



Healthy Lives Healthy People: Transparency in Outcomes Proposals for a Public Health Outcomes Framework

A Consultation Response

NAT (National AIDS Trust)

Introduction

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.

This consultation response is NAT's response to the proposed Public Health Outcomes Framework, and highlights the impact of this proposal on people living with HIV. NAT welcomes the Government's vision 'to improve and protect the nation's health and well being and to improve the health of the poorest fastest'.

NAT strongly supports the inclusion of a specific outcome indicator on the proportion of persons presenting with HIV at a late stage of infection, and welcome the Government's acknowledgement of the importance of tackling this important issue.

It is vital that the late HIV diagnosis outcome indicator is retained in the final version of the Public Health Outcomes Framework.

NAT is happy to provide further information on any of the answers below.

Consultation questions

- 1. How can we ensure that the Outcomes Framework enables local partnerships to work together on health and wellbeing priorities, and does not act as a barrier?**

NAT believes nationally agreed outcome indicators are essential to secure equity in public health provision across the country, to ensure that analysis is evidence-based, and that inequalities and the health needs of vulnerable groups are properly addressed.

There is of course a risk in any national Framework or set of indicators that important local needs specific to a particular community are not included. To mitigate this risk it is important that the joint strategic needs assessments and the resultant joint health and wellbeing strategy do not limit their attention solely to the nationally agreed outcome indicators. There must be clear statutory guidance that in addition to the national outcomes framework, local partnerships are free, and indeed encouraged, to identify other outcomes that local data and health inequalities highlight as important, and to report back to local communities on progress in relation to these additional outcomes also.

2. Do you think these are the right criteria to use in determining indicators for public health?

NAT is supportive, in general, of the criteria identified to determine the indicators for public health. In addition,

indicators should be agreed where there is reason to believe that local action by members of the health and wellbeing board could result in significant improvements to that health outcome

and

an indicator should encourage local attention and action to important health outcomes which may otherwise be neglected at the local level (for example, because the condition is stigmatised or because there are not the financial incentives at the local level to address this area of health improvement).

HIV is an instance of how the above criteria would be relevant. Recent DH-funded testing pilots in a variety of local settings have demonstrated the acceptability, feasibility and effectiveness of rolling out HIV testing to reduce late diagnosis. HIV is a stigmatised condition and in the absence in recent years of local policy levers there has, for example, been significant disinvestment in local prevention work. Under the proposed commissioning arrangements, HIV treatment and care are to be commissioned nationally, but prevention and testing are the responsibility of the local Health and Wellbeing Board.

3. How can we ensure that the Outcomes Framework, along with the Local Authority Public Health allocation, and the health premium are designed to ensure they contribute fully to health inequality reduction and advancing equality?

It is important that local authorities are legally required to coordinate planning and commission services to meet health and social care needs comprehensively, in line with NICE Guidelines and with particular attention to health inequalities in their area. To this end the Joint Strategic Needs Assessment and the Joint Health and Wellbeing Strategy developed by the Board must take account of more than just the outcomes included in the framework, and consider the needs of vulnerable groups in the area and the health issues specific to the local population (for example, HIV prevention needs).

Health inequalities need to be assessed not just in terms of poverty but also according to all the protected characteristics of the Equality Act 2010 – gender, race, disability, sexual orientation, religion or belief, and age. But in addition for some of these characteristics, further disaggregation will be needed – overly general analysis could, for example, obscure particular inequalities experienced by African communities (race) or people with HIV (disability). There should also be a requirement on local planning and local partnerships to consider health inequalities experienced by migrants including asylum seekers, refused asylum seekers and those of undetermined residency status as they often experience health inequalities more acutely.

We note with concern the reference in the Impact Assessment at A10 to tackling ‘the gender, age, geographical, or socioeconomic health inequalities that currently exist’,

which is a limited account of health inequality, failing to address, for example, those relating to race, disability and sexual orientation.

4. Is this the right approach to alignment across the NHS, Adult Social Care and Public Health frameworks?

See comment below to Q.11

5. Do you agree with the overall framework and the domains?

Generally agree but no specific comments

6. Have we missed out any indicators that you think we should include?

An indicator promoting safer sexual behaviour, which could be disaggregated by risk group, could go a considerable way towards focussing action on the rising rates of UK-acquired HIV and STI infections. This would, in turn, have a significant public health impact, helping to keep people well and reducing the cost of treatment for HIV and STIs.

It is vital that HIV prevention work be incentivised in the Outcomes Framework or that there are alternative mechanisms to ensure HIV prevention is undertaken - this provision is neglected in the current consultation documents.

Targeted prevention work at a local level is vital to reduce HIV infection in England. However in the current proposals local HIV prevention work has no directly relevant outcome indicator and faces competition for ring-fenced public health funding with issues such as obesity, smoking and alcohol, issues which affect larger numbers and without the same levels of stigma. There is a real risk that HIV prevention targeted to the most at risk communities will not be prioritised and may not be funded locally.

Targeted HIV prevention work is vital in protecting the long term health outcomes of at risk communities. It also has a financial benefit; the HPA have estimated that for every infection prevented up to £360,000 is saved in direct lifetime medical costs, let alone the cost of social care support, the impact on the economy of fewer people able to work and the costs of any onward HIV transmission from the infected person. However, it is less likely that Local Authorities will take these economic considerations into account when weighing up the value of HIV prevention work, as savings in clinical costs will not bring direct cost-benefit to local authorities but rather to the NHS centrally since HIV inpatient and outpatient care will be commissioned by the NHS Commissioning Board.

One challenge in identifying an outcome indicator for the prevention of HIV and STIs is accessing nationally and locally consistent data around sexual behaviour. If an appropriate indicator cannot currently be agreed, it is nevertheless important for Public Health England to explore the development of such a dataset. And it is also important that the indicators are regularly revisited and consulted on so that when the data and knowledge to develop an indicator on HIV and STI prevention has been gathered such an indicator can be incorporated into the framework.

In the absence of such an indicator, **the Government should commit to include wider and community-based HIV and STI prevention work within the comprehensive sexual health services which Public Health England legally require local authorities to commission either within their own local authority area or 'supra-locally'.**

7. We have stated in this document that we need to arrive at a smaller set of indicators than we have had previously. Which would you rank as the most important?

'Proportion of persons presenting with HIV at a late stage of infection' should be ranked as one of the most important indicators and retained in the smaller set of indicators to be agreed.

In 2009 52% of people with HIV were diagnosed late, after the point at which they should have commenced treatment. This equates on average to several years undiagnosed during which time they and their sexual partners could have benefited from safer sex support, and during which time the person with HIV could have begun treatment to maximise its benefits (which include prevention benefits) and minimise costly ill-health.

It is therefore vital that people infected with HIV are diagnosed early both for their long-term health and for public health more generally. Most people with HIV can have an almost normal life expectancy but this is dependent on being diagnosed early enough to begin treatment when it is necessary. Recent figures from the HPA reveal that of those dying of HIV-related illnesses, 73% were diagnosed late.

Additionally evidence shows that the longer someone with HIV remains undiagnosed, the more likely it is that they will require more complex treatment and expensive hospital care. In 2010 London hospitals estimated that a week's stay in an Intensive Care Unit (ICU) was between £14,250 and £25,000. A major Midlands hospital estimated the cost of a week in ICU, before any treatments or other medical interventions, at £8,750 and a week in an ordinary ward at £3,850. Given that the cost of first line HIV treatment in London was £5,485 per annum in 2010, and given that someone not using HIV treatment will, once ill, have repeated admissions to hospital, it is clear that it is much cheaper to test and diagnose early so that people can begin treatment at the point it is needed, rather than at a later stage of infection.

Similarly data from Canada has shown that HIV-related hospital care costs for late presenters are 15 times higher than for those diagnosed and treated in a timely fashion.¹

Late diagnosis of HIV also has a considerable public health impact. A number of recent models have suggested that the majority of HIV transmissions are from the undiagnosed. The undiagnosed are less aware of the risks of transmission and do not benefit from safer sex support to the same degree nor to the reduction of infectiousness that arises from HIV treatment and the suppression of viral load. However, diagnosing people enables them to make the behaviour changes necessary to prevent onward transmission. One study of newly diagnosed HIV-positive men who have sex with men reported that, three months after diagnosis, 76% had eliminated the onward risk of transmission (Fox J et al. Reductions in HIV transmission risk behaviour following diagnosis of primary HIV infection: a cohort of high-risk men who have sex with men. *HIV Med* 2009;10:432–438). Reducing the number of people diagnosed late will help to reduce infection rates and improve public health.

¹ Krentz et al (2008) 'Costs of medical care for HIV-infected patients within a regional population from 1997 to 2006' *HIV Medicine* 9:9 721-30; and see also for additional costs of intensive care in the UK Fowler et al (2006) 'HIV, HAART and overseas visitors' *Sexually Transmitted Infections* <http://sti.bmj.com>

Reducing onward transmission will of course bring significant cost benefits. According to data from the HPA, if all the 3,780 UK-acquired HIV infections diagnosed in 2010 had been prevented, over £32 million annually or £1.2 billion over a lifetime in costs would have been saved.²

The late diagnosis indicator will bring great benefits in addressing health inequalities – contributing to meeting the significant health needs of gay men and of African and Caribbean communities especially and leveraging broader healthcare access and health benefits. For example, a study amongst black Africans diagnosed with HIV of their engagement with health services in the 12 months prior to diagnosis, found 76% had seen their GP, 38% had been to an outpatient service and 15% had been seen in inpatients in the previous years without discussion of HIV or the offer of a test. 49.8% of this group had been diagnosed with late stage disease.³ This starkly demonstrates the health inequality and need which has to be addressed.

Looking at the criteria for indicator inclusion set out in the consultation document, HIV late diagnosis clearly meets them. Late HIV diagnosis is a meaningful indicator which is a major cause of health inequality, disease and premature mortality. There are evidence-based interventions to support the indicator developed, including those in recent pilots funded by the Department of Health and others, and also assessed and identified by NICE in its Public Health Guidance on HIV testing amongst MSM and African communities. The data is available at national and local level already, can be disaggregated by equality strands and progress against the indicator will result in significant health improvements.

In relation to HIV, local authorities need the HIV late diagnosis indicator to promote effective action on HIV at the local level since they will not under the proposed arrangements bear the 'incentivising' direct costs of failings in HIV prevention and testing. The indicator will also play an essential role in counteracting any tendency for stigma to mean HIV is ignored or downplayed as a significant health condition.

A final reason to retain this indicator is that there is not only considerable need (with over half of people with HIV being diagnosed late), but also evidence that testing behaviour can be significantly altered by interventions. In five years, for example, there was an increase nationally of 15% in the proportion of gay men who have ever tested for HIV in response to greater emphasis on testing in gay men's health promotion work (source: GMSS, Sigma Research) and also improvements in how many gay men had tested recently. This indicator can make a real difference.

8. Are there indicators here that you think we should not include?

We question the rationale for significantly reducing the number of outcome indicators in the final version of the Public Health Outcomes Framework.

The indicators which have been proposed all highlight areas which the Government has identified as important concerns in improving the public health of the nation. Therefore it seems unhelpful to reduce their number.

The indicators are meant already to use as far as possible data collated and analysed nationally, with existing systems to collect the data and that data also available at the appropriate spatial level (local authority). Therefore the continued

² HPA HIV Annual Report 2010

³ Burns FM et al. Missed opportunities for earlier HIV diagnosis within primary and secondary healthcare settings in the UK. *AIDS* 2008; 22:115-122.

inclusion of all the indicators listed will not create a significant cost or reporting burden on Local Authorities.

It can also be argued that a larger number of indicators enhances local autonomy, flexibility and discretion, avoiding the straitjacket of a few indicators which might distort local priorities and misrepresent the local health picture.

9. How can we improve indicators we have proposed here?

The definitions of disability and of those with long-term conditions used in the indicators in Domain 2 (wider determinants of ill health) must include people living with HIV, and the data collected on these indicators must be disaggregated by different categories of disability and different conditions. Processes by which to gather data on these indicators must be developed that respect confidentiality, but which also accurately give, for example, a sense of employment rates and settled accommodation rates for people with HIV.

10. Which indicators do you think we should incentivise through the health premium?

‘Proportion of persons presenting with HIV at a late stage of infection’ should be incentivised through the health premium.

As outlined above, this indicator will have a significant impact on both the long term health outcomes of those already infected with HIV, and on public health across the country. However the negative associations and stigma attached to HIV make it vulnerable to prejudice and can silence local voices of people with HIV and affected communities. In some places HIV sector organisations have already begun to experience barriers when working with local politicians. Therefore, not only is an outcome indicator tackling HIV late diagnosis vitally important, the inclusion of this outcome within the health premium is a key method to incentivise appropriate action at a local level.

11. What do you think of the proposal to share a specific domain on preventable mortality between the NHS and Public Health Outcomes Frameworks?

NAT agrees with this proposal. Late HIV diagnosis is a key contributor to preventable mortality amongst people with HIV. There should be further consideration as to whether and how interventions undertaken by the NHS on behalf of Public Health England, such as screening, testing and timely diagnosis, are captured in specific outcome indicators within the NHS Outcomes Framework. It does not make sense for the NHS Outcomes indicators to be limited strictly to ‘treatment activity’ given the significance of so much NHS activity to public health. NAT believes that a shared specific domain on preventable mortality must involve a shared indicator around late HIV diagnosis.

12. How well do the indicators promote a life-course approach to public health?

No specific comments

**NAT
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