

Liberating the NHS:

Transparency in outcomes
- a framework for the

NHS

Your response to the consultation questions

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CHAPTER 2: Scope, purpose and principles of an NHS Outcomes Framework	
Principles	
<p>1. <i>Do you agree with the key principles which will underpin the development of the NHS Outcomes Framework (page 10)?</i></p>	<p>Patient Reported Outcome Measures The emphasis on Patient Reported Outcome Measures (PROMs) in this process is very welcome. We hope PROMs will improve the measurement and monitoring of healthcare for genetic, long term, and rare conditions where curative interventions are lacking.</p> <p>However the development of valid (scientifically) and appropriate (from a patient perspective) PROMs will take time and need research. Genetic Alliance UK would like to see explicit commitment to developing these, and to making resources available to academics, patient organisations and others to bring this about.</p> <p>Properly developed PROMs will improve quality in the NHS, boost staff engagement and reduce waste by helping secure targeted use of scarce expertise and resources.</p> <p>Monitoring against international comparators Genetic Alliance UK supports monitoring against international comparators. This will add important benchmarks for the evaluation of NHS services, especially for rare genetic disease patients where UK expertise may be in short supply.</p> <p>As the consultation document has recognised, international comparison is not easy. Care must be taken to ensure that like is being compared with like.</p> <p>For example; in Germany the number of genetic tests/unit of population is much higher than in the UK, but the number of clinical geneticists is fewer, making comparison between the effectiveness of clinical genetic services hard to establish. Cultural differences, and differences in reimbursement methods can also make it hard to draw comparisons.</p>
<p>2. <i>Are there any other principles which should be considered?</i></p>	<p>Access to available services The aim to follow principles set out in High Quality Care for All (2008), are welcome; but commitments to achieve quality and</p>

	<p>excellence should follow the implementation of minimum standards of healthcare delivery.</p> <p>The elimination of a postcode lottery in access to services and support should be named as an important first step to improving quality and delivering equity.</p> <p>Family We would extend the focus on patients and professionals to include relatives and family members, especially where genetic risk is an issue, if the service is truly to take account of end-user perspectives.</p>
<p>3. <i>How can we ensure that the NHS Outcomes Framework will deliver more equitable outcomes and contribute to a reduction in health inequalities?</i></p>	<p>Health inequalities should not be seen as solely access and socio-economic issues. There are stark inequalities in the care and allocation of funds that patients affected by a rare cancer and patients affected by a rare genetic disorder can expect to receive.</p> <p>This inequality should be recognised alongside the recognition that outcome measures will, however they are designed and positioned, influence health priorities in the NHS. Inevitably, as care providers strive to appear in a good light on the scorecard mentioned in paragraph 2.8 (page 10), they will take account of the measured outcomes. It is therefore essential that outcome measures are designed that do not favour more common conditions such as heart disease and obesity over other conditions.</p>
<p>4. <i>How can we ensure that where outcomes require integrated care across the NHS, public health and/or social care services, this happens?</i></p>	<p>Joined up service provision across boundaries is essential to high quality care. This is not only important between the NHS, social care, and public health at local level, but also within the NHS, "vertically", where elements of care provided in specialist centres are integrated with those provided by GP consortia or other authorities. The NHS Commissioning Board should ensure that its monitoring framework is sufficiently sensitive to capture both the vertical and the horizontal dimensions in good quality care.</p> <p>Genetic Alliance UK has carried out practical research in this area. The Family Route Maps Project is one of these studies: www.geneticalliance.org.uk/projects/familyroutemap.htm The aim of this project was to assist families' access to care and support in the NHS.</p> <p>Key findings of this work are:</p> <ul style="list-style-type: none"> * Communication between healthcare professionals is important to ensure that care is properly coordinated within a multidisciplinary team, and to counter fragmentation through organisational boundaries. The project reported many instances of patients having to repeat themselves to healthcare professionals. This lesson should be carried across to integration of care between the NHS, public health, and social care services. * Patients' access to information is valuable to assist their navigation between care providers. Both good quality

	<p>communication from their healthcare provider, and good quality information in material form, allow patients to understand better which components of their care they should be accessing from which care provider. We expect new HealthWatch bodies to contribute to this role.</p> <p>Genetic Alliance UK is continuing this work with the project Routemaps for Rare Conditions, a project funded by the Department of Health. This will develop a practical and cost-effective framework for improving information, access and coordination of health and social care services for individuals and families with a wide range of rare genetic conditions. This pilot scheme will support eight user-led support groups to develop a series of condition specific Route Maps. A toolkit and a written methodology will be created alongside the Route Maps so that in the future other groups can develop a Route Map for their own condition.</p>
Five Domains	
<p>5. <i>Do you agree with the five domains that are proposed in figure 1 (page 14) as making up the NHS Outcomes Framework?</i></p>	<p>Domain 1: "Preventing people from dying prematurely" should also consider humane palliation of symptoms at the end of life, and not seek to unnecessarily prolong life beyond the point at which it can be agreed to have lost reasonable quality.</p> <p>A good death and proper support for the living is an essential component of good health care. Prevention of premature death is clearly important, but a humane and sensitively supported death is also a valuable health outcome. (This should not be taken as advocacy for euthanasia by the Genetic Alliance UK).</p> <p>Genetic Alliance UK welcomes the recognition of, and focus upon, enhancing quality of life for people with long-term conditions in Domain 2.</p>
<p>6. <i>Do they appropriately cover the range of healthcare outcomes that the NHS is responsible for delivering to patients¹?</i></p>	<p>Genetic Alliance UK believes these five domains fail to take account of the familial impact of chronic disease, whether these are consequences of a genetically determined condition or the consequences of caring for an affected family member.</p> <p>It is important to capture the importance of the quality of life and health expectations of family members and carers, as this is an important component of healthcare experience for those affected by chronic disease. This should perhaps be an addition to the scope of Domain 2 and Domain 4.</p> <p>It is important to ensure that the lives, and indeed health, of carers and families are not unreasonably impaired by the delivery of health care to the affected patient. A measure of success for this has the potential to create direct health gain for family members as well</p>

¹ **Please note** that public health and prevention will be covered in a separate consultation, linking to this framework where appropriate

	as the delivering substantial social, psychological and economic benefits to individuals, families and society.
Structure	
7. <i>Does the proposed structure of the NHS Outcomes Framework under each domain seem sensible?</i>	<p>NICE Quality Standards</p> <p>Genetic Alliance UK supports the concept of the design of quality standards to inform the expected quality of care that a patient can expect to receive.</p> <p>However, the lack of commitment to patient involvement in the design of quality standards is concerning. Paragraph 2.30 (page 16) states that these will be developed with NICE working in partnership with clinicians, leading experts and healthcare specialists. In many disease areas, patients are the leading experts; we would like to see patient input to this process become a requirement.</p> <p>NICE's track record on patient involvement is not exemplary. In Genetic Alliance UK's, and our members' experience, the level of patient involvement, whether cursory or genuine, in NICE's work varies according to the ethos of those leading meetings and processes. Patients should be allowed to contribute to the design of quality standards on an equal basis to other stakeholders.</p> <p>In addition to these concerns, we believe 150 quality standards would leave the majority of health conditions unsupported. All patients should be able to access a pathway outlining the quality of care they can expect.</p>

CHAPTER 3: What would an NHS Outcomes Framework look like?	
Domain 1 – Preventing people from dying prematurely	
8. <i>Is 'mortality amenable to healthcare' an appropriate overarching outcome indicator to use for this domain? Are there any others that should be considered?</i>	Genetic Alliance UK has concerns with the concept of overarching indicators, and proposed improvement areas; we direct you to our answer to question 27.
9. <i>Do you think the method proposed at para 3.7-3.9 (page 20) is an appropriate way to select improvement</i>	Genetic Alliance UK has concerns with the concept of overarching indicators, and proposed improvement areas; we direct you to our answer to question 27.

<i>areas in this domain?</i>	
10. <i>Does the NHS Outcomes Framework take sufficient account of avoidable mortality in older people as proposed in para 3.11 (page 21)?</i>	Genetic Alliance UK does not have a comment to make.
11. <i>If not, what would be a suitable outcome indicator to address this issue?</i>	Genetic Alliance UK does not have a comment to make.
12. <i>Are either of the suggestions at para 3.13 (page 21) appropriate areas of focus for mortality in children? Should anything else be considered?</i>	We support the argument for including measures to understand mortality specifically relating to children.
Domain 2 – Enhancing the quality of life for people with long-term conditions	
13. <i>Are either of the suggestions at para 3.19 (page 24) appropriate overarching outcome indicators for this domain? Are there any other outcome indicators that should be considered?</i>	Genetic Alliance UK has concerns with the concept of overarching indicators, and proposed improvement areas; we direct you to our answer to question 27.
14. <i>Would indicators such as those suggested at para 3.20 (page 24) be good measures of NHS progress in this</i>	Genetic Alliance UK has concerns with the concept of overarching indicators, and proposed improvement areas; we direct you to our answer to question 27.

<p><i>domain? Is it feasible to develop and implement them? Are there any other indicators that should be considered for the future?</i></p>	
<p><i>15. As well as developing Quality Standards for specific long-term conditions, are there any cross cutting topics relevant to long-term conditions that should be considered?</i></p>	<p>When considering quality of life, the patient and the family's situation needs to be considered as a whole. Diseases rarely occur in isolation, co-morbidity is the rule rather than the exception for most people, diseases rarely follow a typical course, and critical factors impacting on quality of life can and do vary from individual to individual and between families. Outcome measures need to be sufficiently flexible to take account of this.</p> <p>The relevance of PROMs to this dimension is obvious. We refer back to our answer to question 1 regarding the need for R&D to develop robust, appropriate methods to capture these. Patient organisations' input to such a programme will be crucial to its success and to sustaining its credibility.</p> <p>Quality of life is not dependent solely on services provided by the NHS. Effective interventions from elsewhere can contribute substantially to this, and measures must integrate data from other sources in the public, private and voluntary sectors.</p>
<p>Domain 3 - Helping people to recover from episodes of ill health or following injury</p>	
<p><i>16. Are the suggestions at para 3.28 (page 27) appropriate overarching outcome indicators for this domain? Are there any other indicators that should be considered?</i></p>	<p>Genetic Alliance UK has concerns with the concept of overarching indicators, and proposed improvement areas; we direct you to our answer to question 27.</p>
<p><i>17. What overarching outcome indicators could be developed for this domain in the longer term?</i></p>	<p>Genetic Alliance UK has concerns with the concept of overarching indicators, and proposed improvement areas; we direct you to our answer to question 27.</p>

<p>18. <i>Is the proposal at paras 3.30-3.32 (page 28-29) a suitable approach for selecting some improvement areas for this domain? Would another method be appropriate?</i></p>	<p>Genetic Alliance UK has concerns with the concept of overarching indicators, and proposed improvement areas; we direct you to our answer to question 27.</p>
<p>19. <i>What might be suitable outcome indicators be in these areas?</i></p>	<p>Genetic Alliance UK has concerns with the concept of overarching indicators, and proposed improvement areas; we direct you to our answer to question 27.</p>
<p>Domain 4 - Ensuring people have a positive experience of care</p>	
<p>20. <i>Do you agree with the proposed interim option for an overarching indicator set out at para 3.43 (page 32)?</i></p>	<p>Genetic Alliance UK has concerns with the concept of overarching indicators, and proposed improvement areas; we direct you to our answer to question 27.</p>
<p>21. <i>Do you agree with the proposed long term approach for the development of an overarching outcome indicator set out at para 3.44 (pages 32-33)?</i></p>	<p>Genetic Alliance UK has concerns with the concept of overarching indicators, and proposed improvement areas; we direct you to our answer to question 27.</p>
<p>22. <i>Do you agree with the proposed improvement areas and the reasons for choosing those areas set out at para 3.45 (pages 33-34)?</i></p>	<p>Genetic Alliance UK has concerns with the concept of overarching indicators, and proposed improvement areas; we direct you to our answer to question 27.</p>

<p>23. <i>Would there be benefit in developing dedicated patient experience Quality Standards for certain services or client groups? If yes, which areas should be considered?</i></p>	<p>Quality standards, whether established by NICE or adopted/adapted from other sources must adequately reflect and respect patient perceptions of quality, and must measure those aspects of conditions which patients and families deem to be important as well as those currently amenable to direct intervention and/or measurement. Specialist services may not fit easily into frameworks developed for common conditions, and measures of quality must be appropriate to the service delivered (including the avoidance of harm where appropriate in respect of services such as clinical genetics).</p>
<p>24. <i>Do you agree with the proposed future approach for this domain, set out at paras 3.52–3.54 (pages 36-37)?</i></p>	<p>Genetic Alliance UK supports this approach and looks forward to contributing to these processes in the future.</p>
<p>Domain 5 - Treating and caring for people in a safe environment and protecting them from avoidable harm</p>	
<p>25. <i>Do you agree with the proposed overarching outcome indicator set out in para 3.58 (page 38)?</i></p>	<p>Genetic Alliance UK has concerns with the concept of overarching indicators, and proposed improvement areas; we direct you to our answer to question 27.</p>
<p>26. <i>Do you agree with the proposed improvement areas proposed at para 3.63 (page 39-40) and the reasons for choosing those areas?</i></p>	<p>Genetic Alliance UK has concerns with the concept of overarching indicators, and proposed improvement areas; we direct you to our answer to question 27.</p>

GENERAL CONSULTATION QUESTIONS

27. What action needs to be taken to ensure that no-one is disadvantaged by the proposals, and how do you think they can promote equality of opportunity and outcomes for all patients and, where appropriate, NHS staff?

Whilst an Outcomes Framework is a useful tool it can be associated with many of the same problems that have affected process indicators: incentives can be created that take people away from their focus on the clinical needs of the patient and move them towards the items which are counted in the outcomes framework.

The concepts of overarching indicators, and of improvement areas, unavoidably disadvantage those affected by conditions which are not being highlighted, supported or boosted with these methods of focusing improvement and measuring results.

Paragraphs 3.7 and 3.8 are a good example of this issue; heart disease, stroke and cancer are singled out as improvement areas for Domain 1.

The combination of these three causes of mortality must deliver a majority of all mortality in the UK. As such large contributors to mortality, we would expect them to receive a great deal of attention, support and investment without designation as improvement areas.

Genetic Alliance UK represents those affected by conditions with a genetic cause. There are more than 6000 of these conditions, and a large number of them are rare or poorly understood; they may lack a comprehensive treatment protocol, or any medicinal therapy. We cannot provide an accurate figure of their incidence because they are not recorded properly by current healthcare data collection systems. Our conservative estimate is that genetic disease affects more than 3 million people in the UK.

(This figure is based on European Commission estimates of the incidence of rare disease, 80% of which is genetic, combined with recognised incidence of genetic disease outside the threshold for rare disease.)

Taken together, these 6000 conditions create a significant burden on the NHS. If the NHS is to be judged on five overarching indicators, with three or four improvement areas each, it is vital that these indicators are designed in such a way that they do not marginalise those that have complex, rare, or undiagnosed conditions.

To continue the examination of Domain 1, of the 15 indicators describing both improvement areas and overarching indicators, none of them describe a health outcome that could be reliably used to focus on inherited disease. Only three measures have any relevance to any of the conditions that our members represent, and these are buried within infant mortality and cancer.

	<p>Genetic Alliance UK therefore believes that Domain 1 does not describe success or failure in the treatment of the 3 million plus patients that we represent.</p> <p>Examining Domain 2, "Enhancing quality of life for people with long-term conditions", a domain that should describe the care of many of those whom we represent; of the 24 indicators for improvement areas, only 1 covers tangible outcomes for a patient population covered by Genetic Alliance UK's umbrella. 16 indicators do not describe any of our members, and the remainder will hide individual conditions behind vague, broad indications.</p> <p>In its current state, it is clear to Genetic Alliance UK and our members, that this system of measuring outcomes and prioritising improvements will neglect the vast number of conditions with small patient populations, which taken together deliver a significant health burden to the UK.</p> <p>Appropriately weighted PROMs may help to counter-balance this tendency. Case by case measures will be needed to ensure the relevance of the outcomes framework adopted especially where these are relating to rare diseases that are complex and which cross the boundaries of a number of clinical specialisms.</p>
<p>28. <i>Is there any way in which the proposed approach to the NHS Outcomes Framework might impact upon sustainable development?</i></p>	<p>Genetic Alliance UK does not have a comment to make.</p>
<p>29. <i>Is the approach to assessing and analysing the likely impacts of potential outcomes and indicators set out in the Impact Assessment appropriate?</i></p>	<p>Genetic Alliance UK does not have a comment to make.</p>
<p>30. <i>How can the NHS Outcomes Framework best support the NHS to deliver best value for money?</i></p>	<p>Genetic Alliance UK does not have a comment to make.</p>
<p>31. <i>Are there any other issues you feel have been missed on which</i></p>	<p>Data collection As we have stated, there are many thousands of different diseases that affect the population of England. Each imposes specific</p>

<p><i>you would like to express a view?</i></p>	<p>requirements on those affected, and services must be responsive to the particular demands of each condition if they are to be effective.</p> <p>A comprehensive image of the burden of disease upon the UK is vital for proper planning and allocation of health resources. Data collected must be sufficiently granular to allow disease specific information to be collected and evaluated, but frameworks should be constructed in ways that allow these disease specific measures to be collapsed into large categories that will promote effective planning, resource allocation, research and meeting of identified staffing needs. The early, robust introduction of ICD11 and its systematic use across the NHS will be an important tool for achieving this.</p> <p>Recognising unwelcome outcomes Whilst the desire of couples for a healthy baby is obvious and completely understandable, and maternity services should strive to achieve this, for some couples this will not be possible due to a genetic disease in the family. Where this is the case then high quality maternity services take the form of enabling an outcome no one would have wished for but which with today's knowledge is unavoidable.</p> <p>Similarly a system for recording outcomes should be able to give proper weight and value to the avoidance of future harms (for example by giving parents the choice not to have a child affected by a severe life limiting genetic disorder).</p>
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ANNEX A: IDENTIFYING POTENTIAL OUTCOME INDICATORS	
Potential Indicators	
<p><i>32. What are the strengths and weaknesses of any of the potential outcome indicators listed in Annex A with which you are familiar?</i></p>	<p>Genetic Alliance UK does not have a comment to make.</p>
<p><i>33. Are other practical and valid outcome</i></p>	<p>Genetic Alliance UK does not have a comment to make.</p>

<i>indicators available which would better support the five domains?</i>	
34. <i>How might we estimate and attribute the relative contributions of the NHS, public health and Social Care to these potential outcome indicators?</i>	Genetic Alliance UK does not have a comment to make.
Principles For Selecting Indicators	
35. <i>Are the principles set out on page 48 and 49 on which to select outcome indicators appropriate? Should any other principles be considered?</i>	Genetic Alliance UK does not have a comment to make.

Please send your responses via email to:

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or via post to:

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You can also respond to this consultation by coming along to one of our regional events for NHS staff and patients which will be held across the country, details of which will be posted on the DH website shortly.

