MANCHEstER 1824

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PRIMER: Primary care Research In Manchester Engagement Resource. Patients, the public and researchers working together to improve primary care

Aims

- Advise on best practice in patient and public involvement & engagement (PPIE)
- Contribute to research design, delivery and dissemination
- Suggest topics for future research
- Develop and test innovative approaches to PPIE
- Share resources and expertise with others

Plain English Summary

PRIMER was set up in 2009 and is a PPIE group comprised of patients, carers and members of the public from diverse backgrounds and with a common interest in primary care research. Members work in partnership with researchers at the Centre for Primary Care and more widely.   There are two types of members – 'attending', who meet every 6-8 weeks, and 'corresponding', who form a virtual group. The group has elected a Lay Chair and Vice-Chair and is supported on a day-to day basis by Centre staff (including full administrative and financial support). Members attending meetings receive reimbursement of travel costs and an honorarium which is paid on-the-day. Researchers are encouraged to bring their 'initial idea' proposals to PRIMER for discussion before formal application for funding; this ensures initial public acceptability and feasibility is considered. Researchers attending a PRIMER meeting deliver a short presentation on their research idea or proposal which is followed by open discussion between PRIMER members and researchers. If appropriate, members can request to be further involved in the project. PRIMER also suggests ways to involve other members of the public with relevant experience.

Collaboration

PRIMER collaborators include: INVOLVE, Research Design Service, CLAHRC, North West People in Research Forum (NWPIR), R&D Forum, Primary Care Research Network, and other UK based PPIE groups.

Activities

- PRIMER members have suggested topics of importance which have been developed into two CLAHRC funded research projects- ISIS[2] and PHIEBI[3].

- In April 2014 PRIMER facilitated the delivery of the first ever 'Patient Hack' day. Members of the public 'pitched' potential research topics to a mixed audience of researchers and public, who then worked collaboratively to turn these ideas into exiting new research proposals.

- PRIMER has provided feedback on over 40 research projects (including quantitative and qualitative methodologies) at an early stage in their development, offering a public perspective on research design, delivery, and dissemination.

- Involvement can occur at any (and all) stages in the research cycle, in a number of different ways and for the duration of a study or specific parts. PRIMER members have been involved as co-applicants, steering or advisory group members, best practice 'advisors' or critical friends.

- PRIMER co-deliver PPI training sessions for a range of stakeholders including Centre for Primary Care staff, PhD students, SPCR trainees (in 2012) and the NWPIR.

- PRIMER has co-produced an impact assessment strategy which enables feedback to be collected throughout the duration of a research project from initial PRIMER meeting onwards.

- Members deliver a PPI-themed annual departmental seminar to Centre for Primary Care staff. The seminars are interactive, educational and aimed at promoting meaningful PPI collaborations.

- Most importantly, PRIMER has fun!

Outputs

- The PRIMER website advertises the work of the Group and promotes PPIE in primary care research: www.population-health.manchester.ac.uk/primer/

- PRIMER co-produced resources are made available for others to use and adapt for their own PPIE work. These can be downloaded from the PRIMER website and include role descriptions, terms of reference for meetings, a plain-English research summary form and project agreement forms. We also have a PPI in primary care research induction pack in development.

- The 'research tool kit' is a hands-on interactive activity for creative involvement, first piloted at the Patient Hack day. It supports researchers and the public to work together to develop research proposals.

- The PHIEBI study blog chronicled its PPI work throughout the duration of the study from the perspective of different team members: http://phiebi.wordpress.com/2013/07/25/welcome-to-the-phiebi-study-blog/

PRIMER co-authored publications:

- Knowles S, Combs, R Griffiths, M, Kirk S, Patel N, Sanders C. (Under review) Hidden caring in everyday management of vascular disease: Barriers to identifying as a carer for people with long term conditions. Submitted to Health & Social Care in the Community. June 2014.

- Combs R, Planner C, Britt D, Bower P, Harte J, Kennedy A, Roe B, Drinkwater J. Urinary incontinence in the context of vascular multimorbidity: a qualitative exploration of psychosocial impact and self-management (due for submission).

- PRIMER representatives are currently working with primary care research organisations to collate and publish the first ever collection of PPI in Primary Care Research case studies. This is due to be published by the NSPCR in September 2014.

[1] For a full list of members, see: www.population-health.manchester.ac.uk/primer/members/
[2] www.population-health.manchester.ac.uk/primarycare/research/longterm/health/research/?ID=2960&Control=TagList1
[3] www.population-health.manchester.ac.uk/primarycare/research/longterm/health/research/?ID=2817&Control=TagList2

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School for Primary Care Research

NHS National Institute for Health Research