NHS Commissioning Board

Service Specifications – Specialised HIV Services for Adults

Positively UK Response

Do you find this clinical policy or service specification clear and comprehensive?

Overall we found the specification comprehensive. However it must be noted that the service specification is dependent upon clinical networks and referrals to other services. Positively UK has concerns that many of these networks are not in place, not operating effectively. There is also uncertainty as to whether services will exist or be sufficient to cope with capacity. We refer here to Clinical Nurse Specialists (CNS) who we agree play a vital role in supporting patients, however are commissioned locally, in some areas do not exist and in others the position is under threat. We also refer to voluntary sector and patient groups who are at risk of being hit hard by cuts in funding and the uncertainty as to who should be commissioning HIV support services – local authorities or Clinical Commissioning Groups. Positively UK is also concerned about the emphasis on GPs and primary care and refers to this later in the consultation. In our view, on paper the specification is clear and comprehensive; however this may not be reflected in actual operation and there is still much work needed to achieve this.

Page 7 Service elements – overview: the statement ‘Promotion of HIV prevention including partner notification, sexual health risk behavioral support, peer and self-management and information’ is confusing. It lacks clarity as to whether it considers peer and self-management as supporting HIV prevention or stating they should be promoted in their own right. This needs to be separated into two statements one on health promotion including partner notification, the other on health and social care support including peer, self-management and information.

Page 11 Service elements – General Requirements: states ‘Regular communication with GPs where patients have disclosed their status will be implemented to avoid drug interactions.’. The use of the word ‘regular’ is too vague in this instance and suggests that communication could occur after drugs have been prescribed. It is unacceptable for patients to be prescribed drugs that interact with HIV medications. This statement needs to be more robust to state that where there is any doubt or questions to interactions, communication is immediate, and the health of the patients is not placed at risk.

In your opinion, does the clinical policy or service specification reflect the evidence base? Is there any additional information or evidence that you think should be taken into account?
Treatment as Prevention

Page 4 in reference to health improvement and treatment as prevention states “initiatives require a process of evaluation and approval before being commissioned.”. This statement is accurate in terms of Pre-Exposure Prophylaxis for people who are HIV negative. However, the service specification is inaccurate in omitting evidence for the provision of treatment as prevention for people living with HIV. A position statement on the use of antiretroviral therapy to reduce HIV transmission issued by The British HIV Association (BHIVA) and the Expert Advisory Group on AIDS (EAGA) states:

“There is now conclusive randomised clinical trial evidence, from heterosexual couples where one partner has HIV and the other does not, that if the partner who is HIV positive is taking effective ART, transmission of HIV through vaginal sex is significantly reduced (by 96%)” [Cohen MS, Chen YQ, McCauley M et al. Prevention of HIV-1 infection with early antiretroviral therapy. N Engl J Med 2011; 365: 493–505.]

In addition NICE have also recognised the evidence that treatment as prevention is effective for heterosexual couples who want to conceive. HIV is a transmissible long-term health condition, and as such places greater stresses on couples where one partner is HIV positive; living with the fear of transmitting HIV to a partner places great strain on the person living with HIV. The opportunity to access treatment as prevention alleviates this pressure. Positively UK urges the NCB to provide clear guidance on this issue, within the specifications. This guidance be issued by the NCB to ensure equitable access to HIV treatments and not left to the discretion of local or regional commissioners. The latter would result in a post-code lottery. Treatments should be available for people with a CD4 count over 350 where this will reduce onward transmission to partners, including but not restricted, to couples aiming to conceive. This should be commissioned through the NCB as part of the care of treatment for people living with HIV to ensure equitable access across the country.

STI Screening

Page 7 Service elements – overview states ‘Referral to sexual and reproductive health services for annual STI screening’. STI Screening is recommended whenever a person has a new sexual partner. Cohorts of high risk groups such as gay men will have multiple partners in a year and will require STI screening on a more regular basis. The specification should be modified to read ‘Referral to sexual and reproductive health services for STI screening every 3 – 12 months depending on need.’

Commencing Treatments with CD4 count over 350

Page 14 – Specific patient group covered: The specification states that ‘in some cases’ treatment could be initiated when CD4 count is 500. There are clear guidelines for when this should happen e.g. people with Hepatitis co-infection, and these are stated in the British HIV Association guidelines for the treatment of HIV-1-positive adults with antiretroviral therapy 2012. These guidelines must be referenced here and adhered to. With regards to treatment as prevention please refer to earlier point.
In your opinion, is this clinical policy or service specification inclusive of all the people who may be affected by it including minority groups? Please provide examples with your response.

Page 6 (2.1) Objectives: We welcome the statements that patients should be central to decisions about the management of their condition. However if patients are to take a greater role in self-management and making decisions there needs to be support and education to enable patients to undertake this role. This is crucial in terms of increasing patient’s understanding of HIV, but also enabling patients to effectively engage with healthcare staff and ask pertinent questions. Patient education and the role of voluntary sector and patient groups is included later under Service elements – detailed pathway inclusions – HIV centres (page 10). However if patient involvement and the Government’s strategy of ‘no decision about me without me’ is to become a reality the need for patient education needs to be a the core of clinical services and a prime objective of the service specification.

Page 11 Service elements – detailed pathway inclusions – outpatient services: states that services should be in accordance with principles of ‘patients as self-managers’. Whilst we agree with this statement generally it must be noted that some groups will not be in a position to self-manage. This can include those with severe learning disabilities or groups who have periods where they are unable to self-manage when experiencing periods of poor mental or physical health. The statement needs a caveat to recognise the needs of those groups and ensure greater support provided to patients in those cases.

Page 15 – Acceptance Criteria: the list of eligibility irrespective of, should include residency status, reflecting changes to the charging of HIV treatments introduced in October 2012.

Page 14 – Specific patient group covered: We welcome the inclusion of people living with HIV in prison and detention centres by Specialised HIV Services. Positively UK has undertaken work in prisons over many years and know that, in contradiction to Government policy, people experience poorer healthcare provision within these institutions. This specification here should reference and reinforce Prison Service Order 3200 that ‘The Prison Service in partnership with the NHS has a responsibility to ensure that prisoners have access to health services that are broadly equivalent to those the general public receives from the NHS’.

Do you think that this service specification or clinical policy as described will enable all relevant sections of the population to access the service?

Home Delivery

Page 12 Service elements – General Requirements: It should be stated that there are two types of delivery – home and local, the latter where ARVs are delivered to another address such as the post office, local organisation etc. For many people disclosure of HIV and fear of stigma is real issue, and where people are in shared accommodation home delivery is not an option. Local delivery however is an option for this group and should be named alongside home delivery.
Secondly there have been instances where the formulation of drugs have changed. When patients collect drugs at the pharmacy, the pharmacist will inform the patient if formulations have changed and doses should be altered. While Positively UK support the move to home and local delivery, protocols must be in placed to inform patients immediately of any drug formulations and ensure patient health is protected. Arrangements for this must be included within the specifications.

**Can you envisage any barriers to putting this service specification or clinical policy into practice from April 2013?**

Positively UK are concerned at the emphasis placed on primary care within these specifications. GPs traditionally have no history of managing HIV and whilst work is being undertaken to improve this and there are General Practices demonstrating good practice in shared care, the level of knowledge and care provided by GPs remains patchy across England. There also recorded examples of discrimination against patients living with HIV, poor quality of healthcare provision to people living with HIV within primary care and that people diagnosed long term with HIV are less likely to access GPs ‘Primary Care Access: How General Practice Can Better Respond to the Needs of People Living with HIV, Positively UK 2010 (www.positivelyuk.org). The specifications do not take account of this transition and the scale of work required to ensure care pathways between primary care and HIV specialist care are in place and ensuring patient health outcomes are not affected during this period. In failing to do so it also places certain groups, notably long-term diagnosed, those not registered with GPs, at risk. While we welcome the work being undertaken by BHIVA and Royal College of GPs there is still uncertainty with patients as well as across the medical field as to who is responsible in certain instances for patient care. The specifications do not state who should lead on patient care; there is evidence of patients being passed from GP to HIV clinician, each stating the other responsible for care. There needs to be a clear lead on patient health for HIV; and Positively UK recommend this lead position resides with the HIV clinical team. Positively UK urge that greater attention be given to the role and interaction with GPs and primary care within these specifications.

**In the next year we will be developing the quality standard section of the service specification. Can you identify any particular standards that should be considered?**

British HIV Association (BHIVA) Standards of Care for People Living with HIV 2013, published December 2012.

Positively UK
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