

## **Liberating the NHS: Local Democratic Legitimacy in health**

### **Consultation Response**

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

##### **1. Introduction**

1.1 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.

1.2 This consultation response will outline NAT's views under each of the main headings discussed in the consultation document. It covers the potential impact of the proposed changes to patient involvement, integrated working, and local authority leadership, on people living with HIV.

##### **2. Strengthening public and patient involvement (the role of local HealthWatch)**

**Should local HealthWatch have a formal role in seeking patients' views on whether local providers and commissioners of NHS services are taking account of the NHS Constitution?**

**Should local HealthWatch take on the wider role outlined in paragraph 17 with responsibility for complaints advocacy and supporting individuals to exercise choice and control?**

**What needs to be done to enable local authorities to be the most effective commissioners of local HealthWatch?**

2.1 NAT agrees that involving public and patients in healthcare is vital, and believes that the current provisions require further development if public and patient involvement is to have a real impact on how healthcare is commissioned and delivered.

2.2 HIV is a stigmatised condition. As a result of this people with HIV are often reluctant to disclose their status. This may therefore prevent their participation in involvement schemes such as HealthWatch. There is no mention in the White Paper of how local HealthWatch would take concerns such as these into account and what requirement for confidentiality there would be. Such a vital element to ensuring the involvement of the widest possible section of patients should be a central element of the scheme and should be a requirement of all HealthWatch contracts, it should not be left to the discretion of the Local Authority, as the omission of such guarantees has the potential to invalidate the legitimacy of the involvement and input from those groups.

2.3 There is also insufficient information set out as to the practicalities of how local HealthWatch bodies will be constituted. In particular, as the involvement of Local Authorities in the provision of health services increases, we are concerned about the potential conflict of interest if Local Authorities are both the subject of a local HealthWatch and also the body which awards the local contract. **It is essential that the system ensures consistency, transparency and equity of access to HealthWatch. A vital element of this is that there is a clear framework and**

**mode of operation which although defined and locally tailored, must have central direction and draw on learning from LINKs to avoid conflict of interests.**

2.4 Taking responsibility for advocacy and supporting individuals to exercise choice and control requires a considerable degree of specialist knowledge, both about the issues around information provision to patients, and also about the specific condition upon which support is being provided. In order to undertake these roles to the standard which is required in complex conditions such as HIV, **advanced training in providing advocacy and support would be required for the HealthWatch members, so as to ensure they were able to undertake this role effectively and safely.**

2.5 Involving public and patients in the commissioning and development of healthcare is vitally important, however most involvement systems are based on an 'opt-in' model. There is no indication that local HealthWatch will be based on a different model. Although the organisation facilitating a HealthWatch will, undoubtedly, do everything in their power to reach out to as wide a section of society as possible, involvement tends to be limited to the white middle classes, and it is notoriously difficult to engage with harder to reach groups. However hard to reach groups tend to suffer different health conditions and have different experience of healthcare. For example, Black African communities are notoriously hard to reach but have a far higher prevalence of HIV than white middle class groups. Groups such as this are often best involved via local community based organisations, therefore it is important that HealthWatch works with these smaller groups, which form a vital part of the Big Society, but who would not have the capacity to take on the local HealthWatch contract. **For HealthWatch to be truly representative it must involve a proper cross-section of society. Otherwise not all healthcare conditions will be proportionally represented, and this in turn may skew the view of health needs and experiences presented by HealthWatch. If HealthWatch is to play an important role in commissioning healthcare, it is vital that they avoid this pitfall, and unless this can be guaranteed the weight given to the information provided by HealthWatch must be balanced against more representational information.**

### 3. Improving integrated working

**Do you agree with the proposal to create a statutory health and wellbeing board or should it be left to local authorities to decide how to take forward joint working arrangements?**

**Do you agree that the proposed health and wellbeing boards should have the main functions described in paragraph 30?**

**Is there a need for further support to the proposed health and wellbeing boards in carrying out aspects of these functions?**

3.1 NAT believes that improved integration between health and other services such as adult social care, disability services, housing, etc, has considerable potential to provide more joined up services, which in turn can provide a better level of overall care to the patient. **Single care pathways that cover the patient from diagnosis, through treatment and into long term social care support have the potential to considerably improve the experience of the patient, and meet the needs of the patient effectively.** This is particularly relevant for people living with long term

conditions such as HIV in which the debilitating element may mean that the patient requires support from a wide range of services.

3.2 It is important that there is consistency across the country in terms of how joint working should be taken forward so as to ensure the processes used in each area are capable of meeting the often complex needs of people living with long term conditions such as HIV. A statutory format, such as the proposed Health and Wellbeing Board, has the potential, if constituted correctly, to ensure the more complex issues in public health and delivery of integrated health and care can be effectively achieved within the new proposals.

3.3 However there must be a good understanding of the needs of people living with HIV, so that the services people need, across all areas, continue to be funded, and patient needs met. **The proposed Health and Wellbeing Boards must be populated by experienced professionals, and must be supported by accurate, high quality data, such as is currently collected by the Health Protection Agency.** Additionally, the potential reduction/loss of grants such as the AIDS Support Grant and the threat this poses to the level of provision of specialist services such as the HIV specialist support services provided in many areas. If the services no longer exist then more integrated working will not help, as there will not be services for health to integrate with.

#### 4. Local authority leadership for health improvement

4.1 NAT believes that **proposals for a ring-fenced health improvement budget and jointly appointed Directors of Public Health presents a good opportunity for embedding the importance of public health and prevention of HIV and other conditions into the thinking of Local Authorities**, and enabling these concerns to influence the design of a wider range of public services. This opportunity for a holistic approach to health improvement and public services should not be missed.

4.2 However **it is important that full consideration is given to the complexity of sexual health services.** Sexual health services are not as readily categorised as services such as smoking cessation, and the apportioning of responsibility between Local Authorities and GP Consortia may be problematic if not approached with a good understanding of both the local and national context of these services. Testing and early diagnosis, prompt and effective treatment and safer sex support and advice, as well as partner notification and contact tracing form a pathway of care which have both clinical benefits for the patient and vital public health benefits. The wide range of interlinked services that are a necessary part of sexual health services will result in NHS commissioning services having significant responsibilities for the public health agenda.

4.3 As HIV services will be commissioned nationally or regionally by the NHS Commissioning Board this creates an additional layer of complexity in terms of integrated working. To this end, we would suggest **for HIV and other conditions that are commissioned at this level and have public health elements to their care pathway, Local Health and Well-Being Boards should meet regionally, so as to capture the joint working required for these conditions.** This would also present an opportunity for a strategic approach to health and well-being to be discussed at a regional level.

4.4 Although there are considerable opportunities for integrated working to produce better sexual health services we are concerned that if the integration is not as

effective as it could be or there is uncertainty about the allocation of responsibility for different aspects of the service, there is a real danger of some important public health interventions not being picked up either by local authorities or NHS commissioners. We are concerned that the reliance on cooperation at the level of the Health and Well-Being Board with only limited opportunities to appeal or require action makes these problems more likely. Such an outcome could result in vital services such as HIV testing programmes, or partner notification, for example, not being delivered, which in turn could have devastating consequences. In order to reduce the possibility of this situation occurring **NAT propose that a sixth domain be added to the NHS outcomes framework, around public health aspects of NHS commissioning focusing in particular on matters such as early diagnosis, the prevention of the spread of infection, clinic-based advice and counselling and integration with Local Authority health improvement and social care. We feel that this would add a necessary element of accountability within the NHS for public health outcomes.**

4.5 The proposed system has the potential to deliver an effective and holistic approach to HIV and sexual health services which will be both cost-effective and provide a good level of service for patients. However such a service will only be achieved if effective and fully integrated working between NHS commissioning and Local Authorities can be delivered across the country.