’s Disease and a clinical trial team investigating the disease. Although the study did not contain much detailed information about how to conduct the comparison, it could be developed and used as the basis for an approach to assessing public involvement impact on recruitment levels.

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Recruitment

Tool or method:

Quantitative comparison of recruitment levels

Source:

Guarino, P., Elbourne, D., Carpenter, J. & Peduzzi, P. (2006). "Consumer involvement in consent document development: a multicenter cluster randomized trial to assess study participants' understanding." *Clinical Trials 3*(1): 19-30.

Type of tool or method:

Quantitative

Indicators of impact:

Levels of recruitment to a study where potential participants read an information sheet developed by either researchers or researchers and public-involved

Quality appraisal:

Unclear or N/A

The approach to public involvement in the main study:

Unclear – public involvement not likely to have taken place

Public involvement in assessment of impact:

Unclear – public involvement not likely to have taken place

Summary:

This study was embedded within a larger randomised controlled trial to evaluate the use of cognitive behaviour therapy and exercise to treat Gulf War Veterans' illnesses. For the assessment of public involvement impact, participants were cluster-randomised to receive either a public-involved or a researcher developed information sheet.

Associations between participation rates and type of information sheet were analysed using Chi-Square analysis.

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Recruitment

Tool or method:

Quantitative comparison of recruitment levels where peer status is disclosed, peer status is not disclosed and where non-peers will conduct the interviews

Source:

Hamilton, S., V. Pinfold, et al. (2011). "The effect of disclosure of mental illness by interviewers on reports of discrimination experienced by service users: A randomized study." *International Review of Psychiatry 23*(1): 47-54.

Type of tool or method:

Quantitative

Indicators of impact:

Differences in recruitment levels between the experimental conditions

Quality appraisal:

Unclear

The approach to public involvement in the main study:

Collaboration?

Public involvement in assessment of impact:

A paragraph about the extent of public involvement in the study was included in the Discussion section. The authors acknowledged that the study design and the selection of the questionnaire took place before the public were involved. The authors were academic researchers. The public-involved participated in data collection, but they were not involved in the analysis.

Summary:

The study examined the impact of disclosure and status as a service user on the administration of a structured scale. A structured interview was used as part of a randomised study comparing interviews where peer status had been disclosed, peer status had not been disclosed and where non-peers had carried out the interview. All the interviewers taking part received training in how to conduct interviews. The authors suggested that further in-depth analysis of the interview transcripts could provide more qualitative information about the level of detail gone into and interviewee comfort during the interviews.

Potential recruits were sent information about the interview study. They were randomly assigned to one of three conditions: Peer-disclosing (where information about the interviewers' personal experience of mental health issues was disclosed), peer non-disclosing (where information about the interviewers' personal experience of mental health issues was not disclosed) and non-peer (where the interviewer had no personal experience mental health issues). Pearson's chi-square was used to compare response rates.

Staley et al. (2012) described this paper as a good example of a realist approach to evaluation[6].

Return to Methods and Tools table

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[6] Staley, K., Buckland, S., Hayes, H., & Tarpey, M. (2012). 'The Missing Links': Understanding How Context and Mencahnism Influence the Impact of Public Involvement in Research. *Health Expectations*. doi: doi: 10.1111/hex.12017)

Recruitment

Tool or method:

Case study

Source:

Iliffe, S., McGrath, T. & Mitchell, D. (2011). "The impact of patient and public involvement in the work of the Dementias & Neurodegenerative Diseases Research Network (DeNDRoN): case studies." *Health Expectations*. Date of electronic publication Sept. 2011. doi: 10.1111/j.1369-7625.2011.00728.x

Type of tool:

Qualitative

Indicators of impact:

Changes to recruitment processes as a result of public involvement

Quality appraisal:

Unclear

Public involvement taook place through a variety of structures and mechanisms and was organised at both a central and a local level. Public involvement included both strategic oversight of public involvement and the research programme and practical support provided to individual research projects.

Public involvement in assessment of impact:

In addition to academic researchers, the PPI co-ordinator of the DeNDRoN was included as an author. The authors acknowledged the contribution of public-involved in discussing the ideas contained within the paper.

Summary:

Three case studies of public involvement in research were carried out in order to address the question 'What benefits (if any) does PPI in research bring to the research process?' (p.5). The case study documented how the DeNDRoN co-ordinating centre supported the recruitment processes of three studies.

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Data Collection Impacts

Impact Research
(Benefits & Challenges)

Agenda
Design and Delivery
Ethics
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Writing Up
Dissemination
Time and Cost

Overview

In their reviews, Staley (2009) and Brett et al. (2010) identified a range of positive and negative impacts of public involvement in the data collection stage of research. Positive impacts included:

- An increase in participant response rates
- Public-involved eliciting deeper and more personal insights from their interviewees
- A greater likelihood that participants would disclose sensitive information.

Negative impacts were also reported such as:

- Pragmatic problems associated with low public-involved attendance at project meetings
- Methodological issues when public-involved did not follow the interview schedule or did not use sufficiently probing questioning whilst conducting interviews

But, Barber et al. (2012) reported that public involvement stakeholders who took part in a Delphi process reached consensus that it was not feasible to report the impact of public involvement on collecting data. Although we found a large number of studies that reported that public involvement did have an impact on data collection, many of them did not adopt a formal reflection or did not describe the methods by which these impacts were identified and so we did not include them.

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Data Collection: Impacts

Impact Research
(Benefits & Challenges)

- Agenda
- Design and Delivery
- Ethics
- Recruitment
- **Data Collection**
- Analysis of Data
- Writing Up
- Dissemination
- Time and Cost

Overview of Impacts on Data Collection:

Positive

- Increasing a sense of ownership of a research project increased response rates to questionnaire and so enhanced the quality of data
- Public as peer interviewers (or co-facilitators of focus groups) enhanced the collection of qualitative data and increased its relevance
- Involving peer interviewers in research into services increases chance of honest and reliable feedback on treatments
- Helped gain deeper, more personal insights due to rapport with participants

Negative

- Lay interviewers: ‘shared experience’ between interviewer and interviewee can limit discussion so certain issues have not been fully explored
- Difficulty recruiting diverse range or representative sample of members of the public
- Difficulty getting the balance between traditional academic criteria for reliability and user perspectives in a protocol for research
- Difficulty in maintaining user confidentiality within meetings, where users may discuss personal experiences
- In consultation focus groups members of the public can:
    - Influence each other over-emphasising particular problems, neglecting others
    - Be dominated by a strong character who ‘shouts loudest’
    - Be too focused on personal stories when the aim is to identify research topics

Methods and tools that have been used in published studies to assess the impact of public involvement on data collection

Impacts	**Context**	**Tool/Method**	**Source**	**Page No.**
Increased response rates	Randomised study using structured interviews about mental health service users' experiences of discrimination	Quantitative comparison of the rates of responding to questions where peer status is disclosed, peer status is not disclosed and where non-peers conducted the interviews	Hamilton, S., Pinfold, V., Rose, D., Henderson, C., Lewis-Holmes, E., Flack, C. & Thornicroft, G. (2011) The effect of disclosure of mental illness by interviewers on reports of discrimination experienced by service users: A randomized study. *International Review of Psychiatry 23*(1): *47-54.*	50
Quality/relevance of data	Questionnaire administered by interview to obtain scores for client satisfaction with mental health services	Quantitative comparison of scores on client satisfaction scores administered either by clients or staff	Clark et al. (1999) Effects of Client Interviewers on Client-Reported Satisfaction With Mental Health Services. *Psychiatric Services, 50*(7), 961-963.	51
	Randomised study using structured interviews about mental health service users' experiences of discrimination	Quantitative comparison of responses to the DISC-II (32-item questionnaire) where peer status has been disclosed, peer status has not been disclosed and where non-peers have carried out the interview.	Hamilton, S., Pinfold, V., Rose, D., Henderson, C., Lewis-Holmes, E., Flack, C. & Thornicroft, G. (2011) The effect of disclosure of mental illness by interviewers on reports of discrimination experienced by service users: A randomized study. *International Review of Psychiatry 23*(1): *47-54.*	52
Deeper/more personal insights	Semi-structured interviews about the experiences of detained psychiatric patients	Secondary analysis of interview transcripts	Gillard et al. (2010) 'What difference does it make? Finding evidence of the impact of mental health service user researchers on research into the experiences	54

Impacts	**Context**	**Tool/Method**	**Source**	**Page No.**
			of detained psychiatric patients. *Qualitative Health Research 22*(8): 1126-1137.	
	Semi-structured interviews to evaluate hospital services for adolescents	Informal comparison of the quality of public-involved interviews with interviews from a previous study	van Staa, A., Jedeloo, S., Latour, J. & Trappenburg, M. (2010). "Exciting but exhausting: experiences with participatory research with chronically ill adolescents." *Health Expectations 13*(1): 95-107.	56

Data collection

Tool or method:

Quantitative comparison of the rates of responding to questions where peer status was disclosed, peer status was not disclosed and where non-peers conducted the interviews

Source:

Hamilton, S., V. Pinfold, et al. (2011). "The effect of disclosure of mental illness by interviewers on reports of discrimination experienced by service users: A randomized study." *International Review of Psychiatry 23*(1): 47-54.

Type of tool:

Quantitative

Indicator of impact:

Differences in response rates between conditions

Quality appraisal:

Unclear

The approach to public involvement in the main study:

Collaboration?

Public involvement in assessment of impact:

A paragraph about the extent of public involvement in the study was included in the Discussion section. The authors acknowledged that the study design and the selection of the questionnaire took place before the public were involved. The authors were academic researchers. The public-involved participated in data collection but they were not involved in the analysis.

Summary:

This study examined the impact of disclosure and status as a service user on the administration of a structured scale. A structured interview was used as part of a randomised study comparing interviews where peer status had been disclosed, peer status had not been disclosed and where non-peers had carried out the interview. All the interviewers taking part received training in how to conduct interviews. The authors suggested that further in-depth analysis of the interview transcripts could provide more qualitative information about the level of detail gone into and interviewee comfort experienced during the interview. Staley et al. (2012) described this paper as a good example of a realist approach to evaluation[7].

The study compared the mean number of unanswered questions to a structured interview in each condition: peer-disclosing, non peer-disclosing and non-peer. The authors used an independent t-test to conduct comparisons.

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[7] Staley, K., Buckland, S., Hayes, H., & Tarpey, M. (2012). 'The Missing Links': Understanding How Context and Mencahnism Influence the Impact of Public Involvement in Research. *Health Expectations*. doi: doi: 10.1111/hex.12017)

Data collection

Tool or method:

Quantitative comparison of scores from client satisfaction questionnaires administered by clients and staff of a mental health service

Source:

Clark, C., Scott, E., Boydell, K. & Goering, P. (1999). Effects of client interviewers on client-reported satisfaction with mental health services. *Psychiatric services 50* (7) 961-3.

Type of tool or method:

Quantitative

Indicators of impact:

Levels of satisfaction as assessed through the client satisfaction questionnaire

Quality appraisal:

The questionnaire was reviewed for face validity by clients and staff and was piloted twice successfully.

The approach to public involvement in the main study:

Consultation in developing the questionnaire

Potentially collaboration through service user involvement in collecting data

Public involvement in assessment of impact:

The authors were healthcare professionals/ academics

We infer that the assessment of impact was carried out by the authors

Summary:

Clients and service staff developed a 22-item questionnaire with 5-point Likert scale response options. The analysis involved the comparison of means and standard deviations of scores and an ANOVA was conducted to identify interviewer effects.

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Data collection

Tool or method:

Quantitative comparison of responses to the DISC-II (32-item questionnaire) where peer status had been disclosed, peer status had not been disclosed and where non-peers had carried out the interview to identify whether there are any differences in reports of discrimination between the conditions.

Source:

Hamilton, S., V. Pinfold, et al. (2011). "The effect of disclosure of mental illness by interviewers on reports of discrimination experienced by service users: A randomized study." *International Review of Psychiatry 23*(1): 47-54.

Type of tool:

Quantitative

Impacts assessed:

Differences in reported levels of discrimination or anticipated discrimination

Quality appraisal:

The structured interview schedule (DISC-11) was adapted from the Discrimination & Stigma Scale (DISC-9)

The approach to public involvement in the main study:

Collaboration?

Public involvement in assessment of impact:

A paragraph about the extent of public involvement in the study was included in the Discussion section. The authors acknowledged that the study design and the selection of the questionnaire took place before the public were involved. The authors were academic researchers. The public-involved participated in data collection, but they were not involved in the analysis.

Summary:

This study examined the impact of disclosure and status as a service user on the administration of a structured scale. A structured interview was used as part of a randomised study comparing interviews where peer status had been disclosed, peer status had not been disclosed and where non-peers had carried out the interview. All the interviewers taking part received training in how to conduct interviews. The authors suggested that further in-depth analysis of the interview transcripts could provide more qualitative information about the level of detail gone into and interviewee comfort during the interview.

The overall discrimination and anti-discrimination scores were compared using independent t-tests for: peer vs. non-peer conditions and for disclosing peer vs. non-disclosing peers. Responses to individual questions were explored using Chi-square analysis.

Staley et al. (2012) described this paper as a good example of a realist approach to evaluation[8].

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[8] Staley, K., Buckland, S., Hayes, H., & Tarpey, M. (2012). 'The Missing Links': Understanding How Context and Mechanism Influence the Impact of Public Involvement in Research. *Health Expectations*. doi: doi: 10.1111/hex.12017)

Data collection

Tool or method:
Secondary analysis of interview transcripts

Source:
Gillard, S., L. Simons, et al. (2012). "Patient and Public Involvement in the Coproduction of Knowledge: Reflection on the Analysis of Qualitative Data in a Mental Health Study." *Qualitative Health Research 22*(8): 1126-1137.

Type of tool:
Qualitative and quantitative

Indicators of impact:
Differences in the category of questions (e.g. related to the environment, staff, service/treatment, agency etc.) asked by academic and lay interviewers

Quality appraisal:
The authors described the project as a pilot for a methodological approach to assessing public involvement impact.
The coding frame was developed by the first author but checked with the interviewers.
The authors acknowledged a concern that because their sample of interviewers was quite small that they might be comparing the personal qualities of interviewers rather than types of interviewers.
The authors recommend that in future a number of researchers with different perspectives should be involved in developing the coding frame.

The approach to public involvement in the main study:
Three of the authors were identified as service user researchers

The research team was described as a 'collaborative team' – 3 service user researchers and 3 university researchers carried out the interviews with participants

The whole research team was involved in developing the semi-structured interview schedule and in the primary coding of the interview transcripts for the original study.

Public involvement in assessment of impact:
The coding of interviews was undertaken by the 1st author rather than by the interviewers to reduce the possibility of coding bias. Interviewers were however invited to reflect on the coding frame, the coded transcripts and the 1st authors' interpretation.

Summary:
A secondary analysis of interview transcripts was conducted in order to assess the impact of public involvement on data collection. Inductive thematic analysis was used to identify question categories along with content analysis to identify the prevalence of questions in each category. The number of questions asked in each question category by either lay or academic researchers were presented as a percentage of the total questions asked.

Staley et al. (2012) described this paper as a good example of a realist approach to evaluation[9].

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[9] Staley, K., Buckland, S., Hayes, H., & Tarpey, M. (2012). 'The Missing Links': Understanding How Context and Mencahnism Influence the Impact of Public Involvement in Research. *Health Expectations*. doi: doi: 10.1111/hex.12017)

Data collection

Tool or method:

Informal comparison of the quality of public involved interviews with interviews from a previous study

Source:

van Staa, A., Jedeloo, S., Latour, J. & Trappenburg, M. (2010). "Exciting but exhausting: experiences with participatory research with chronically ill adolescents." *Health Expectations 13*(1): 95-107.

Type of tool:

Qualitative

Indicators of impact:

Interview length and quality of the questions

Quality appraisal:

The authors reported a number of limitations on both the quality of the public involvement and the research process itself in the paper. They noted limitations on the opportunities to provide training for the adolescent co-researcher interviewers and the difficulties of ensuring the young people continued to be involved beyond the data collection stage. They also identified problems with the study’s sampling technique which led to concerns about generalizability as well as issues associated with the quality of the interviews and transcription.

It is unclear whether the interviews were piloted.

The approach to public involvement in the main study:

Collaboration. Participatory research approach. 9 adolescents were recruited as co-researchers and involved in developing the interview protocol, carrying out interviews and dissemination of the findings.

Public involvement in assessment of impact:

All the authors had higher academic or medical degrees – not clear whether public-involved or not

Unclear who carried out the impact assessment – most likely to be the authors.

Summary:

Informal comparison (based on authors’ reflections) of interviews conducted by young people with interviews carried out by authors in previous studies led to claims about reduced interview length quality. This approach could be used to develop more rigorous assessment of impact.

The authors discussed negative as well as positive impacts of involvement.

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Tools and methods for assessing the impact of public involvement in health and social care research: Data Analysis

Impact Research
(Benefits & Challenges)

Agenda
Design and Delivery
Ethics
Recruitment
Data Collection
Analysis of Data
Writing Up
Dissemination
Time and Cost

Overview

The reviews carried out by Brett et al. (2009) and Staley (2009) identify positive impacts on data analysis that have been attributed to public involvement by the authors of existing studies. Public involvement provides wider perspectives on and different, more relevant insights on the interpretation of research findings (Brett et al., 2009). Public involvement has also had an impact through:

- Correcting the misinterpretations of academic researchers
- Generating themes that would otherwise have been missed
- Challenging the perceptions of academic researchers.

It is likely that public involvement has had more impact on the analysis of qualitative rather than quantitative research data (Staley, 2009).

However views about the impact of public involvement on data analysis and the potential for its assessment appear to be mixed. Staley (2009) for example noted that some researchers expressed ambivalence about whether public involvement could have an impact on the analysis of findings. Whilst Barber et al. (2012) found that a range of stakeholders considered that it would not be feasible to assess the impact of public involvement.

Return to Impacts on Research Overview

Impacts of public involvement on data analysis

Impact
Research
(Benefits & Challenges)

Agenda
Design and Delivery
Ethics
Recruitment
Data Collection
Analysis of Data
Writing Up
Dissemination
Time and Cost

Overview of impacts on Data Analysis

- Check the validity of researchers’ conclusions
- Correct researchers’ misinterpretation of data
- Identify themes that researchers might have otherwise missed
- Assisted in identifying relevant knowledge gaps
- Identify which findings would be most relevant to patients or the public
- Knock-on effect of enhancing their level of commitment to a study
- Greater sense of ownership of the results leading to an increased likelihood of action being taken in response to the findings
- Ensured emerging themes and trends were interpreted from the user perspective as well as the academic researcher perspective

Methods and tools that have been used in published studies to assess the impact of public involvement on data analysis

Impacts	**Context**	**Tool/Method**	**Source**	**Page No.**
Identify themes that researchers might otherwise have missed	Service user involvement in mental health research	Content analysis of thematic codes generated by public involved and academics during a qualitative analysis of interview transcripts	Gillard, S., Borschmann, R., Turner, K. Goodrich-Purnell, N., Lovell, K. & Chambers, M. (2010). "'What difference does it make?' Finding evidence of the impact of mental health service user researchers on research into the experiences of detained psychiatric patients." *Health Expectations 13*(2): 185-194.	60
Ensured emerging themes and trends were interpreted from the user perspective as well as the academic researcher perspective	Service user involvement in mental health research	Conceptual tool – reflecting on the process of public involvement in research as knowledge co-production	Gillard, S., Simons, L., Turmer, K., Lucock, M. & Edwards, C. (2012). "Patient and Public Involvement in the Coproduction of Knowledge: Reflection on the Analysis of Qualitative Data in a Mental Health Study." *Qualitative Health Research 22*(8): 1126-1137.	61

Data Analysis

Tool or method:

Content analysis of thematic codes generated by public-involved and academic researchers

Source:

Gillard, S., Borschmann, R., Turner, K. Goodrich-Purnell, N., Lovell, K. & Chambers, M. (2010). "'What difference does it make?' Finding evidence of the impact of mental health service user researchers on research into the experiences of detained psychiatric patients." *Health Expectations 13*(2): 185-194.

Type of tool or method:

Quantitative

Indicators of impact:

The different codes assigned to interview transcripts by public-involved compared with academic researchers

Quality appraisal:

The authors described the project as a pilot for a methodological approach to assessing public involvement impact.

Unclear what methods for checking validity and reliability were used.

The approach to public involvement in the main study:

The research team was described as a 'collaborative team' – 3 service user researchers and 3 university researchers carried out the interviews with participants

The whole research team was involved in developing the semi-structured interview schedule and in the primary coding of the interview transcripts for the original study.

Public involvement in assessment of impact:

Three of the authors were identified as service user researchers

It is unclear who carried out the content analysis of the codes assigned to the interview schedules – probably the 1st author.

Summary:

A content analysis was used to compare the codes assigned to the interview transcripts by service user researchers and the academic researchers. The number of times a researcher coded to a particular theme was presented as a percentage of the total number of codes used. Staley et al. (2012) describe this paper as a good example of a realist approach to evaluation[10].

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[10] Staley, K., Buckland, S., Hayes, H., & Tarpey, M. (2012). 'The Missing Links': Understanding How Context and Mencahnism Influence the Impact of Public Involvement in Research. *Health Expectations*. doi: doi: 10.1111/hex.12017)

Data Analysis

Tool or method:

Conceptual tool – reflecting on the process of public involvement in research as knowledge co-production

Source:

Gillard, S., Simons, L., Turmer, K., Lucock, M. & Edwards, C. (2012). "Patient and Public Involvement in the Coproduction of Knowledge: Reflection on the Analysis of Qualitative Data in a Mental Health Study." *Qualitative Health Research 22*(8): 1126-1137.

Type of tool or method:

Qualitative

Indicators of impact:

Reflections on the socially situated nature of the respective contributions of public-involved and academic researchers to the production of knowledge

Quality appraisal:

An iterative process of checking interpretations within the whole team was undertaken, but the authors were careful to distinguish this process from that of assessing inter-rater reliability. The authors argued that they were not concerned with triangulation of data as a way of assessing validity, but explored validity by reflecting upon the analytic lens that each member of the project team brought to their interpretation of the data.

The approach to public involvement in the main study:

The authors described the project as having a high level of public involvement. There were 17 members of the project team including the public-involved and academic researchers. The authors pointed out that some project team members had more than one role. Members of the public-involved contributed to the development of the proposal, collecting and analysing the data and disseminating findings.

Public involvement in assessment of impact:

One author was identified as a public-involved researcher.

Summary:

A 'radical, reflexive approach' (Cunliffe, 2003) to considering the impact of public involvement on the research process was adopted. The stages of analysis were:

- Preliminary analysis
- Development of an analytic framework
- Application of the analytic framework
- Stakeholder conference
- Asking questions of the qualitative data
- Writing up the research

This approach allowed the authors to address three questions: ‘How were service user and carer researchers involved in the research?’, ‘To what extent did we coproduce knowledge in our research?’ and ‘How did co-production affect research findings?’.

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Tools and methods for assessing the impact of public involvement in health and social care research: Writing Up

Impact Research
(Benefits & Challenges)

- Agenda
- Design and Delivery
- Ethics
- Recruitment
- Data Collection
- Analysis of Data
- Writing Up
- Dissemination
- Time and Cost

Overview

Staley (2009) noted the relative absence of reports of public involvement impact on writing up in existing studies and suggested that this may be a result of a lack of involvement during this stage of the research process. However where impact has been identified it has generally been found to be positive. Improved accessibility of reports and findings were associated with an increase in the user-friendliness, usefulness to the target audience and being written in plain English (Staley, 2009). In addition Brett et al. (2009) noted that where reports were grounded in the experiences of the public-involved they had a greater credibility with stakeholders.

The purpose of this resource is to provide examples of tools and measures that have been used to assess the impact of public involvement on ethics that could be used or adapted in order to develop a plan for the assessment of its impact. However, currently no formal methods or tools for assessing the impact of public involvement on writing up have been identified.

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Impacts of public involvement on writing up

Impact Research

(Benefits & Challenges)

- Agenda
- Design and Delivery
- Ethics
- Recruitment
- Data Collection
- Analysis of Data
- Writing Up
- Dissemination
- Time and Cost

Overview of impacts on Writing Up

- Made reports more hard-hitting, accessible and useful to the target audience
- Final research report benefited from being grounded in the experiences of members of the public
- Improved the way in which results have been described in reports

Methods and tools that have been used in published studies to assess the impact of public involvement on writing up

The typology developed from the evidence review of the PiiAF identified a number of impacts that public involvement had on writing up that had been reported in previous studies as discussed above. However, the informal and time-limited review of studies which informs this database did not identify any studies that described in detail the methods, tools or measures to assess the impact of public involvement on writing up. It is intended that this database should reflect the growth and development of the field of public involvement impact assessment therefore if you have developed or discovered a tool to measure the impact of public involvement on writing up and would like to share it please send it to piiaf@lancaster.ac.uk for inclusion in the database.

Impacts	**Context**	**Tool/Method**	**Source**	**Page No.**

Tools and methods for assessing the impact of public involvement in health and social care research: Dissemination

Impact Research
(Benefits & Challenges)

- Agenda
- Design and Delivery
- Ethics
- Recruitment
- Data Collection
- Analysis of Data
- Writing Up
- Dissemination
- Time and Cost

Overview

Both Staley (2009) and Brett et al. (2009) describe the positive impacts of public involvement on the dissemination of research findings. These impacts include the dissemination of findings to a wider audience than would otherwise have been the case, for example as a result of dissemination through established networks of or as a result of novel forms of feedback developed by the public-involved (Brett et al., 2009; Staley, 2009). Public involvement was also felt to lead to the findings having a greater impact on audiences, either in terms of an increased likelihood that the findings would be taken up and implemented or because they were felt to have an enhanced credibility.

A concern that public-involved might disseminate findings prior to their publication in an academic journal was identified as a negative impact (Brett et al., 2009).

Public involvement stakeholders considered that it was feasible to assess the impact of public involvement on dissemination (Barber et al., 2012). There was a good degree of consensus across all stakeholders groups about its feasibility.

Return to Impacts on Research Overview

Impacts of public involvement on dissemination

Impact Research
(Benefits & Challenges)

Agenda
Design and Delivery
Ethics
Recruitment
Data Collection
Analysis of Data
Writing Up
Dissemination
Time and Cost

Overview of impacts on Dissemination

Positive

- Helped engage the target audience
- Helped with the dissemination and implementation of research findings due to the dedication and influence of members of the public to their community
- Made the findings more accessible and the message more powerful
- Increased the likelihood of people acting on the findings
- Encouraged the direct use of research (i.e. changing policy and practice) as well as its more conceptual use (i.e. changing awareness, knowledge and attitudes)
- Enhance the credibility of the findings
- Helped devise novel forms of feedback

Negative

- Led to research findings being disseminated before the academic papers were published therefore jeopardising academic publication

Methods and tools used in published studies to assess the impact of public involvement on dissemination

Impacts	**Context**	**Tool/Method**	**Source**	**Page No.**
Helped with the dissemination and implementation of research findings	Semi-structured interviews to evaluate hospital services for adolescents	Log the range and number of outlets in which dissemination is carried out	van Staa, A., Jedeloo, S., Latour, J. & Trappenburg, M. (2010). "Exciting but exhausting: experiences with participatory research with chronically ill adolescents." *Health Expectations 13*(1): 95-107.	69
	Generic – reporting of public involvement in health research	GRIPP checklist to improve the reporting of public involvement in health research	Staniszewska, S., Brett, J., Mockford, C. & Barber, R. (2011). "The GRIPP checklist: strengthening the quality of patient and public involvement reporting in research." *International Journal Of Technology Assessment In Health Care 27*(4): 391-399.	70

Dissemination

Tool or method:
Log the range and number of outlets in which dissemination is carried out

Source:
van Staa, A., Jedeloo, S., Latour, J. & Trappenburg, M. (2010). "Exciting but exhausting: experiences with participatory research with chronically ill adolescents." *Health Expectations 13*(1): 95-107.

Type of tool or method:
Qualitative/quantitative

Indicators of impact:
Wide range of outlets for dissemination used that go beyond conventional academic channels.

Quality appraisal:
Unclear

The approach to public involvement in the main study:
Collaboration. Participatory research approach. 9 adolescents were recruited as co-researchers and involved in developing the interview protocol, carrying out interviews and dissemination of the findings.

Public involvement in assessment of impact:
All the authors had higher academic or medical degrees – not clear whether members of the public-involved or not

Unclear who carried out the impact assessment – most likely to be the author

Summary:
The authors logged the number and range of outlets in which dissemination occurred. They also reflected upon how the involvement of young people inspired them to disseminate findings more widely and creatively than they would otherwise have done so. The authors did not provide a formal mechanism through which impact of involvement on dissemination could be logged, but their work could form the basis of a more systematic approach.

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Dissemination

Tool or method:

GRIPP checklist

Source:

Staniszewska, S., Brett, J., Mockford, C. & Barber, R. (2011). "The GRIPP checklist: strengthening the quality of patient and public involvement reporting in research." *International Journal of Technology Assessment In Health Care 27*(4): 391-399.

Type of tool or method:

Qualitative

Indicators of impact:

Not applicable

Quality appraisal:

Not applicable

The approach to public involvement in the main study:

Not applicable

Public involvement in assessment of impact:

Not applicable

Summary:

The GRIPP checklist provided a structured approach to the reporting of public involvement impact and was developed from two reviews of public involvement in health research and health services delivery and evaluation (PIRICOM and PAPIRIS).

The checklist does not provide a method for assessing impact but it does help to ensure that the impact of public involvement is reported accurately and effectively.

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Tools and methods for assessing the impact of public involvement in health and social care research: Time and cost

Impact Research
(Benefits & Challenges)

- Agenda
- Design and Delivery
- Ethics
- Recruitment
- Data Collection
- Analysis of Data
- Writing Up
- Dissemination
- Time and Cost

Overview

Increased costs and amounts of time taken for public involvement were found to be associated with planning and managing effective public involvement, developing relationships and partnerships and ensuring diversity amongst public-involved (Brett et al., 2009).

Potentially negative impacts of public involvement on the time and cost of research projects were identified by Brett et al.'s (2009) review. The authors also acknowledged however that in some cases decisions about whether public involvement had a positive or negative impact was a matter of judgement and perspective. They give the example of a member of the public gaining important skills or knowledge as a result of training obtained from being involved in a project as a positive impact but suggest that the cost of that training on the projects' budget could be classified as a negative impact.

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Impacts of public involvement on time and cost

Impact
Research
(Benefits & Challenges)

- Agenda
- Design and Delivery
- Ethics
- Recruitment
- Data Collection
- Analysis of Data
- Writing Up
- Dissemination
- **Time and Cost**

Overview of negative impacts on Time and Cost

- Increased time and cost due to the practical aspects of planning and managing public involvement in research
- Time and cost of building up relationships within the community and setting up user groups
- Training and education for both members of the public and researchers
- Additional time needed for users to read and comment on documentation

Methods and tools used in published studies to assess the impact of public involvement on time and cost

Impacts	**Context**	**Tool/Method**	**Source**	**Page No.**
Time and cost of building up relationships	Development of a tool to assess academic-community partnerships	REAP tool	Pearce, J., Pearson, M. & Cameron, S. (2007). *The ivory tower and beyond: Bradford University at the heart of its communities: Bradford University's REAP approach to measuring its community engagement - Final report.*	74

Time and cost

Tool or method:

REAP tool

Source:

Pearce, J., Pearson, M. & Cameron, S. (2007). *The ivory tower and beyond: Bradford University at the heart of its communities: Bradford University's REAP approach to measuring its community engagement - Final report.*

Type of tool or method:

Quantitative

Indicators of impact:

Costs associated with facilitating public involvement

Quality appraisal:

The REAP tool was used to assess community engagement in six projects. Amendments to the tool were made on the basis of the piloting process.

The approach to public involvement in the main study:

Not applicable

Public involvement in assessment of impact:

Not applicable

Summary:

The authors reporedt on the development of a tool to facilitate the rigorous assessment of community engagement in academic partnerships. One section of the tool includes a focus upon the costs associated with community engagement.

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Figure 2: Typology of impacts on people

Impacts on People: Overview of Typology of Impacts on People

Public Involved

Positive
- Knowledge
- Skills
- Personal rewards
- Financial rewards

Negative
- Personal
- Emotional cost
- Practical restraints
- Financial loss
- Communication

Academic researchers

Positive
- Public relations
- Career benefits
- Challenges beliefs and attitudes

Negative
- Demands resources/Slower pace
- Loss of power
- Changes in working practices
- Questioning values, work and impact

Research participants

Positive
- Accessing information and services
- Increasing user-friendliness
- Peer researchers
- Benefiting from emotional support
- Offered hope and inspiration

Negative
- Sharing issues with peer interviewers may be inappropriate

Wider community involved

Positive
- Enhancing relations
- Raising awareness
- Community Benefit (focus on needs, ownership, potential change)
- Researcher benefit (credibility, advocacy)

Negative
- Failing to involve seldom-heard groups
- Conflicting interests

Community organisations

Positive
- Fostering knowledge
- Benefiting the community
- Increasing credibility
- New members
- Linking public and health system

Negative
- Carrying additional expenses for time and cost
- Being blamed for not meeting needs of public

Funders

Positive
- Making sure research is relevant
- Making funding transparent
- Increasing accountability of funding organisations

Negative
- Lacking funding support for PI
- Valuing scientific criteria over public interest
- Funder's remit preventing PI in agenda-setting

Policy makers

Positive

Enhancing legitimacy of research in policies

Negative

Increasing uncertainty of policy-making

Return to Introduction

Tools and methods for assessing the impact of public involvement in health and social care research: On Public-involved

Impact
People

(Benefits & Challenges)

- Public Involved
- Researchers
- Research participants
- Wider community involved
- Community organisations
- Funders
- Policy makers

Overview

Both Staley (2009) and Brett et al. (2009) identified a large number of impacts, both positive and negative of involvement on the public-involved. Positive impacts were associated with the development of new skills and knowledge, opportunities for friendship and support and feelings of enjoyment and satisfaction. Negative impacts included feeling emotionally burdened and being overloaded with work. Brett et al. (2009) noted that many of the negative impacts arose as a result of poor communication, increased time burdens which sometimes occurred as a result of poor planning and the potential financial costs associated with involvement.

Assessing the impact of public involvement on members of the public-involved was agreed to be highly feasible by a range of stakeholders taking part in a Delphi study (Barber et al., 2012). In fact, this item received the highest percentage agreement in comparison to the other potential impacts of involvement.

Return to Impacts on People overview

Impacts of public involvement on public-involved

Impact People

(Benefits & Challenges)

Public Involved
Researchers
Research participants
Wider community involved
Community organisations
Funders
Policy makers

Overview of impacts on Public-involved

Knowledge

- Increased research knowledge – both general and specific to the research topic
- Increased knowledge of their condition, practical knowledge that could directly benefit peers

Skills

- Training in research methodology
- May improve employment chances (e.g. computer skills, team working, research skills, study skills –writing etc.)

Personal rewards

- Feel useful, valued and listened to
- Feel empowered, greater self-confidence, more control, friendships and more assertive in interactions with clinicians, contribute to own recovery

Financial rewards

- Opportunity to earn money
- Obtain regular (and fair) payment for their contribution

Impact
People
(Benefits & Challenges)

- **Public Involved**
- Researchers
- Research participants
- Wider community involved
- Community organisations
- Funders
- Policy makers

Overview of negative impacts on Public-involved:

Personal cost

- Frustration at not being listened to, marginalised in research team, dominated by academic experts, not valued, intimidated, out of depth
- Members of the public had difficulty in being taken seriously by funders

Practical cost

- Difficulties travelling, being paid (benefits problems) lack of equal opportunities with others in team, lack of support, heavy workload

Financial cost

- Financial burden of travelling, child care and respite care if financial backing is not provided, time consuming often without payment

Emotional cost

- Hearing about the hardships of their peers reminded them of own negative experiences

Knowledge & Skills

- Inadequate training made people feel they couldn’t contribute, thrown in at deep end and confused about lack of clarity about their role

Communication

- Left out of communication across research team, routine use of email, conferences etc. could exclude as could unfamiliar processes, acronyms and technical language

Methods and tools used in published studies to assess the impact of public involvement on public-involved

Impacts	**Context**	**Tool/Method**	**Source**	**Page No.**
Knowledge and skill development	Generic measure of the impact of research partnerships on the community	Community Impacts of Research Oriented Partnerships (CIROP) measure	King, G., Servais, M., Currie, M., Kertoy, M., Law, M., Rosenbaum, P., Specht, J., Willoughby, T., Forchuk, C. & Chalmers, H. (2003). The Community Impacts of Research Oriented Partnerships (The CIROP Measure). Published at www.impactmeasure.org.	81
	Lay researchers' experiences of involvement in a study into older peoples experiences of social isolation	Reflective case study exploring the experiences of members of the public involved in a research project	Williamson, T., Brogden, J., Jones, E. & Ryan, J. (2010). Impact of public involvement in research on quality of life and society: A case study of research career trajectories. *International Journal of Consumer Studies 34*(5): 551-557.	82
Personal impacts of involvement	Community-based participatory research on a dietary intervention for African American	Questionnaire to measure perceptions of trust, benefit, satisfaction and burden	Corbie-Smith, G., Ammerman, A., Katz, M., St. George, D., Blumenthal, C., Washington,m C., Weathers, B., Keyserling T. & Switzer, B. (2003). Trust, Benefit, Satisfaction, and Burden. *JGIM: Journal of General Internal Medicine 18*(7): 531-541.	83

	The experiences of service users affected by cancer who are involved in cancer services, palliative care and research	Focus groups and individual face-to-face interviews and qualitative collaborative analysis	Cotterell, P., Harlow, G., Morris, C., Beresford, P., Hanley, B., Sargeant, A., Sitzia, J. & Staley, K. (2011). "Service user involvement in cancer care: the impact on service users." *Health Expectations 14*(2): 159-169.	84
	Parent researchers' involvement in a community consultation on Sure Start services	Survey of parent researcher experiences (using questionnaires, diaries and focus groups)	Rowe, A. (2006). The effect of involvement in participatory research on parent researchers in a Sure Start programme. *Health & Social Care in the Community 14*(6): 465-473.	85
	The experiences of immigrant women in Canada of lay health promotion and participatory health research	Qualitative study into the experiences of members of the public involved in a research project	Meyer, M. Torres, S., Cermeno, N., MacLean, L. & Monzon, R. (2003). Immigrant Women Implementing Participatory Research in Health Promotion. *Western Journal of Nursing Research 25*(7): 815-834.	86
	Needs assessment of young intravenous drug users not accessing health services	Survey of involvement in a participatory action research project (involving semi-structured interviews and focus groups)	Coupland, H. and Maher, L. (2005). Clients or colleagues? Reflections on the process of participatory action research with young injecting drug users. *International Journal of Drug Policy 16* (3): 191-198.	87

Public-Involved

Tool or method:

Community Impacts of Research Oriented Partnerships (CIROP) measure

Source:

King, G., Servais, M., Currie, M., Kertoy, M., Law, M., Rosenbaum, P., Specht, J., Willoughby, T., Forchuk, C. & Chalmers, H. (2003). The Community Impacts of Research Oriented Partnerships (The CIROP Measure). Published at www.impactmeasure.org.

Type of tool or method:

Mostly quantitative

Indicators of impact:

Changes to the knowledge and skills of members of the public involved in the research project

Quality appraisal:

The developers of the measure described it as valid and reliable. The measure underwent piloting with community members and researchers involved in the partnerships developing the measure. The tool was refined on the basis of feedback.

The approach to public involvement in the main study:

Not applicable

Public involvement in assessment of impact:

Not applicable

Summary:

A 33-item generic measure of the impact of involvement in community-academic research partnerships. Two areas (11 items) of the measure assessed the impacts on public-involved and focus upon:

- Personal knowledge development
- Personal research skill development

Each item had 9 response options.

Return to Methods and Tools table

Public-Involved

Tool or method:

Reflective case study exploring the experiences of public involved

Source:

Williamson, T., Brogden, J., Jones, E. & Ryan, J. (2010). "Impact of public involvement in research on quality of life and society: A case study of research career trajectories." *International Journal of Consumer Studies 34*(5): 551-557.

Type of tool or method:

Qualitative

Indicators of impact:

Personal experiences of the impact of being involved in research

Quality appraisal:

The lead author interpreted transcripts but checked interpretations with the co-researchers.

The approach to public involvement in the main study:

A participatory study –volunteers recruited from the community as co-researchers and involved in the design and conduct of the study and dissemination activities.

Public involvement in assessment of impact:

Two of the co-researchers collaborated in the development of the reflective case study and were cited as co-authors of the paper.

Summary:

The reflective case study drew upon interviews with the co-researchers, the lead author's (academic researcher) reflective diary and other documents including conference papers. A qualitative analysis based upon Miles & Huberman (1994) was used.

Return to Methods and Tools table

Public-Involved

Tool or method:

Questionnaire to measure perceptions of, trust, benefit satisfaction and burden

Source:

Corbie-Smith, G., Ammerman, A., Katz, M., St. George, D., Blumenthal, C., Washington,m C., Weathers, B., Keyserling T. & Switzer, B. (2003). "Trust, Benefit, Satisfaction, and Burden." JGIM: *Journal of General Internal Medicine 18*(7): 531-541.

Type of tool or method:

Quantitative

Indicators of impact:

Levels of perceived trust, benefit, satisfaction and burden in those participants taking part in a community-based participatory research project compared with those in a delayed intervention control group.

Quality appraisal:

The scale was developed from focus groups and interviews. The authors reported that it underwent extensive piloting during its development. Its internal reliability was assessed with Cronbach's alpha and found to be acceptable. The sampling strategy led to concerns about the generalizability of the findings from the questionnaire.

The authors acknowledged that it might also have been useful to have had an additional control group of people participating in a conventional health intervention.

The approach to public involvement in the main study:

Community-based participatory research. The authors reported that members of the church communities were involved at an early stage of developing the project and provided advice and guidance on the nature and structure of the project. Church leaders and community members were also employed as staff members and so had a further decision-making role.

Public involvement in assessment of impact:

Unclear what involvement community members had in the assessment of impact beyond participating in the study. All of the authors had higher medical or academic qualifications.

Summary:

The questionnaire was administered at twelve months follow-up to participants who had taken part in the intervention and those waiting to take part. Two response options were provided with 1 indicating agreement with a statement and 0 indicating disagreement. The responses were analysed using Chi-square and t-tests and a multivariate regression model produced.

Return to Methods and Tools table

Public-Involved

Tool or method:

Qualitative collaborative analysis of the experiences of public-involved

Source:

Cotterell, P., Harlow, G., Morris, C., Beresford, P., Hanley, B., Sargeant, A., Sitzia, J. & Staley, K. (2011). "Service user involvement in cancer care: the impact on service users." *Health Expectations* *14*(2): 159-169.

Cotterell, P. (2008). "Exploring the value of service user involvement in data analysis: 'Our interpretation is about what lies below the surface'." Educational Action Research 16(1): 5-17.

Type of tool or method:

Qualitative

Indicators of impact:

Self-reported personal impacts of involvement activities

Quality appraisal:

The academic researcher and two public-involved researchers analysed the qualitative data collaboratively.

The approach to public involvement in the main study:

A participatory approach to the research was adopted. One academic researcher and two public-involved researchers were involved in all stages of the research process from developing the idea for the study to dissemination of the findings.

A Research Advisory group which consisted of researchers experienced in public involvement and cancer and palliative care provided advice to the project.

Public involvement in assessment of impact:

As above

Summary:

Personal experiences of public involvement were collected using focus groups and interviews. The data were analysed using a collaborative thematic analysis approach. Analysis took part in two phases: the first phase was an initial thematic analysis carried out by the academic researcher. The second phase adopted a collaborative approach and consisted of the following stages (Cotterell, 2008):

- Interpretation sessions
- Theme generation sessions
- Extending/collapsing into final themes
- Integration of phase 1 and phase 2 themes

Return to Methods and Tools table

Public-Involved

Tool or method:

Survey of parent researcher experiences

Source:

Rowe, A. (2006). "The effect of involvement in participatory research on parent researchers in a Sure Start programme." *Health & Social Care in the Community 14*(6): 465-473.

See also: Rowe, A. F., J. (2006). *The experiences of parent researchers: North East Derbyshire Sure Start. A report on the experiences of the parent researchers involved in the Community Consultation for the North East Derbyshire Sure Start.* ScHARR, University of Sheffield.

Type of tool or method:

Mostly qualitative

Indicators of impact:

Parent researchers' perceptions of the personal impact of their involvement in a participatory research project.

Quality appraisal:

The author used triangulation of multiple data sources to ensure 'credibility'.

The approach to public involvement in the main study:

Parent researchers were recruited to take part in a participatory research study. The parent researchers were involved in the development of the project, data collection and analysis, writing-up and dissemination.

Public involvement in assessment of impact:

The parent researchers provided data for the assessment but it is unclear whether they had any involvement in the planning or analysis of the assessment. The author of the paper was an academic researcher.

Summary:

Three approaches to collecting data on impact were used:

- Pre and post-involvement questionnaire
- Parent researchers kept a diary
- Unstructured focus groups

A content analysis and thematic analysis were used to analyse the qualitative data. Descriptive statistics were used to summarise the quantitative data.

Return to Methods and Tools table

Public-Involved

Tool or method:

Qualitative study of the experiences of public-involved

Source:

Meyer, M. Torres, S., Cermeno, N., MacLean, L. & Monzon, R. (2003). Immigrant Women Implementing Participatory Research in Health Promotion. *Western Journal of Nursing Research 25*(7): 815-834.

Type of tool or method:

Qualitative

Indicators of impact:

Perceptions of personal and professional changes as a result of involvement

Quality appraisal:

The authors argued that the credibility of their findings was enhanced because they used more than one coder and established inter-rater reliability.

The approach to public involvement in the main study:

Participatory Action Research. Unemployed/under-employed Spanish-speaking women were recruited to and trained for an assessment of the health needs of women within their community. All formal decision-making meetings (including those involving analysis) were open and accessible to all the participatory researchers.

Public involvement in assessment of impact:

Two of the Lay health promoters/participatory researchers and one academic researcher carried out the interviews and the analysis. Two of the participatory researchers were included as authors.

Summary:

Semi-structured qualitative interviews were carried out with as many participatory researchers as possible. In the interviews, participants were asked to reflect upon their experiences of becoming participatory researchers, collecting data, impact upon the community etc.

The data were analysed through collective analysis meetings.

Return to Methods and Tools table

Public-Involved

Tool or method:

Survey of involvement in a participatory action research project (involving semi-structured interviews and focus groups)

Source:

Coupland, H. and Maher, L. (2005). Clients or colleagues? Reflections on the process of participatory action research with young injecting drug users. *International Journal of Drug Policy 16* (3): 191-198.

Type of tool or method:

Qualitative

Indicators of impact:

Expectations about and actual experiences of involvement

Quality appraisal:

The data obtained from the interviews and focus groups with the public-involved researchers were triangulated with observations and field notes made by the academic researchers

The approach to public involvement in the main study:

Collaborative, although the authors acknowledged that initially the public-involved researchers lacked confidence in their ability and skills. Young intravenous drug users were recruited to collaborate with health workers and academics to collect data.

Public involvement in assessment of impact:

Unclear - beyond their participation in the interviews and focus groups. The two main authors were affiliated with a university. A number of other authors were included – but unclear what their status or affiliation is.

Summary:

Semi-structured individual interviews were carried out with the public-involved researchers at the end of the data collection phase of the main study. These interviews were carried out by the ‘supervisory researcher’. Focus groups were carried out with the research teams (including both public-involved researchers and health-worker researchers) by the academic researcher who had had the least contact with the teams.

Return to Methods and Tools table

Tools and methods for assessing the impact of public involvement in health and social care research: Impacts on academic researchers

Overview

Both Brett et al., (2009) and Staley (2009) found that positive and negative impacts of public involvement on academic researchers had been reported – with Brett finding more negative than positive impacts. Positive impacts included academic researchers reporting that their views and attitudes had been challenged and their knowledge and understanding of the community with which they were working had increased. Better knowledge and understanding of the community led for example, to academic researchers feeling that they were better able to design and deliver appropriate research projects and to interpret their findings more effectively (Staley, 2009).

Negative impacts included academic researchers finding it difficult to relinquish control and an increase in time and resources needed for doing public involvement. In some cases changing working practices may have resulted in conflict between the academic researchers and public-involved (Brett et al., 2009) whilst the increased time taken to conduct research led to some academic researchers having to re-negotiate time scales with funding bodies (Staley, 2009).

Assessing the impact of public involvement on academic researchers was considered to be feasible by the stakeholders taking part in Barber et al.'s (2012) Delphi process. There was a good degree of consensus across all stakeholder groups (members of the public, academic researchers and 'others') concerning the feasibility of assessing public involvement impact on academic researchers. However of all the impacts it was considered feasible to assess, impact on academic researchers received the least agreement.

The purpose of this resource is to provide examples of tools and measures that have been used to assess the impact of public involvement on ethics that could be used or adapted in order to develop a plan for the assessment of its impact. However, currently no formal methods or tools for assessing the impact of public involvement on writing up have been identified

Return to Impacts on People overview

Impacts of public involvement on academic researchers

Impact People

(Benefits & Challenges)

- Public Involved
- Academic Researchers
- Research participants
- Wider community involved
- Community organisations
- Funders
- Policy makers

Overview of impacts on Academic Researchers:

Positive

General

- Gained fresh insights into the issues of the study
- Better knowledge, understanding of and commitment to ‘community’
- Building friendships and a good rapport with service users
- Finding it to be a rewarding process: new friends, members of the public often bring a lot of energy and enthusiasm
- Gained respect for ‘lay’ expert knowledge and commitment to the study
- Ensured that the researchers remained focussed on the service users
- Learnt more interpersonal skills and sensitivity towards research ‘subjects’
- The researcher’s role became more about technical advice in the study and one of support for users

Career benefits

- Public recognition for their work with service users
- Internal recognition and validation from their employers

Challenges to beliefs and attitudes

- Changed their attitude towards involvement itself

Teamwork

- Can make them re-think their views of service users
- PI gave researchers the opportunity to work in a diverse team
- Makes the research team more representative

Impact
People
(Benefits & Challenges)

- Public Involved
- Academic Researchers
- Research participants
- Wider community involved
- Community organisations
- Funders
- Policy makers

Overview of impacts on Academic Researchers:
Negative

Higher demands on resources and a slower pace of research

- Required a lot of time, energy and money
- Had to renegotiate timescales and deadlines with funders
- Time needed to support users and keep them well-informed
- Time needed to get honorary contracts for members of the public
- Additional time and cost to develop working relationships with users, to train users
- Difficulties caused by the conflicting time frames of researchers and members of the public
- Researchers not always convinced the additional effort and resources were worthwhile

Loss of power

- Involving the public inevitably means giving up some power but the shift is essential for projects to become genuinely collaborative
- Felt uncomfortable relinquishing control or sharing power over the research
- Difficulty accepting views of others when they did not match their own

Forced changes in working practice

- Having to change working practices to accommodate PI
- Requires specific skills which are often new to the academic researchers
- Described as a benefit by some researchers, others described it as a difficult challenge

Challenging researchers’ values and beliefs

- Caused organisations to question their traditional ways of working
- This has been uncomfortable for some researchers

Methods and tools used in published studies to assess the impact of public involvement on academic researchers

The typology developed from the evidence review of the PiiAF identified a number of impacts that public involvement had on academic researchers that had been reported in previous studies as discussed above. However, the informal and time-limited review of studies which informs this database did not identify any studies that described in detail the methods, tools or measures to assess the impact of public involvement on academic researchers. It is intended that this database should reflect the growth and development of the field of public involvement impact assessment therefore if you have developed or discovered a tool to measure the impact of public involvement on academic researchers and would like to share it please send it to piiaf@lancaster.ac.uk for inclusion in the database.

Impacts	**Context**	**Tool/Method**	**Source**	**Page No.**

Tools and methods for assessing the impact of public involvement in health and social care research: On Research participants

Impact
People
(Benefits & Challenges)

Public Involved
Researchers
Research participants
Wider community involved
Community organisations
Funders
Policy makers

Overview

In their reviews both Brett et al. (2009) and Staley (2009) noted that a range of positive impacts of public involvement on research participants had been reported. The impacts were mainly associated with interview and focus group research and included perceptions that the research process was carried out with greater sensitivity and was more acceptable. The impact of public involvement may be greater for those groups who are seldom heard or people who may not trust authority figures (Staley, 2009). Brett et al. (2009) noted one negative impact that participants may not want to share information about themselves in interviews with people they know well.

Return to Impacts on People overview

Impacts of public involvement on participants

Impact
People
(Benefits & Challenges)

- Public Involved
- Researchers
- **Research participants**
- Wider community involved
- Community organisations
- Funders
- Policy makers

Overview of positive and negative impacts on Research Participants

Positive

- Providing access to information and services
- Increasing sensitivity, acceptability and user-friendliness of processes
- Using peer researchers, research participants reported:
    - feeling a greater sense of shared experience and understanding
    - feeling more comfortable and relaxed
    - perceiving the encounter to be less threatening and less hierarchical
    - being more willing to talk and raise issues
    - being more honest and sharing their true experiences and views
    - felt emotional support from peer researchers
- Emotional experience of interview: benefit from ‘unburdening’
- Offering hope and inspiration

Negative

- Tension that could build up between lay researcher and participant
- Participants reported not wanting to share personal experiences with peer researchers if they know them well

Methods and tools used in published studies to assess the impact of public involvement on research participants

Impacts	**Context**	**Tool/Method**	**Source**	**Page No.**
Increasing user-friendliness and Sharing issues with peer interviewers may be inappropriate	User-involvement research into psychiatric service users’ satisfaction with services	Qualitative study of participants’ perceptions of being interviewed by a service user researcher	Bengtsson-Tops, A. & Svensson, B. (2010). Mental health users' experiences of being interviewed by another user in a research project. A qualitative study. *Journal of Mental Health 19*(3): 234-242.	95

Research Participants

Tool or method:

Qualitative study of participants' perceptions of being interviewed by a service user researcher

Source:

Bengtsson-Tops, A. & Svensson, B. (2010). Mental health users' experiences of being interviewed by another user in a research project. A qualitative study. *Journal of Mental Health 19*(3): 234-242.

Type of tool or method:

Qualitative

Indicators of impact:

Self-reported perceptions of being interviewed by a service user researcher

Quality appraisal:

The authors referred to Graneheim & Lundman's (2004) and Lincoln & Guba's (1985) criteria for assessing the rigour of qualitative research. The authors argued that: credibility was obtained through the varied sample and the rich and detailed responses they received; dependability by using the same interviewers and conducting an independent analysis of the transcripts; but transferability was limited because of the high rate of attrition between participants agreeing to be interviewed about their perceptions and actually taking part in the interviews.

The approach to public involvement in the main study:

The authors reported a high level of public involvement in the main study, with service users being trained as researchers and carrying out the interviews with other service users. It is unclear how far the public-involved were involved in setting the research question or in designing the study.

Public involvement in assessment of impact:

This is likely to have been very limited. The two authors were academics. It is likely that the authors carried out individual and group interviews with a sample of service users who had been interviewed for the main study. The two authors coded the interview transcripts independently.

Summary:

5 group interviews and 3 individual interviews were carried out with service users who had participated in the satisfaction with services study. The topics guide covered the following areas:

- The basis on which decisions about participating in interviews carried out by service users was taken
- Their experience of participating in such interviews
- Factors that may have affected the information given as a result of being interviewed by service users
- Their lasting impression of the interviews

A content analysis was carried out on the transcripts that focused upon both their manifest and latent content (Graneheim & Lundman, 2004).

Return to Methods and Tools table

Tools and methods for assessing the impact of public involvement in health and social care research: On the wider community and Community Organisations

Impact
People
(Benefits & Challenges)

- Public Involved
- Researchers
- Research participants
- Wider community involved
- Community organisations
- Funders
- Policy makers

Overview

A number of mostly positive impacts of public involvement on the wider community were noted in the reviews carried out by Brett et al., (2009) and Staley (2009). They found public involvement led to an increase in the community's trust and acceptance of the research being carried out, improved relationships with academic researchers and that the research itself was likely to be more grounded and focused upon the needs of the community. Public involvement was thought to have a particularly positive impact on members of the community from seldom heard groups.

A small number of negative impacts of public involvement on the wider community were reported. For example community organisations may have to absorb the increased costs of public involvement and public involvement may lead to or uncover conflict within the community.

The impact of public involvement on the wider community was not identified as a distinct area of impact by Barber et al. (2012) and so did not form part of the Delphi study looking at the feasibility of assessing public involvement impact.

Return to Impacts on People overview

Impacts of public involvement on the Wider Community and Community Organisations

Impact People

(Benefits & Challenges)

- Public Involved
- Researchers
- Research participants
- Wider community involved
- Community organisations
- Funders
- Policy makers

Overview of impacts on the Wider Community-involved:

Positive

Enhancing relations between communities and professionals/services

- Developing partnerships based on mutual respect and trust
- Improving services and increasing take-up of services

Raising awareness of health issues

- Increasing knowledge and awareness of health issues within the community
- Promoting greater awareness of the community amongst service providers leading to more effective health promotion
- Raising awareness of disability within the community

Community Benefit

- Ensuring that research is focused on, grounded in and accountable to the community
- Identifying the needs of the community to developing more effective services
- Promoting shared ownership of research to increase the chances of sustainable change

Researcher benefit

- Making the research more credible and visible to the community
- Helping to overcome potential barriers and resistance within communities
- Establishing new advocacy relationships with members of the community

Negative

- Problems associated with failing to involve seldom heard groups
- Conflicting interests between the research and the community may cause tensions

Impact
People
(Benefits & Challenges)

- Public Involved
- Researchers
- Research participants
- Wider community involved
- Community organisations
- Funders
- Policy makers

Overview of impacts on Community Organisations:

Positive

Fostering knowledge and understanding

- Research provides tangible benefits to the community organisation
- Research has increased credibility and visibility within the community through the organisation
- May facilitate the recruitment of new members to the community organisation
- The community organisation may provide a link between the community and health system

Negative

- The community organisation may carry additional expenses for the time and cost of the research
- The community organisation may be blamed if the needs of the community are not met by the research

Methods and tools used in published studies to assess the impact of public involvement on the wider community and community organisations

Impacts	**Context**	**Tool/Method**	**Source**	**Page No.**
Community Benefit	Generic community participation	Auditing community participation questions	Burns, D. & Taylor, M. (2000). *Auditing community participation: an assessment handbook*. The Policy Press for the Joseph Rowntree Foundation.	100
Community Benefit and Enhanced Relations between Communities and Professionals/ Services	Generic approach to assessing the impact of research partnerships on the community	Community Impacts of Research Oriented Partnerships (CIROP) measure	King, G., Servais, M., Currie, M., Kertoy, M., Law, M., Rosenbaum, P., Specht, J., Willoughby, T., Forchuk, C. & Chalmers, H. (2003). The Community Impacts of Research Oriented Partnerships (The CIROP Measure). Published at www.impactmeasure.org.	101

Wider Community and Community Organisations

Tool or method:

Audit of community participation questions

Source:

Burns, D. & Taylor, M. (2000). *Auditing community participation: an assessment handbook*. The Policy Press for the Joseph Rowntree Foundation.

Type of tool or method:

Qualitative

Indicators of impact:

Impacts of that would not have been identified without public involvement are identified

Quality appraisal:

Not applicable – the document provides examples of suggestions of activities for impact assessment.

The approach to public involvement in the main study:

Not applicable

Public involvement in assessment of impact:

Not applicable

Summary:

Identified a series of questions that could form part of a focus group or questionnaire including:

- What real differences have resulted from community participation?
- Who has benefited?
- Are there examples of problems that have resulted from the community not being listened to?
- Are there any negative impacts of participation?

Return to Methods and Tools table

Wider Community and Community Organisations

Tool or method:

Community Impacts of Research Oriented Partnerships (CIROP) measure

Source:

King, G., Servais, M., Currie, M., Kertoy, M., Law, M., Rosenbaum, P., Specht, J., Willoughby, T., Forchuk, C. & Chalmers, H. (2003). *The Community Impacts of Research Oriented Partnerships* (The CIROP Measure). Published at www.impactmeasure.org.

Type of tool or method:

Mostly quantitative

Indicators of impact:

Enhanced community research capacity and community development

Quality appraisal:

The developers of the measure reported it to be valid and reliable. The measure underwent piloting with community members and researchers involved in the partnerships who developed it. The tool was refined on the basis of feedback.

The approach to public involvement in the main study:

Not applicable

Public involvement in assessment of impact:

Not applicable

Summary:

A 33-item generic measure of the impact of involvement in community-academic research partnerships. Two areas (12 items) of the measure assess the impacts on the community

Each item had 9 response options.

Return to Methods and Tools table

Tools and methods for assessing the impact of public involvement in health and social care research: On funders

Overview

Many funding bodies require evidence of public involvement in the research projects they fund but there appears to be little evidence of the impact of public involvement on the funders themselves.

Brett et al. (2009) identified a small number of positive impacts as well as some challenges for funders in facilitating public involvement in research. Public involvement in research may lead funders to feel more assured that the research they fund is relevant to the community. In addition public involvement may lead to greater transparency in the allocation of funds and that funding organisations may be more accountable. However, tensions between the scientific validity demanded by funding bodies and the focus on empowerment by the public-involved may lead to significant challenges in encouraging the growth of public involvement.

The purpose of this resource is to provide examples of tools and measures that have been used to assess the impact of public involvement on funders that could be used or adapted in order to develop a plan for the assessment of its impact. However, as yet no formal methods or tools for assessing the impact of public involvement on writing up have been identified. Lindenmeyer et al. (2007) argue that feedback from funding bodies about the impact of public involvement should be made available in order to facilitate the assessment of public involvement impact.

Return to Impacts on People overview

Impacts of public involvement on Funders

Impact
People
(Benefits & Challenges)

- Public Involved
- Researchers
- Research participants
- Wider community involved
- Community organisations
- **Funders**
- Policy makers

Overview of impacts on Funders:

Positive

- Making sure that research that receives funding is relevant to the public
- Making the process of providing money for research more transparent
- Increasing the accountability of funding organisations

Methods and tools used in published studies to assess the impact of public involvement on funders

The typology developed from the evidence review of the PiiAF identified a number of impacts that public involvement had on funders that had been reported in previous studies as discussed above. However, the informal and time-limited review of studies which informs this database did not identify any studies that described in detail the methods, tools or measures to assess the impact of public involvement on funders. It is intended that this database should reflect the growth and development of the field of public involvement impact assessment therefore if you have developed or discovered a tool to measure the impact of public involvement on funders and would like to share it please send it to piiaf@lancaster.ac.uk for inclusion in the database.

Impacts	**Context**	**Tool/Method**	**Source**	**Page No.**

Tools and methods for assessing the impact of public involvement in health and social care research: On policy makers

Impact
People
(Benefits & Challenges)

- Public Involved
- Researchers
- Research participants
- Wider community involved
- Community organisations
- Funders
- Policy makers

Overview

There appears to be little published evidence on the impact of public involvement on policy makers. In her review of the impacts of public involvement on health and social care research, Staley found some evidence of impact in the policy making arena. However, typically this impact was reported from the point of view of the public-involved whose social capital increased as a result of their influence on policy decision-making.

Brett et al. (2009) identified a small number of positive and negative impacts of public involvement for policy makers. Public involvement in research might give policy makers additional insight into their decision-making and help to legitimise it. But policy makers were reported as potentially facing difficulties associated with reconciling the conflicting priorities of different stakeholders including the public-involved.

The purpose of this resource is to provide examples of tools and measures that have been used to assess the impact of public involvement on funders that could be used or adapted in order to develop a plan for the assessment of its impact. However, as yet no formal methods or tools for assessing the impact of public involvement on writing up have been identified. Abelson et al. (2007) call on policy-makers to be clear about the goals of their public involvement so that the appropriate involvement methods can be used and the impact of public involvement on decision-making clearly articulated.

Return to Impacts on People overview

Impacts of public involvement on Policy-makers

Impact
People
(Benefits & Challenges)

- Public Involved
- Researchers
- Research participants
- Wider community involved
- Community organisations
- Funders
- Policy makers

Overview of impacts on Policy Makers

Positive

- Enhancing the legitimacy and credibility of research in policy-making

Negative

- Increases the uncertainty of policy-making as different viewpoints might need to be reconciled

Methods and tools used in published studies to assess the impact of public involvement on policy-makers

The typology developed from the evidence review of the PiiAF identified a number of impacts that public involvement had on policy-makers that had been reported in previous studies as discussed above. However, the informal and time-limited review of studies which informs this database did not identify any studies that described in detail the methods, tools or measures to assess the impact of public involvement on policy-makers. It is intended that this database should reflect the growth and development of the field of public involvement impact assessment therefore if you have developed or discovered a tool to measure the impact of public involvement on policy-makers and would like to share it please send it to piiaf@lancaster.ac.uk for inclusion in the database.

Impacts	**Context**	**Tool/Method**	**Source**	**Page No.**

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