Patient and public involvement in KT research and KT activity: a UK perspective

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What do we mean by Patient and Public?

- People who use health services – patients and potential patients

- Informal carers and families

- Members of the public and communities who may be targeted by public health programmes

- Organisations representing the users of NHS services and community groups

INVOLVE 2009

What do we mean by Involvement?

- An active partnership between the public and researchers in the research process, rather than the use of people as 'subjects' of research.

- Involves doing research 'with' or 'by' the public, rather than 'to', 'about' or 'for' the public.

- May include public involvement in
  - assisting in the design of a project
  - advising on a research project
  - carrying out the research

INVOLVE 2009

Models of PPI

- Consultation – where community members are consulted with no sharing of power in the decision-making

- Collaboration – that involves an active ongoing partnership with community members in the research process

- User control – where community members design, undertake and disseminate the research of research

Grant 2010

Range & extent of involvement

- Identifying topics for inquiry
- Prioritising topics for inquiry
- Commissioning research
- Designing research
- Managing research
- Undertaking research
- Analysing and interpreting information obtained
- Writing up reports
- Disseminating results
- Evaluating the process

INVOLVE 2006

Levels of community involvement in research

Community-led

Community members have overall control of the research process

'Professional' and community researchers work as colleagues, and all contribute skills, or experience that are equally valued

Community members and researchers collaborate in conducting a process that has been instigated elsewhere

Community members act as advisors to the researchers

Community members are engaged to conduct part of the exercise, but take no part in planning and design – e.g. users are employed as interviewers but use an interview schedule designed by researchers

The views and experiences of community members are sought but they are not otherwise involved at any stage of the research process

Targeting TB: an integrated KT project involving the Somali community

Aims

▸ To understand socio-cultural influences on the prevention, diagnosis and treatment of TB within the Somali community

▸ To gain insight into health professionals' perceptions of the Somali population, its general health needs, responses to TB and experiences of TB services for Somali

▸ To identify avenues through which culturally appropriate health promotion initiatives regarding the prevention of TB can reach the Somali community.

▸ Providing the Somali community and health care professionals with a knowledge base to inform action

▸ Foster closer relationships between the Somali community-based organisations and health professionals to support initiatives to promote the prevention and effective screening, diagnosis and treatment of TB

▸ Developing network of partners to initiate and carry out future research projects

Methodology

- Community participatory approach

- Ethnographic fieldwork

- Qualitative methods
  - interviews, focus groups

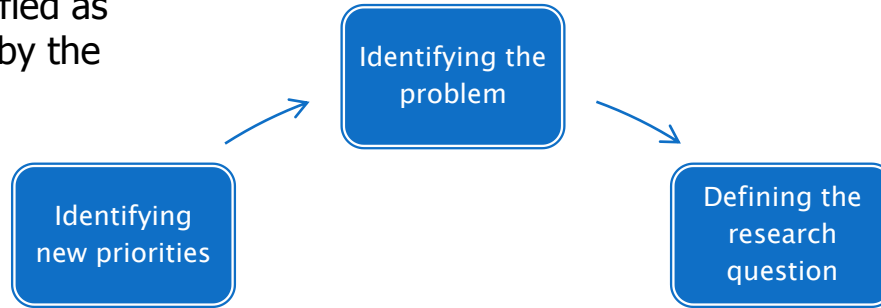- 'Framework' approach to data analysis

(Ritchie and Spencer 1994)

An integrated approach to KT

Health care professionals Somali community leaders identified need for research

Type 2 diabetes identified as new research priority by the Somali community

Researchers, community members and health care professionals worked together to define research questions, design the study and seek funding

Somali community organisations, Somali health workers and health care professionals implementing public health actions and training for health care professionals

Community participatory approach

Research team comprised academic researchers, TB specialist nurse and Somali community members as Research Assistant and community researchers

Findings disseminated to different audiences by different means e.g. reports, action briefings, poetry, stories

Data collection and analysis undertaken as a collaborative enterprise

Identifying the problem

Defining the research question

Identifying new priorities

Designing the study

Taking action informed by research

Disseminating the findings

Conducting the research

Challenges of PPI

▸ Managing expectations

  ◦ Time scales perceived to be slow

    • Delay in securing funding

    • Bureaucracy of approval mechanisms

  ◦ Impatient to share findings

  ◦ Funding for dissemination

  ◦ Impact of research findings on policy and practice

Challenges of PPI

- Community researchers
  - hard to detach personal experience from that of interviewees (over-identification)

  - dealing with interviewee's emotions

  - hard to know when to stop probing

  - difficult not to interrupt to offer 'instant' solutions

Challenges of PPI

- Academic researchers
  - Need for flexibility, openness to new ideas, willingness to learn
  - Being prepared to be culturally challenged
  - Power sharing
- Protecting against the unpredictability of risk
  - When in the field
  - After the research has been completed.
- Transparency of community involvement in data analysis
- Analytic methods
  - How far is theory development and knowledge gain traded off against the pragmatism of involvement?
  - Are participatory research methods 'downgraded' in the process?
- Balancing different interests and agendas