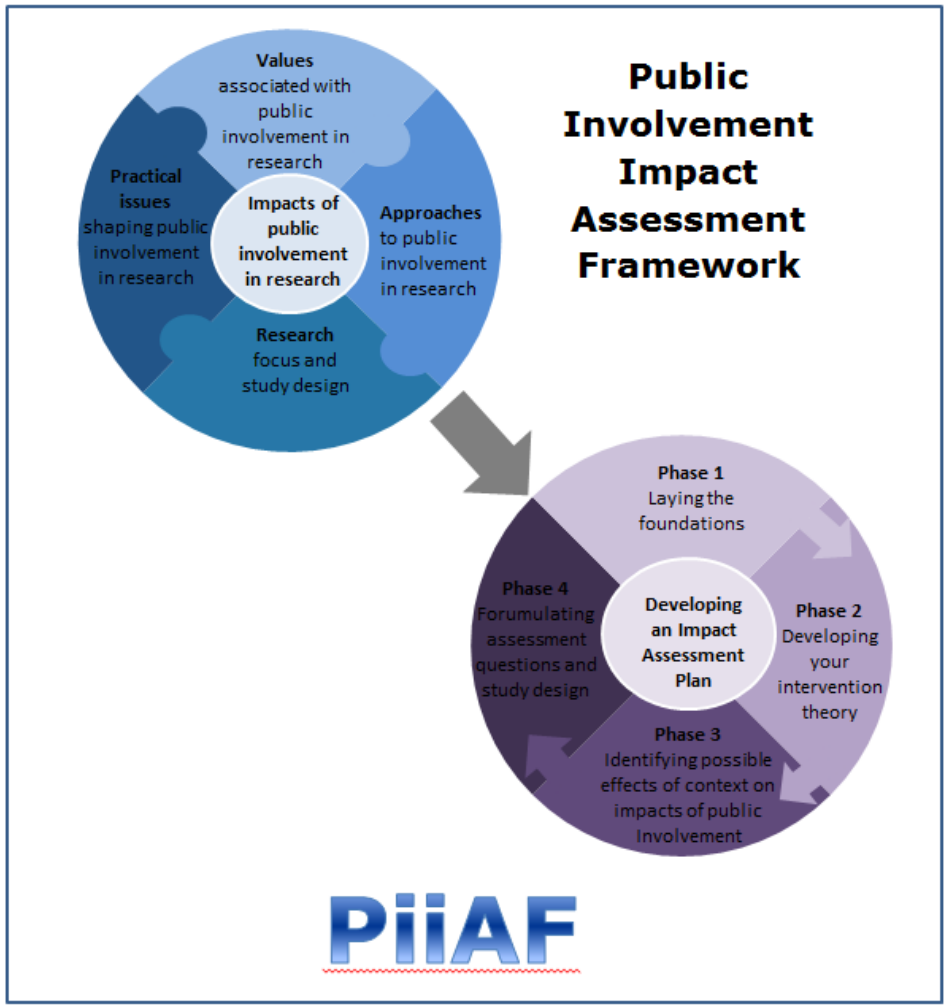


http://piiaf.org.uk Twitter #PiiAF

About PiiAF

- PiiAF - the Public Involvement Impact Assessment Framework – is an online resource developed with funding from the Medical Research Council to support people to develop ways of assessing the impact of PI

- These slides briefly described
  - the evidence review and adapted Delphi Study that contributed to the development of PiiAF
  - The structure and content of the PiiAF online resource.

Funded by MRC Medical Research Council

- PiiaF was funded by the Medical Research Council's Methodology Programme

- The PiiAF study group was a collaboration between academics/user investigators at Universities of Lancaster, Exeter and Liverpool and public Involvement facilitators from the NIHR Medicine for Children Research and Mental Health Research Networks. It included: Jennie Popay, Nicky Britten, Ann Jacoby, Michelle Collins, Katherine Froggatt, Felix Gradinger, Andy Gibson, Elaine Hewis, Fiona Lobban, Debbie Mayes, Jenny Preston, Tim Rawcliffe, Dee Snape,, Katrina Wyatt.

- Members of our Public Advisory Group (PAG), Advisory Network and members of PenPIG part of the Peninsula CLAHRC also contributed

- The PiiAF Public Advisory Group included: Bert Green, Faith Harris-Golesworthy, Irene McGill, Nigel Pyart. The PiiAF National Advisory Network included: Heather Bagley, Jonathan Boote, Sarah Buckland, Sally Crowe, David Evans. Kath Maguire, Elspeth Mathie, Sandy Oliver, Sophie Staniszewska, Derek Stewart, Maryrose Tarpey and Patricia Wilson

Funded by MRC Medical Research Council

PiiAF is the output of multi-phased Research Project

Formative Internal Evaluation

Phase 1

Evidence review

Phase 2

Delphi Study

Phase 3 Developing a PI Impact Assessment Framework & Guidance

Disseminating PiiAF and other outputs

Funded by MRC Medical Research Council

The evidence review

Aimed to identify and collate evidence on:

(i) values associated with PI in research
(ii) impacts of involvement
(iii) contextual factors affecting impacts
(iv) Methods used in previous assessments of impacts

Included:

- Diverse literatures in health & social care
- Particular focus on existing reviews research & non–research e.g. textbooks
- Covered wide range of perspectives

Funded by MRC Medical Research Council

Reported impacts of public involvement in research

Impact on Research	Agenda	Design and Delivery	Ethics	Recruitment	Data Collection	Data Analysis	Writing Up	Dissemination	Time and Cost	TOTAL
No of positive impacts	9	10	2	9	4	8	3	8		**53**
No of negative impacts		3			8			1	4	**16**
Total No of impacts	9	13	2	9	12	8	3	9	4	**69**

Impact on People	Public involved	Researchers	Research participants	Wider community involved	Funders	Policy-makers	TOTAL
No of positive impacts	30	15	10	20	3	2	**80**
No of negative impacts	36	16	2	7	3	2	**66**
Total No of impacts	66	31	12	27	6	4	**146**

Impact Overall	Overall N
No of positive impacts	**133**
No of negative impacts	**82**
Total No of impacts	**215**

Funded by MRC Medical Research Council

Identified three value systems

Normative Values: moral, ethical, or political value systems	Substantive Values: quality-related value systems	Good practice Values: relationship-/process-related value systems
Empowerment	Effectiveness	Partnership/Equality
Rights	Quality/Relevance	Respect/Trust
Change/Action	Validity/Reliability	Openness/Honesty/ Flexibility/ Commitment
Accountability/ Transparency	Representativeness/ Objectivity/ Generalisability	Independence
Ethical values	Evidence base	Clarity

Funded by MRC Medical Research Council

Modified Delphi Study

- **Aims**
  - to explore **values** around and perceived **impacts** of PI
  - to identify areas of consensus and conflict
  - to explore possible conflict resolution

- '**Modified**' Delphi as no attempt to force 'consensus'

- Round 1 – 318 respondents (43% response rate) consensus defined as:
  - **Critical** (endorsed by 70% or more)
  - **Clear** (endorsed by 60% or more)

- Round 2 – 231 respondents (73% response rate
  - Explored issues where lack of consensus in Round 1

- Sample self-selected into 'stakeholder' groups:
  - Clinical academic (20%),
  - Non-clinical academic (28%),
  - Member of the public (17%),
  - Research manager/funder/ commissioner (24%),
  - Multiple roles (11%)

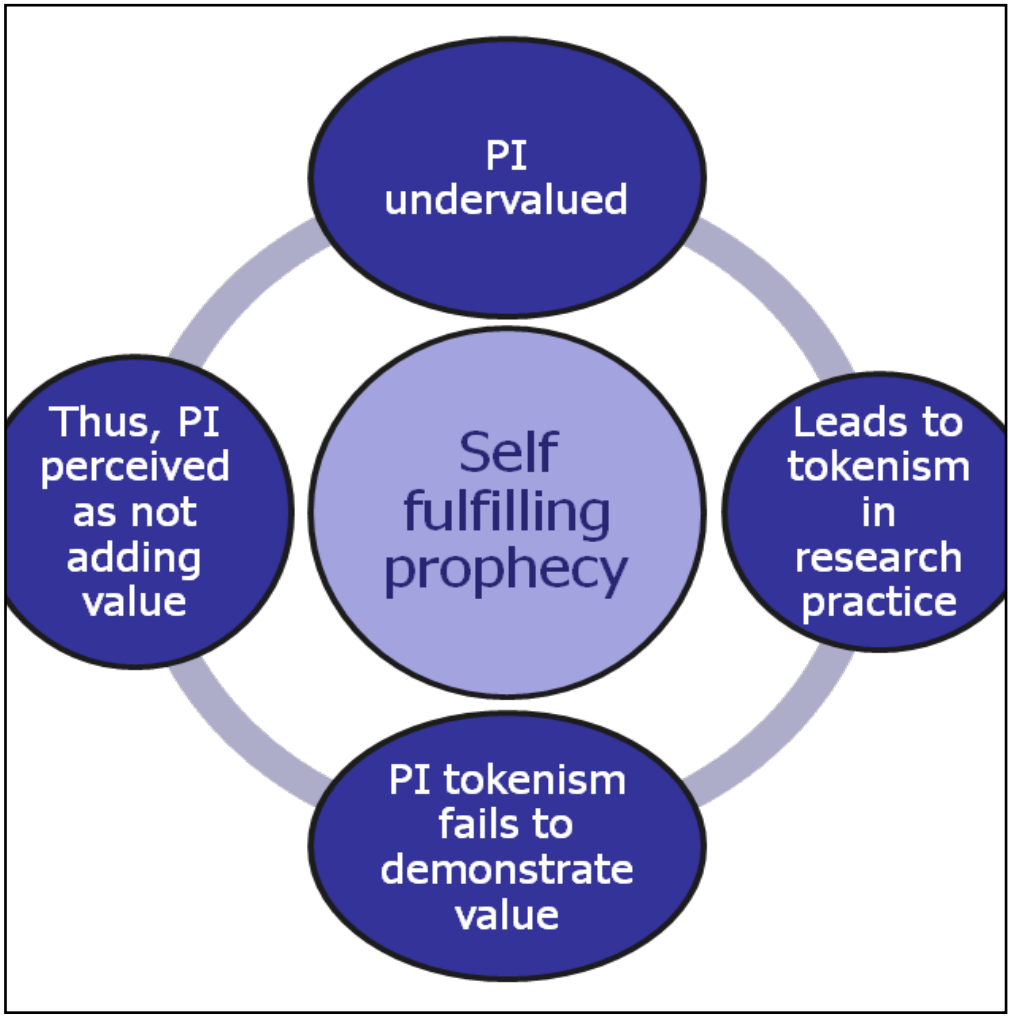
- Public advisers involved in design and interpretative of results

Funded by MRC Medical Research Council

Key findings

- High levels of consensus identified e.g. public can be involved in all/any research albeit involvement in basic science seen to be more problematic/less appropriate .
- Highlights extent to which PI already embedded in health research
- Areas of conflict also identified, strong agreement on key barriers & facilitators
  - Attitudes of researchers
  - Level of public's research experience /knowledge
  - Different views about the importance of public involvement
- Almost 90% agreed that it was important to assess the impacts of PI:
- Addressing tokenism in public involvement is a priority

The tokenism cycle



Suggested solutions:

- Provide clear guidance on *meaningful* PI/models of good practice
- Redress power imbalances
- Provide appropriate education/training/support
- Define measurable standards
- Address accountability through monitoring
- Provide funding for PI early in research process
- Demonstrate added value through examples/body of evidence

Funded by MRC Medical Research Council

PiiAF

The Public Involvement Impact Assessment Framework

- Designed to support teams, including members of the public, to develop tailored plans for assessing the impact of public involvement in their research
- Can be used in other contexts i.e. training for public involvement and research prioritisation processes
- Not a **quick fix** or single method - a development process supported by a series of practical resources
- So how is it structured and what does it contain?

Funded by MRC Medical Research Council

LANCASTER UNIVERSITY

PiiAF

UNIVERSITY OF LIVERPOOL

Mental Health Research Network

mcrn

UNIVERSITY OF EXETER MEDICAL SCHOOL

The PiiAF website http://piiaf.org.uk/

Public Involvement Impact Assessment Framework (PiiAF)

- Introduction
- Structure
- Part 1: PiiAF
- Part 2: Assessment Planning
- Resources
- Summary of our Research
- Glossary
- Further Reading
- Record Card
- Feedback
- And finally...

Welcome to the PiiAF website

PiiAF has been produced to help researchers assess the impacts of involving members of the public in their research in diverse fields from health care to local history.

How are the public involved in research?

Examples include helping decide which research should be done and how it is done; collecting and analysing data and developing research instruments.

Who is PiiAF for?

PiiAF is aimed at researchers but members of the public interested in getting involved in research may also find it useful and some people have used it in training for researchers and the public.

Why do researchers need this?

Most major funders in health research now require applicants to involve members of the public. The guidance is designed to be used at the time research ideas and funding proposals are being developed.

Who are we?

The PiiAF Study Group includes academics, public involvement facilitators from NIHR Research Networks and members of the public, supported by a grant from the UK Medical Research Council

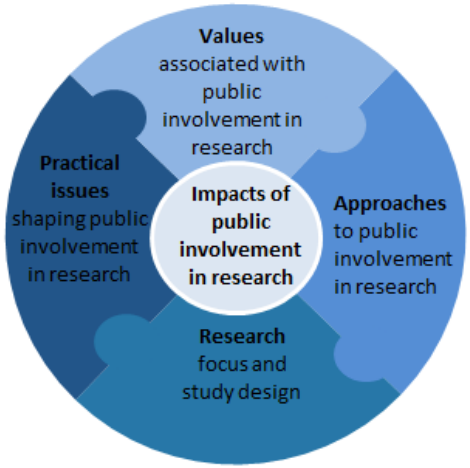
PDF

Download Executive Summary

Funded by MRC Medical Research Council

Figure 1: The Structure of the PiiAF Guidance

Part 1: Using the PiiAF to explore impacts and how they are shaped



We present each of the 5 elements in turn in this Guidance. For each element we include sections on:

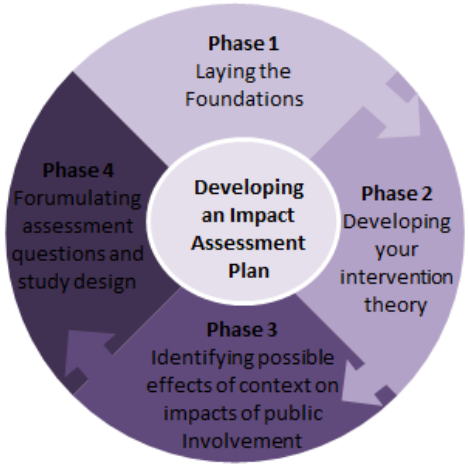
- *Key issues for that topic*
- *Questions for discussion and debate*
- *A resource list*

Recording key points from your discussion	
Values	
Approaches to PI	
Research Focus and Study Design	
Practical Issues	
Identifying the Impacts of PI in Research	

A recording card is provided to capture points arising from discussion of each element in Part 1. This record card provides the building blocks for developing an impact assessment plan in Part 2

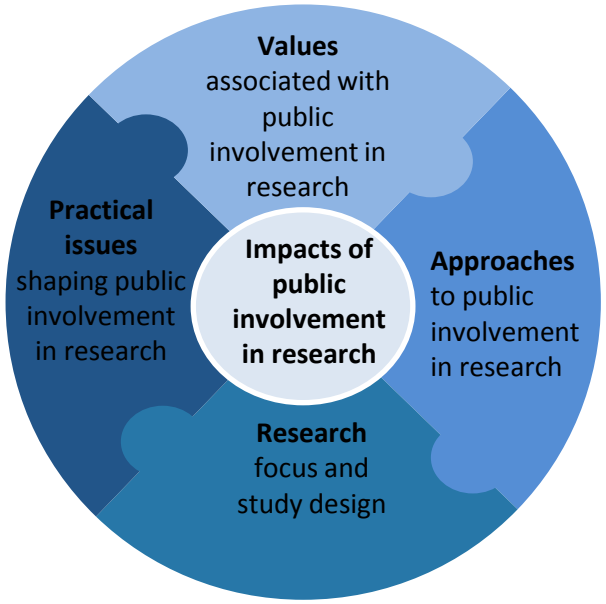
A series of resources are provided to support users of the guidance including:
Summaries of more information on a topic
Resources to stimulate discussion of issues raised in PiiAF
In-depth information and reference lists
Searchable databases of previous impact studies and tools and techniques to assess impact

Part 2: Developing an impact assessment plan



Funded by MRC Medical Research Council

PART 1



PiiAF's 5 elements:

- Impacts
- Values,
- Approaches to PI
- Research focus and study design
- Practical issues

For each element we:

1. Define what we mean
2. Identify some key issues
3. Ask you a series of questions

Part 1 aims to encourage you to:

1. Acknowledge potentially diverse values in your team
2. Clarify your approach to public involvement
3. Identify the specific impacts you want public involvement to have
4. Explore ways in which these elements - values, approach to involvement, research focus and study design and practical issues may shape the impacts public involvement can have in your research.

Funded by MRC Medical Research Council

ELEMENT 1

VALUES ASSOCIATED WITH PUBLIC INVOLVEMENT IN RESEARCH

Resource number	Description
	Summary of findings from a review on values and PI in research
	Summary of findings from a review of literature on debates about values and PI
	Cards on the Table Discussion Resource: A game based on findings from our evidence review that aims to promote discussion of values associated with public involvement in health and social care research
	Values Associated with Public Involvement in Health and Social Care Research: A Narrative Review: Academic paper by PiiAF study group
	F study group's review of debates sociated with PI in research
	of consensus and conflict around ing public involvement in health and search: A modified Delphi study. based on findings from the PiiAF study search

What are the issues?

Public involvement in research can challenge many of the values and assumptions that academic researchers hold. These may be values about what constitutes research quality or about the appropriate role of lay people in the research process.

The scientific values underpinning research may have positive and/or negative impacts on d the people who are involved. For example, eeds and aspirations of members of the public gative experiences of PI and reduce its beneficial s might disrupt relationships during the research e outcomes of the research itself.

uding members of the public involved in your public involvement in research. It is important to ape the impacts that people anticipate from the acknowledge values as early as possible in the earch is being designed so that strategies for both within the project team and the wider leveloped. Values associated with PI operating in ocietal domains may impact differently and/or acts PI may have.

What do we mean by values?

A number of different ways of defining values are used in research and everyday conversations.

Values associated with public involvement might relate to inter-personal issues (e.g. relationships between researchers and the public based on respect and trust), organisational (e.g. public involvement leading to research of greater quality and relevance to the healthcare system) or societal (e.g. accountability and transparency of research processes to the wider community).

Using our definition of values (see Annex 3: the glossary) we have identified three broad categories of values that are associated with public involvement:

- Ethical and/or political concerns associated with public involvement in research – we call these *normative values;*
- Concern with the consequences of public involvement in research – we call these *substantive values;*
- Issues associated with the conduct of public involvement in research – we call these *process values.*

ır research team?

which your research will be

olvement, the involvement

inical trial research

there is any potential for conflict over the values associated with public n your team and/or the organisation(s) in which the research will be based?

es can you put in place to manage divergent values?

your team;

organisation(s) where public involvement will take place;

organisation funding your research or from which you intend to apply for g.

n impact assessment be designed to take into account the values you have identified in your team and the potential for conflict between values?

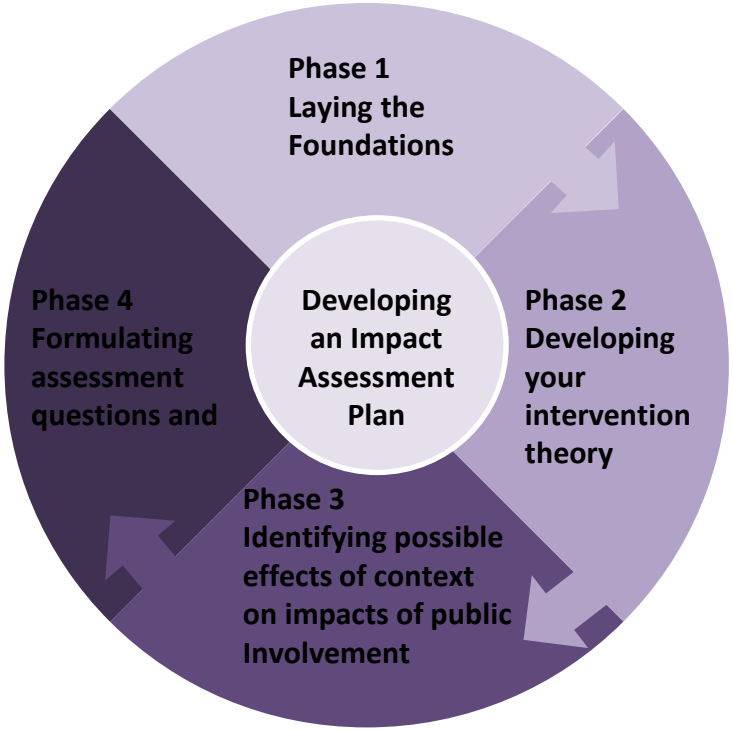
tified. d with s to ing ngaged ic

e of nsions ues. team

hat PI really crucial – but very helpful to make these researchers with previous trial a lot on PI as way to improve ention rates as this is biggest Clinicians believed service take part and will improve for participants if input to at strategies, data collection e users keen ensure people find art and that findings are ely as possible. Want to avoid academic exercise!

Funded by MRC Medical Research Council

PART 2



Part 2 takes you through 4 phases to develop an impact assessment plan:

1. Laying the foundations: what's the purpose of your impact assessment and who should be involved in designing it?
2. Developing an intervention theory: describing how your PI approach will produce the impacts you want
3. Identifying possible effects of the context in which your research will take place, including your values, study focus and design and practical issues
4. Formulating research questions and deciding on study design and methods

Phase 4

Formulating assessment questions and designing the assessment

The key questions to consider here are:

- **What specific questions do you want your assessment to answer?**
- **What challenges will you need to address and which might limit what is feasible?**
- **What approach to impact assessment will you use?**
- **What specific data will you need to collect and how will you do this?**

What specific questions do you want your impact assessment to answer?

As in any research it is important to formulate clear and realistic questions, which your impact assessment will aim to answer. You may identify more than one question, particularly if different stakeholders (e.g. funders) and different members of the team have different perspectives on the desired impacts. The approach illustrated in Table 2 may help you formulate your questions. In this case the researchers wanted to assess whether:

- Involving young people (WHO)
- In advisory group discussions to help develop outcome measures (HOW)
- Produced evidence seen as more credible and relevant by young people (WHAT)?

Table 2 Using the framework to generate your impact assessment question

WHO?	HOW?	WHAT?
Does involving young people	Via an advisory group helping to select appropriate outcome measures	Lead to evidence that is perceived to more credible and relevant by a range of stakeholder?

You will find examples of research questions used in previous evaluations of the impacts of PI in our searchable database. [Resource #20]

Developing an impact assessment plan: Case example *Summary*

About:

What:

What challenges will you have to address?

There are significant challenges involved in assessing the impacts of public involvement in
ghted below and you should consider whether these are
v you can address them in your impact assessment plan.

the system:

npacts to particular causes is not specific to public
nges in the illness status of people with a chronic illness
nges in their quality of life [QOL] because other factors
security) help them adapt, so influence QOL outcomes.
be possible to identify whether a successful change in
with a 'public' or academic member of a team/group.
llow some attribution of responsibility, but often this is
ggests that more cohesive team dynamics make it more
acts of PI. [See annex 4: Further reading]

ssing unintended impacts:

rticularly those involving pre-specified quantitative
unintended impacts if there is no means built in to
acts of the confidence of members of the public may be
cus only on impacts on recruitment. However, there are
source #23]

to emerge and may not do so in the lifespan of your
nvolvement in an international collaboration developing
research on treatments for rheumatic conditions led to
ignored outcome measure – tiredness - but it has taken
idely used in research. [See http://www.omeract.org/]

What approach to assessing PI will you use?

Once you have formulated research questions that are feasible to address you can decide on the most appropriate study design and methods to address them. A wide range of
een reported in the literature [Resource # 17] and as our
trates, diverse study designs and methods have been
quantitative and qualitative. [Resources #14, #20]. Your
collection methods should be driven by the purpose of
you want to address. However, ideally you should aim to
y them where appropriate and explore the processes
a mixture of qualitative and quantitative methods and

you move from your intervention theory and research
gn and data collection methods.

ctive into evidence (*Adapted from RCUK, 2011*).

n	Data collection methods	Develop Measures/ Indicators
der what study is required to ss these questions ualitative, itative, imental,	*Where will you collect the data from and how will you collect it e.g. interviews, diaries,*	*How will you assess whether an impact has been achieved?*

53

	research from PiiAF Study Group's evidence review
	Database – Methods and tools to assess impacts: Signposting resource to published case examples of methods and tools
Resource #23	Case study of the PiiAF project internal evaluation

latabase:
dies that
research
eview of
ment in

The PiiAF website http://piiaf.org.uk/

Public Involvement Impact Assessment Framework (PiiAF)

- Introduction
- Structure
- Part 1: PiiAF
- Part 2: Assessment Planning
- Resources
- Summary of our Research
- Glossary
- Further Reading
- Record Card
- Feedback
- And finally...

Feedback to PiiAF

Feedback form

Your name:

Your email address:

Please enter your feedback/question below:

Send your feedback

Contact Us

Mental Health Research Network · mcrn · University of Exeter Medical School · Lancaster University · University of Liverpool

The PiiAFstudy was funded by the Medical Research Council's Methodology Research Programme (G0902155/93948)

Thank you

http://piiaf.org.uk

Funded by MRC Medical Research Council