



Faculty of Public Health

of the Royal Colleges of Physicians of the United Kingdom

Working to improve the public's health

FPH response to *Liberating the NHS: Transparency in outcomes – a framework for the NHS*

The UK Faculty of Public Health (FPH) is the standard setting body and the leading professional body for public health specialists in the UK. It aims to advance the health of the population through three key areas of work: health promotion, health protection and healthcare improvement. In addition to maintaining professional and educational standards for specialists in public health, FPH advocates on key public health issues and provides practical information and guidance for public health professionals. We welcome the opportunity to respond to the NHS White Paper and contribute to the government's plans for the development of a Public Health Service.

The UK Faculty of Public Health (FPH) welcomes the opportunity to contribute our views on the principles and structure of the outcomes framework. We broadly agree with the principles, and the five domains outlined. However, we believe that a sixth domain should be added; that of "Preventing ill health across the population". While this is not solely the responsibility of the health service, and will involve working with other sectors on the social determinants of health, to abnegate the NHS entirely of this responsibility by not including it would be rash.

1. Do you agree with the key principles which will underpin the development of the NHS Outcomes Framework?

Yes, in general. A note of caution should be made with respect to international comparisons. Even when care is taken to ensure like is being compared with like, those comparisons are fraught with problems, especially with respect to 'attribution'. Cancer 'survival' is an example of so many of the problems. A more detailed explanation of this is given in the response to question 9.

2. Are there any other principles which should be considered?

Efficiency and value for money. Healthcare that delivers little patient benefit at the cost of a great deal of clinical input or financial resource is poor quality, inefficient care. It is imperative that public health expertise is seen as an integral part of developing care pathways and commissioning care.

3. How can we ensure that the NHS Outcomes Framework will deliver more equitable outcomes and contribute to a reduction in health inequalities?

By including issues of value for money/efficiency. Resources diverted to costly but marginally effective treatments disproportionately accessed by affluent patients increase inequalities. Outcomes focused on 'upstream' prevention targeted at those in greatest need will reduce inequalities. Often these interventions will not be directly health service related. Again, the input of public health expertise is integral to this.

4. How can we ensure that where outcomes require integrated care across the NHS, public health and/or social care services, this happens?

These are, of course, process measures not outcome measures: where, when, by whom. This can only be achieved through the development of care pathways and the commissioning of care in accordance with the pathway. This highlights the importance of ensuring that public health is seen as an integral part of the NHS and of commissioning, ensuring complete pathways of care for patients. Care should be a seamless whole, not commissioned in a fragmented way.

Data would need to be gathered to demonstrate progress along the pathway. Electronic recording of clinical activity, linked to pathways, must become routine and will result in improvements in care.

Commissioners will need relevant expertise and sufficient understanding of the local context to ensure that contracts enhance integration and that opportunities for improvement are identified and addressed. Feedback from patients and carers will be essential

A statutory annual public report by the Director of Public Health (DPH) on the health and wellbeing needs of the population and the extent to which these are being met would offer further evidence and leverage for improvement.

Structure of the NHS Outcomes Framework

5. Do you agree with the five outcome domains that are proposed in Figure 1 as making up the NHS Outcomes Framework?

No.. There should also be a sixth domain, which should read: "Preventing ill health across the population". Stopping people dying prematurely is not the same thing; see later points about 'survival'. If the NHS is truly to change from a 'sickness' service to a 'wellness' service, then a domain that expresses that objective explicitly is essential. Preventing disease and supporting people to live more healthily, and therefore reducing the likelihood of them needing health interventions later on in life, will have financial gains in the longer term through a reduced need for future healthcare services. Public health and prevention of disease should remain a focus for the NHS and the new Health & Wellbeing Boards, and not be seen as just the concern of the emerging Public Health Service. If improved health and wellbeing and a reduced need for care are not seen as key health care outcomes, the system risks perpetuating the perverse incentives currently extant: rewards for activity encourage more activity.

Similarly, the first outcome domain is too crude a measurement; outcomes should not merely be measured by premature mortality. Quality of life and wellbeing should also be taken into account, otherwise outcomes may focus disproportionately on certain life-threatening conditions, rather than chronic or long-term ones. Quality of life and length of life are also interrelated. For example, research suggests that people who have ever had contact with mental health services have a mean 8.8 years' shorter life expectancy than controls (Dembling et al, 1999). Pursuing improvements in outcomes related to quality of life does not mean neglecting those that are related to preventing people dying prematurely.

6. Do they appropriately cover the range of healthcare outcomes that the NHS is responsible for delivering to patients?

No. Preventing ill-health should also be regarded explicitly as a healthcare outcome. For example, most clinical interactions offer some potential for advice and/or intervention related to lifestyle, environment, screening or immunisation.

It should be noted that Domain 4 outcomes contribute to effectiveness, and the focus on shared decision-making within the White Paper is welcomed.

7. Does the proposed structure of the NHS Outcomes Framework under each domain seem sensible?

Yes.

DOMAIN 1: PREVENTING PEOPLE FROM DYING PREMATURELY

8. Is 'mortality amenable to healthcare' an appropriate overarching outcome indicator to use for this domain? Are there any others that should be considered?

The overarching indicator is acceptable but any intervention to prevent premature death needs to be evidence-based and cost-effective.

9. Do you think this is an appropriate way to select improvement areas in this domain?

No.

A focus on reducing the burden of disease across a population, and developing interventions which are prevention-focused and that address the determinants of disease would be more appropriate.

Health care interventions are commonly inefficient at changing outcomes, whilst addressing the determinants of disease is highly efficient. Stroke services address a tiny proportion of the disease burden and have little impact: this is particularly so for acute stroke services (thrombolysis). Population reductions in Blood Pressure e.g. through reduced salt intake or proactive treatment of hypertension in Primary Care, have far bigger effects at a fraction of the cost per benefit.

International comparisons in these instances are usually unenlightening. Differences may be due to a number of determinants with differences in healthcare typically contributing only a small difference in outcomes.

"Survival" is open to misinterpretation and misunderstanding. It is the measure of the time between diagnosis and death. The goal is to make the date of death later, even to the extent of beyond the date of death from another cause (changing the cause of death). Changing the date of diagnosis to an earlier one lengthens survival but does so without changing the date of death (the lead-time effect). Furthermore, identifying cancers through screening that would otherwise not have been diagnosed during the life of the patient grossly distorts survival rates without improving real outcomes (the length-time effect). Early detection typically increases the

denominator, thereby improving survival rates, and lengthens survival without delaying death. The impact of early treatment (which has to be early enough for treatment to have an impact, not simply earlier) may be difficult to attribute against these larger effects. One-year survival is particularly prone to the lead-time effect.

Add to this problems with completeness of registration data, the distortions caused by 'death certificate only' registrations and screen detected 'benign' cancers then survival rates are a poor indicator (with differential problems between countries prohibiting comparisons).

A more important measure might be the average age at death (so detecting the delaying of death), but this too is a problem as cancer rates rise with age and we are living longer. Any improvement in survival for those with 'premature' cancer, may be undetectable due to improvements in environmental determinants of cancers and the ageing population. Trends in age-specific mortality may be more productive and comparing such changes internationally may be more valid measures of improvement of performance. Indeed age-specific (e.g. 5-year age bands) average age at death from cancer may be a way forward: this should detect the delaying of the date of death, though any 'signal' may not be detectable against the background noise of random fluctuations.

Establishing evidence based care pathways in cancer to counter variations in clinical practice and then measuring adherence may be more productive in improving quality.

No measure is particularly valid and certainly not good at the attribution of the effects of NHS care.

10. Does the NHS Outcomes Framework take sufficient account of avoidable mortality in older people as proposed?

No.

11. If not, what would be a suitable outcome indicator to address this issue?

This is a very difficult area and great caution is needed. Longer life comes with longer periods of ill-health and disability: the NHS has not resulted in us all living in perfect health into our eighties or nineties and then dying quickly and comfortably. Equally, the framework must not incentivise the use of age in itself as a discriminator for intervention. FPH would be happy to work with the Department of Health to explore ways of addressing this.

12. Are either of these appropriate areas of focus for mortality in children? Should anything else be considered?

Infant mortality remains a general marker of progress and should be used, though again attribution to the NHS is difficult.

Respiratory disease is inappropriate. There are about 100 respiratory deaths each year in England, excluding pneumonia and influenza. Identifying changes therein

against the background noise of random, stochastic variation is just about impossible: every 10 years there would be a change of +/- 30 per cent by chance alone.

DOMAIN 2: ENHANCING QUALITY OF LIFE FOR PEOPLE WITH LONG-TERM CONDITIONS

13. Are either of these appropriate overarching outcome indicators for this domain (LTC)? Are there any other outcome indicators that should be considered?

"percentage of people with long-term conditions where day to day activity is affected";

This is a measure of need not outcome and will worsen with the inexorable demographic changes.

"percentage of people feeling supported to manage their condition"

This is an acceptable intermediate measure of improved health outcome.

14. Would indicators such as these (PROMs and EQ-5D) 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 for the future?

Existing PROM and EQ-5D data should be evaluated for usefulness first.

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?

Current pathways are often inadequate. They are too vague and insufficiently detailed. A good pathway would identify 'cross-cutting' issues including the what, who, where, when, how and why (the why being the evidence based Quality Standards). Adherence to agreed pathways should be measured.

DOMAIN 3: HELPING PEOPLE TO RECOVER FROM EPISODES OF ILLNESS OR FOLLOWING INJURY

16. Are these appropriate overarching outcome indicators for this domain? Are there any other indicators that should be considered?

These two are acceptable.

Conditions that *could be* managed in Primary Care (rather than *usually*) might also be considered. For instance, were the majority of health care of the elderly services moved into primary care settings, giving more responsibility to specialist clinicians to maintain patients' independence within their homes, rather than picking up the pieces of failed care, outcomes should improve. GPs will be given the budgets: they

need to think radically differently about the where, when, and who, about the resources those budgets buy and what they can achieve.

Outpatient referrals that could be managed within primary care could also be considered. Dermatology, rheumatology, could be managed within primary care by current specialist staff (now in large numbers), as they do not need a hospital setting with its associated high tariffs. This would be cheaper and better quality than GPs with a Special Interest. An indicator of inappropriate referrals would be useful, and a driver/incentive for radical change in the way the new Clinical Commissioning Consortia use their funding to ensure appropriate (time place person etc) care is delivered.

17. What overarching outcome indicators could be developed for this domain in the longer term?

Difficult if overarching. Condition specific may be possible.

18. Is this a suitable approach for selecting some improvement areas for this domain? Would another method be more appropriate?

Yes.

19. What might suitable outcome indicators be in these areas?

Better clinical data are needed to deliver on outcome measures.

Outcomes in figure 5 (school, work, independence) could be equally applied here.

DOMAIN 4: ENSURING PEOPLE HAVE A POSITIVE EXPERIENCE OF CARE

20. Do you agree with the proposed interim option for an overarching outcome indicator?

Mostly, but nutrition for patients should be included. Also, most adverse events are not reported. Patients do not like complaining: they are fearful of the consequences for their care. Any system needs to ensure patients do report problems.

21. Do you agree with the proposed long term approach for the development of an overarching outcome indicator?

Yes.

22. Do you agree with the proposed improvement areas and the reasons for choosing those areas?

Yes.

23. Would there be benefit in developing dedicated patient experience Quality Standards for certain services or client groups? If yes, which areas should be considered?

They should be an integral part of all pathways of care with a requirement that clinical notes record routinely these items if clinically relevant.

24. Do you agree with the proposed future approach for this domain?

Yes, see above.

DOMAIN 5: TREATING AND CARING FOR PEOPLE IN A SAFE ENVIRONMENT AND PROTECTING THEM FROM AVOIDABLE HARM

25. Do you agree with the proposed overarching outcome indicator?

Yes. See above.

Patients must be encouraged to report problems and reassured that it will not affect their care.

Whistle blowers should be rewarded not punished.

26. Do you agree with the proposed improvement areas and the reasons for choosing those areas?

Yes.

We suggest that annual reports be required to record each and every adverse event AND the planned response to it.

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?

Outcomes that focus on work related outcomes could potentially disadvantage those out of work.

All outcomes should be Patient Oriented Outcomes, not Disease Oriented Outcomes. Disease Oriented Outcomes focus on small improvements in the duration or severity of disease without assessing whether this makes any real difference to the patient.

28. Is there any way in which the proposed approach to the NHS Outcomes Framework might impact upon sustainable development?

If there is a willingness to focus on maximising outcomes with what we have, rather than obsessing over marginal gain at great cost, then affordable pathways will deliver sustainable development, including ridding the NHS of harmful waste (such as the use of PSA tests to 'diagnose' prostate cancer).

29. Is the approach to assessing and analysing the likely impacts of potential outcomes and indicators set out in the Impact Assessment appropriate?

No additional comments.

30. How can the NHS Outcomes Framework best support the NHS to deliver best value for money?

It should be concerned with what is achieved rather than what is done. And with outcome evidence-based pathways of care that seek to maximise patient outcomes with the resources available so that efficiency will be secured.

31. Is there any other issues you feel have been missed on which you would like to express a view?

The framework does not include any outcomes for related to sensitive and appropriate care for patients, of every age, who are approaching the end of life.

'Right Care' and 'End Of Life' programmes offer a way forward. A desirable outcome would be for a patient to have gone through one of these programmes thereby establishing their personal wishes and preferences: this is not just a process measure as psychologically it represents a beneficial outcome. An outcome of compliance with an agreed individual care pathway is also a measurable and desirable outcome where death is inevitable.

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