

Liberating the NHS: Commissioning for Patients

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 HIV presents a unique challenge for commissioning. It is infectious, but yet also a long term, manageable condition. Therefore the very nature of HIV means that the commissioning arrangements must be examined carefully so as to ensure the service provided is able to meet the needs of people living with HIV, play a role in public health and remain cost effective.

1.3 This consultation response will outline the issues and lay out what NAT believes to be the 'best fit' for the commissioning of HIV services within the framework set out in the White Paper. In particular our response will focus on the scope of GP commissioning in relation to HIV care, the role of the NHS Commissioning Board and HIV care in difficult settings.

2. The Right 'Level' for Commissioning HIV Treatment and Care - GP Consortia or the NHS Commissioning Board?

2.1 HIV paediatric care and HIV inpatient care are currently included within the Specialised Services National Definitions Set, and therefore, as stated in the consultation paper, these will be commissioned by the NHS Commissioning Board. **NAT feels that this is the correct level for this care to be commissioned at, as both HIV paediatric care and HIV inpatient care are highly specialised services.**

2.2 However the majority of HIV care is carried out at outpatient level. HIV outpatient care was removed from the Specialised Services National Definitions Set in 2009. Nevertheless since then since then HIV outpatient care has continued to be commissioned at a regional level, a system that has worked very effectively.

2.3 Although there has been a significant increase in the number of HIV patients in the last decade, HIV remains a relatively low volume high cost service, especially outside London, Brighton and Manchester. Commissioning at a regional level will share the financial burden of high cost drugs for what is often a small cohort of HIV patients. For GP consortia to commission HIV outpatient services would involve for many excessive financial risk ('insurance risk'). Furthermore, commissioning at regional or national level will allow for greater negotiating power over drug pricing with pharmaceutical companies.

2.4 Currently HIV care is often delivered as an open access, self-referral service with distinct and high threshold confidentiality protocols. This particular service model is vital in ensuring that people with HIV feel secure in initially accessing testing, in accessing care where they feel comfortable, and in the confidentiality provided, which is important when dealing with such a stigmatised condition as HIV. However this model of care presents considerable problems for the localised commissioning

proposed by GP consortia. People frequently move outside their locality to access HIV treatment and care.

2.5 The current model of HIV treatment and care works very effectively for individual patients, but it is likely to negate many of the projected advantages of GP commissioning in relation to HIV positive patients. In particular cross-charging for HIV treatment and care between GP consortia would be especially burdensome and problematic.

2.6 Furthermore, a significant minority of people with HIV have not disclosed their HIV status to their GPs (estimates vary by clinic but overall it is probably between 20 and 50 per cent). This model of care has resulted in many GPs not developing expertise in HIV treatment and care, even in relation to primary care needs, which can be made more complex as a result of the drug regime for HIV. Most GPs do not currently have the relationship with their HIV positive patients, the skills and the expertise to bring much added value to this aspect of commissioning. We trust this will change over time - and that we see increasing involvement of primary care in clinical pathways for people with HIV, accompanied by appropriate training. But at present the advantages cited for GP commissioning in relation to other conditions do not apply in relation to HIV.

2.7 Therefore, so as to maintain commissioning expertise, spread financial risk and reflect the particular circumstances of open access, self-referral services, **NAT recommends that HIV outpatient care is commissioned for the near future by the NHS Commissioning Board at a regional level.**

3. Healthcare in challenging settings

3.1 NAT strongly supports the commissioning of prison healthcare centrally by the NHS Commissioning Board, and we also recommend that the NHS Commissioning Board commission healthcare in Immigration Removal Centres.

3.2 Immigration Removal Centres present a very specific set of healthcare challenges, and the provision of healthcare in this difficult setting will create unnecessary burdens on the local commissioning budgets and expertise. In particular, the movement of detainees between centres, and the numbers and healthcare issues of detainees are difficult, if not impossible to plan for. Therefore we feel that the only way to ensure consistent high quality care comparable to that in the rest of the NHS across the whole of the detention estate is for the NHS Commissioning Board to commission healthcare in Immigration Removal Centres.

4. HIV and primary care

4.1 It is vital for the continued provision of excellent care to people living with HIV that the integration of primary care and HIV outpatient commissioning be improved.

4.2 Currently much of the routine, non-HIV related care for HIV patients is carried out by specialist clinics because patients are unwilling to see their GP. Either because they do not feel comfortable disclosing their status, or because their GP does not have the necessary knowledge or experience to treat them effectively, as the interaction between HIV drugs and other treatments can be complex. NAT believe that this needs to change, and that there is potential within the proposed systems for the gradual, responsible development of the role of GPs in HIV care.

4.3 NAT firmly believes that GPs should be increasingly involved both in HIV testing and in the care of HIV positive patients.

4.4 Whilst for the present commissioning of HIV outpatient services should be situated with the NHS Commissioning Board, it is essential that a commissioning framework for HIV outpatient care is agreed with appropriate clinical care pathways. The development of this framework must promote GP involvement in the primary care of HIV positive patients, including in the appropriate referral to other non-HIV secondary care specialties.

4.5 This approach also has the potential, over time, to facilitate the transfer of some routine aspects of HIV care which could be better placed in primary care. This normalisation of HIV care could also impact on the stigma and discrimination experienced by people with HIV. However such a transfer of care must only be considered when we are certain that non-HIV care for those with HIV is being provided consistently to a high standard.

4.6 The transfer of more care for HIV patients to GPs must not, however, compromise the principle of open access and self referral GU clinics. These services are vital for HIV care, and also have an important public health role.

4.7 It is essential that the interests of HIV positive patients are properly represented at the local level to ensure properly integrated care. The NHS Commissioning Board will have to ensure it is appropriately and effectively involved in meetings and planning of Health and Well-Being Boards. It is also important that the NHS Commissioning Board develops, with appropriate consultation and involvement of people living with HIV, clinical pathways for people with HIV which ensure HIV outpatient care is appropriately joined up with primary care, other secondary care specialties, local authority health improvement, social care and psychological support. Such clinical pathways should be informed by appropriate NICE quality standards.

5. Patient and Public Involvement

6.1 NAT recognises the importance of involving patients in commissioning, however it is vital that the implications of seeking the voice of patients with a stigmatised condition such as HIV be properly considered.

6.2 It is important that measures are undertaken to ensure that patient involvement is carried out in a sensitive and confidential way, recognising that HIV positive patients may not wish to disclose their status outside of their involvement in service development, and as such strict confidentiality must be ensured.

6.3 The involvement of marginalised and 'hard to reach' groups has long posed a significant problem for patient involvement, and has been a barrier to making such involvement truly representative. If the needs of these groups, including people living with HIV, are to be truly taken into account when commissioning then the NHS Commissioning Board must look for involvement beyond the 'usual suspects'. Local voluntary organisations supporting people living with HIV have a potentially important role to play in this context.

6.4 NAT is proposing that the NHS Commissioning Board commission HIV outpatient services. Further consideration must be given as to how the NHS Commissioning Board can itself be sensitive to patients' voices and agree appropriate drivers for the improvement of the quality of treatment and care. It will be a challenge for a national body to be as sensitive to the patient voice and experience, with all its local variation, when compared with local authorities and GP consortia. **Detailed proposals should be developed as to how the NHS Commissioning Board can effectively involve and listen to the voices of patients and the public, with appropriate local information, in relation to those conditions which it commissions.**

NAT
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