A tale of two projects!

Jennie Popay
Lancaster University

Tale 1: The Public Involvement Impact Assessment Framework – PiiAF

Tale 2: The impact of Community Involvement in the New Deal for Communities Regeneration Initiative

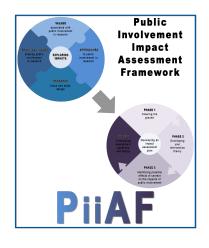












Tale 1 The Public Involvement Impact Assessment Framework (PiiAF)

- 1. An online resource aimed at supporting people to improve public involvement in research and measure the impacts
- Production involved
 - review of values and impacts
 - A Delphi study
- 3. Team comprised academics and 'lay experts'

Three value systems associated with Public Involvement in decision making

Normative: moral, ethical, or political aspects	Substantive: consequential aspect of PI	Process-related: best practice aspects
Empowerment	Effectiveness	Partnership/Equality
Accountability/ Transparency	Acceptability	Openness/Honesty
Rights	Generalisability	Respect/Trust
Ethical values	Quality/Relevance	Clarity

Reported Impacts of PI in research

Impact on Research	Agenda	Design and Delivery	Ethics	Research process	Writing Up/ dissemin ation	Time and Cost	TOTAL
positive impacts	9	10	2	21	11		53
negative impacts		3				4	16
Total impacts	9	13	2	29	12	4	69

Impact on People	Public involved	Research ers	Research participan ts	Wider com- munity involved	Funders & policy makers	TOTAL
positive impacts	30	15	10	20	5	80
negative impacts	36	16	2	7	5	66
Total impacts	66	31	12	27	10	146

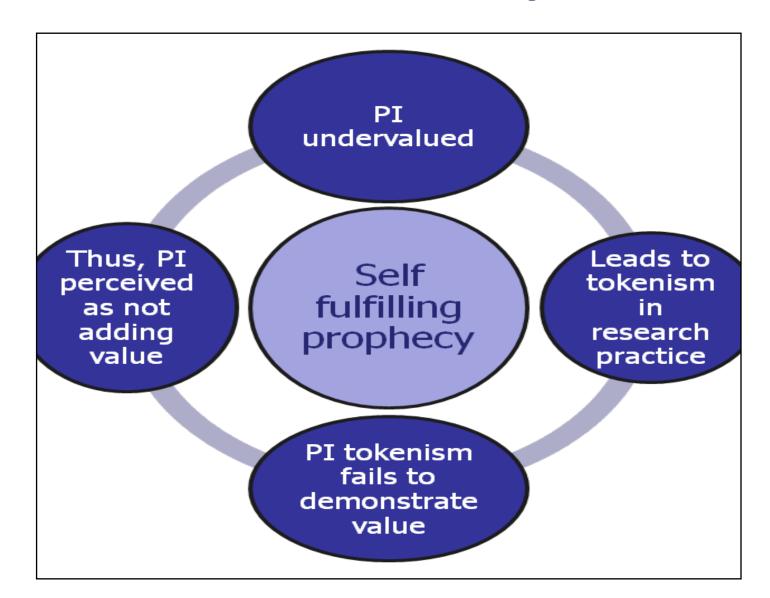
Overall impacts			
positive	133		
negative	82		
Total	215		

Delphi Study



- Round 1: 43% RR = 318 people Round 2: 73% RR 231
- **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 & social care 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
- Strong endorsement of PI facilitators as effective way to address barriers
- Addressing tokenism in public involvement remains a priority

The tokenism cycle













Conceptualising public involvement in decision making as a complex intervention

Practical context

Resources

Skills

Systems Policies

Values shaping beliefs and behaviours

Normative

Substantive

Process-related

Focus of the involvement e.g.

Service development

Behaviour change

Social conditions (e.g. Housing improvements Approaches to PI e.g

Instrumental/ Consultation

Collaboration

Public lead

Impacts on activity e.g.

Agenda setting

Design and Delivery

Time and cost

Impact on people

On public involved

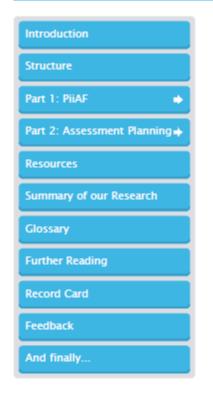
On professionals

On wider community

On funders/policy makers



Public Involvement Impact Assessment Framework (PiiAF)



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.



Download Executive Summary

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

rigare in the surreture of the rinar surrance

Public Involvement Impact Assessment Framework

We present each of the 5 PiiAF elements in

associated with public involvement in research Approaches Practical to public ssues shaping Impacts of involvement public public in research involvement involvement in research in research Recording key points Research

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

from your discussion

Values

Approaches to PI

Research Focus and Study Design

Practical Issues

Identifying the Impacts of PI in Research

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

Part 2: Developing an impact assessment plan

Phase 1 Clearing the ground Phase 4 Phase 2 Developing an Developing sessment Impact intervention questions and Assessment study design theory Plan Phase 3 Identifying possible effects of context on impacts

Values

focus and

study

design

Resources

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

Tale 2 Evaluating the impact of community engagement in the New Deal for Communities Regeneration Initiative

Jennie Popay[,] Margaret Whitehead[,] Roy Carr Hill[,] Chris Dibben[,] Paul Dixon[,] Emma Halliday, James Nazroo, Edwina Peart, Sue Povall, Mai Stafford, Jill Turner, Pierre Walthery

NIHR Policy Research Programme
NIHR Public Health Research Programme











New Deal for Communities

- Launched in 1998 in England aiming to close gap been NDC areas and rest of country viz:
 - physical environment and housing; Education; health;
 Employment and crime
- In 39 areas of high deprivation funded for 10 years and received ~ £50 million
- Community engagement at all levels a key aspect
- Our study
 - developed typologies of local NDC programmes and their approaches to CE
 - Used secondary data to look at impact on health inequalities and social determinants of these

Types of approaches to CE

Type A Resident led – underpinned by community empowerment values	Type B Resident led and underpinned by community empowerment values initially but not sustained	Type C Balancing instrumental focus and community empowerment values from start	Type D emphasis on instrumental approach to engagement driven by external priorities
13 NDC areas	12 NDC areas	9 NDC areas	5 NDC areas

Trends in social cohesion, sense of 'influence' and health related outcomes by CE type

Residents in Type A areas with a 'empowerment' approach to CE

- More positive reports across the nine indicators of trust, social cohesion and 'influence' in 2002 compared to other areas – advantage was retained over time
- showed a greater increase over time in the proportions feeling they could influence decisions in their area relative to all other areas
- On mental health measures results are in the direction of these residents being most mentally healthy.

Residents in Type C areas combining empowerment and instrumental approaches to CE from the start had higher proportions reporting 'good health', no limiting illness and not smoking in 2002 and retained this advantage over time after controlling for socio-economic and demographic differences

Residents in areas with Type D instrumental approach to CE from the start of the NDC initiative were the only group to report an absolute decrease in 'influence' over time.

Concluding remarks

- My values participation in decisions that impact on our lives is a basic human right – doesn't need to be justified in instrumental or cost effective terms
- But it is necessary to maximise the positive benefits and avoid doing harm
 - Some evidence that instrumental approaches that prioritise NHS/LA agendas may be harmful DIY welfare in age of austerity
 - In health context may be helpful to see 'engagement' as complex intervention in complex systems
 - Comprises number of elements that interact potentially in unpredictable ways to generate impacts
 - Values and resources are a key element of the system driving other elements - too often values not made explicit and can conflict and resources are inadequate
- PiiAF may be useful general resources for those with responsibility for community engagement in health sphere

Thank you

http://piiaf.org.uk

