Involving the public in health research

Purpose and impacts

Professor Jennie Popay
Drawing on the work of the PiiAF study Group
Lancaster University

Purpose – can access to experiential knowledge

- Aristotle's practical wisdom:

"the complex responsiveness of ordinary people to the concrete situations they experience in their everyday lives"

- Attempts to explain contingencies of everyday life, seeking understanding at the level of morality and *meaning*

- Integrates elements of 'scientific' knowledge – provides rich insights into many of today's major health challenges

But in much health research

individuals dominate
but as accumulations of risks,
vulnerabilities and resiliencies
or sets of freely chosen
behaviours

Not as
'knowing subjects' using
experiential knowledge to make
logical decisions
in context of their lives

Problematic status of experiential knowledge

"knowledge .. can be used to produce, concentrate, and exercise discursive power in ways that privilege some definitions of health and social problems and marginalize others" (Murphy, et. al. 2012).

As a result experiential knowledge is neglected: *some examples:*

- Evidence based interventions assume autism must be 'treated' – 'experiential' perspective sees autism as " neurological diversity that needs to be recognized as a legitimate identity"
- Diabetes management focuses primarily on control of blood glucose levels – experiential perspective prioritises how best to live 'normally' with diabetes
- Lifestyle interventions assume 'bad' behaviour results from lack of 'knowledge' or irresponsibility – experiential perspective focuses on coping with difficult life circumstances
- Clinical researchers prioritised control of pain in rheumatic conditions people with conditions prioritise alleviation of fatigue.

Public Involvement can 'revalue' experience

- In theory, public involvement in research can re-balance these inequalities in knowledge/power relationships.

- Ideally, people with relevant experiential knowledge can be involved in defining what the problem 'is', identifying possible solutions, deciding how the solutions should be evaluated and interpreting and disseminating findings.

- But we are not in an ideal world – in practice the public are:
    - Mainly involved in how the impact of 'solutions' are to be evaluate,
    - Less often involved in developing and prioritizing solutions to be evaluated,
    - Rarely influence how the problems are defined in the first place.

And diverse purposes of involvement may conflict

- For politicians: a technology of legitimacy (Harrison and Mort)
  - Enhance democratic accountability – public money requires public 'voice'
  - Encourage more industry run trials.

- For research funders : a mechanism to improve the relevance and quality of research
  - Expert patients – she who wears the shoes know where they pinch
  - Greater relevance leading to enhanced recruitment and retention to studies and more rapid uptake of evidence

For researchers……

In UK because we have to……! NIHR policy

But dig a bit deeper……….?

Democratic imperative – it is public money

Ethical imperative – "nothing about us without us"

Utility imperative - maximising relevance

Quality imperative – improving the science

Gradinger, F; Britten, N; Wyatt, K; Froggatt, K; Jacoby, A; Lobban, F; Mayes, D; Snape, D;Rawcliffe, T; Popay,J (forthcoming) Values associated with Public Involvement (PI) in Health and Social Care Research: a Narrative Review, **Health Expectations**, First published online: 10 DEC 2013 | DOI: 10.1111/hex.12158

For the public:
altruism, self interest, empowerment

So what do we know about the impacts of PI in research
Results from research by the PiiAF study group – piiaf.org.uk

Impact Overall	Overall N	Impacts on Research	Impacts on People
No of positive impacts	133	53	80
No of negative impacts	82	16	66
Total No of impacts	215	69	146

- Quite a bit of research reporting impacts published since this review in 2012
- But still only minority of studies are rigorous evaluations – most case studies
- Numbers very crude - general pattern more important
- More impact on people reported than impacts on research process
- Around a third of reported impacts were negative

Impact on public Involved: positive

Results from research by the PiiAF study group – piiaf.org.uk

Impact
People
(Benefits & Challenges)

Public Involved

Researchers

Research participants

Wider community involved

Community organisations

Funders

Policy makers

Increased knowledge

e.g. Knowledge of their condition, practical knowledge that could directly benefit them and their peers

New skills

e.g. training can improve employment chances (e.g. computer skills, team working, research skills, study skills – writing etc)

Personal

e.g. Feeling valued, empowered, greater self confidence, more control, friendships and more assertive in interactions with clinicians, contribute to own recovery

. Financial rewards

- opportunity to earn money

Impact on public involved: negative

Results from research by the PiiAF study group – piiaf.org.uk

Impact People
(Benefits & Challenges)

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

Personal e.g.

- Frustration at not being listened to, marginalised in research team, dominated by academic experts, not valued, intimidated, out of depth
- Inadequate training made people feel they couldn't contribute, thrown in at deep end and confused about lack of clarity about their role and

Practical e.g.

- Difficulties travelling, being paid (benefits problems) lack of support, heavy workload

Financial e.g.

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

Impact on researchers: positive

Results from research by the PiiAF study group – piiaf.org.uk

Impact
People
(Benefits & Challenges)

Public Involved

Researchers

Research participants

Wider community involved

Community organisations

Funders

Policy makers

General

- Gained fresh insights into the issues being studied
- Rewarding process: new friends, public bring energy and enthusiasm
- Ensured that the researchers remained focussed on service users

Career benefits

- public recognition for their work with service users
- internal recognition and validation from their employers

Challenges to beliefs and attitudes

- Can make them rethink their views of service users
- More positive attitude towards involvement itself.

Teamwork

- PI gave researchers the opportunity to work in diverse team
- learnt more interpersonal skills and sensitivity towards research 'subjects'

Impact on researchers: negative

Results from research by the PiiAF study group – piiaf.org.uk

Impact People (Benefits & Challenges)
Public Involved
Researchers
Research participants
Wider community involved
Community organisations
Funders
Policy makers

Higher demands on resources and a slower pace of research

- required a lot of extra time, energy and money that isn't always felt to be worthwhile
- difficulty caused by the conflicting time frames of researchers and users

Loss of power

- uncomfortable relinquishing control/sharing power over the research
- difficulty accepting views of users when they did not match their own

Forced changes in working practice

- change working practices to accommodate PI
- requires specific skills, which researchers didn't have

Challenging researchers' values and beliefs

- Questioning traditional ways of working uncomfortable for some researchers

Impact Research: Design & Delivery

Results from research by the PiiAF study group – piiaf.org.uk

Impact Research
(Benefits & Challenges)

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

<u>Positive</u>

- Early involvement helped to reshape and clarify the research question
- Influenced what outcomes are measured and how they are measured
- improvements in e.g. questionnaires, interview schedules and questions
- Ensured study conducted in a way that made it easier for people to participate
- increased recruitment and retention
- Made research findings more relevant and useful to end-users

<u>Negative</u>

- Scientific and ethical conflict in protocol design
- Power struggles between researchers and users delayed research

Impact on research: Time and Cost

Results from research by the PiiAF study group – piiaf.org.uk

Impact Research
(Benefits & Challenges)

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

Negative

- increased time and cost due to the practical aspects of planning and managing the users involvement in the research

- time and cost of building up relationships within relevant publics and setting up user groups

- training and education for both members of the public and researchers

- additional time needed for public representatives to read and comment on documentation

What do those involved think?
# Results of a recent survey*

- Round 1 318 respondents (43% response rate); Round 2 – 231 respondents (73% RR)
    - Clinical academics (20%),
    - Non-clinical academics (28%),
    - Members of the public (17%),
    - Research managers/funders/ commissioners (24%),
    - Multiple roles (11%)

- 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 .

- Almost 90% agreed it was important to assess the impacts of PI in research

- But strong agreement on barriers & facilitators
    - Attitudes of researchers
    - Level of public's research experience /knowledge
    - Divergent views about the importance of public involvement

- And majority indicated that TOKENISM had to be addressed before positive impacts can be maximised and negative impacts minimised

Snape D, Kirkham J, Britten N, Froggatt K, Gradinger F, Lobban F, Popay J, Wyatt K, Jacoby A, (2014) Exploring perceived barriers, drivers, impacts and the need for evaluation of public involvement in health and social care research: a modified Delphi study, BMJ Open. http://bmjopen.bmj.com/cgi/content/full/bmjopen-2014-004943?ijkey=r8q7EYTz71vQVNQ&keytype=ref

Snape, D; Jacoby, A; Popay, J (2013) Exploring areas of consensus and conflict around values underpinning public involvement in health and social care research: A modified Delphi study, BMJ Open, http://bmjopen.bmj.com/content/4/1/e004217

The tokenism cycle
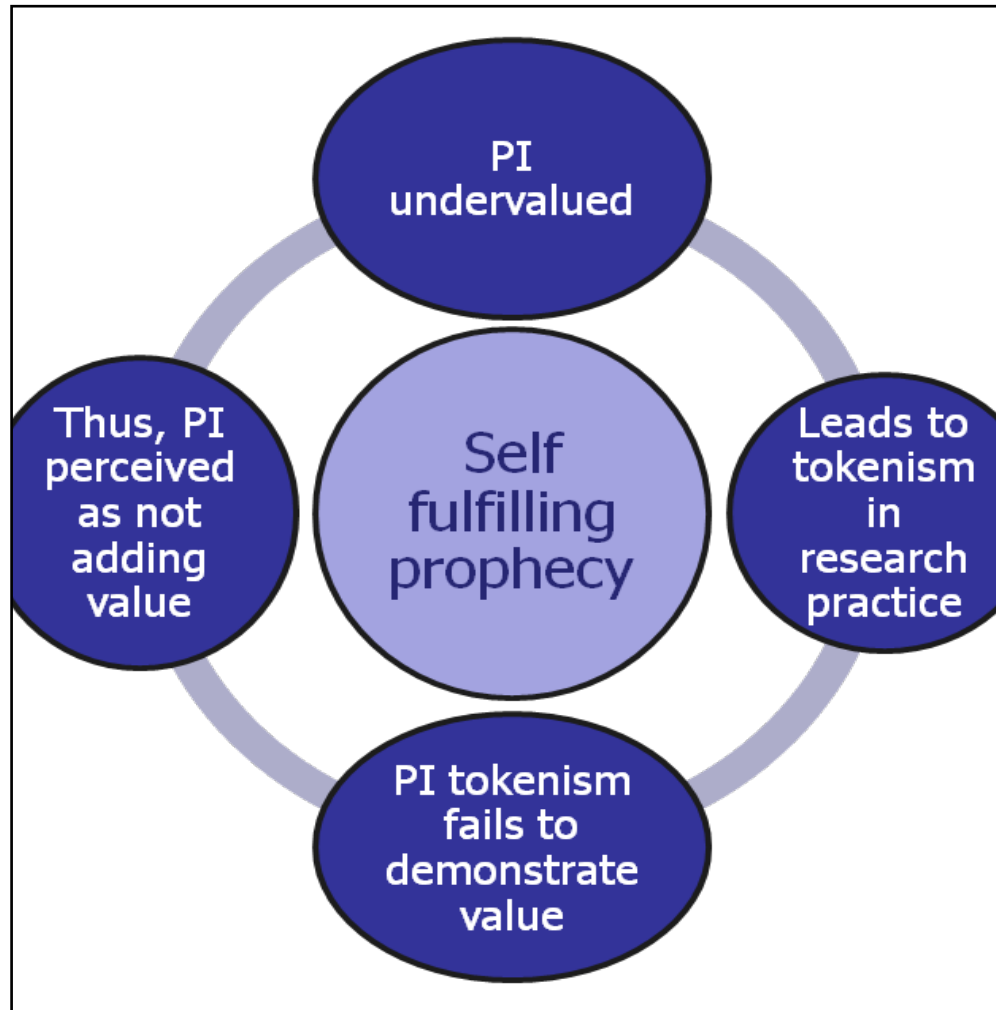
PiiAF – an online resource piiaf.org.uk

- Designed to support research teams to:
  - Clarify why they want to involve the public in research, how they want to do this and what impact they want PI to have
  - Identify potential barriers and enablers to PI
  - 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

PiiAF

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.
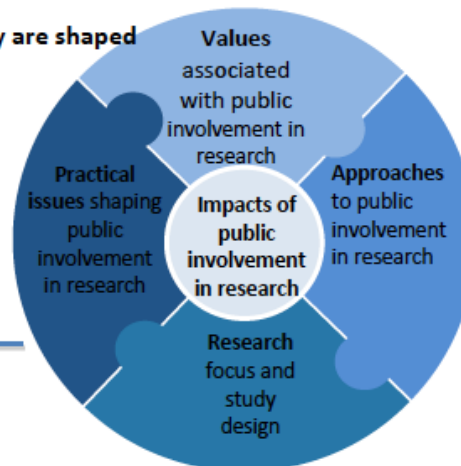
Who are we?

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

Figure 1: The Structure of the PiiAF Guidance

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

Values associated with public involvement in research

Approaches to public involvement in research

Research focus and study design

Practical issues shaping public involvement in research

Impacts of public involvement in research

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 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 2 Developing intervention theory

Phase 3 Identifying possible effects of context on impacts

Phase 4 Forumulateas sessment questions and study design

Developing an Impact Assessment Plan
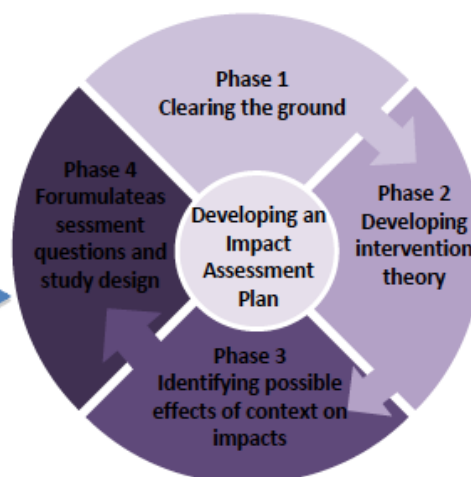
Resources

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

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Purpose and impact: Danger of missing the point

- Bringing experiential knowledge into the research process – as different but equal - can improve study quality, relevance and utility but should not be restricted to instrumental purposes

- Involving 'lay' people in research can build their self confidence, build shared identity and engage people in dialogues about how ill health is managed and health is to be protected and promoted

- To achieve the positive impacts we need to:
  - Address inequalities in status of knowledges by giving the public 'real' influence throughout research process
  - Ensure PI processes are 'fit for purpose'
  - Make divergent values and aspirations explicit and manage these
  - Identify and address contextual factors

- And must measure impacts – positive & negative!

Thank you

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