

# Getting the Ducks (and PIGs) in Line: Public Involvement (PI) in Research

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# Context: Quality and Outcomes of person-centred care Research Unit (QORU)

- Funded by England's Department of Health
- PSSRU at University of Kent and LSE
- Public Health & Primary Health Care at University of Oxford
- Tizard Centre at Kent University
- Expertise:
  - Health and social care
  - Diverse range of disciplines and skills

## Context: QORU mission

*To improve the quality of health and social care of people with **long-term conditions** through **high quality evidence** about need, **quality** and **outcomes** of **person-centred care***

# The P's - Principles & Policies

- Have a policy focus and respond flexibly to policy requirements
- Use robust scientific methods
  - Maintain long-term scientific excellence
- **Ensure patient and service user involvement in the research (and the 'public')**
- Focus on quality and outcomes,
  - but also understand the cost implications
- Awareness of equality issues in research and evidence

# One P and the I – The Importance of PI for QORU

- Achieve high-quality research reflecting the priorities of the public whilst achieving the ultimate goal of ensuring improved health and social care.
- PPI raising awareness and helping to improve the understanding of the unit's work
- PPI should be seen throughout QORU

# The importance of PI for researchers

- Commenting and developing on:
  - Research funding/ethics application
  - Research protocols
  - Research tools & study documents (consent/PIS)
  - Lay summaries
  - Reviewing publicity materials
- Members of the research advisory group
  - Reviewing reports & disseminating findings
- Undertaking interviews with research participants

# Public Involvement at QORU:

## Key features

- Establishment of PI Implementation Group (PIIG) to develop, oversee & monitor implementation
- Group of lay research advisors 25 across England to support individual research projects
- PIIG = 5 researchers & 5 members of the public
- Recruitment through [www.peopleinresearch.org](http://www.peopleinresearch.org)
- Public members are patients, service users, carers and/or have an interest in health & social care research, particularly long term conditions

# The PIIGs (or Ducks):

## *What have we been up to?*

- Guidance on payment for PI shared with other institutions as model of good practice
- Set up of pool research advisors
- Development & refinement of monitoring mechanisms of PI to ensure it works best for all
- Supported PI with advisors/researchers - resource development, peer support, events & training for researchers
- Input into identifying research priorities



# Research advisors: 4 Ws: *Who, what, where & why?*

- Requests for PI received & advertised amongst advisors by university contact
- Interest expressed & projects allocated
- Remote and/or face-to-face meeting
- Non-employee contracts with the university
- Paid for 'work' & expenses
- Peer support offered & annual meeting
- Feedback gathered from advisors/researchers

# Research advisors:

## *What have they been up to?*

- 12 month period 22 projects supported
- Project examples include:
  - Developing PROMS and outcome indicators for people with long-terms conditions (QORU)
  - The continued impact of personal health budgets (Department of Health)
  - Developing methods to improve the participation of hard-to-engage people in research and so to enable their experiences to be reflected in the evidence base (QORU)

# PI for QORU:

## *What makes us so special.....?*

- Incorporates both strategic and practical approaches to PI
- Researchers & public work alongside each other for solutions & to improve research
- PIIG actively looks at different ways to engage with researchers
- Involved with diverse portfolio of research

# PI & QORU: the future

- Demonstrate the benefits of PI to all
- Monitor consistency of involvement
- Keep up-to-date with the evidence base
- Collect feedback on experiences
- Monitor representation i.e. who is involved
- Consider on-going resource implications of effective PI strategy
- Development of processes & methods for rigorous evaluation

# The LIs: Lessons Learned

## *What can others learn from us?*

- Primary Benefit – improved research quality & impact
- Potential Pitfalls: payment, competing agendas, ‘them vs us’ – how to avoid them? Follow our lead....we’ve got the bruises to prove it (researchers & pi advisors)

# Further information

- [QORU: http://www.qoru.ac.uk/about/public-involvement](http://www.qoru.ac.uk/about/public-involvement)

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- [PI Resources: http://www.invo.org.uk/](http://www.invo.org.uk/)