

## **INVOLVE response to the NHS Constitution Consultation – 28 January 2013**

This consultation follows work carried out by the [NHS Future Forum](#) on how the NHS Constitution could be strengthened.

INVOLVE responded to questions in the following sections of the NHS Consultation:

1. Patient involvement
2. Patient data
3. Raising awareness and embedding the NHS Constitution
4. Giving the NHS Constitution greater traction.

### **Patient involvement**

#### **Question 1: What are your views on the proposed changes to strengthen patient involvement in the NHS Constitution? ([Q. 4 on submission form](#))**

The proposed changes move us in the right direction of strengthening public involvement in the NHS Constitution. We welcome the amended Principle 4 of 'putting patients at the heart of everything it does' and the amended Principle 3 which now explicitly alludes to the values of respect and dignity for patients as well as staff. We also welcome the commitment to active patient involvement in decisions about their care and treatment.

However, we are disappointed that opportunities for patients and the public to influence research are not included as a right or a pledge. It is important that patients and the public are involved in the priority setting, design, conduct and reporting of NHS funded research to ensure its future relevance to patient needs. As acknowledged by the National Institute for Health Research (NIHR) public involvement activity is distinct from the role that patients play as participants in research.

Patient and public involvement should be a core principle in the NHS Constitution – as it is for NIHR. This would ensure that the insights and perspectives of patients and the public are central to research conducted in the NHS.

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## Patient Data

### Question 8: Do the proposed changes to the NHS Constitution make clear how the NHS will safeguard and use patient data? (Q.11 on submission form )

We welcome some of the changes to this section however feel that further clarification is required to ensure there is no confusion over how personal information and data is handled in care and service delivery and in research.

General comments some of which are also relevant to Q.15:

- the need for a clear explanation of the terms ‘anonymised’, ‘identified’ and ‘confidential’ to avoid misunderstanding or the use of an alternative, agreed term
- details on how people can find out about information and support on patient data and raise objections
- information about people’s rights, who and why data might be accessed or used
- information about safeguards in place to protect people’s confidentiality.

Specific comments on the following proposed rights and pledges:

- ‘you have the right to request that your **confidential** data is not used beyond your own care and treatment and to have your objections considered and where your wishes cannot be followed, to be told the reasons including the legal basis’. This right does not make it clear how patients will make this request, how their objections will be considered or how it will be communicated to them that confidential data is being used beyond care.
- ‘the NHS pledges that where **identifiable** data has to be used, to give you the chance to object wherever possible’. We suggest this becomes a right rather than a pledge and it is made clearer that identifiable data will only be used in exceptional circumstances.
- We welcome the pledge to inform people of research studies in which they may be eligible to participate. However the pledge does not address who or

how patients will be informed and how confidentiality of their personal data will be addressed.

It is important that the NHS Constitution is a clear, concise, easy to read document that provides people with a clear understanding of its principles and their rights. Signposting to further more detailed information will also be important.

We note that the Caldicott 2 Review will shortly report and it will be important for the NHS Constitution to reflect Caldicott's recommendations from a patient perspective.

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## **Raising awareness and embedding the NHS Constitution**

### **Q15: Do you have further recommendations for re-launching, rolling out and embedding the Constitution from next spring? ([Q. 18 on submission form](#))**

The consultation states that the purpose of the NHS constitution is to help people understand what they should expect from the NHS and what their responsibilities are in turn. However it also acknowledges that this can only work if people are aware of, and understand the content of the constitution.

Currently, public awareness of the constitution is very low. It essential to improve ways to raise awareness amongst the public but in doing so, it is equally important to make sure that the information provided is accessible, transparent and that patients can see the relevance of the information to their own situation.

Making sure that people understand their rights is as (or even more) important than creating new ones. For example, many people are concerned and confused about confidentiality of their data and this needs to be made much more transparent. For example providing information on how data is used for research and the benefits and safeguards and how people will be approached to participate in research.

We support the proposal to include easy read versions and summaries of the Constitution, and recommend that patients and the public are involved in the writing of these documents by commenting and reviewing suggested content and format. In addition, the rights, pledges and responsibilities need to be conveyed in a variety of other ways to ensure patients are fully informed, such as by making reference to the NHS Constitution at the foot of patient appointment letters; including the key pledges on people's National Insurance cards; annual public awareness campaigns focused on one pledge at a time etc.

## **Giving the NHS Constitution greater traction**

**Q16. To help shape our future consultation, do you have views on how the NHS Constitution can be given greater traction to help people know what they should do when their expectations of the NHS are not met? ([Q. 19 on submission form](#))**

We welcome the suggestion that more needs to be done to help patients understand what the rights and the pledges in the constitution mean and the commitment to giving greater traction to the NHS Constitution. However, the Constitution needs to address questions around the role of PALS and HealthWatch in relation to the Constitution and the balance between local and national accountabilities. Healthwatch would be expected to act as custodians/guardians of the Constitution at local level, whilst at the national level, the operation of the Constitution should be monitored by the Health Service Ombudsman.

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