

GLOSSARY

ACADEMIC RESEARCHERS

We use the term academic researchers to include those people sometimes also referred to as 'researchers', 'clinical researchers' or 'professional researchers'. 'Academic researchers' refers to those people who would not primarily self-identify as public-involved, have undergone formal training in and have experience of conducting academic research.

APPROACHES TO PI

This refers to the way in which PI within a project is organised. We have distinguished between Approaches to PI which include consultation, collaboration and control and methods of PI which include service user researchers, public representatives on advisory groups, public-only project teams.

ASSESSMENT

Assessment is finding out whether PI has made a difference. We use it to include all approaches to judging whether PI has had an impact including narrative reflections on PI impact and quantitative, standardised impact assessment tools.

COMPLEX INTERVENTION

An intervention that is made up of different but interacting elements, is influenced by the context in which it is carried out and might potentially produce a range of outcomes. See the MRC guidance for a more detailed explanation and guidance on its assessment.¹

ELEMENT

We have called the components of the framework (e.g. Approaches to PI, Values) elements. For each element we discuss the issues and questions associated with it, provide some resources to support exploration of the element and signpost on to other sources of reading.

GUIDANCE

The guidance is the resource we have produced to help people use the PiiAF. It is divided into two parts; the first part includes a detailed overview of the framework and its elements; the second part focuses upon how to design an impact assessment.

IMPACT

We adopt a broad approach to understanding what 'impact' is. We take it to mean any difference that PI has made either to the research or the people involved in the research. We include short-term, medium-term and long-term impacts as well as outcomes. We recommend that project teams using the framework have a clear and consistent understanding of what they understand impact to be.

¹ Medical Research Council (2000). *A framework for development and evaluation of RCTs for complex interventions to improve health: p.1*

LAY EXPERTS

Lay experts are people who would not primarily self-identify as academic researchers or health professionals who have lived experience of, for example illness or using a service. The expertise of lay experts is often contrasted with professional or academic knowledge.

METHODS OF PI

The way in which PI happens within a research project such as employment of a service user researcher or public representatives on a Public Advisory Group is described as the Method of PI. We distinguish between Methods of PI and Approaches to PI (see definition above).

NORMATIVE DEBATES

Normative debates are public discussions about rules or standards of behaviour that represent at least two different positions informed by values. An example of a normative debate would be where substantive research values such as objectivity or neutrality conflict with process-related values such as partnership or equality. The different value positions reflected in the debates are likely to inform what people expect or believe about, and/or do in PI in health and social care research.

PiiAF

Our framework to help people think about the issues and questions associated with assessing the impact of PI in health and social care research. It consists of 5 elements: Values; Approaches to PI; Research Focus and Study Design; Practical Issues and Identifying the Impacts of PI in research.

PRACTICAL ISSUES

We use practical issues to refer to all those material or tangible aspects of the context in which PI happens which might have an influence on its impact. For example the availability of training for PI might shape its impact.

PUBLIC

Health researchers may refer to the people who participate in or who are involved in their research as “patients” but we use “public” to cover the wide range of people who may be recruited to research including carers, relatives of patients, ex-patients, staff of advocacy groups etc.

INVOLVE (NIHR) define public as: people who use health and social services; informal carers; parents or guardians; disabled people; recipients of health promotion/public health

/social service interventions; groups exposed to potentially harmful substances or products (e.g. pesticides or asbestos); and organisations representing users of services².

We feel that the general term 'public' may be more appropriate than 'patient' or 'service users' because people involved in research may not necessarily identify primarily as patients or they may be asked to draw upon experiences that go beyond their use of services.

PUBLIC INVOLVEMENT

Throughout the PiiAF we draw upon INVOLVE's definition of public involvement as 'research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them'³. This refers to the involvement of members of the public in decisions about what the focus of research should be, how it should be carried out, analysed and disseminated.

The decision to use the term 'public involvement in research' rather than other terms is in part a pragmatic response to managing the diverse terminologies that have been used in the published papers which were reviewed. There would be practical difficulties with trying to ensure that all the relevant terminologies associated with public involvement were included in the PiiAF. We also intend the PiiAF to be relevant to people working with different approaches to involvement who want to assess its impact, so we hope that having a broad term that covers the range of people and groups that may be involved in research and approaches to involvement will minimise the likelihood of people feeling excluded by terminology.

QUALITATIVE RESEARCH

An approach to research that focuses upon understanding real world situations from the point of view of the people being studied and asks questions such as 'how' or 'why'. Evidence usually consists of words (e.g. what people say, descriptions of observed events etc.)

QUANTITATIVE RESEARCH

An approach to research that systematically manipulates and measures variables in order to ask 'what' and 'how many'. Evidence usually consists of numbers (e.g. health scale scores, reaction times etc.)

² Hanley, B., Bradburn, J., Barnes, M. Evans, C., Goodare, H., Kelson, M., Kent, A., Oliver, S., Thomas, S. & Wallcraft, J. (2003). Involving the public in NHS public health, and social care research: briefing notes for researchers.: Involve.

³ INVOLVE. (2012). Briefing notes for researchers: Involving the public in NHS, public health and social care research. Eastleigh: INVOLVE: p.6

RECORD CARD

This is a tool to capture the outcomes of explorations and discussions of the framework elements. It should be used when developing the impact assessment plan.

RESEARCH PROCESSES

Research processes refers to those activities that result in research being carried out. For example collecting data is an example of a research process.

RESEARCH FOCUS

The research focus refers to all aspects of research including the discipline within which the research is being carried out, the research topic, question and design. It also includes the population for the research and the project team.

RESOURCES

Resources are those aspects of the physical context that can be used to support PI such as funding and training.

SERVICE USERS

Service users are people who use health or social services.

STAKEHOLDERS

Stakeholders are all the people who have an interest in the research including research participants, funding organisations, and policy-makers as well as members of the public-involved and academic researchers.

STUDY DESIGN

The study design is the plan for the research including the ways in which research methods will be used in order to answer the research question. An example of a study design is a randomised controlled trial.

VALUES

The established collective principles and accepted standards of a person or a social group. In the PiiAF values are presented as underpinning approaches to PI and influencing PI processes and impacts

VARIABLES

Anything (property, characteristic, attribute) that can vary or that can be varied e.g. age, gender or number of goldfish owned. Variables are usually found in quantitative research where one variable might be manipulated in order to find out how it affects another variable.