

Liberating the NHS:

Transparency in outcomes  
- a framework for the

**NHS**

Your response to the consultation questions

Your details	
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Organisation type: e.g. individual, Trust, patient organisation etc	PROFESSIONAL ORGANISATION: The Renal Association is a UK wide organisation representing physicians and scientists that provide, manage and research kidney medicine disorders .
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CHAPTER 2: Scope, purpose and principles of an NHS Outcomes Framework	
Principles	
<p><i>1. Do you agree with the key principles which will underpin the development of the NHS Outcomes Framework (page 10)?</i></p>	<p>The Renal Association welcomes the focus in the Consultation document on clinically important outcomes. The Renal Association's UK Renal Registry has published such outcome measures for over 10 years, allowing comparisons of outcomes between centres and between countries. However, we have learnt about the importance of adjustment for case-mix. Outcomes achieved by different healthcare providers (e.g. dialysis units; transplant units) may differ for reasons other than the quality of care provided, for instance because of variation in the degree of co-morbidity, obesity, health-related behaviours, and social deprivation, and because of variation in the ethnic mix of the population (because some ethnic groups have genetically determined susceptibility to disease). The difficulties in adjusting adequately for case-mix before making centre comparisons (which are inevitable if the proposals in the Outcomes Framework are implemented) have been discussed at length in the academic literature, with some authors concluding that intermediate process measures will remain preferable as a lever for driving up quality (e.g. Lilford et al, British Medical Journal 2007; 335: 648-650). While the question of whether process measures are preferable to outcome measures remains debated, the debate centres around the extent to which outcome measures can be adequately adjusted for case-mix before comparisons are made. The Consultation document, however, makes no mention at all of adjustment for case-mix. Publication of raw outcome data is likely to penalise those providers serving deprived communities or older patients for instance in which baseline co-morbidity and risk is high. Equity of access to healthcare(equality) is an important key principle of the framework so needs considered in these indicators of quality.</p> <p>The other main concern about the proposal to focus on outcomes is the lag time between a change in quality of healthcare and a change in outcomes - particularly for chronic conditions. For instance, a reduction in access to specialist care by nephrologists (a process measure) might result, some years later, in an increased risk of death as a result of late presentation associated with failure to plan</p>

	<p>vascular access for dialysis or to arrange pre-emptive kidney transplantation. Similar concerns occur in other specialties - for instance, an increase in door to balloon times, a highly endorsed process measure in heart disease management, might lead some years later to an increase in heart failure from ischaemic cardiomyopathy. We would argue that the NHS should retain some ability to measure and report nationally on important intermediate process measures, even if these are not part of the suite of measures for which the Secretary of State will be held accountable.</p> <p>Failure to retain some valid process measures will provide an unwelcome opportunity for skeptics to claim that the government is abandoning process measures and targets because it costs money to achieve them, while cynically expecting that any change in outcomes will occur some years later; and that the commitment to quality as measured by outcomes is a way of disguising the fact that quality of care is likely to fall as a consequence of financial pressures. This would be highly regrettable, not least because it would move the focus away from 'doing more for less' by redesign of clinical pathways. Valid process measures are important intermediates that any government dependent on a 5 year election cycle should consider.</p> <p>These concerns - that a focus on outcome measures may distort priorities - are particularly relevant to the care of children, in whom there is a long lag phase between poor care in childhood and outcomes in adult life. High-quality care of children with chronic kidney disease may prevent or delay loss of kidney function and eventual kidney failure, but it would take decades of monitoring for this to show up in 'hard' outcome measures.</p> <p>In addition, it is possible that a focus on short-term, easily collected measures might introduce unintended perverse incentives. For instance, kidney transplantation is considered the best treatment for kidney failure in children because of its beneficial effects on growth and quality of life; but achieving a high transplant rate in children by giving them poorly HLA-matched kidney transplants causes HLA sensitisation, making re-transplantation (often required many years later) very difficult. In this example, the short-term outcome measure would be good, but the long-term outcome would be poor.</p>
<p>2. <i>Are there any other principles which should be considered?</i></p>	<p>A key principle should be cost-efficiency of collecting the outcomes measures. The use of routine healthcare data, electronic if possible, should be the cornerstone of measuring outcomes. Resources spent on collecting such apparently 'routine' data naturally detracts from the academic and professional analysis of the information to make meaningful conclusions and plans. Furthermore the current level of ethical and data protection governance required for what should be routine analysis makes these academic exercises far from routine.</p>
<p>3. <i>How can we ensure</i></p>	<p>Publication of high-quality centre-specific outcomes with adequate</p>

<p><i>that the NHS Outcomes Framework will deliver more equitable outcomes and contribute to a reduction in health inequalities?</i></p>	<p>adjustment for case-mix will not, by itself, drive up the quality of care. With increasing cross-boundary flow of patients, it is even possible that the publication of outcome data will have perverse and unintended consequences - for instance, some centres might find ways of refusing care for high-risk patients, who will then receive their care in a neighbouring centre; the second centre will have poorer outcome measures as a consequence. This was alleged to be the case when New York State published the outcome data for cardiac surgery, for instance. Within the English NHS, this is perhaps less likely, but it is still possible to envisage on a small scale.</p> <p>The UK Renal Registry has found that publication of 'league tables' has not by itself resulted in significant narrowing of the gap between best and worst centre performance for most of the clinical performance measures it reports; and has concluded that more needs to be done to learn about the structures and processes in high-performing centres.</p> <p>The routine reporting of outcome measures stratified by equity measures (age, gender, race, social class, etc) is important. translating the differences into improvement for all centres will require a culture change such that a positive change is as important as reaching some arbitrary target. Furthermore sharing of result and ideas at local, national and international meetings will remain a cornerstone for translating results into improved outcomes for patients. Decentralising some resouces to senior clinicians and their management colleagues will be crucial to this.</p>
<p><i>4. 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>This is challenging but we see an important opportunity here. In our own specialty of renal medicine we have moved in 20 years from a substantially tertiary hospital based approach to a system with clinical representation at most district general hospitals (but not all) and importantly a system now that integrates care with primary care colleagues (Chronic Kidney Disease Quality and Outcomes Framework). This type of integration can be strengthened with novel quality measures of integration perhaps or contractual and operational initiatives that recognise and reward integration.</p>
<p><b>Five Domains</b></p>	
<p><i>5. 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>Yes with some additional suggestions. The Institute of Medicine defined quality of healthcare in 6 domains: safety, timeliness, effectiveness, equity, efficiency, and patient-centredness. We and others would argue for the addition of a seventh domain - sustainability. We suggest that the Outcomes Framework should specifically include measures of timeliness (although these could be specified within the 'patient experience' heading), efficiency, equity, and sustainability, so that quality in these domains is not compromised. We recognise that the explicit inclusion of these domains may represent too great a departure from the existing quality framework; however, it might be possible to ensure that some of these are subsumed within the existing headings. For</p>

	instance, timeliness could be specified within Domain 4; and measures of mortality amenable to healthcare could be provided by quintile of social deprivation and by self-reported ethnicity.
6. <i>Do they appropriately cover the range of healthcare outcomes that the NHS is responsible for delivering to patients<sup>1</sup>?</i>	It is impossible to answer this without seeing the Public Health outcomes framework. The outcomes of many long-term conditions, including kidney disease, are influenced by the interaction of active healthcare (operations, drug treatments, medical and nursing consultations including the provision of advice and information) and so-called public health interventions, such as policies that discourage smoking and excessive intake of salt and calories, and those that encourage exercise and the consumption of fresh fruit and vegetables. In long-term conditions such as kidney disease (but also heart failure, diabetes, and arthritis) there is no single transition at which preventive measures stop being important and at which 'curative' measures take over.
Structure	
7. <i>Does the proposed structure of the NHS Outcomes Framework under each domain seem sensible?</i>	Yes

<b>CHAPTER 3: What would an NHS Outcomes Framework look like?</b>	
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>	As a national comparator, for instance as used by OECD and the Commonwealth fund, mortality amenable to healthcare is of some interest, although it should be noted that the existing international comparisons are with the UK as a whole, and not just with England, whereas these proposals relate only to England. However, it is an extremely 'blunt instrument', because many of the conditions are also amenable to prevention - public health care - and many are also amenable to social care, in that social inequity, poor education, poor housing, and poor employment opportunities are also associated with high mortality from the conditions listed.
9. <i>Do you think the method proposed at para 3.7-3.9 (page 20) is an appropriate way to select improvement areas in this domain?</i>	Not if the current examples in Annex A are used. The selection of these improvement areas carries risks that other important improvement areas will be neglected by providers and commissioners because they are 'under the radar', in just the same way as the process measures introduced by the last government led to 'gaming' of waiting time targets - for instance, the 2-week cancer target was said to disadvantage many patients with clinically

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

	<p>urgent, but non-malignant, conditions.</p> <p>The table at Annex A and the highlighting of conditions amenable to improvement could select inappropriate and arbitrary cut-off points unless there is real understanding of the data sources and cognisance given to the clinical experiences. So, absolute differences in a standardised mortality difference between the UK and a EU average needs cautious interpretation: the example of absolute 'excess' deaths from peptic ulcer disease in the UK is close to that of stroke but as a percentage change is 46% versus 5% for stroke. The fact that stroke is so much more common is a good reason for its selection but this data suggests that peptic ulcer disease causes more deaths per 100,000 than cervical cancer, Hodgkins disease and skin cancer with the hugely anomalous respiratory diseases near the bottom of this short list. Any clinician will hopefully see the problems here. Current death certification processes in UK medicine do not lend themselves to robust measures for such an important framework. Having systems to collect better clinical data to develop robust outcomes should be one quality measure.</p> <p>Adequate attention will have to be given to data quality, and the consultation document gives no detail as to how this will be maintained. For instance, the survival rates for cancers, but also for kidney failure, depend critically on the denominator. In the case of kidney failure, the inclusion of patients who develop kidney failure during the course of a critical illness that results in the patient's death will result in low survival estimates, compared to inclusion only of patients who survive the first 90 days of renal replacement therapy and are thus considered to have 'established' renal failure. The same might well apply to cancer survival, depending on whether patients who present for the first time with terminal cancer are included or excluded from the denominator.</p>
<p>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></p>	<p>We are not sure as it would depend on the level of variation in death rates from chronic disease in older people. We agree that there is likely to be more variation in this age range and thus an area to focus on.</p>
<p>11. <i>If not, what would be a suitable outcome indicator to address this issue?</i></p>	<p>We would favour an estimate of hospital-free survival amongst specified groups of patients. For instance, in patients aged &gt;75 with stage 5 chronic kidney disease and significant co-morbidity, survival is longer amongst those opting to undergo dialysis treatment, but this is achieved at the expense of frequent hospitalisation as well as thrice weekly dialysis sessions, usually also in a hospital setting. Additionally for chronic diseases with improving survival there should be slow and proportional growth in stock numbers registered or recorded with the disease (in the absence of significant immigration in this age range). QOF for primary care could be developed better to encourage/incentivise</p>

	case finding of amenable chronic diseases.
<i>12. 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>	<p>Perinatal deaths and respiratory disease are perhaps 2 of the commonest reasons for premature death in children. Cancer death rates and also rates for rarer inherited diseases would become important if assessed over larger populations not least as some rare diseases have expensive therapy often not uniformly prescribed but potentially highly effective.</p> <p>Deaths from diabetic keto-acidosis in children would be also be worth considering.</p> <p>Treatment of kidney failure in neonates and very young children requires special consideration; here, mortality may not be most appropriate outcome measure. This is because survival may be bought at the price of poor quality of life and repeated hospital admissions. For this reason, a measure of survival free of hospital inpatient admissions might be an appropriate outcome measure for this and other complex chronic conditions in childhood.</p>
Domain 2 – Enhancing the quality of life for people with long-term conditions	
<i>13. 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>	<p>Neither of the proposed measures seem likely to be robust enough to allow valid comparisons between centres in different geographical areas and with different chronic diseases and social structures. These important but highly subjective measures need even more careful adjustment and assessment than the traditional more clearly quantitative measures. They will take time and pilot sites perhaps within national audits and registries to better assess this area would be one way to move these forward.</p> <p>However, we would enthusiastically support the development of indicators that measured both disease-specific quality of life and patient empowerment in specific chronic diseases, including kidney disease.</p>
<i>14. Would indicators such as those suggested at para 3.20 (page 24) be good measures of NHS progress in this domain? Is it feasible to develop and implement them? Are there any other indicators that should be considered</i>	<p>We would welcome the development of Patient-Reported Outcome Measures for patients with chronic disease, and believe that these could eventually be collected direct from patients, in the same way as some patients routinely record their blood pressure and pulse on electronic health diaries. The renal information exchange group has developed <a href="http://www.renalpatientview.org">www.renalpatientview.org</a>, a website that provides patients with their own laboratory test results (with explanations) and clinic letters. This website is now well developed with over 10,000 patients (&amp; relatives/carers) registered. It now allows patients to record their home blood pressure (with the eventual aim of 'writing back' to the renal centre IT system). There is no reason in principle why this could not be extended to routine collection of</p>

<p><i>for the future?</i></p>	<p>QoL data. Such an arrangement would prevent the situation in which staff might 'stand over' patients during completion of a questionnaire, or even complete it for them during an episode of care, but would risk inequity given the variation in access to, and use of, the internet.</p> <p>We do not believe that the EQ-5D is sensitive enough to be used to measure differences in health-related quality of life between different groups of patients or those receiving care in different geographical areas, and would favour the development of nationally endorsed disease-specific PROMs for a range of chronic diseases.</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>The measurement of patient empowerment is complex but important to the 'nothing about me without me' agenda. Patients vary in the extent to which they want to be in control, and this has to be taken into account when measuring empowerment. Nevertheless, collection and publication of measures of empowerment in chronic disease would be a major driver to improve patient experience.</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>Both indicators appear reasonable. In many long-term conditions, hospital readmission is both necessary and desirable, where the alternative is a longer primary spell in hospital: for instance, a patient may be readmitted for vascular access surgery soon after recovery from a major illness that has resulted in kidney failure. However, restriction of the readmission indicator to emergency readmissions may improve the utility of this indicator in chronic diseases, so long as the 'emergency' nature of a readmission could be adequately defined to prevent gaming/coding creep.</p>
<p><i>17. What overarching outcome indicators could be developed for this domain in the longer term?</i></p>	<p>Other indicators relevant to helping people recover from acute illness/injury may be milestones in recovery such as time to standing unaided, time to walking etc in a stroke patient. Capturing such time-line data is an important area for renal medicine too with respect to listing for AV fistula, listing time for transplant etc. Variation in delays in acute and chronic disease management are a major frustration for patients but quite complex to accurately collect in the busy ward areas of the NHS. Preventing predictable acute illness in patients with chronic disease would be worth exploring but in some ways is excluded here in the Figure 6.</p>
<p><i>18. Is the proposal at paras 3.30-3.32 (page 28-29) a suitable approach for selecting some improvement</i></p>	<p>Yes for these acute admissions. However the omission of acute admissions in chronic disease is a major deficiency as these patients with cancer, heart, lung and kidney failure contribute substantially to bed days. Quinn and colleagues (Nephron Clin Pract 2009; 113: c315-320) described the impact of dialysis patients on long stay(&gt;30 days) and readmissions. After adjustment for age&amp;gender, those</p>

<p><i>areas for this domain? Would another method be appropriate?</i></p>	<p>dialysis patients admitted were significantly more likely to have a prolonged admission exceeding 30 days (odds ratio 1.46) than patients hospitalised for other reasons. When the admission was an emergency rather than an elective event, the patient was 4.6 times more likely to be hospitalised for over 30 days.</p>
<p><i>19. What might be suitable outcome indicators be in these areas?</i></p>	<p>The development of acute kidney injury during a hospital admission would be a powerful marker. The recent NCEPOD report 'Adding Insult to Injury' demonstrated powerfully that there were major improvement opportunities in the care of patients at risk of acute kidney injury during hospital admission. The improvements required cross boundaries, being equally relevant for acutely admitted patients to medical, surgical, orthopaedic, and other disciplines. The improvements required are generic, and relate to the initial assessment of the patient (fluid status, presence/absence of sepsis, risk factors) and initial management.</p>
<p>Domain 4 - Ensuring people have a positive experience of care</p>	
<p><i>20. Do you agree with the proposed interim option for an overarching indicator set out at para 3.43 (page 32)?</i></p>	<p>Yes the five themes being : access and waiting; safe, high quality coordinated care; better information, more choice; building closer relationships; and clean, friendly comfortable place to be</p>
<p><i>21. 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>Yes</p>
<p><i>22. 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>Yes</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>Yes provided they are tested and validated and can influence clinical management and not detract with the efforts of collection.</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>yes</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>Yes, but with the reservation that it will be very difficult for regulators and commissioners, used to many years of performance management, to resist the temptation to demand early reductions in the numbers of incidents reported: so the utility of this measure will depend critically on how the three indicators will be combined The expectation that the number of incidents reported will rise, but the severity will fall, rests on the assumption that the most serious incidents are reported reliably, and less serious incidents reported less reliably: but there is no evidence to support this assumption, and considerable evidence that the most serious incidents, often resulting in death, go un-reported.</p> <p>An alternative approach would be to measure the safety culture directly, using an approach similar to that pioneered by Sexton et al; but this could be seen as a process, rather than outcome, measure.</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>Yes.</p>

## GENERAL CONSULTATION QUESTIONS

<p>27. <i>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?</i></p>	<p>Usual Department approaches with respect to consultation with stakeholders especially charities and voluntary organisations.</p> <p>The major problem with PROMs is that the tools, often used to administer it, could discriminate against patients without english as their first language. Furthermore any patient with learning or communications difficulty will tend not to be approached or will not engage in the processes.</p> <p>One major concern is that the outcomes framework will inevitably focus on the outcomes of common conditions, and that this will be to the possible detriment of children and adults with rare diseases. Together, patients with rare diseases are common; as pointed out by the Chief Medical Officer, 1 in 17 people has a rare disease (CMO Report, 2009, p39). Because it would be impossible meaningfully to track and report variations in outcomes of each rare disease individually, there is a danger that treatment of these patients, many of whom have lifelong conditions that are expensive to treat, will be ignored, resulting in inequity. The fact that some rare diseases are more common in certain ethnic minority groups amplifies this concern.</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>A focus on patient-reported outcomes, experience, and empowerment will nearly certainly improve progress towards reduction of carbon output in the NHS. Patients are best placed to detect waste, repetition, and unnecessary redundancy within patient pathways - reduction of which is important for sustainability - and systematic collection of feedback on these aspects of care could, with minimal additional investment, contribute to pathway redesign, improved sustainability, and better patient experience.</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>30. <i>How can the NHS Outcomes Framework best support the NHS to deliver best value for money?</i></p>	
<p>31. <i>Are there any other issues you feel have been missed on which</i></p>	

<i>you would like to express a view?</i>	
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## ANNEX A: IDENTIFYING POTENTIAL OUTCOME INDICATORS

### Potential Indicators

<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>	
<i>33. Are other practical and valid outcome indicators available which would better support the five domains?</i>	The UK Renal Registry ( <a href="http://www.renalreg.org">www.renalreg.org</a> ) is omitted from the list of sources of available indicators. Several of the clinical performance measures used by the UKRR have been adopted as Indicators for Quality Improvement.
<i>34. How might we estimate and attribute the relative contributions of the NHS, public health and Social Care to these potential outcome indicators?</i>	Only population wide studies with extensive patient interviews can assess which service impacted their recent health. Routine linkage of healthcare outcome data with socio-economic data would help understand the unmet needs in this area.

### Principles For Selecting Indicators

<i>35. Are the principles set out on page 48 and 49 on which to select outcome indicators appropriate? Should any other principles be considered?</i>	Yes the principles are excellent.
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Please send your responses via email 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.