

Involving consumers in research and development agenda setting for the NHS: developing an evidence-based approach

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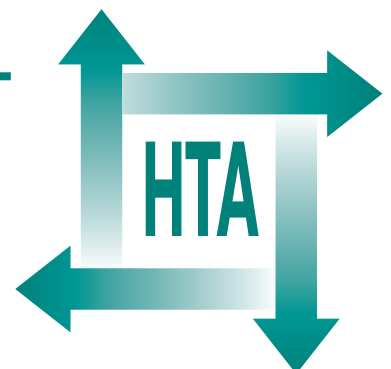
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Executive summary

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Executive summary

Background

This is the first systematic study of consumer involvement in identifying and prioritising possible topics for research and development.

Objectives

The objectives of the study were to:

1. look at the processes and outcomes of identification and prioritisation in both national and regional R&D programmes in health and elsewhere, drawing on experiences of success and failure
2. identify the barriers to, and facilitators of, meaningful participation by consumers in the research identification and prioritisation.

Framework for examining consumer involvement

We devised a framework for examining the diverse ways of involving consumers in research. It identified key distinguishing features as: the types of consumers involved; whether consumers or researchers initiated the involvement; the degree of consumer involvement (consultation, collaboration or consumer control); forums for communication (e.g. committees, surveys, focus groups); methods for decision-making; and the practicalities for implementation. We considered context (institutional, geographical and historical setting) and underpinning theories as important variables for analysing examples of consumer involvement.

We translated the principles for minimising bias and maximising transparency to reviewing a body of literature that is largely descriptive or reflective rather than based on systematic research methods. We assumed, conventionally, that well-conducted research studies would be less biased and more reliable. In order to draw on other reports where necessary, we assumed that reports where consumers shared authorship with researchers would be less biased, that reports originating in

the UK would be more relevant and that findings supported by more reports or by reports originating from both the UK and elsewhere would be more generalisable.

Methods

We systematically sought literature through databases, handsearching and citation tracking, and also through people in the UK who were (a) known to have worked to identify or prioritise health research topics or (b) recognised consumer specialists or advocates.

We included reports if they explicitly mentioned consumer involvement in identifying or prioritising research topics. We also interviewed consumers and research programme managers from some UK examples. We applied the innovative framework to review data from interviews and reports.

Results

We found 286 documents explicitly mentioning consumer involvement in identifying or prioritising research topics. Of these, 91 were general discussions, some of which included a theoretical analysis or a critique of research agendas from a consumer perspective, 160 reported specific efforts to include consumers in identifying or prioritising research topics and a further 51 reported consumers identifying or prioritising research topics in the course of other work. We found detailed reports of 87 specific examples. These included:

- inviting consumer groups to collaborate in setting research agendas (13)
- consulting consumer groups (12)
- inviting individual consumers to collaborate in identifying and/or prioritising research topics (17)
- consulting individual consumers (13)
- responding to consumer action with a collaboration (13)
- responding to consumer action by consulting with consumers (3)

- responding to consumer action by conducting research without consumer input (6)
- consumers independently identifying or prioritising research topics (10).

Most of this literature was descriptive reports by researchers who were key actors in involving consumers. A few reports were written by consumer participants. Fewer still were by independent researchers. Our conclusions are therefore not based on rigorous research, but implications for policy are drawn from individual reports and comparative analyses.

Conclusions

Research programmes have sufficient collective experience of involving consumers to plan their agendas working directly or indirectly with consumers. Appropriate methods depend upon the tasks to be undertaken, the consumers to be involved and the support required. Productive methods for involving consumers require appropriate skills, resources and time to develop and follow appropriate working practices. The more that consumers are involved in determining how this is to be done, the more research programmes will learn from consumers and about how to work with them.

More success might be expected if research programmes embarking on collaborations approach well-networked consumers and provide them with information, resources and support to empower them in key roles for consulting their peers and prioritising topics. To be worthwhile, consultations should engage consumer groups directly and repeatedly in facilitated debate; when discussing health services research, more resources and time are required if consumers are drawn from groups whose main focus of interest is not health.

Barriers to consumer involvement include: poor representation of consumers; consumers' unfamiliarity with research and research programmes' unfamiliarity with consumers; negative attitudes and poor working relationships; difficulties in communication; and time constraints. These barriers can largely be overcome with good leadership, purposeful outreach to consumers, investing time and effort in good communication, training and support and thereby building good working relationships and building on experience.

Organised consumer groups capable of identifying research priorities need to find ways of introducing their ideas into research programmes. They should be aware that consumers making efforts to (re)design structures and procedures have had greater influence over research agendas. Consumers are particularly well placed to reflect on their experience of research agenda setting in order to build the evidence about their priorities and methods for involving them.

Recommendations for research

The following areas are recommended for further research.

- Research to develop and evaluate different training methods, information and education and other support for consumers and those wishing to involve them.
- Research to address the barriers to consumers' ideas influencing research agendas.
- It is suggested that research programmes embarking on working with consumers do so with a view to learning more about these processes using an ethos of reflexive research. At a minimum they should involve consumers in reflecting on and reporting the process and outcome. Whenever possible, they should involve consumers in considering the methods and implications of working together both in advance and with hindsight. There is also a place for independent researchers to work with research programmes and consumers to investigate and record working practices. Consumers should be involved in conducting and reporting this work.
- We suggest carrying out prospective comparative studies of different methods for involving consumers.
- It is suggested that research about collective decision-making be further advanced by addressing the processes and outcomes of consensus development that involves consumers.

Publication

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NHS R&D HTA Programme

The research findings from the NHS R&D Health Technology Assessment (HTA) Programme directly influence key decision-making bodies such as the National Institute for Clinical Excellence (NICE) and the National Screening Committee (NSC) who rely on HTA outputs to help raise standards of care. HTA findings also help to improve the quality of the service in the NHS indirectly in that they form a key component of the 'National Knowledge Service' that is being developed to improve the evidence of clinical practice throughout the NHS.

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The HTA programme commissions research only on topics where it has identified key gaps in the evidence needed by the NHS. Suggestions for topics are actively sought from people working in the NHS, the public, consumer groups and professional bodies such as Royal Colleges and NHS Trusts.

Research suggestions are carefully considered by panels of independent experts (including consumers) whose advice results in a ranked list of recommended research priorities. The HTA Programme then commissions the research team best suited to undertake the work, in the manner most appropriate to find the relevant answers. Some projects may take only months, others need several years to answer the research questions adequately. They may involve synthesising existing evidence or designing a trial to produce new evidence where none currently exists.

Additionally, through its Technology Assessment Report (TAR) call-off contract, the HTA Programme is able to commission bespoke reports, principally for NICE, but also for other policy customers, such as a National Clinical Director. TARs bring together evidence on key aspects of the use of specific technologies and usually have to be completed within a limited time period.

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Reviews in *Health Technology Assessment* are termed 'systematic' when the account of the search, appraisal and synthesis methods (to minimise biases and random errors) would, in theory, permit the replication of the review by others.

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