

Research Topic and Study Design database: Signposting resource showing existing studies that have assessed public involvement impact within a range of research contexts

Summary

<i>About:</i>	<i>This resource provides information about how public involvement impact has been assessed in published studies that have taken place in a range of research and public involvement contexts</i>
<i>What:</i>	<i>This resource categorises published studies according to their research focus and public involvement approach. It also identifies how an assessment of public involvement impact was carried out in each study and includes references and case examples</i>
<i>Who:</i>	<i>For people who are interested in finding out how public involvement has happened in different research contexts using different approaches to involvement. It is also for people who would like to know how an assessment of public involvement impact was carried out in specific research study contexts</i>
<i>How:</i>	<i>To use the resource you should select the research focus and the public involvement approach that you are interested in. Use the diagrams to identify relevant studies and find out how the public involvement impact was assessed</i>

Introduction

Public involvement occurs within a specific research context which include:

- The discipline (e.g. public health, medical research, sociology, psychology)
- The topic (e.g. diabetes, health inequalities, asthma)

- The research design (e.g. randomised controlled trials, community-based participatory research, qualitative research)

It is likely that the topic and design of your research will have an important influence on how public involvement happens in your research in addition to the method for assessing its impact (Staley et al, 2012). For example, in their systematic review of studies that attempted to assess the impact of public involvement, Brett et al. (2010) found that public-led and collaborative approaches tended to be used more often in mental health and health promotion research studies and more often with older and disabled participants. In addition, involvement was more likely to happen throughout all stages of the research study in contrast to clinical research which tended to adopt consultative approaches that took place at one stage of the research only.

This resource provides a snapshot of published studies that have attempted to assess the impact of public involvement in research. The studies were identified by our informal review which drew on 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).

You can use this resource to see how public involvement has happened in different research contexts (e.g. in Randomised Controlled Trials (RCTs) or qualitative designs) and how its impact has been assessed (e.g. through case study, interviews or mixed methods) in published studies.

- The diagram on page 5 provides an overview of the research foci represented in this resource including Research Agenda Setting; Community-Based Participatory Research (CBPR) RCTs; Qualitative research and Large programme grants and PI Approaches including Consultation; Collaboration; Participatory; Emancipatory; Partnership and Formative research
- The diagrams from page 6 onwards go into more detail for each research focus – including PI Approaches and types of impact assessment. There are also references to relevant published studies
- A narrative summary of the diagrams can be found on page 16
- Page 18 and those following contain full references to the studies identified in the diagrams

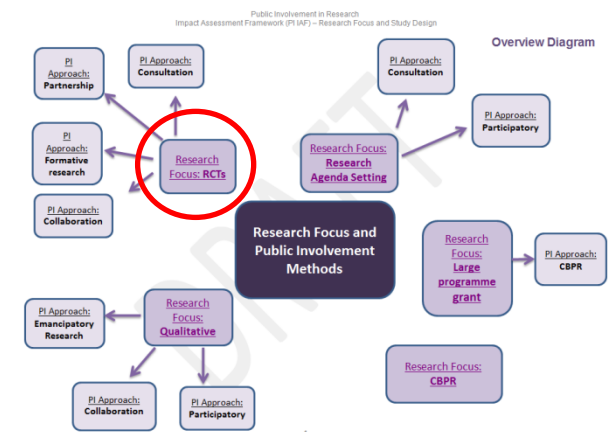
Instructions

- Start with the overview diagram on page 4. Begin at the centre of the diagram work outwards decide which type of research focus is most similar to yours:
 - Research Agenda Setting; RCTs; CBPR; Qualitative designs; or Large programme grant
- Click on the title of the research focus that you are interested in and you will be taken to the relevant detailed diagram
- On the relevant detailed diagram select the PI approach you are interested in (e.g. consultative, participatory) and you will see the different ways in which PI impact has been assessed. Click on the name in each box to be taken to the appropriate reference. Use this reference to get access to the original research paper

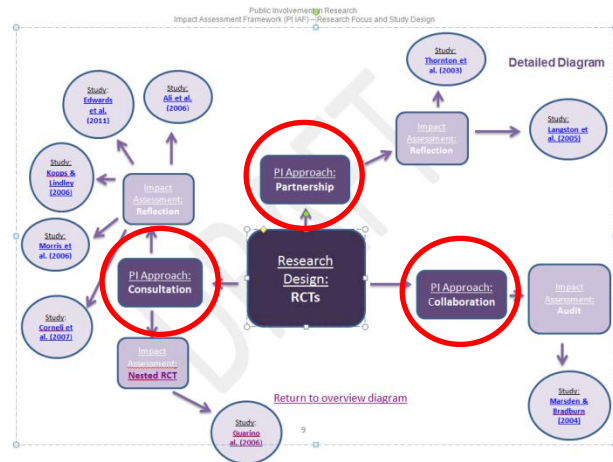
An example...

You might be interested in how the impact of public involvement in the context of a randomised controlled trial has been assessed in previous research studies

1. Click on the RCT box on the overview page (page 5) and you will be taken to the more detailed RCT diagram (page 10).

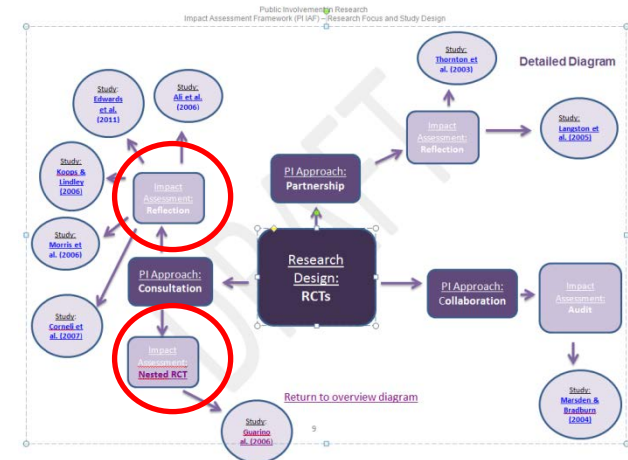


Public Involvement Impact Assessment Framework (PiiAF)

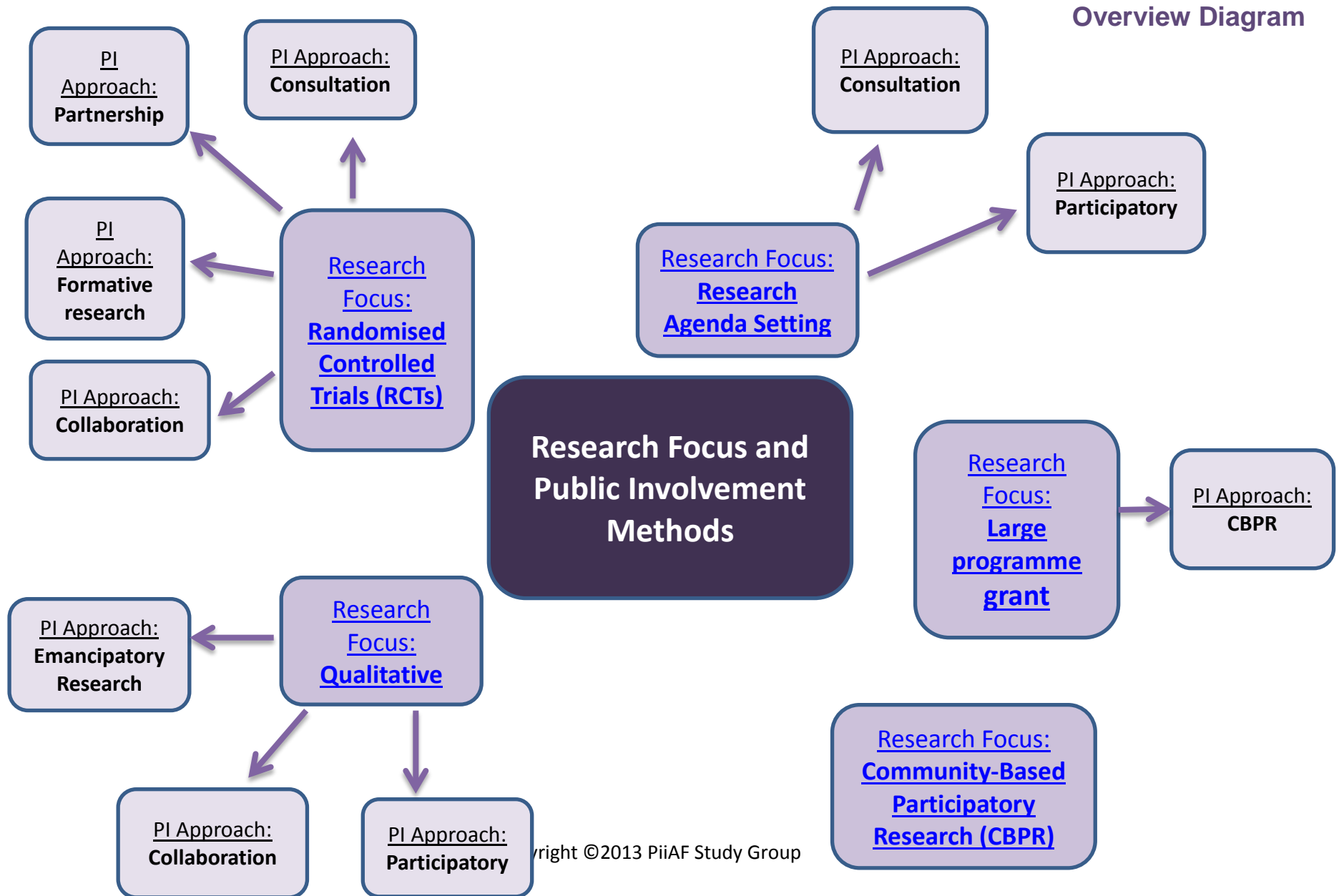


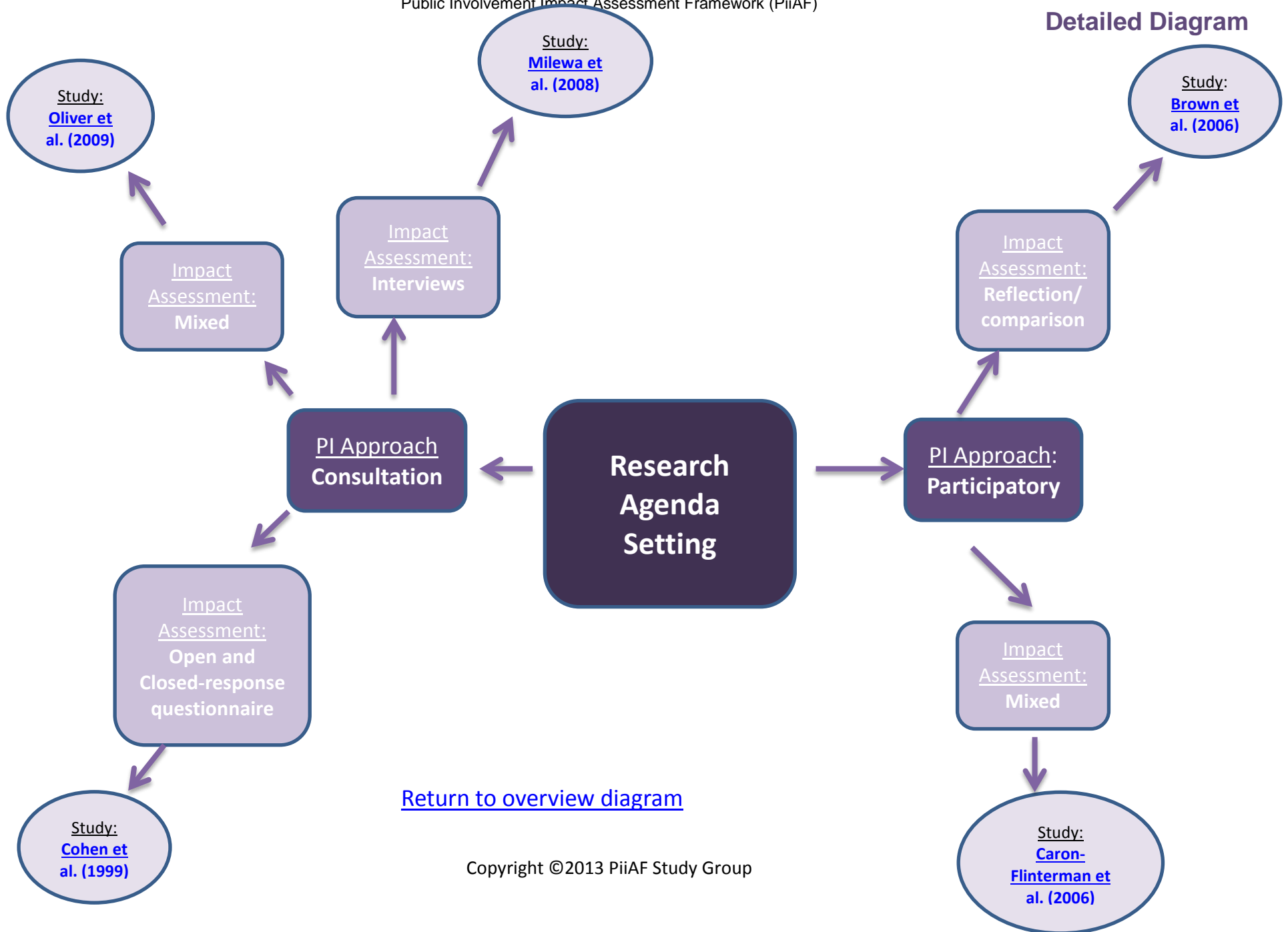
2. The more detailed diagram identifies the different ways in which public involvement has happened (partnership, consultation and collaboration) within the context of the rct papers that are included in this resource

3. If you are interested in finding out about rcts that have used consultative public involvement approaches you will see that its impact has been assessed either through reflection or through the use of a nested rct. Click on author to be taken to the full reference for that paper. Use the full reference to find the original paper.



Overview Diagram





[Return to overview diagram](#)

Case Examples

Research Agenda Setting

PI Approach: Consultative

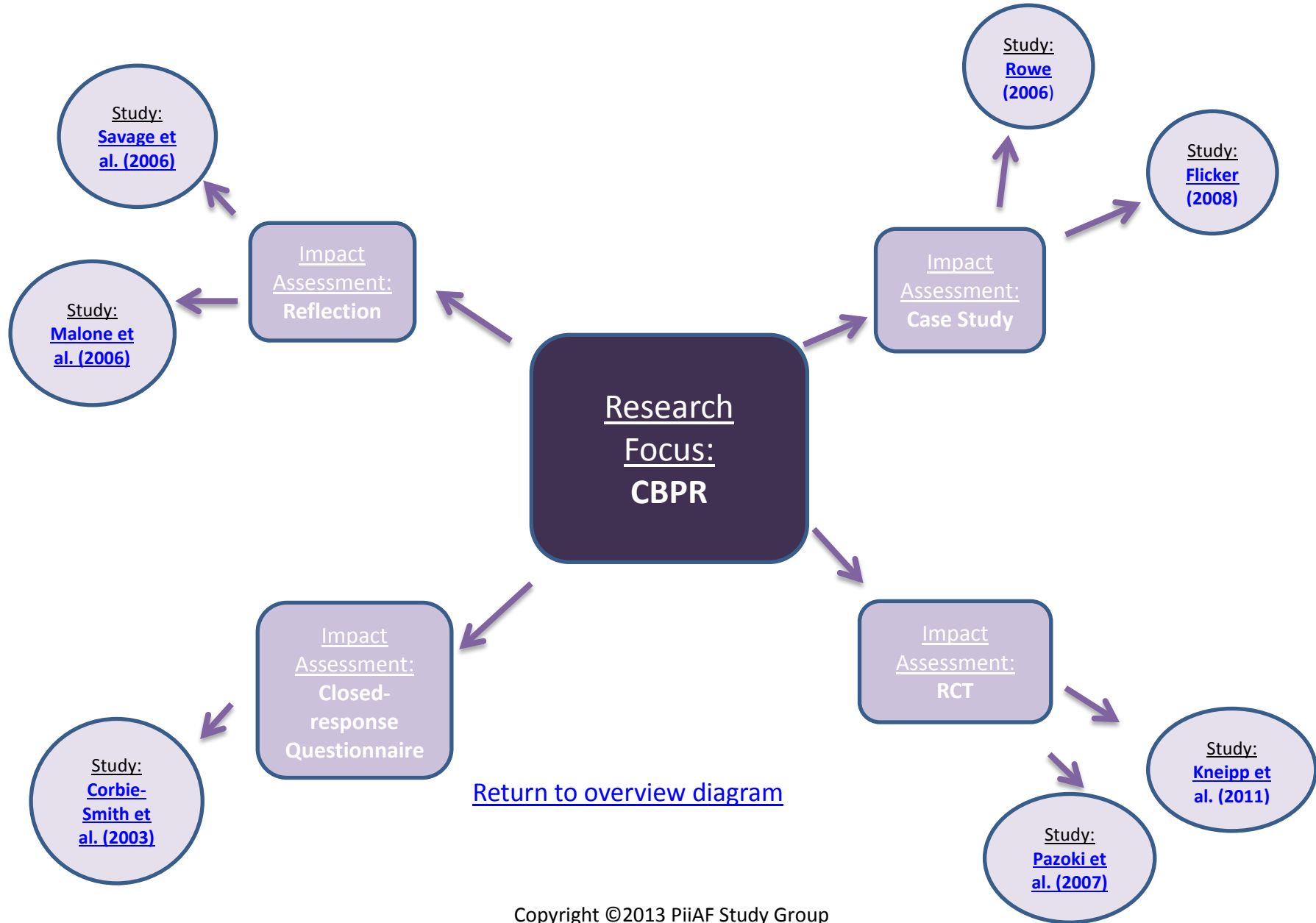
Oliver et al. (2009) wanted to identify the contributions to and influence of public members of an advisory panel in setting the research agenda for a national research programme. The public involvement approach they examined was consultative. Oliver et al. used mixed methods including document analysis, interviews and structured observation of advisory panel meetings in order to assess public involvement impact. Using these methods they were able to identify the unique contributions of the public members of the panel to the research agenda setting process.

Research Agenda Setting

PI Approach: Collaborative

Brown et al. (2006) reported on their collaboration with representatives of people with diabetes which led to a focus group study to identify the research priorities of people with diabetes living in inner-city communities. Two members of the focus group also became members of the research team and contributed to the data analysis. The research priorities generated in the focus groups were compared with the research priorities identified by a Research Advisory Committee for the UK Department of Health and Medical Research Council. This allowed the identification of similarities and differences between the research priorities of members of the public with an interest in diabetes and healthcare professionals.

Detailed Diagram



Case Examples

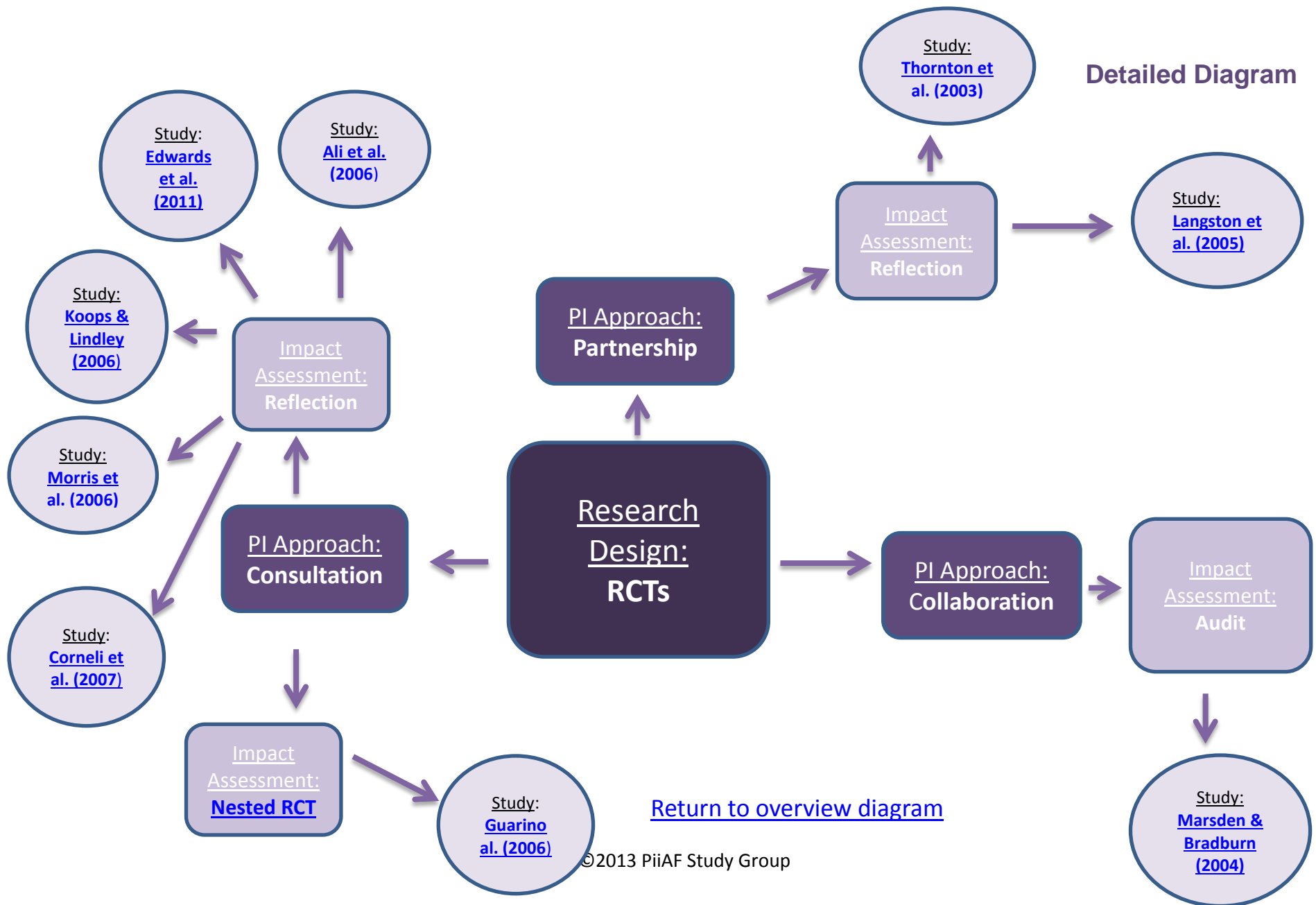
CBPR

Corbie-Smith et al. (2003) wanted to find out about peoples' perceptions of participating in a cbpr-designed rct to test a cancer prevention intervention. Members of the community provided guidance on the nature and structure of the intervention and some community members were employed and involved in decisions about the design and implementation of the project. A closed-response questionnaire was used to measure participants' perceptions of trust, benefit, satisfaction and burden after 12 months. The findings showed that participants in the intervention condition reported higher levels of trust and benefit than those in the delayed-intervention control condition. (The authors also noted as a limitation that they did not compare the cbpr-intervention with a traditional intervention).

CBPR

Flicker (2008) wanted to explore the benefits of using a cbpr approach for a youth HIV project. The project received input from two advisory groups one consisting of HIV positive youth and the other of service providers on protocol development, data analysis and dissemination. Flicker used a case study approach and identified positive impacts on the data including enhanced questions, recruitment and data collection and positive impacts on the young people such as the acquisition of practical or social skills and feeling that they had made a positive contribution. Negative impacts including the increased time taken for the study and a loss of control were also identified.

Detailed Diagram



Case Examples

RCTs

PI Approach: Consultative

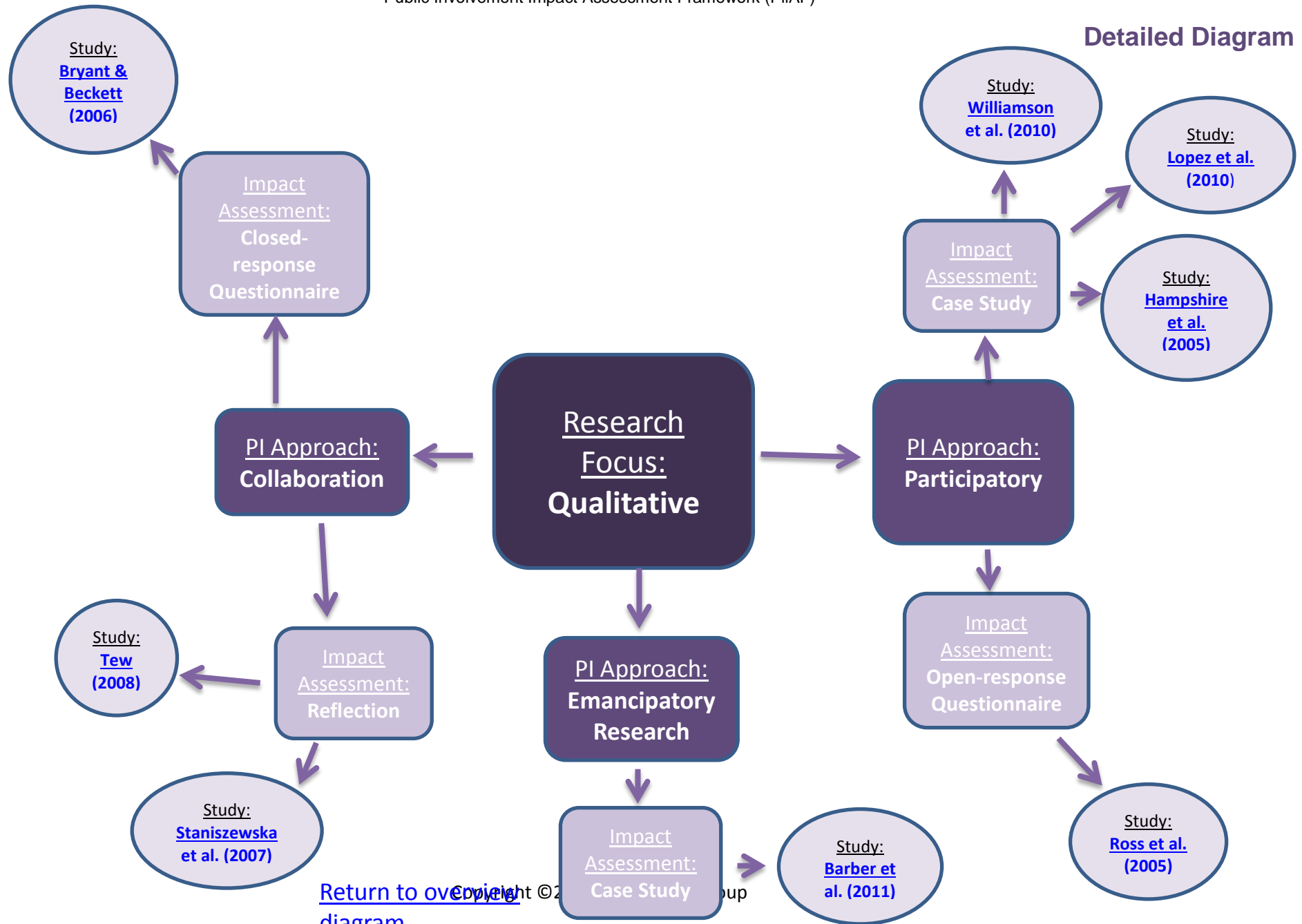
Edwards et al. (2011) assessed the impact of a consultation with parents about the design of an rct to test an intervention for children with cerebral palsy. They consulted 20 parents by carrying out interviews with them. The authors reflected on the impact of the consultation. They felt that public involvement had a positive impact on the design of the rct and on the identification of relevant outcome measures.

RCTs

PI Approach: Collaborative

Marsden & Bradburn (2004) wanted to assess the impact of public involvement in the design of an rct to test a breast cancer intervention. 2 consultative focus groups were held with women who had taken part in a previous rct and with women who belonged to breast cancer support groups. Members of a pre-existing consumer advisory group and patient representatives discussed the findings of the focus groups with clinicians. The advisory group and patient representatives were able to comment on the trial protocol and attended meetings of the national trial steering committee. The authors recorded the extent to which issues raised in the focus groups were adopted in the subsequent trial protocol. They demonstrated positive public involvement impacts on, amongst other things, the research design and the availability of study information.

Detailed Diagram



Return to overview diagram

Case Examples

Qualitative research

PI Approach: Participatory

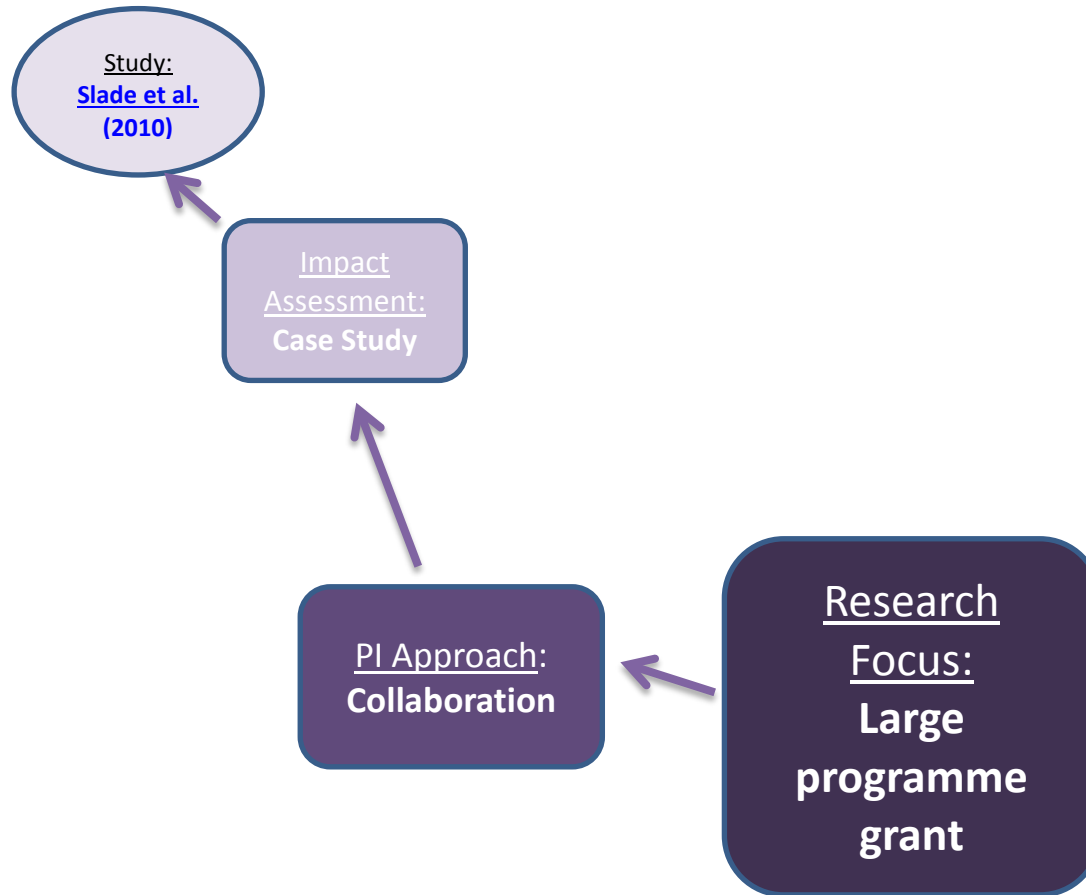
Williamson et al. (2010) wanted to explore the impact of public involvement on lay researchers who had been involved in a qualitative research study into older adults and the prevention or management of loneliness. The paper focused upon 2 of the lay researchers who were involved in the development, implementation, data analysis and dissemination of the research. A case study using a range of methods including interviews, reflective diary and conference papers was used to demonstrate impact. The case study was co-authored by an academic researcher and the 2 lay researchers. Impacts on the lay researchers included increased confidence and sense of personal achievement. The research was found to be more relevant and of an enhanced quality.

Qualitative research

PI Approach: Emancipatory

Barber et al. (2011) conducted a systematic and structured examination of the process and impact of public involvement in a qualitative study to develop principles and indicators for effective public involvement based on the consensus of a wide range of stakeholders. Their Advisory group had 3 consumer advisors who had some influence on the methods and interpretation of findings (Telford et al., 2004). Two consumer advisors and 3 academic researchers took part in structured reflective discussions after 3 Advisory group meetings and at the end of the project. Positive impacts on the design, interpretation and dissemination of findings were identified and mutual learning for both service user and academic researchers took place.

Detailed Diagram



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Case Examples

Large programme grant

PI Approach: Collaboration

Slade et al. (2010) wanted to examine the processes and impacts of public involvement in a large, 5 year research programme to develop and test a complex intervention for adult mental health services. The research programme had 3 advisory groups, two of which included service user representatives amongst others and the third was a mental health service-user only committee. In addition individual mental health service users were involved as experts. The research programme consisted of a number of linked studies including a systematic review, national survey and multi-centre cluster rct. The authors recorded all the recommendations made by all advisors during the first 7 months of the project. They developed a typology of recommendations and examined the recommendations according to who they were made by as well as the number of recommendations that were or were not implemented. Positive impacts on the research including more relevant study design were noted along with negative impacts including increased costs and length of time taken for the research.

Summary

The studies included in this resource are drawn from an informal review of published papers that have reported on attempts to assess the impact of public involvement in research. The informality of the review means that the studies cannot claim to be representative of all public involvement impact studies which means that the following comments are limited to the studies within this resource rather than as a comment on the nature of the whole field.

Research Agenda Setting

Research agenda setting is a significant research context in which public involvement takes place. As the diagrams demonstrate a number of attempts to assess the impact of public involvement on research agenda setting have been identified. We can see that in published studies on research agenda setting, the PI approaches that were adopted were either consultation or participatory. These studies used a range of methods including mixed methods, interviews and questionnaires in addition to authors' reflections to assess the impact of public involvement.

CBPR

We found a number of studies that attempted to assess the impact of public involvement within the context of CBPR. These studies assessed public involvement impact by using authors' reflections, case studies, questionnaires and rcts.

RCT

In those studies for which RCTs were the research context in which public involvement impact assessment took place consultation, collaboration and partnership approaches to assess impact were used. The methods used to assess impact were relatively similar however, with most of the studies drawing upon authors' reflection rather than more systematic attempts to capture public involvement impact. This indicates that more work needs to be done on developing approaches to assessing public involvement impact within the context of rcts.

Qualitative Research

The public involvement impact assessment studies identified in our informal review that took place within a qualitative research context were more likely to use participatory and collaborative rather than consultative PI approaches. These studies also tended to assess impact by using case studies and questionnaires as well as authors' reflection.

Over to you...

What research context will your public involvement happen in?

What approach to public involvement will you and your project team adopt?

How will you assess the impact of public involvement in your project?

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