

Department of Health: Strengthening the NHS Constitution

Response by the Wellcome Trust

January 2013

Key Points

- We welcome the proposals to strengthen the NHS Constitution in relation to patient data. The changes provide much-needed clarification about how confidential information may be shared, which should help to unlock patient data for life-saving research. The provision of high quality information will be essential to ensure that patients are adequately informed about how their data may be used.
- We make some suggestions to further improve the text by adopting more consistent terminology and by adding a clearer statement about the importance of balancing the duty to protect the confidentiality of information with the need to share information to improve care.
- We welcome the proposed changes to strengthen patient involvement; to ensure parity of mental and physical health; and to promote the uptake of research within the NHS.
- We recommend some changes to strengthen further the commitments relating to education and training.

INTRODUCTION

1. The Wellcome Trust is pleased to respond to the consultation on strengthening the NHS Constitution. The Constitution remains a useful document providing a set of guiding principles for patients, staff and the public. However, we entirely agree that awareness of the Constitution is currently far too low and look forward to seeing further proposals to ensure the Constitution has greater traction. We agree with the areas that have been identified as in need of revision, and particularly welcome the focus given to patient data. As a research funder, our comments concentrate mainly on the patient data elements which are of most relevance to our researchers.

Q1. What are your views on the proposed changes to strengthen patient involvement in the NHS Constitution?

2. We support the importance of patient involvement within the NHS Constitution, and agree with the changes to strengthen this. We particularly welcome the proposal to move the pledge “to inform patients of research studies in which they may be eligible to participate” from the Constitution Handbook to the main Constitution text. A national poll last year found that 82 per cent of the public think it is important for the NHS to offer opportunities to take part in healthcare research, including clinical trials. The new pledge should help to deliver this aim.

Q8. Do the proposed changes to the NHS Constitution make clear how the NHS will safeguard and use patient data?

3. Patient records are an invaluable resource for research. Data can be used for epidemiological research, to understand more about the causes of disease, to detect outbreaks of infectious diseases, to monitor the safety and efficacy of drugs and to study the effectiveness of treatments and interventions. Patient records can also be used as a starting point to identify potential participants to take part in health research, including clinical trials.
4. Surveys suggest that the public are generally supportive of research using health information. For example, a survey conducted for the Wellcome Trust in 2009 of 1,179 UK adults found that 74 per cent were willing to allow access to their medical records for medical research. But for too long, researchers have faced a lack of consistency regarding the processes that should be used when information from patient records is required for research. This confusion has prevented potentially life-saving research.
5. We therefore welcome the proposed changes to the NHS constitution, and the helpful clarification that they provide about how anonymised and identifiable information might be used. We believe that the amendments set out on page 7 provide an appropriate summary of the existing legal basis for sharing patient data. It would be helpful if the accompanying Handbook provided further detail that patient data may be shared for research, public health monitoring, audit and commissioning, as well as for direct clinical care.
6. We note that the current draft text uses a range of different terminology – ‘confidential information’, ‘your information’, ‘confidential data’, ‘identifiable data’, ‘health data’ – apparently interchangeably. There is already significant confusion as to what each of these phrases mean and where they overlap; the use of a variety of terms in the Constitution may increase confusion. It would help if the Constitution adopted more consistent terminology or, at the very least, definitions should be included in the accompanying Handbook.
7. The proposed text discusses two types of data: anonymised and identifiable. We recognise that researchers may need to access a third type of data, ‘pseudonymised’ data (also called ‘key-coded’ or ‘linked anonymised’ data). This information cannot directly identify an individual (e.g. name and address are removed), but a ‘key’ or code is available to link data back to the individual. The likelihood of identification increases where data relate to individuals with rare illnesses or to small populations, and as different datasets are linked. The legal basis by which this data may be accessed has often been unclear and researchers have faced inconsistent decision-making.
8. The Information Commissioner has recently provided helpful guidance in relation to pseudonymised and anonymised information in the Anonymisation Code of Practice. We hope that the Caldicott Review of Information Governance will provide further clarity in relation to health data. We therefore agree that it is not necessary for the NHS Constitution itself to include reference to pseudonymised data, but it may be helpful for the accompanying Handbook to give further background.
9. The new text provides a clear statement that patients have a right to be informed about how their information is used. We welcome this commitment and look forward to seeing

further detail about how this will be achieved. Currently, there is little understanding of how patient records are used beyond the direct provision of care. It is essential that NHS patients understand how and why their information may be used. The UKCRC has developed a leaflet, '*Your health data saves lives*', setting out the benefits of sharing patient data. But much more must be done to raise awareness. Responsibility should lie with the Department of Health, the NHS Commissioning Board and the NHS Clinical Commissioning Groups to ensure this information is provided, in an easily accessible manner through a variety of different media.

10. We are also pleased to see amendments in the section on 'Staff responsibilities' in relation to the duty to protect the confidentiality of personal information. We agree with the view that the existing wording of the Constitution does not adequately reflect the balance between protecting and sharing information for patient care. However, we are concerned that the proposed amendments still do not strike the right balance.
11. The revised duty on p.12 that staff should "*protect the confidentiality of personal information that you hold*" could still be taken out of context to mean that data should not be shared. While the additional statement on p.13, that staff have a responsibility "*to provide access to a patient's data to other relevant professionals, always doing so securely, and only where there is a legal and appropriate basis to do so*", is presumably intended to address this, the separation of the two elements means that the symmetry between them is lost. We suggest that there should be a clearer statement about the importance of balancing the duty to protect the confidentiality of information with the importance of sharing information to improve care. We understand that the Caldicott Information Governance Review will provide advice on this issue and we hope that this will be reflected in the final version of the Constitution.

Q9. Staff rights, responsibilities and commitments

12. High-quality and effective education and training are essential elements of a successful health service. We therefore welcome the amendments on p.11 in relation to the provision of education and training to all staff. However, we have concerns about the equivalent responsibility on staff to take up these opportunities:

'You should aim to take up training and development opportunities provided over and above those legally required of your post.'

13. We do not think this statement adequately reflects the importance of continuous professional development to ensure the best possible healthcare. We therefore suggest it should be replaced with the following wording:

'You should aim to take up education, training and continuous professional development opportunities provided to ensure you stay at the forefront of delivering the highest standards of care and service.'

14. Overall we welcome the proposals to ensure that staff feel supported and able to provide more compassionate care. However, we have specific reservations about the new addition on p.10:

'Care professionals should be supported to maximise the time they spend directly contributing to the care of patients.'

15. While we applaud the intention behind this statement, it is not clear how widely it is intended to apply. It is important to recognise that for some health professionals, such as research nurses or clinical academics, there needs to be a balance between time spent providing direct clinical care and time spent away from patients, for example at a lab bench. While the quality of care provided still needs to be of the highest standard, this may only account for a limited amount of their time. It would be helpful if the accompanying Handbook could recognise this context, or at least provide a definition of what is intended by the term 'care professional'.

Q10. Do you agree with the wording used to emphasise the parity of mental and physical health?

16. We fully support the importance of making clear that mental health should be treated on a par with physical health throughout the NHS Constitution. We agree with the proposal that the term 'physical and mental health' should be defined once at the beginning, and then the word 'health' used to encompass both for the rest of the document.

Q19. Do you have any further comments about our proposals for strengthening the NHS Constitution?

17. Promoting the uptake of research and innovation in the NHS is essential. We therefore welcome the amendment to the overarching Principles to emphasise the importance of the use of research to improve the delivery of healthcare.

The Wellcome Trust is a global charitable foundation dedicated to achieving extraordinary improvements in human and animal health. We support the brightest minds in biomedical research and the medical humanities. Our breadth of support includes public engagement, education and the application of research to improve health. We are independent of both political and commercial interests.