

Patient and public involvement in implementation research and quality improvement

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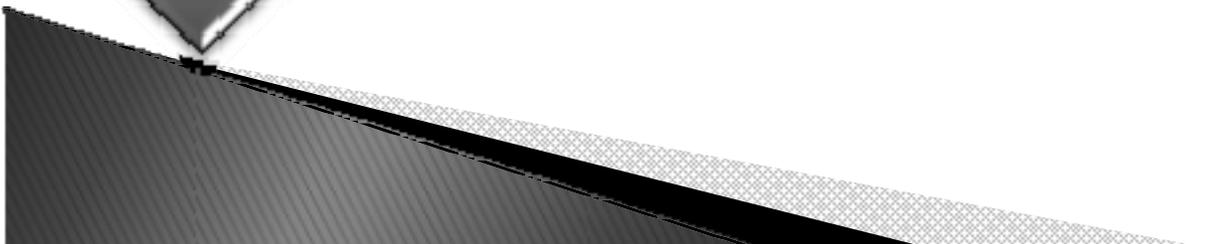
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Overview of seminar

- 
- The UK context

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- Patient and public involvement – what do we mean?
 - Definitions and models of engagement

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- Research exemplar
 - Quality improvement example

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- Conclusions
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Personal profile

- ▶ Professorial appointment between university and hospital to support research and knowledge translation
 - University NHS Trust comprising 4 hospitals
 - acute secondary and tertiary services
 - 2,250 beds
 - 5,000 nurses / nursing aides
 - 1 million patient episodes per year
- ▶ Implementation lead for NIHR Collaboration for Leadership & Applied Health Research and Care (CLAHRC) for South Yorkshire
- ▶ Lead programme of knowledge translation within CLAHRC focused on implementation of evidence into practice

Sheffield

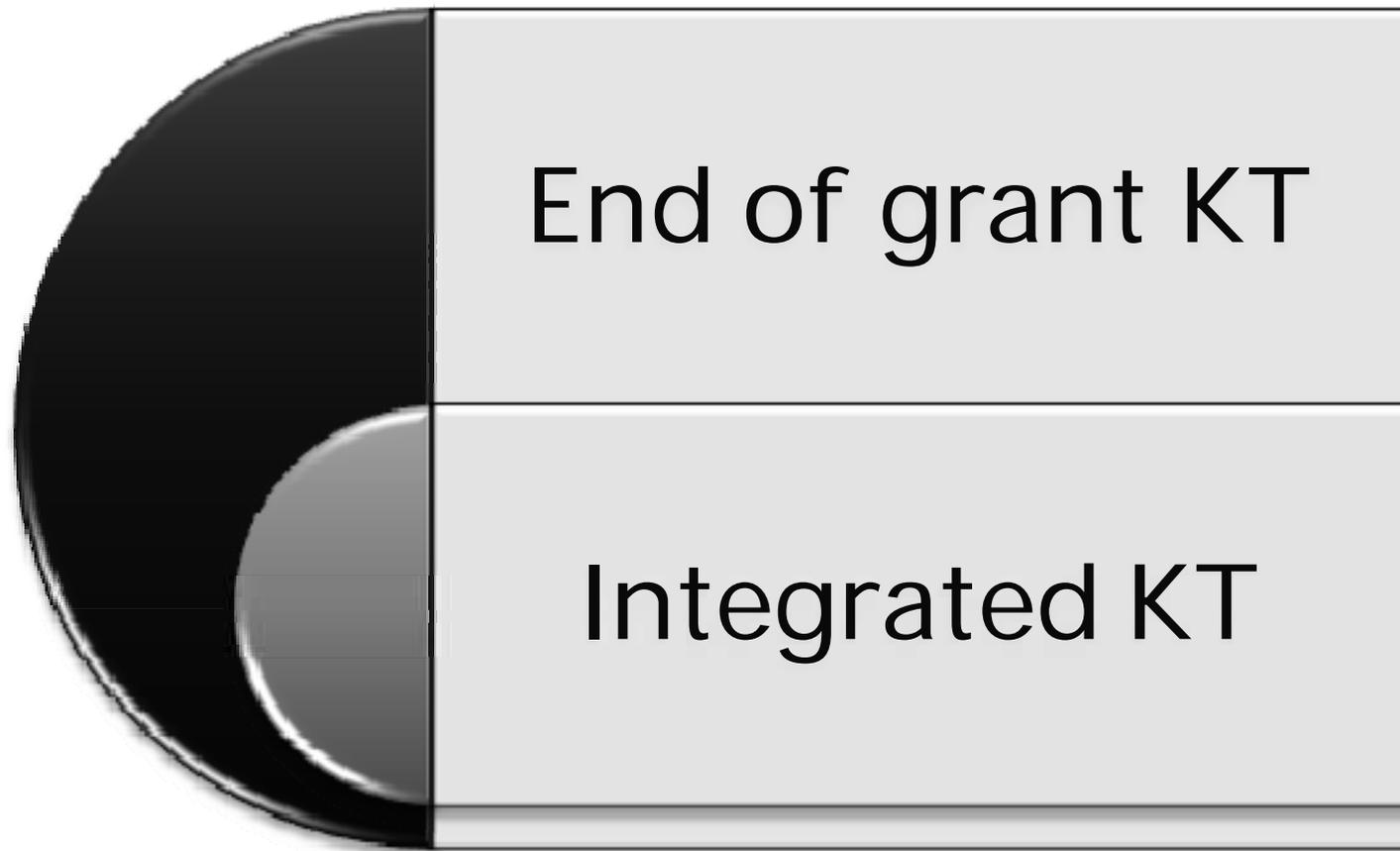


Knowledge translation

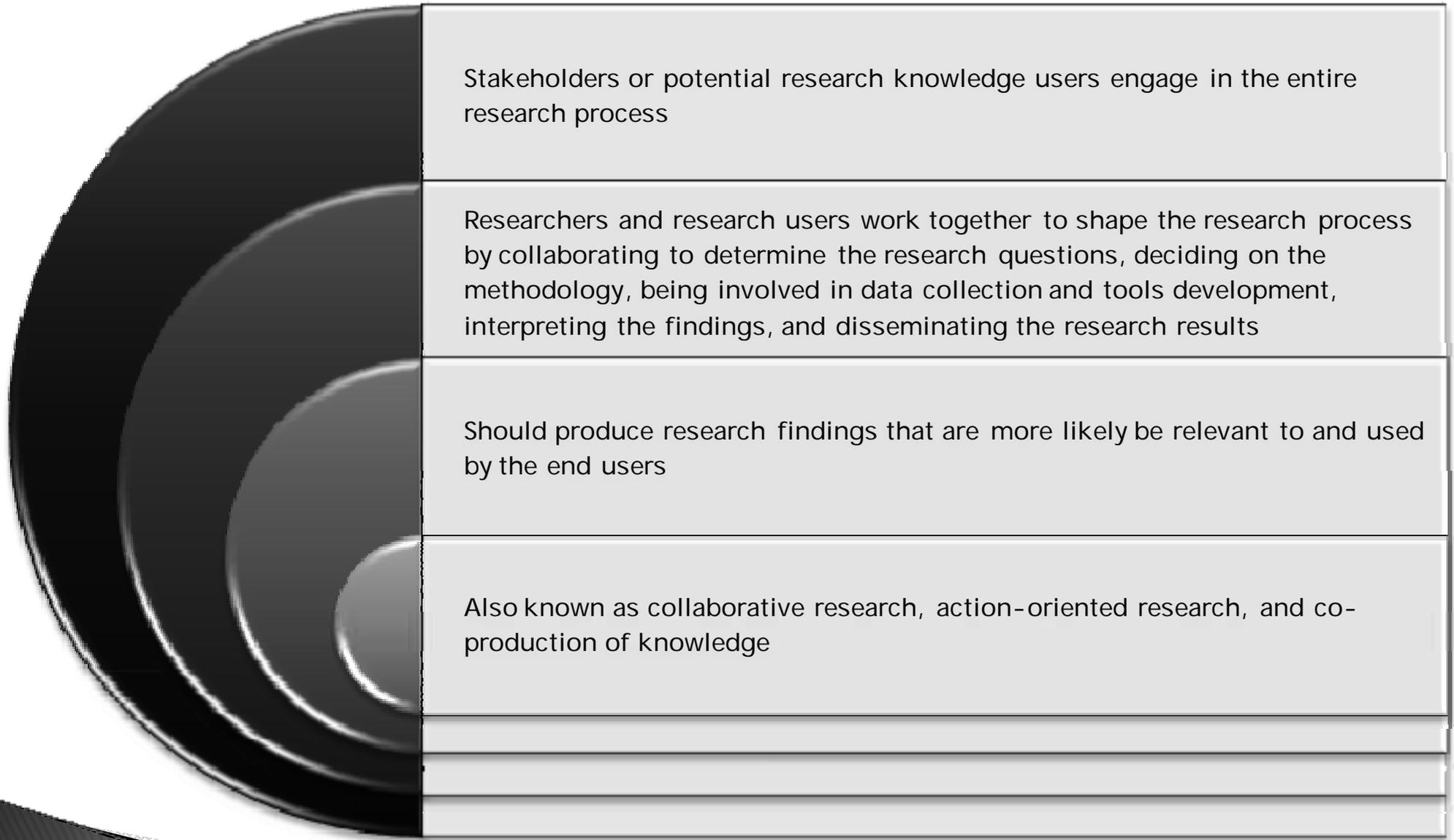


A dynamic and iterative process that includes the synthesis, dissemination, exchange and ethically sound application of knowledge to improve the health of Canadians, provide more effective health services and products and strengthen the healthcare system

KT – the researcher's challenge



Integrated knowledge translation



National Health Service – UK



KT & QI leverage factors impacting upon NHS

Economic recession

- NHS to save £2.3 billion in 2011
- Emphasis on productivity and efficiency in climate of spending restrictions

Health organisation performance

- Increased emphasis on quality outcome measures
- Monitored against achievement of quality
- Innovation essential to performance of organisations

Policy drivers

- Evidence-based practice
- Quality improvement

Research agenda

- Knowledge creation
- Knowledge translation

Patient / public expectations

- Patient choice and patient experience
- Patient and public involvement

What do we mean by Patient and Public?



Common terms used



Patients
Public
Service users
Community members
Lay members

What do we mean by Involvement?



“I think we’re all agreed that it is invaluable to have input from local people with real experience of health issues.”

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

Models of PPI

Consultation

- Patients / the public are consulted with no sharing of power in the decision-making

Collaboration

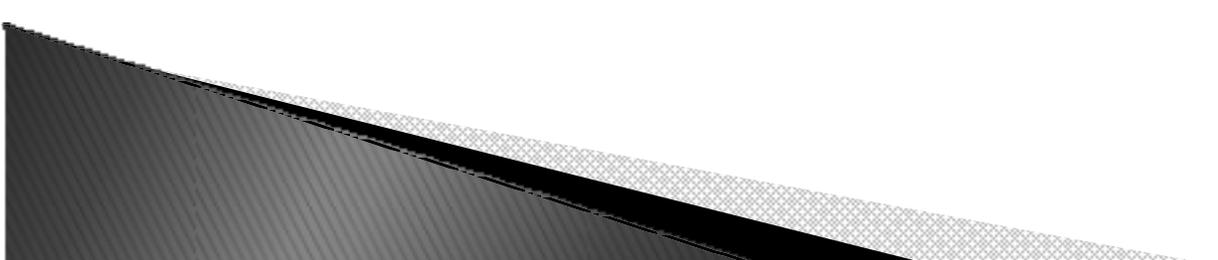
- Involves an active ongoing partnership with patient / public members in the research process

User control

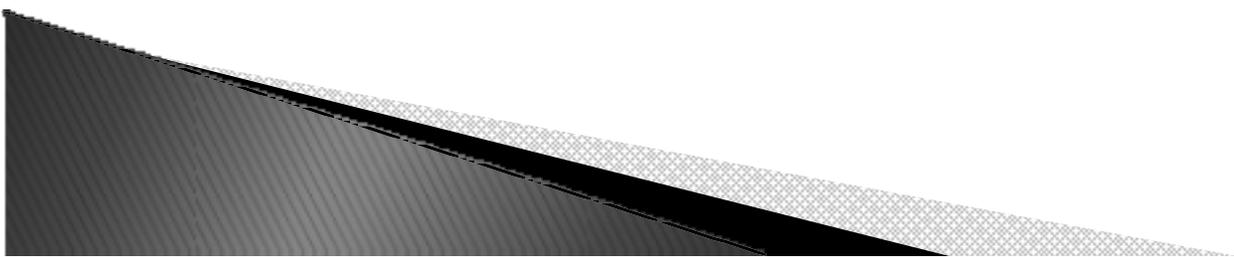
- Patient / public members design, undertake and disseminate the research

Poll question: Have you involved patients or the public in your research / quality improvement work?

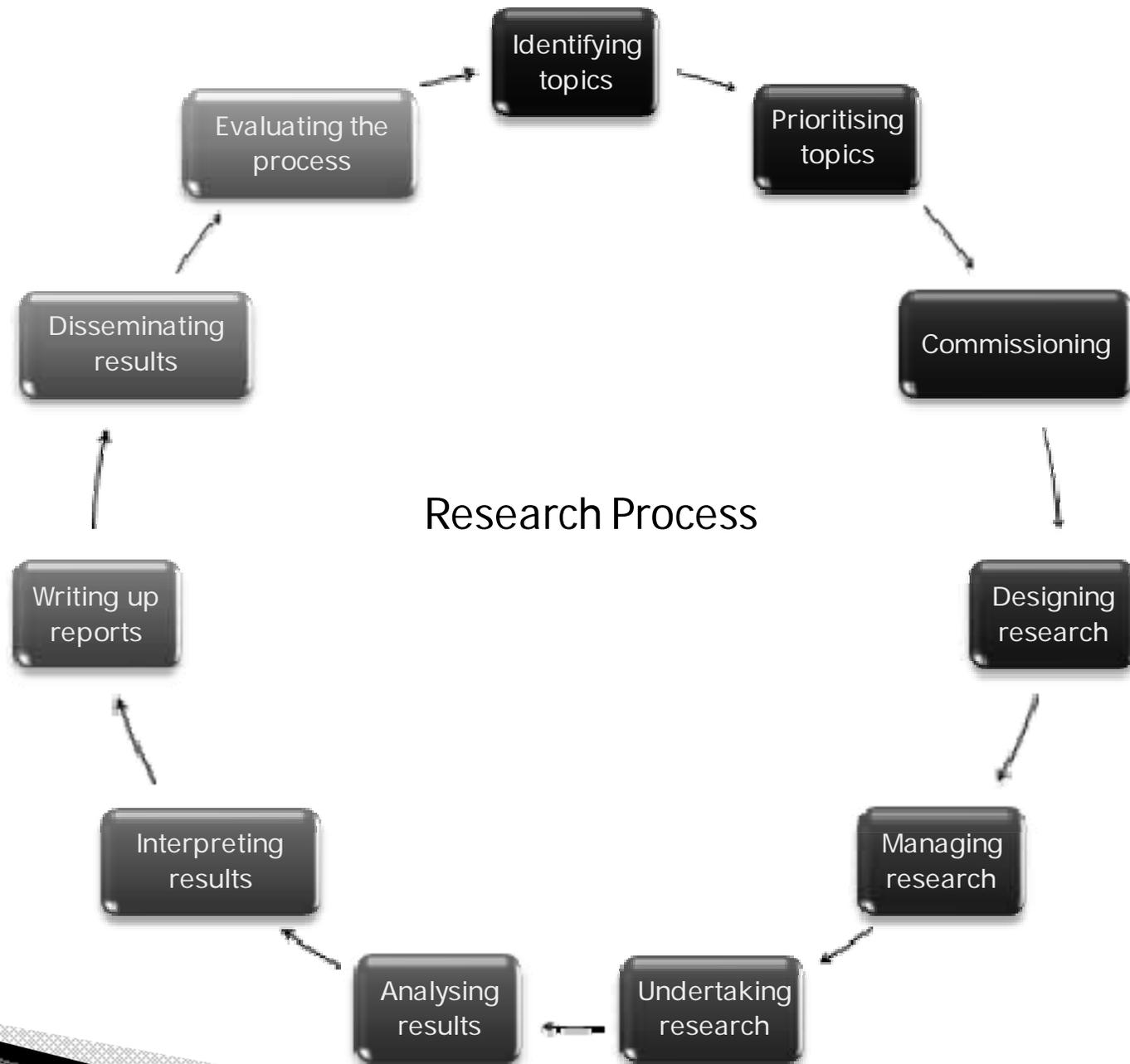
- ▶ Yes
- ▶ No



White board: In what ways have you involved patients or the public in your research / quality improvement work?



PPI: range & extent of involvement



Levels of PPI in research

Patient/public led



Patients/the public have overall control of the research process

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

Patients/the public and researchers collaborate in conducting a process that has been instigated elsewhere

Patients/the public act as advisors to the researchers

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

The views and experiences of patient / the public 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



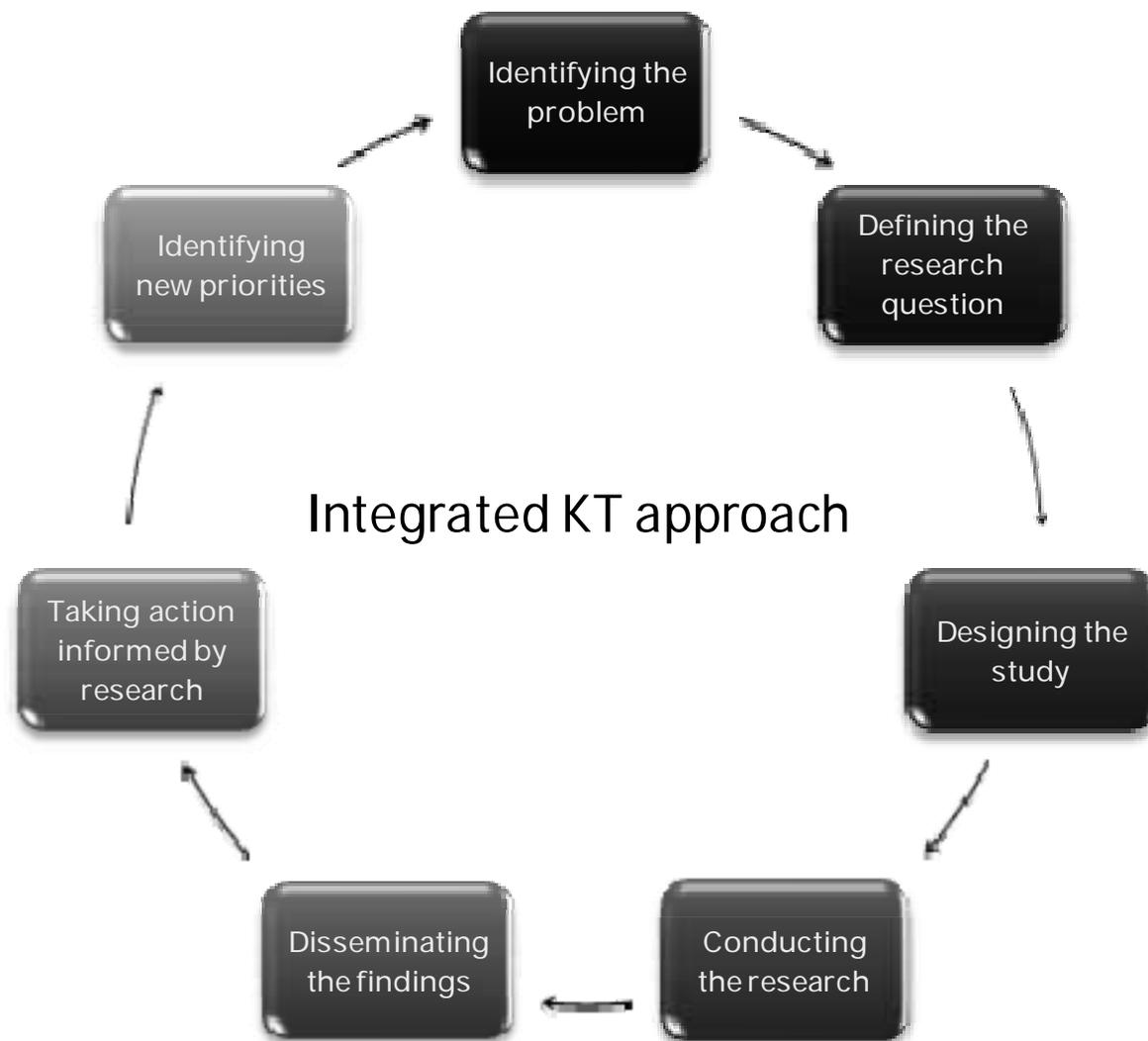
- ▶ To provide the Somali community and healthcare professionals with a knowledge base to inform action
 - To understand socio-cultural influences on the prevention, diagnosis and treatment of TB within the Somali community
 - To gain insight into healthcare professionals' perceptions of the Somali population's responses to TB and their experiences of TB services for Somalis
- ▶ To identify avenues through which culturally appropriate health promotion initiatives regarding the prevention of TB can reach the Somali community.
- ▶ To foster closer relationships between Somali community-based organisations and healthcare professionals to support initiatives to promote the prevention and effective screening, diagnosis and treatment of TB
- ▶ To develop network of partners to initiate and carry out future research projects



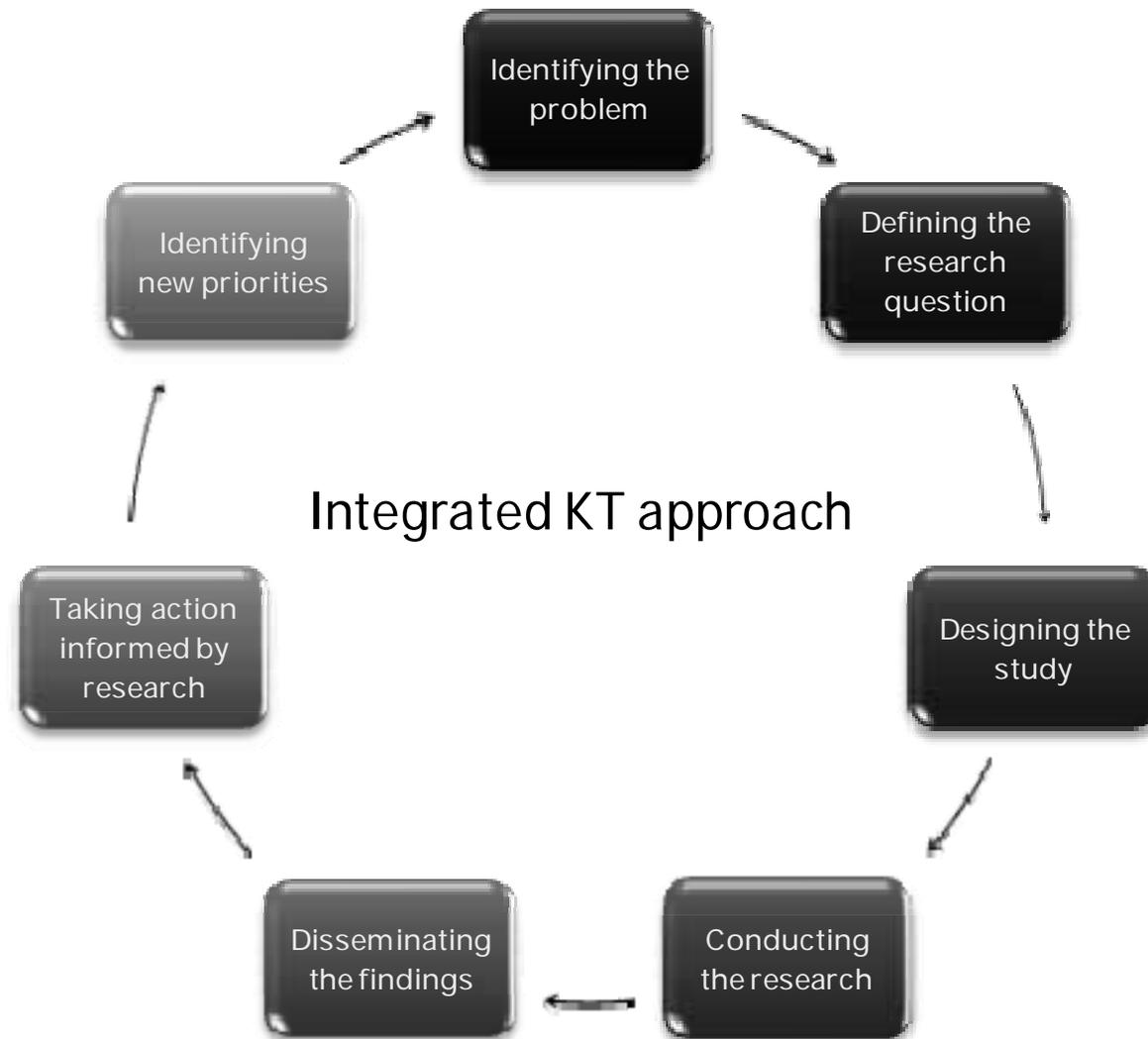
Methodology

- ▶ Community participatory approach
- ▶ Ethnographic fieldwork
- ▶ Qualitative methods
 - interviews, focus groups
- ▶ 'Framework' approach to data analysis (Ritchie and Spencer 1994)

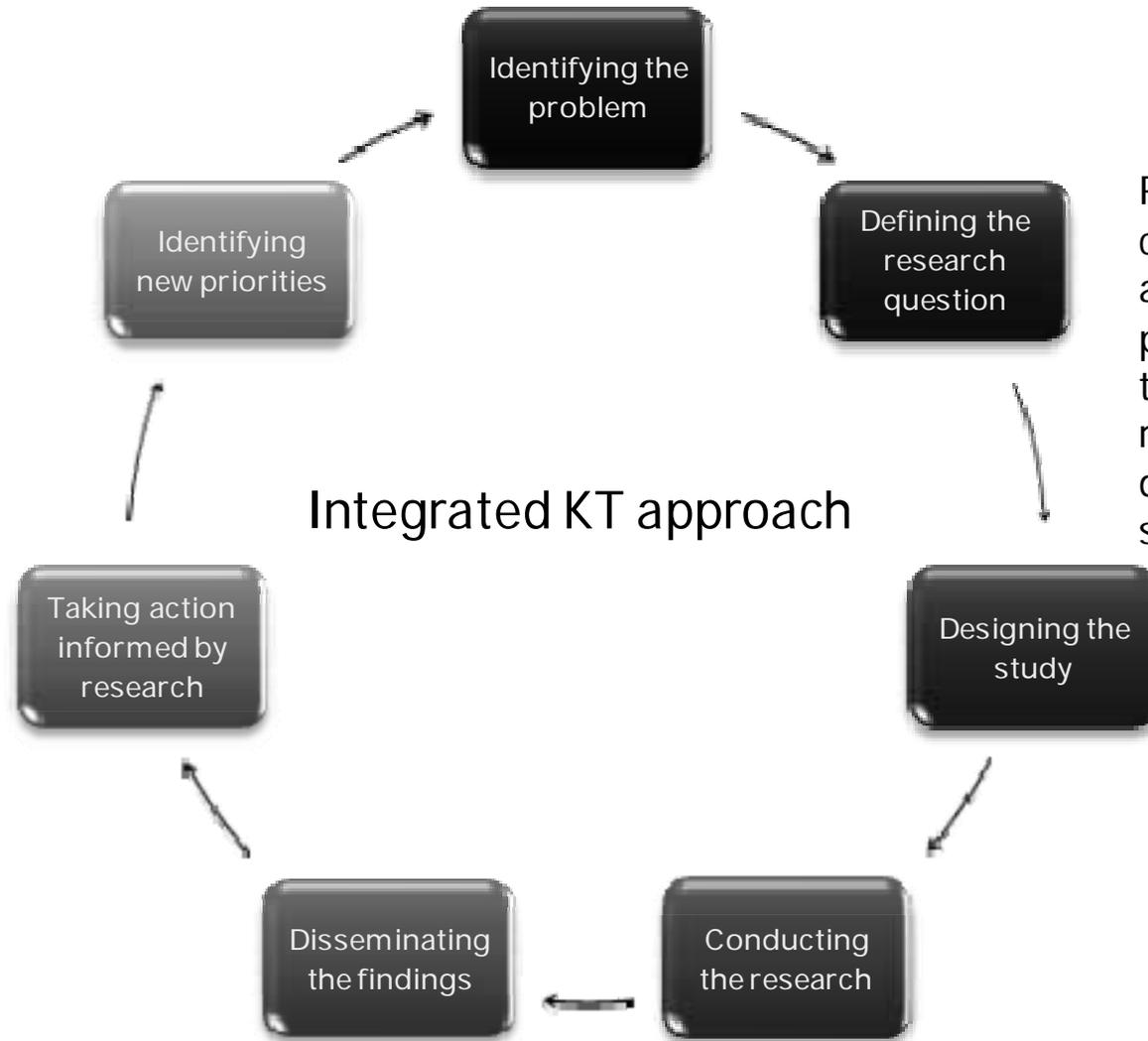




Healthcare professionals and Somali community leaders identified need for research



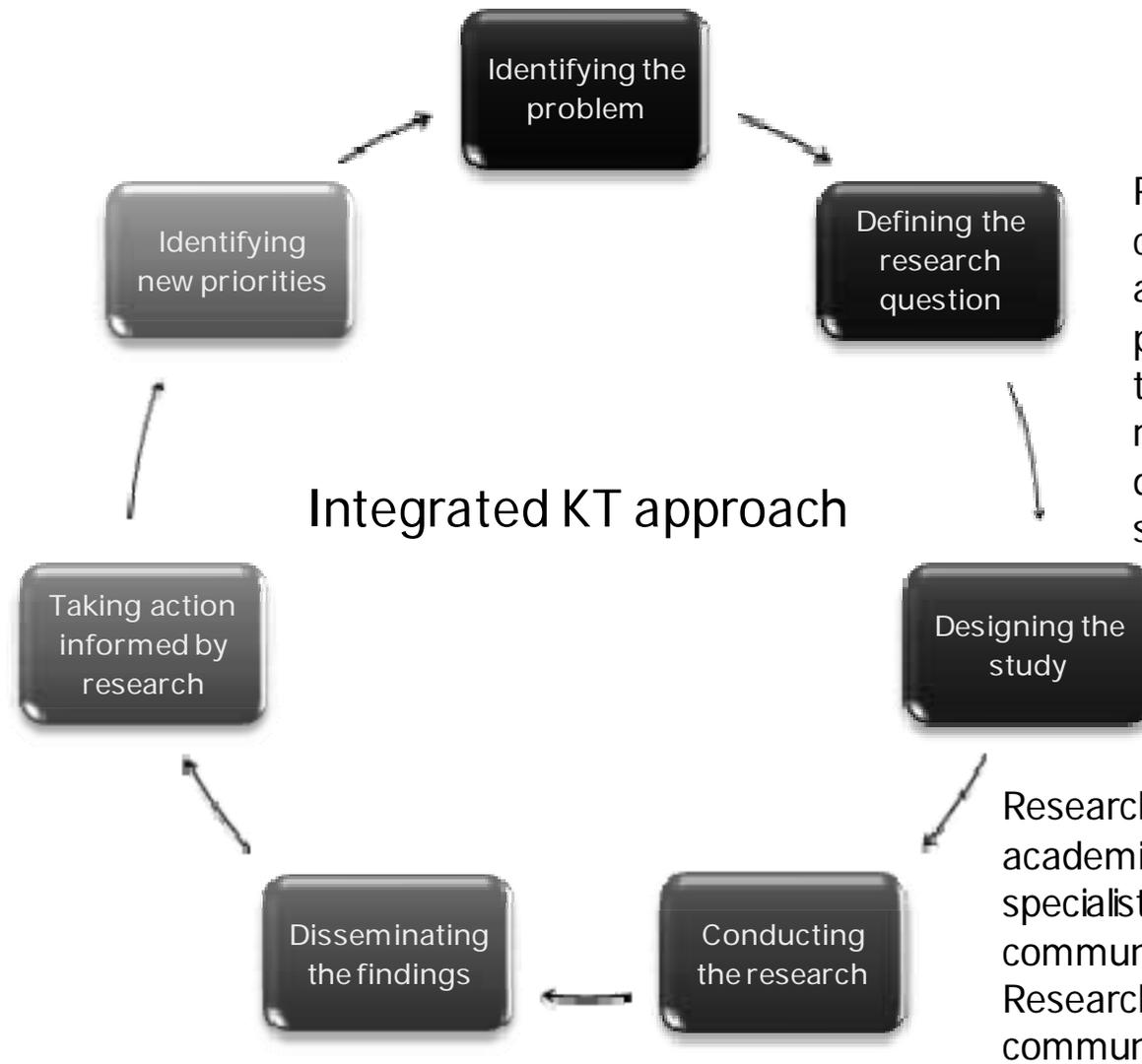
Healthcare professionals and Somali community leaders identified need for research



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

Integrated KT approach

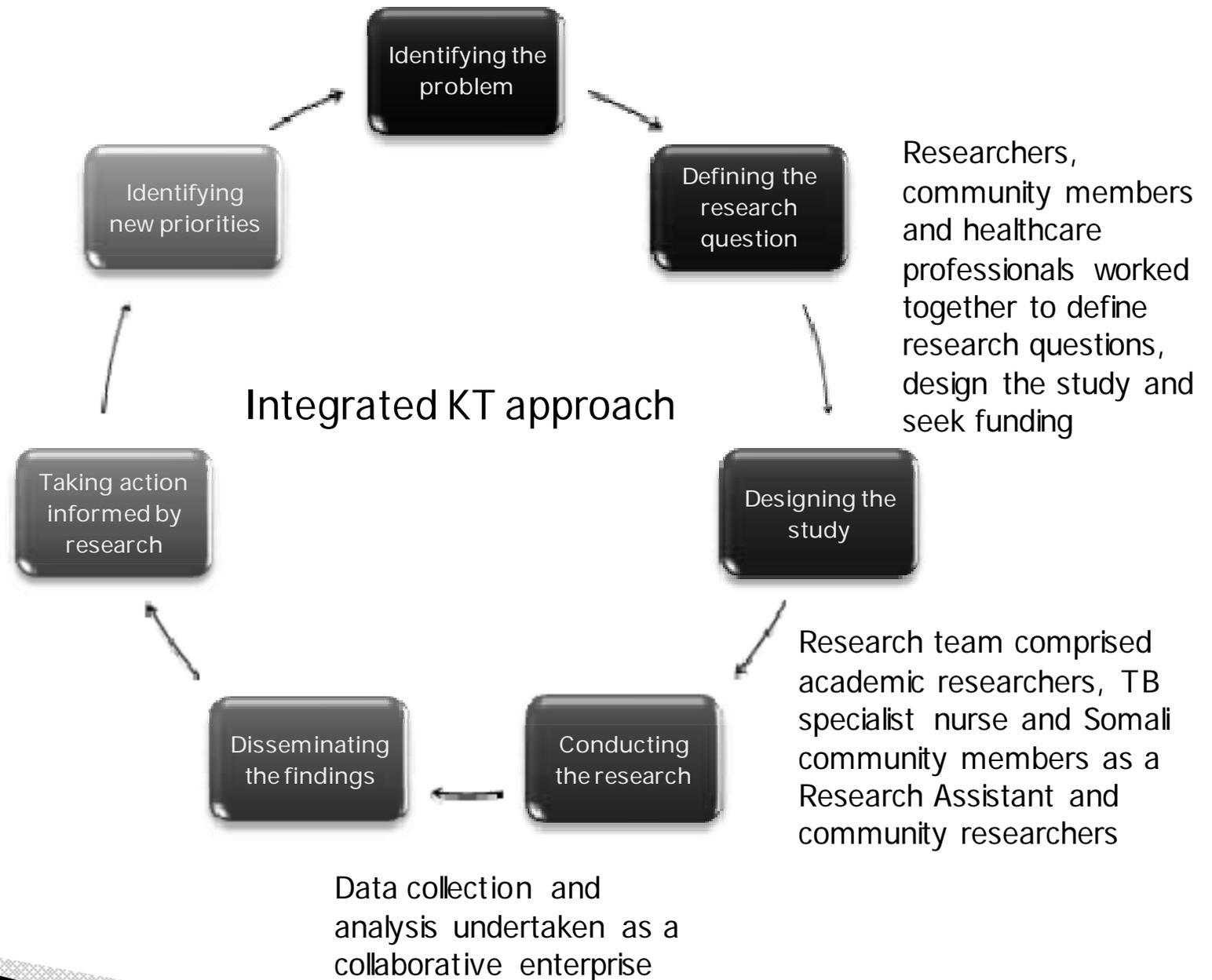
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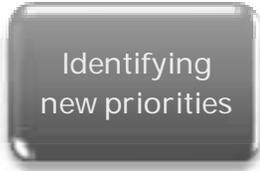
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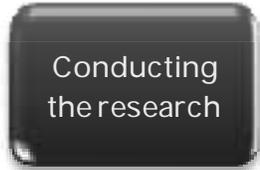
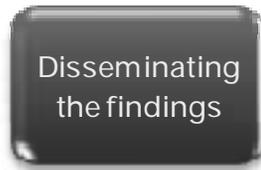
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Integrated KT approach



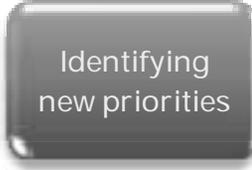
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Findings disseminated to different audiences by different means e.g. reports, action briefings, poetry, stories



Data collection and analysis undertaken as a collaborative enterprise

Healthcare professionals and Somali community leaders identified need for research

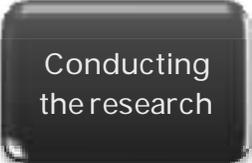


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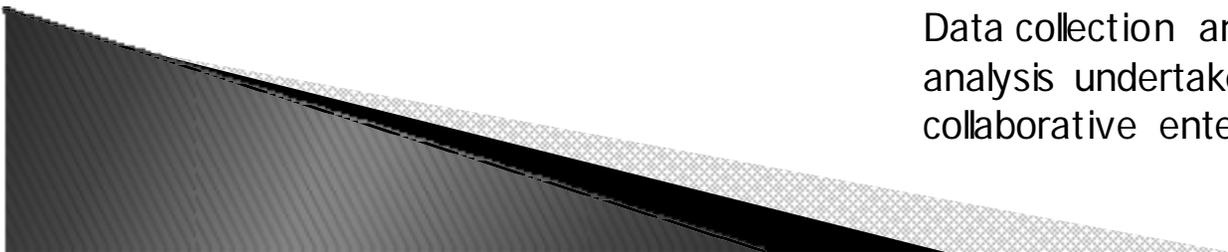
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Somali community organisations, Somali health workers and healthcare professionals implement public health actions and training for healthcare professionals



Healthcare professionals
Somali community leaders
identified need for research

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

Identifying
new priorities

Identifying the
problem

Defining the
research
question

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

Integrated KT approach

Taking action
informed by
research

Designing the
study

Disseminating
the findings

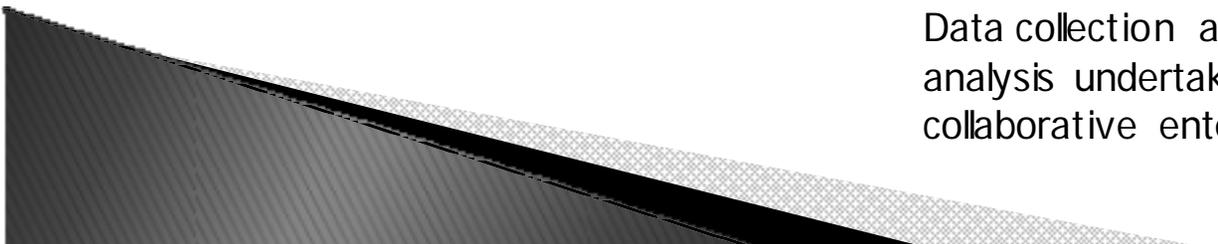
Conducting
the research

Research team comprised
academic researchers, TB
specialist nurse and Somali
community members as a
Research Assistant and
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Findings disseminated to
different audiences by
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Data collection and
analysis undertaken as a
collaborative enterprise

Somali community
organisations, Somali health
workers and healthcare
professionals implement
public health actions and
training for healthcare
professionals



Challenges: managing community expectations



Time scales perceived to be slow <ul style="list-style-type: none">- Delay in securing funding- Bureaucracy of approval mechanisms
Impatient to share findings
Funding for dissemination
Impact of research findings on policy and practice

Challenges: 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: researchers



Balancing different interests and agendas

Need for flexibility, openness to new ideas, willingness to learn

Being prepared to be challenged

Power sharing

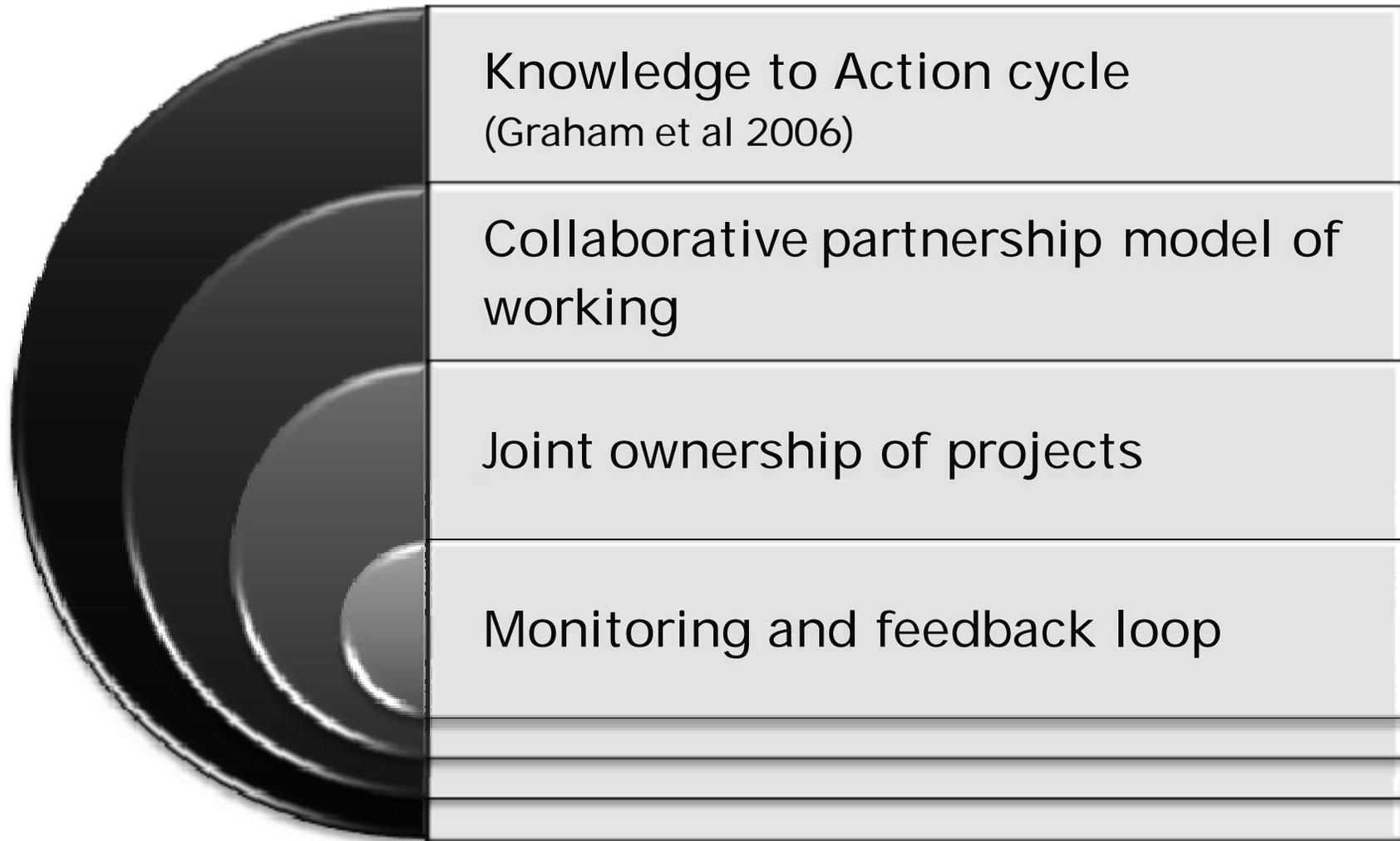
Analytic methods

How far is theory development and knowledge gain traded off against the pragmatism of involvement?

PPI in quality improvement projects



Approach



Enhancing quality of oral nutrition support

Defining the problem

- Patient & public governors from NHS Trust Board

Adapting knowledge to local context

- Patient Information Group involved in guideline review

Assessing barriers

- Hospital volunteers collecting data using Age UK questionnaire

Project planning and management

- Patient & public governors members of Project Steering Group

Evaluating the patient perspective

- Observation data of nutrition in hospital wards – informal information from patients

Scaling up and out

- Project Steering Group - recommendations & dissemination
- NHS Trust Board – promoting uptake across organisation(s)

Principles of successful PPI



• Roles of researchers and patient/public members are agreed



• Researchers respect the differing skills, knowledge and experience of patient/public members



• Researchers ensure that they have the necessary skills to involve patient/public members in the research process



• Patient/public members are offered training and personal support to aid their research involvement



• Patient/public members are involved in decisions about how participants are recruited and kept informed about the progress of the research



• Patient and public involvement is described in research reports



• Research findings are made available to patients and the wider public in formats and in language that they can easily understand



• Budgets should include all costs of PPI in research

Why pursue PPI?



References

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- ▶ Telford R, Boote J, Cooper C. (2004) What does it mean to involve consumers successfully in NHS research? A consensus study. *Health Expectations*, 7(3) 209–220