



**Genetic Alliance UK**  
Supporting. Campaigning. Uniting.

## Consultation Response

### Setting the mandate to NHS England for 2016 to 2017

Genetic Alliance UK response, 23<sup>rd</sup> November 2015

#### Introduction

1. Genetic Alliance UK is the national charity working to improve the lives of patients and families affected by all types of genetic conditions. We are an alliance of over 180 patient organisations. Our aim is to ensure that high quality services, information and support are provided to all.
2. Rare Disease UK (RDUK) is a campaign run by Genetic Alliance UK. It is the national alliance for people with rare diseases and all who support them. RDUK is a stakeholder coalition brought together to work with Government to develop a UK Strategy for Rare Diseases, which was published by the Department of Health in November 2013. RDUK continues to campaign for the implementation of the Strategy across all four home nations of the UK.
3. SWAN UK (Syndromes Without A Name) is a patient and family support service run by Genetic Alliance UK. It is a UK-wide network providing information and support to families of children without a diagnosis. It works to support the development of high quality information and services for families of children affected by undiagnosed genetic conditions and raise public and professional awareness of undiagnosed genetic conditions and the unique challenges faced by affected families.

#### Question 2 - Is there anything else we should be considering in producing the mandate to NHS England?

4. In November 2013, the Department of Health published the UK Strategy for Rare Diseases, which seeks to improve services and research and to help reduce the barriers that people with rare diseases have to overcome when living with their condition. It is the first time since the establishment of the NHS that patients and families affected by rare conditions have had a clear and specific commitment from the Governments of the UK that their healthcare needs will be met. The UK Strategy for Rare Diseases is signed by the health ministers of each country in the UK, with cross-party support, and contains 51 distinct commitments that are designed to improve health and social care for rare disease patients. The challenge now is to maintain progress, to ensure the promise of the Strategy becomes reality in the years ahead.
5. It is key to the coordinated and rational implementation of the UK Strategy for Rare Diseases that it is included as a strategic objective in the Government's mandate for NHS England. Following the Strategy's publication, NHS England was defined by the Department of Health as the key implementation authority in England. Though a "Statement of Intent" was published in February 2014, very little strategic activity has happened since. Where there has been some activity within certain teams at NHS England it seems to be primarily the result of our organisation's campaign rather than the adoption of Department of Health approved policy.

Unit 4D, Leroy House, 436 Essex Road, London, N1 3QP  
+44 (0) 20 7704 3141  
[contactus@geneticalliance.org.uk](mailto:contactus@geneticalliance.org.uk)  
[www.geneticalliance.org.uk](http://www.geneticalliance.org.uk)

Registered charity numbers: 1114195 and SC039299  
Registered company number: 05772999

6. Reference to policy priorities, such as implementation of the UK Strategy for Rare Diseases, as objectives in the annual mandate would substantially increase the likelihood of achieving progress in these areas.
7. We therefore ask that in producing the mandate to NHS England, the Department of Health references not only what it considers to be the most strategically important objectives for the health service going forward, but also the policy commitments it has made but not yet implemented. By utilising the potential for better alignment between government policy and NHS strategy provided by the setting of the new mandate, the DH could take a vital step toward the full and prompt implementation of the UK Strategy for Rare Diseases. In contrast, omitting to mention or consider these commitments may lead to further delays in their implementation, leaving patients and families affected by life limiting rare diseases struggling to get a diagnosis and to access services that meet their needs.

**Question 3 What views do you have on our overarching objective of improving outcomes and reducing health inequalities, including by using new measures of comparative quality for local CCG populations to complement the national outcomes measures in the NHS Outcomes Framework?**

8. We enthusiastically support the objective of improving outcomes and reducing health inequalities. We note that the draft mandate being consulted on acknowledges that differences in health status or in the distribution of health determinants exist not only between different population groups based on social, economic or geographic factors, but also recognises that inequalities also occur between different patient groups. The mandate mentions a health gap between the general population and people with dementia, learning disabilities, autism spectrum conditions or mental health conditions, and identifies these as targets for improvement. We believe that the rare disease patient community should be added to this list of patient groups experiencing disparities in health outcomes.
9. The UK government published the UK Strategy for Rare Diseases in 2013 as a first step to addressing the unmet healthcare needs of the millions of people living with a rare disease in the UK, and who currently struggle to get access to integrated care and support from the NHS. Genetic Alliance UK believes that an effectively implemented plan for rare diseases has the opportunity to address many of the inequalities currently experienced by patients affected by rare diseases and their families.
10. We recognise the importance of tools such as the NHS Outcomes Framework for local transparency and accountability, providing a means for benchmarking progress within each local CCG and across CCGs, and driving sector-led improvement. However, we consider it problematic that the NHS Outcomes Framework 2015 to 2016 contains no outcomes measures applicable to patients with rare diseases, unlike for those with dementia or mental illness for example. It is thus unable to provide transparency about the comparative quality of care and outcomes for those living with a rare condition compared to the broader group of individuals living with a long term condition.
11. If the NHS Outcomes Framework is intended, as the document itself suggested, to be a tool which reflects the current landscape of the health and care system, it is important not to focus solely on the most common conditions, as this can leave a blind spot of rarer conditions adding up to more than 3.5 million Britons. We therefore hope that the work currently underway to develop “a new scorecard” will permit these health inequalities experienced by rare disease patients in access to services, in experiences and in outcomes, to be measured and to be reduced.
12. There are several aspects to health inequality experienced by rare disease patients: between people living with the same rare condition; between people living with one rare condition and those with a different rare condition; between people living in communities with a high prevalence of rare conditions, and those in communities with a lower prevalence; and between people living

with rare conditions and those living with common conditions. Many of the most important outcomes, such as relating to time to diagnosis and access to treatment for those with rare diseases, are not easily measurable in the manner expected of framework indicators at the moment.

13. The challenges of identifying suitable indicators to add to the next version of the NHS Outcomes Framework that would help us understand how well we are improving and protecting the health of people affected by rare and genetic conditions in fact demonstrate the blind spot of the current outcomes framework process. However, this is evidence of the need to better understand how we can both achieve and measure these positive health outcomes, such as conducting further work to fully specify the indicators, rather than a sign that this health inequality is not important.

#### Question 4 - What views do you have on our priorities for the health and care system?

14. As mentioned above, it is our experience that if a policy objective is not explicitly mentioned in the mandate document, even if it is official Government policy or contained in a document published by the Department of Health, such as the UK Strategy for Rare Diseases, NHS England does not necessarily deliver it.
15. We therefore believe that in order to strengthen NHS England's obligations to adopt innovation in an appropriate and rapid manner, that the mandate for 2016 to 2017 should also include the objective of implementing the recommendations of the Accelerated Access Review. Due to slippage in the timetable, the final report of the Accelerated Access Review is due to be published April 2016, approximately the same time that this mandate will come into force. We are concerned that if the mandate does not specifically state that NHS England must implement its recommendations, these important reforms may be delayed for a full year until the next refreshing of the mandate.

#### Question 5 - What views do you have on how we set objectives for NHS England to reflect their contribution to achieving our priorities?

16. While we can see how the objectives contained in the consultation document have been set in order to reflect their relationship to the government's priorities, we feel that there should be far more detail provided as to what specifically should be delivered in each of these areas. The objective setting process in the mandate has the potential to more clearly demonstrate the alignment between government policy and NHS strategy, and provides one of the few formal opportunities for both the populace and the government to hold NHS England accountable for activities. In this time of budgetary constraints, we are concerned that all targets and objectives must be made as explicit and mandatory as possible.
17. The selection of priorities, objectives and outcomes measures in the mandate and the NHS Outcomes Framework are important documents in that they communicate what patients can expect to receive from their NHS, and NHS England is legally mandated to deliver. This annual process presents a vital opportunity to formally recognise the responsibility that NHS England, and the NHS bodies of the devolved nations, has in delivering the commitments of the UK Strategy for Rare Diseases. Genetic Alliance UK would welcome an opportunity to meet with the Department of Health to discuss how the commitments made within the UK Strategy of Rare Diseases could be appropriately incorporated into this mandate and outcome framework, including such as how an appropriate indicator might be designed.



Alastair Kent OBE  
Director