

## **Liberating the NHS: Transparency in outcomes – a framework for the NHS**

### **Consultation Response**

#### **NAT (National AIDS Trust)**

##### **A. Introduction**

1. NAT (National AIDS Trust) is the UK's leading charity dedicated to transforming society's response to HIV. We provide fresh thinking, expert advice and practical resources. We campaign for change.
2. NAT supports the proposals to create a focussed set of national outcome goals to provide an indication of the overall performance of the NHS. We believe that having publicly available outcomes against which performance is measured is vital for ensuring health services are accountable and are genuinely meeting patients' needs.
3. There is no mention of HIV in the consultation document and this is a matter for concern. There will be 100,000 people with HIV in the UK by 2011 and this number will continue to grow, simply because HIV is an infectious disease. It is important in identifying Improvement Areas that due account is taken not just of numbers but of the disproportionate impact a condition may have on certain socially excluded or marginalised groups. This is essential if the NHS Outcomes Framework is going to be an effective tool to address health inequalities. We know that amongst men who have sex with men (MSM) and amongst African communities about one in 20 people have HIV, and in some areas the prevalence is much higher - for example, one in ten amongst gay men in London. A comprehensive healthcare service must pay particular attention to a burden of ill-health which is being disproportionately borne by certain communities, especially when already disadvantaged.

##### **B. The NHS Outcomes Framework and Public Health**

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

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

4. The consultation document rightly states that there will 'be outcomes that can only be delivered for patients and carers if the NHS works in partnership with the new public health service that will be created and with social care services' [2.20]. It states that separate outcomes frameworks will be developed for public health and social care to encourage such 'an integrated cross-service approach'. But to achieve such integration we need all services, including the NHS, specifically to have outcomes requirements relating to such cross-service activity.
5. Instead the five domains for the NHS Outcomes Framework cited in the consultation document are limited to individually-focussed clinical care for those diagnosed as ill. Wider public health considerations and prevention are in a footnote explicitly excluded.

6. For HIV this simply makes no sense. The same can be said for all other STIs and indeed we are sure for many other health conditions. As a result the proposals as they stand fail the test of being 'balanced' in accordance with the key principles meant to underpin the development of the NHS Outcomes Framework, which aim to see commissioned a 'comprehensive healthcare service'.

7. HIV is a serious infectious disease. Appropriate and timely treatment and care can have an immense impact on whether an individual passes HIV on to others. It is the NHS above all which undertakes testing and diagnosis and which provides for people with HIV the treatment which will reduce their infectiousness. In addition, services such as contact tracing and partner notification, and clinic-based health advice and counselling all have immense importance in reducing the spread of disease.

8. HIV is both a serious long-term condition and a significant public health challenge as an infectious disease. It is therefore especially hard to judge the NHS White Paper in the absence of the Public Health White Paper which should complement it.

**9. NAT believes it essential that the NHS Outcomes Framework include an additional domain which captures the specific NHS responsibility and contribution to screening, testing and diagnosis, to the prevention of illness and infection and to broader public health. It might be called 'Ensuring public health and prevention benefit from the provision of NHS services'. This domain would be the key 'point of contact' with relevant and integrated outcomes for public health and social care, and thus help ensure full integration of the NHS, the Public Health Service, and Local Authority health improvement and social care services.**

**10. NAT expects that within this domain there will be HIV-specific improvement areas agreed, given the particular cross-cutting relevance of this serious condition to the NHS, to public health and to social care.**

### **C. Domain 2: Enhancing Quality of Life for People with Long-Term Conditions**

#### **Views on Outcome Indicators at Annex A**

11. HIV is an incurable long-term condition and as such should benefit from the indicators and improvement areas proposed for Domain 2: Enhancing Quality of Life for People with Long-Term Conditions. Sadly long-term condition policy to date has not clearly or explicitly included HIV within its scope and remit. The National Service Framework from 2005 limits its reference to long-term neurological conditions, for example. It may well be that the Government has HIV in mind as one of the long-term conditions to which this Domain applies. But this needs to be put explicitly beyond doubt.

12. This has implications for the overarching indicators proposed for Domain 2, where there is reliance on the Labour Force Survey and the GP Patient Survey. Looking at the current versions of these surveys, they do not as yet seem appropriately designed to capture the desired information reliably.

13. In the list of improvement areas for this Domain there is no mention as yet of HIV, but one does read for example of the 'Range of outcome measures for diabetes, 17 years and over'. Similarly **it is appropriate for there to be an Improvement Area under Domain 2 for HIV covering a range of outcome measures. Important work has for example been done across London in collaboration with the Health Protection Agency, agreeing and monitoring such outcomes, and these, with any relevant addition and amendment, should now be rolled out nationally via the Improvement Areas for this Domain.**

14. **These should include CD4 count at diagnosis, emergency hospital admissions, and suppressed viral load one year on from treatment commencement, as well as other relevant, clinically determined areas.**

15. **For most long-term conditions, and certainly for HIV, timely diagnosis is very important if the condition is to be well-managed and morbidity minimised. NAT believes timely diagnosis to be a cross-cutting issue it could be worth considering for all long-term conditions.**

16. NAT is recommending that HIV outpatient care be commissioned by the NHS Commissioning Board, probably at a regional level. The White Paper documentation is not clear on the process of agreeing Improvement Areas for conditions which the NHS Commissioning Board will directly commission itself. But it does not seem appropriate for them simply to be determined by the NHS Commissioning Board itself. **The Secretary of State should ensure that appropriate Improvement Areas are agreed with the NHS Commissioning Board for conditions, such as HIV, which are commissioned by the Board itself.**

#### **D. Quality standards**

17. NAT is supportive of the role of NICE and the proposed development of a library of NICE quality standards. However, we would like reassurances as to how the NICE processes will be conducted. If the process of developing the quality standards is to be genuinely evidence based and inclusive it will take some time. In the interim, until standards are developed, **the Government should ensure, in advance of relevant NICE quality standards being produced, that the many excellent examples of guidance from clinical, professional and other bodies, developed over recent years, are used by commissioners. They should be used also to assess the quality of that commissioning.**

NAT  
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