

30 January 2014

Dear Colleagues,

### **NHS England Draft Research Strategy: A Response from INVOLVE**

We welcome the opportunity to respond to the consultation on NHS England's Draft Research and Development Strategy: *'Research is everybody's business'*.

INVOLVE is the national advisory group for the advancement and promotion of public involvement in NHS, public health and social care research. The organisation brings together expertise, insight and experience in the field of public involvement in research, to help create a research community that undertakes NHS, public health and social care research, which reflects the needs and views of patients and the public. INVOLVE takes forward its work by: working with others to influence policy and practice across the NIHR and beyond; increasing awareness and sharing experiences of where and how the public can be involved and contribute to the research agenda; offering advice and guidance; and helping to build an evidence base for public involvement.

The following is a summary of the comments made by INVOLVE's advisory group members. INVOLVE has also contributed to the consultation through a number of fora including the NIHR Advisory Board.

#### **Overall comments**

- The draft strategy could make a stronger statement on the link between research, patient experience and quality of care and treatment in the NHS.

- There is a need for greater clarity in the document about NHS England's vision of its role in advancing and promoting research in the new landscape of provider and commissioning organisations.
- The strategy could better articulate the challenges and opportunities for research in the current NHS operating environment and how NHS England will work with others to resolve or manage these.
- The strategy should describe in more detail the partnerships and connections that it expects to be established between the NHS, the National Institute for Health Research (NIHR) and others in support of activities such as research prioritisation.
- More narrative is needed on the anticipated benefits for patients that will arise out of 'strategic localism' in NHS research. A clear definition of the role and purpose of Academic Health Science Networks (AHSNs) as well as other bodies is needed.
- It would be useful to provide a flow chart of the organisations who will be expected to deliver the strategy.
- The strategy should be re-written in a way that can be understood clearly by patients and the public or, at the very least, a separate lay summary produced.

### **Specific comments on the strategy's public involvement intentions**

- We applaud the fact that the strategy embraces the importance of the public's contribution to research. But it remains unclear the thinking behind this and, in particular, how NHS England believes its relationship with the public can be developed to drive what it does in this arena.
- The strategy could be strengthened by inclusion of an explicit principle that its aim is to 'promote and advance research of patient and public benefit'. We would recommend that the existing objectives on public involvement and public participation be enshrined in a single objective that is the first stated.
- The document refers variously to patient involvement, participation and engagement. Clearer definitions of what NHS England means by these terms would be helpful as would examples of any associated activities. Moreover, at the moment, these activities are not woven into the strategy. Rather they are considered separately. This will diminish the overall accountability of the strategy and the value of its outputs to the NHS and its users.

- The balance of the document is towards encouraging participation in research studies. It does not sufficiently grasp the value of people's contribution to designing and developing high quality research and its delivery in NHS settings. Nor does it sufficiently acknowledge how good public involvement in research design and ongoing public engagement can improve participation in research. (see Staley K.(2009) Exploring Impact: Public involvement in NHS, public health and social care research. INVOLVE, Eastleigh and Ennis, L. et al. 'Impact of patient involvement in mental health research: longitudinal study' *British Journal of Psychiatry* (Sept 2013) [doi: 10.1192/bjp.bp.112.119818](https://doi.org/10.1192/bjp.bp.112.119818))
- The document would be strengthened with some suggested success measures. We would also welcome a commitment to ensure that the public contribution to, and experience of, research is measured in the range of patient surveys conducted across the NHS.
- There is confusion as to which 'involve' is being referred to on pages 14 and 22. These references to involve (lower case) are, we believe, an error and should be to NIHR INVOLVE (upper case) ([www.involve.nihr.ac.uk](http://www.involve.nihr.ac.uk))
- There is no information on the governance arrangements for delivering NHS England's Research Strategy, in particular how patients and the public will be involved. Nor are any clear links made with patient experience work happening across the wider NHS or, conversely, how NHS England will assist its research partners to ensure that research is reflected in this work.
- Members felt it was essential that those involved in the development of the R&D Strategy, worked closely with the NIHR INVOLVE in developing plans for public involvement.

Please do not hesitate to contact us if you have any questions or would like more information.

Yours faithfully



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