

INVOLVE

Promoting public involvement
in NHS, public health and
social care research

(formerly Consumers in NHS
Research)

Consultation Response

National Institute for Health and Clinical Excellence (NICE) Operating model for the Centre for Public Health Excellence (CPHE)

Comments given below relate to the numbered headings within the original consultation document.

The document can be read at <http://www.nice.org.uk/page.aspx?o=248187>.

1. Introduction

INVOLVE believes that public involvement in research leads to research that is more relevant to people's needs, more reliable and more likely to be implemented. If public involvement is embedded in the operating model for the CPHE it will complement the core business of NICE. NICE's commitment to public involvement should be explicitly reflected in the operating model.

INVOLVE welcomes the fact that the work of the CPHE will be addressing a wider audience than the NHS. But, in discussing audiences (1.3.3/1.3.5) no explicit references are made to members of the public. We recommend that the public are explicitly included because they occupy a unique position with the potential to shape the research process, to support the dissemination of guidance into the wider community and the translation of research into practice. Since an objective of guidance is to bring about multi-level change (1.4.1) it is necessary to address members of the public as a primary audience in addition to the public health workforce.

2. Topics and perspective for the development of guidance on public health

INVOLVE welcomes the inclusion (Tables 1 & 2) of members of the public as stakeholders in defining the scope of guidance. The 'Choosing Health' consultation invited contributions from the public and therefore their responses may have contributed to the identification of the nine key theme areas (2.2 and 2.3) in the resulting White Paper. However, whilst NICE clearly supports the principles of public involvement, there is no stated mechanism for ensuring that members of the public are given the opportunity to contribute to the process of identifying topics.

Research has shown that members of the public can have very different research priorities to other stakeholders involved in the research process. If the end users and potential recipients of programmes and/or interventions are involved in identifying and prioritising research topics, research is more likely to reflect the needs of the public and is therefore more likely to produce results that can be used to improve health and social care services.

3. Structure and operation of CPHE

There are already ways in which members of the public can contribute to NICE's work, all supported by the work of the Patient Involvement Unit (PIU). But in describing the CPHE (3.1) no mention is made as to any additional structures necessary to deliver active public involvement. It is not clear if the PIU will extend its remit to support public involvement in the CPHE nor is there any acknowledgement of the different types of 'publics' that will necessarily be involved in the work of the CPHE.

CPHE will need to work in partnership with the public as generic potential users of services with no particular expertise by experience to contribute. Involving such members of the public requires additional skills and resources to complement the excellent work already being undertaken by the PIU. It also requires a cultural shift from a medical based approach to public involvement around ill health to a multidisciplinary approach that is based on a much broader understanding of the key determinants of good health.

4. Collaboration with the other Centres and Directorates in the Institute

In discussing the work of the implementation systems directorate (4.5) NICE recognises that the implementation of public health guidance will require co-working across a wide range of organisations. INVOLVE recommends that the public are also explicitly named

as partners in this work. When members of the public get actively involved in the research process they are also likely to take an active part in the dissemination and implementation of research findings. Members of the public generally have access to organisations, networks and communities that health care practitioners and researchers cannot otherwise easily access. Members of the public are the ultimate end users of research and as such have a vested interest in ensuring that research is relevant to their needs and that research findings lead to measurable improvements in health care practice.

5. The process for the development of guidance

INVOLVE recommends the model explicitly states that all public health programme development groups will include lay members (5.3.2), but without creating an expectation of 'representing' the general public.

The guidance development processes include fieldwork. Active involvement of the public in fieldwork is crucial in delivering guidance that will be used in practice. There are additional barriers that may inhibit members of the public from accepting, accessing or adopting changes in practice.

INVOLVE considers the work of the National Collaborating Centre for Community Engagement to be particularly valuable to the CPHE. Supporting community engagement and releasing capacity in the community are key issues to any future success for the CPHE. If public health researchers and practitioners fail to work successfully in partnership with members of the public the implementation of guidance into practice will inevitably remain low and there will be no significant impact on health improvement or inequalities.

6. Presentation of the guidance

Whilst we strongly support the provision of a version of guidance specifically written for the general public (6.1) it would be more widely understood and therefore perhaps more widely disseminated and implemented, if it were written in plain language rather than the 'language of the informed lay person' (6.2).

INVOLVE
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