



Department
of Health

Refreshing the Mandate to NHS England: 2014 – 2015

Response form

September 2013

Instructions for responding to the consultation

The Government wants your views on the proposals set out in *Refreshing the Mandate to NHS England 2014 – 2015*. The response form below can be used to help you do that.

Alongside the Mandate refresh, the Government is proposing to update the NHS Outcomes Framework to reflect progress made in developing the placeholder outcome indicators. These will be published in the autumn.

You can find out more and respond to this consultation at:

<https://www.gov.uk/government/consultations/refreshing-the-nhs-mandate>

You can also contact us via: mandate-team@dh.gsi.gov.uk

The closing date for responses is Friday 27th September 2013.

Responses received after this date may not be read. Consultation responses should be returned to: mandate-team@dh.gsi.gov.uk

Or if you would prefer to send your response by post:

**Mandate Team
Department of Health
Area 229
Richmond House
79 Whitehall
London
SW1A 2NS**

What we will do next

We will read and consider all responses and publish a response to the consultation alongside the publication of the refreshed Mandate in the autumn. The Government response will set out how comments and views shaped the final decisions for refreshing the Mandate to NHS England for 2014 – 2015.

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We would appreciate it if all responses over four pages in length had a summary of the key response points.

Summary of key response points:

GeneWatch UK is a not-for-profit organisation which aims to ensure genetic technologies are used in the public interest. Our response to this consultation focuses on the proposal regarding “Supporting economic growth” in paragraphs 64 to 66 of the consultation and the proposal to change the mandate to refer to the 100,000 genomes project.

GeneWatch UK does not agree that NHS England’s role is to support the recovery of the economy, as this could lead to significant conflicts with the best interests of patients. Excessive use of whole genome sequencing can be (1) bad for health (by expanding the use of unvalidated screening tests and unnecessary preventive medication); (2) bad for the NHS (by encouraging commercial exploitation of patients using personalised marketing, and incurring substantial costs); (3) bad for privacy and patients’ right to choose who gets access to their medical records and genetic data.

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Consultation questions

Refreshing the mandate

Question 1: What views do you have on the proposed approach to refreshing the Mandate?

Question 2: What views do you have on assessing NHS England's progress to date against the objectives?

Helping people live well for longer

Question 3: What views do you have on the proposal to help people live well for longer?

Managing ongoing physical and mental health conditions

Question 4: What views do you have on using the refreshed Mandate to reflect the plans to strengthen A&E services?

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| <p>Question 5: What views do you have on the proposal to reflect NHS England's ambition to diagnose and support two-thirds of the estimated number of people with dementia in England?</p> | |
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Helping people recover from episodes of ill health or following injury

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| <p>Question 6: What views do you have on updating the Mandate to make it a priority for NHS England to focus on mental health crisis intervention as part of putting mental health on a par with physical health?</p> | |
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| <p>Question 7: What views do you have on the proposals to ask NHS England to take forward action around new access and / or waiting time standards for mental health services and IAPT services?</p> | |
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Making sure people experience better care

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| <p>Question 8: What views do you have on the ambitions and expectations for the vulnerable older people's plan?</p> | |
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| <p>Question 9: What views do you have on how we should achieve our ambitions on the vulnerable older people's plan, particularly on how to strengthen primary care?</p> | |
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| <p>Question 10: How should the ambitions for vulnerable older people be reflected in the refreshed Mandate?</p> | |
| <p>Question 11: What views do you have on updating the Mandate to reflect the Francis inquiry and the review of Winterbourne View hospital?</p> | |
| <p>Question 12: What views do you have on updating the objective to reflect NHS England's role in supporting person centred and coordinated care?</p> | |
| <p>Question 13: What views do you have on updating the existing objective to reflect the pledges in <i>Better health outcomes for children and young people</i>?</p> | |
| <p>Question 14: What views do you have on updating the existing objective to reflect the challenge for NHS England to introduce the 'friends and family test' to general practice and community and mental health services by the end of December 2014 and the rest of NHS funded services by the end of March 2015?</p> | |

Providing safe care

Question 15: What views do you have on these proposals to improve patient safety?

Transforming services

Question 16: What views do you have on the proposal to update the Mandate for NHS England to work with Monitor towards a fair playing field for providers?

Question 17: What views do you have on the proposal for Government to provide additional leadership on delivery of agreed pre-existing Government commitments?

Question 18: What views do you have on the proposal to update the objective to challenge NHS England to support the NHS to go digital by 2018?

Question 19: What views do you have on the proposal to be more explicit on the expectation around reporting?

Supporting economic growth

Question 20: What views do you have on the proposals to update the objective in asking NHS England to support the recovery of the economy where they can make an important contribution?

GeneWatch UK does not agree with the proposed update to the objective. The best interests of patients are not automatically coincident with using NHS data to support economic growth. In particular, introducing new genomic screening tests has the potential to harm health and the NHS if such tests do not meet medical screening criteria. The 100,000 genomes project is an attempt to create a market for whole genome sequencing in the NHS that may go well beyond what is necessary and useful for patients. It is a pilot project for a proposal by the Human Genomics Strategy Group and the Wellcome Trust to sequence and store the whole genomes of everyone in the population as attachments to their NHS England medical records. There are certainly useful applications for whole genome sequencing (e.g. for persons with unidentified genetic disorders) but there are problems with the 100,000 genomes project as currently conceived, including:

- Whether this is a good use of resources [1] ;
- Poor ethical standards, particularly the "ethics" report's proposal that no one using the NHS in England will be able to have genetic data collected without it being shared with government-funded institutes and private companies worldwide without people's knowledge or consent [2];
- The blurring of the distinction between risk assessments as research results, and the clinical use of tests (including screening tests) with established validity and utility.

GeneWatch UK does not agree that NHS England's role is to support the recovery of the economy, as this could lead to significant conflicts with the best interests of patients. Excessive use of whole genome sequencing can be (1) bad for health (by expanding the use of unvalidated screening tests and unnecessary preventive medication); (2) bad for the NHS (by encouraging commercial exploitation of patients using personalised marketing based on stored genomes and health data, and incurring substantial costs for infrastructure and unnecessary tests and treatments); (3) bad for privacy and patients' right to choose who gets access to their medical records and genetic data [3].

References:

[1] 'Big science', big hype, big mistake. Times Higher Educational Supplement. 27th June 2013.

<http://www.timeshighereducation.co.uk/comment/opinion/opinion-big-science-big-hype-big-mistake/2005124.article>

[2] Department of Health commissioned working group (2003): recommendations on ethics.

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| | <p>https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/210830/ethics_advice_letter_to_CMO.pdf Part of: Mapping 100,000 genomes: strategic priorities, data and ethics.</p> <p>https://www.gov.uk/government/publications/mapping-100000-genomes-strategic-priorities-data-and-ethics</p> <p>[3] A DNA database in the NHS: Your freedom up for sale? GeneWatch UK. May 2013.</p> <p>http://www.genewatch.org/uploads/f03c6d66a9b354535738483c1c3d49e4/DNAinNHS_GWbriefing_fin.pdf</p> |
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Making better use of resources

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| <p>Question 21: What views do you have on the proposals to make better use of resources?</p> | |
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Confidentiality of information

If you would like any part of the content of your response (as distinct from your identity) to be kept confidential, you may say so in a covering letter. We would ask you to indicate clearly which part(s) of your response are to be kept confidential. We will endeavour to give effect to your request but as a public body subject to the provisions of the Freedom of Information legislation, we cannot guarantee confidentiality.

We manage the information you provide in response to this consultation in accordance with the Department of Health's Information Charter. Information we receive, including personal information, may be published or disclosed in accordance with the access to information regimes (primarily the Freedom of Information Act 2000 (FOIA), the Data Protection Act 1998 (DPA) and the Environmental Information Regulations 2004).

If you want the information that you provide to be treated as confidential, please be aware that, under the FOIA, there is a statutory Code of Practice with which public authorities must comply and which deals, amongst other things, with obligations of confidence. In view of this, it would be helpful if you could explain to us why you regard the information you have provided as confidential. If we receive a request for disclosure of the information we will take full account of your explanation, but we cannot give an assurance that confidentiality can be maintained in all circumstances. An automatic confidentiality disclaimer generated by your IT system will not, of itself, be regarded as binding on the Department.

The Department will process your personal data in accordance with the DPA and, in most circumstances this will mean that your personal data will not be disclosed to third parties.