



Strategy for Promoting and Supporting Patient and Public Involvement in Research

“No matter how complicated the research, or how brilliant the researcher, patients and the public always offer unique, invaluable insights. Their advice when designing, implementing and evaluating research invariably makes studies more effective, more credible and often more cost efficient as well.”

Professor Dame Sally Davies, Chief Medical Officer¹

Introduction

Patient and public involvement in research (PPIR) has been defined by INVOLVE as ‘research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them’.²

Researchers are being encouraged – and, indeed, required by some research organisations - to involve patients and the public in their research in these ways. There is consequently a rapidly growing body of PPIR activity and increasing evidence that PPIR can have a positive impact on researcher processes and outcomes,^{3,4} on public confidence in research⁵ and also on the researchers and patients/members of the public involved.³ Additionally, some argue for PPIR on the grounds of democracy, transparency and accountability.⁶

Good practice guidance for PPIR already exists and standards are in the process of being finalised.⁷ Moreover, when Asthma UK outlined its strategy to establish a multi-site, multi-disciplinary Asthma UK Centre for Applied Research, people with asthma were at the heart of the vision they set out. The Asthma UK Centre for Applied Research (AUKCAR) is consequently committed to having meaningful PPIR, which accords with best practice, in all research within its remit. This is evidenced by AUKCAR having involved patients and the public in its activities since its inception. Leadership regarding PPIR is provided through the PPIR Strategic Platform (see <http://www.aukcar.ac.uk/public>). Core activities of the platform include developing a UK-wide body of patient and public advisors and supporting researchers in developing PPIR in their research. This document outlines the Centre’s strategy for promoting, developing and embedding PPIR.

Vision

'To embed meaningful involvement of people affected by asthma in all research within the Asthma UK Centre for Applied Research

Achieving the Vision

In order to achieve the vision, a strategic approach will be taken, focusing on four areas:

- Developing a patient and public advisory group
- Ensuring meaningful PPIR in AUKCAR projects and other activities, including governance
- Supporting researchers and patient and public advisory group members
- Contributing to the evidence base on the impact of PPIR

Activity on delivering the strategy will be led by the PPIR Strategic Platform's lead (Dr Allison Worth), co-lead (Prof Ann-Louise Cares), PPI Platform Research Fellow (Melissa Goodbourn) and core lay members (Elisabeth Ehrlich, Michael Bang, Leo Campbell and Olivia Fulton). These will be supported by the Centre Management Committee, Core Programme leads, Strategic Platform leads and colleagues from Asthma UK. Actions will be linked with other relevant Centre and Asthma UK activity and informed by current policy and good practice guidance.

Developing a Patient and Public Advisory Group

Goal

- To develop a UK-wide network of people affected by asthma who will advise AUKCAR researchers
- To develop a Children and Young People's Group to advise on research pertinent to that age group
- To develop strategic partnerships with other PPI-active organisations to complement AUKCAR PPIR

Actions

- Develop recruitment materials regarding the role of the patient and public advisory group
- Identify a lead for recruitment of patient and public involvement advisors at each site
- Provide mentoring, training and networking opportunities for patient and public advisory group members

- Identify and make contact with key strategic partners (to include Asthma UK, INVOLVE and existing PPIR groups in AUKCAR sites)
- To develop a PPI Social Media strategy for building the Patient Advisory Group and CYP Group

Ensuring meaningful PPIR in AUKCAR projects and other activities, including governance

Goals

- To embed PPI in Centre governance
- To ensure that PPI in all AUKCAR research activity accords with recognised best practice
- To build capacity and capability in PPIR among researchers and people affected by asthma
- To ensure that PPIR is appropriately funded in all AUKCAR research activities
- To promote and develop a culture across AUKCAR whereby PPIR is both valued and normalised

Actions

- Appoint four people affected by asthma to the Centre Management Committee; one to act as PPI Lead for each research programme and one for the Children and Young People Group
- Develop an AUKCAR statement of intent regarding PPIR, to be adopted by the Centre Management Committee, widely distributed across AUKCAR and displayed on the AUKCAR website
- Actively work to maintain commitment to PPIR from the Centre leadership (i.e. Centre Management Committee), e.g. by maintaining a presence at key meetings and supporting AUKCAR core activities
- Engage Strategic Platform Leads, Programme Leads and Principal Investigators in promoting and providing leadership regarding PPIR in their teams, through meetings, promotional material and provision of case studies
- Appoint a patient panel to review all AUKCAR PhD studentships

- Engage AUKCAR PhD students regarding the value of meaningful PPIR, through meetings, promotional material and provision of case studies
- Raise awareness of best practice regarding PPIR across AUKCAR (e.g. via email, the website and at Centre Scientific meetings)
- Secure commitment, via the Centre Management Committee, to inclusion of information regarding PPIR in all public output and internal reports produced by AUKCAR members
- Disseminate information regarding tools and processes for evaluation of PPIR activity (e.g. PiiAF, GRIPP) and develop bespoke materials as needed
- Collect annual data regarding PPIR activity in AUKCAR (volume, process and impact)
- Require all AUKCAR grant applications to include properly costed PPIR
- Develop a position statement regarding funding/payment for PPIR to be adopted by the Centre Management Committee, widely distributed across AUKCAR and displayed on the AUKCAR website
- Obtain funding to support development/sustainability of AUKCAR PPIR
- Ensure People affected by asthma sit on appointment committees for staff and PhD students

Supporting researchers and patient and public advisors

Goals

- To ensure that AUKCAR patient and public involvement advisors are adequately trained and supported in their role
- To ensure that AUKCAR researchers are adequately trained and supported to undertake PPIR

Actions

- Facilitate partnerships between researchers and people affected by asthma for all AUKCAR research activities
- Provide advice/support for researchers and people affected by asthma to enable effective PPIR for individual research projects and programmes

- Signpost and, where required, develop information, good practice guidance and training materials for researchers and patient and public advisors, to be distributed across AUKCAR
- Develop a network of mentors/'buddies' for patient and public advisors
- Distribute templates for role descriptions for various types of PPIR activity, to ensure that patient and public advisors and researchers are adequately informed about expectations
- Develop and distribute a tool for assessment of AUKCAR researchers' PPIR skills and training needs
- Disseminate information regarding tools and current best practice re funding of/payment for PPIR (e.g. from NIHR and INVOLVE) and develop bespoke materials as needed
- Improve accessibility of research to the public by promoting effective public engagement across AUKCAR

Contributing to the evidence base for PPIR

Goals

- To contribute to developments in methodology and practice relating to PPIR
- To communicate evidence of the impact of PPIR to the public and research community

Actions

- To set up a system for reporting the impact of PPIR on AUKCAR research
- To promote evaluation of the impact of PPIR on people, processes and outcomes
- To ensure appropriate reporting of PPIR in AUKCAR outputs
- To contribute case studies on PPIR to national databases (e.g. INVOLVE)

Success Criteria

- A national patient and public advisory group covering all areas of the UK by the end of 2015

- A named lead for recruitment to be identified at each AUKCAR member and affiliate by end of 2015
- Each AUKCAR member and affiliate to be demonstrating evidence of PPIR activity and related mechanisms by the end of 2016
- Demonstrable evidence of people affected by asthma being involved meaningfully in AUKCAR research projects from pre-application to dissemination, as indicated through annual reporting

References

1. Davies S. Foreword in Staley K. *Exploring Impact: public involvement in NHS, public health and social care research*. INVOLVE, Eastleigh, 2009.
2. INVOLVE. *What is public involvement in research?* <http://www.invo.org.uk/find-out-more/what-is-public-involvement-in-research-2/> INVOLVE, Eastleigh, 2013.
3. Brett J, Staniszewska S, Mockford C et al. A systematic review of the impact of patient and public involvement on service users, researchers and communities. *Patient* 2014; 7:387–395
4. Evans D, Coad J, Cottrell K, Dalrymple J, Davies R, Donald C, et al. Public involvement in research: assessing impact through a realist evaluation. *Health Serv Deliv Res* 2014;2(36).
5. Health Research Authority. *Patient and Public Engagement Project: Patient and Public Dialogue Workshops*. London: Health Research Authority. 2013
6. Gradinger F, Britten N, Wyatt K et al. Values associated with public involvement in health and social care research: a narrative review. *Health Expectations* 2015; 18: 661–675.
7. INVOLVE. Values, principles and standards for public involvement in research. Eastleigh: INVOLVE. 2013 Available at: <http://www.invo.org.uk/about-involve/current-work/standards-for-public-involvement-in-research/>

Version number	Effective Date	Reason(s) for Change(s)
1.0	October 2015	New document
2.0	06 February 2017	New logo updated