
INVOLVE

Response to consultation - Best Research for Best Health: A New National Health Research Strategy (2005)

Challenges To Take Account Of (Q1)

INVOLVE welcomes the opportunity to respond to the “Best Research for Best Health: A New National Health Research Strategy” consultation. We support the emphasis that the Government is placing on patients at the centre of the healthcare system and the value given to health research which is for the benefit of patients and the wider public. The strategy highlights the importance of research being patient centred and becoming even more responsive to the needs of patients. The Government is also clearly supportive of involving the public (i.e. patients, carers, service users and advocates of service users and carers) in research, reflected in numerous policy documents.

With this clear commitment to public involvement in research, it is concerning that there is so little focus on the importance of public involvement and how this can assist in taking forward the aims and objectives of the research strategy. For the strategy to achieve its’ aims, it is vital that people who use services are actively involved throughout the research process.

We believe that active public involvement in research must be embedded into the mainstream of research practice. This would contribute towards improving levels of public confidence and understanding of research as well as to the quality, relevance and acceptability of research. Research that is more relevant, appropriate and acceptable to participants is likely to encourage greater participation in research.

- **The strategy needs to provide a clear and strong lead on public involvement. Researchers and research funders should be encouraged to build capacity and to resource public involvement, to facilitate involvement in all stages of the research process**
 - **Greater public involvement is necessary to enable researchers and research funders to fully deliver in providing research for the benefit of patients and the wider public**
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The Building Blocks (Q2)

The value of public involvement is already recognised within the UK Clinical Research Collaboration and Networks, the NHS R&D Programmes and other research support units. However, there is still much to do in supporting researchers to involve the public in their work.

We value the plans to further develop the infrastructure of research to support research and researchers within the NHS. As part of this, the strategy should provide the opportunity to further develop the infrastructure to build capacity to support public involvement. Emphasis within the strategy of the importance of ensuring public involvement within the whole research cycle would help to encourage greater involvement.

Embedding public involvement in research within the new and existing structures (such as the research networks, RDSU's, Primary Care networks, Academic Medical Centres and Central Commissioning Function) would assist in improving the quality, relevance and acceptability of research to the end users of NHS and social care research.

- **We encourage the Department of Health to include public involvement as one of the criteria used in the selection of organisations to undertake the proposed new roles**
- **Additional ways that public involvement could be encouraged and supported are through considering incentives and rewards for involvement. For example:**
 - **ring fenced funding;**
 - **pump priming to researchers and user researchers to assist in developing research proposals involving the public;**
 - **support to local service user networks promoting public involvement;**
 - **providing scholarships to people who use services, to enable them to develop their own capacity and to assist in promoting and supporting public involvement;**
 - **the promotion of public involvement within undergraduate / postgraduate education**

INVOLVE is keen to work with these new structure to further support and encourage public involvement.

National Institute for Health Research Structure (Q3, 4)

We welcome the proposals to bring together through the National Institute for Health, the ability to develop strategic direction across the different R&D activities.

- **The position of Senior Investigators should be expanded to embrace leaders from other related fields**
 - Criteria for the selection of Senior Investigators should include experience / commitment to public involvement, alongside publications and grant income
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Infrastructure (questions 5-10)

We welcome plans to ensure that research funding is redirected towards individuals and research organisations that deliver. However, there are difficulties in the proposal that money should follow patient participation in studies. This implies that the criteria for funding will be purely based on the numbers of participants in research, which may not reflect the quality of research activity. Such an approach will also bias research funding towards large multi-centred clinical trials, potentially jeopardising funding for other areas (e.g. social care) and methods of research (e.g. systematic reviews, exploratory studies and qualitative research).

- **To assist in assessing the allocation of funding, a broader set of criteria are needed**
- **We suggest that involvement of the public in research should be one of the criteria. INVOLVE would be happy to assist the Department of Health in the development of such criteria**

Support and encouragement for public involvement by the Academic and Specialist centres would reinforce the importance of the public's contribution to research in the UK.

- **The substantial funding being proposed for the Academic and Specialist Medical Centres should include public involvement as one of the criterion for funding, as well as the requirement for funding to be allocated by the Centres to promote and support involvement.**
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Research Programmes (Q 11)

We value plans to strengthen the research programmes, making them even more responsive to the needs of patients and the public. Many of the existing research programmes are continually striving to improve public involvement in their work. A more centralised system has the potential to further encourage and support such involvement across all programmes. However, it is equally important that the experience and commitment of the existing programmes is not lost through the establishment of new systems.

- **As in other areas, it is vital that public involvement is embedded in the new schemes and programmes to be adopted**

Plans to reintroduce responsive funding will be of great value in enabling less well established researchers to apply for funding, as well as to enable people who use services to propose new areas of research.

- **The criteria for funding such research should include relevance to the public (patients, carers, service users etc) as well as to the NHS**
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Research Networks (Q 12)

The proposals to develop generic networks in addition to the topic specific research networks will help to address areas currently outside the existing networks. Demonstrating plans to support public involvement throughout the topic specific networks (and the UKCRNCC) was an important criterion for the selection of these networks.

- **We would encourage the Department of Health to ensure that public involvement is also a criterion in the establishment of the generic networks**
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Bureaucracy Busting (Q 13)

Reducing unnecessary complexity and duplication are shared goals for both researchers and the public. However, it is also vitally important that all the appropriate checks are in place.

- **Public involvement throughout the development of plans to address bureaucracy can help to ensure the appropriateness and acceptability of proposed approaches to the public, and thus in turn can help to strengthen public confidence in research**
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Transition (Q14)

We agree that it is important to ensure that any new system for the allocation of research funds is transparent. This will help to engender confidence in the research process amongst the public as well as the research community.

Overall – criteria to judge the impact of the strategy (Q15)

Active public involvement in research is vital if research is to answer the real questions that face people about health, and if health research is to be truly responsive to the needs of patients. Thus one of the main criteria to assess the impact of this strategy would be the extent of public involvement within research funded by the Department of Health.

Any other comments

We are aware that patients have a holistic view of their health care and not just the management of their specific clinical conditions. We therefore believe that the strategy would be further improved if it reflected this patient centred view.

- **We would encourage greater recognition within the strategy, of the importance and value of social care and public health research as integral to patient and public health needs.**
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