British HIV Association
BHIVA

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Patron: The Rt Hon Lord Fowler

13 December 2013

Andrew Wilkinson
NHS England Medical Directorate Specialised Services
Skipton House
80 London Road
SE1 6LH

By email to: dorothy.chen@shca.info

Dear Mr Wilkinson

Re: Specialised services five year strategy

The British HIV Association (BHIVA) welcomes the development of a strategic approach to specialised commissioning and the opportunity to respond to NHS-England's (NHS-E) consultation on "Specialised Services Five Year Strategy". Whilst our responses to the consultation are informed by our expertise in HIV they are applicable across the English health economy and are not topic specific. HIV treatment and care is a specialised service that is nationally commissioned through the NHS –E specialist commissioning route.

BHIVA is a national professional organisation committed to excellence in the prevention, diagnosis, treatment and care of HIV. The 1,000-strong membership is multidisciplinary and includes doctors and other professionals from a wide range of backgrounds and skills, including pharmacists, clinical psychologists and other professions allied to medicine. Patients and patient organisations are strongly represented within the Association. BHIVA's activities include the production of NHS Information accredited, nationally recognised HIV treatment guidelines, care standards, audit programmes, and publication of an academic journal, *HIV Medicine.* BHIVA has a seat, as a key professional body, on the Clinical Reference Group (CRG) for HIV. The Association's standards for care and treatment guidelines are a core component of the 2013 national service specification.

Almost all people with HIV in England are treated in NHS organisations. In 2013, people with HIV who are diagnosed in time and who access high quality specialist NHS care life expectancy approaches that of people who are HIV- free. Based on world class surveillance and data collection systems managed by Public Health England (PHE), clinical outcomes for people with HIV in England are amongst the very best in the best in the resource-rich world. NHS-England's (NHS-E) "Specialised Services Five Year Strategy" must ensure that specialised services such as those for HIV are able to at least maintain and ideally improve on their current outcomes across the health economy.

GENERAL PRINCIPLES

1. Although BHIVA agrees that the post-1 April 2013 arrangements for specialised commissioning bring together many areas that were previously fragmented, the current arrangements have introduced new, and arguably far more serious, issues of fragmentation that now impact across the patient pathway. Within any one patient journey/ pathway there may be up to 3 commissioning bodies (Local authorities, NHS-E and Clinical Commissioning Groups) with different agendas, priorities, values, working cultures and approaches to health and social care. Without meticulous, joined up working across all these commissioning organisations there is a significant risk of degradation of services and outcomes. For example, the separate commissioning of HIV services (at a national level) and sexual health services (by local authorities), which prior to April 2013 were commissioned together risks destabilising both services, with the attendant risk of poorer services and worsening public health.

2. The NHS-E strategy must work to the principles of the NHS constitution and be informed by the NHS outcomes framework.

   RECOMMENDATION: BHIVA urges NHS-E to specify and demonstrate models of "joined up" commissioning by all those with responsibilities across the patient pathway within the five year strategy.

   BHIVA recommends the strategy emphasises greater joined up working between and across CRGs to take secure best practice and outcomes for those with multiple specialist comorbidities

3. BHIVA is committed to the active participation of people living with HIV in shared decision making. This applies to all aspects of the treatment and care of individual patients as well as to the wider issues of service design, delivery and implementation together with active engagement in research and innovation

   RECOMMENDATION: NHS-E strategic approach to specialised commissioning must secure mechanisms and partnerships that situate patients at the centre of the specialised commissioning process. This will require recognition of and engagement with the entire patient pathway, including those aspects that fall outside the remit of the specialist commissioning bodies

ACCOUNTABILITY

4. Across many patient pathways in which there are complex relationships between prevention treatment and care the post April 2013 system no longer has any single line of responsibility or accountability. This is causing confusion and has the potential to undermine existing high quality care when the lines of accountability are so difficult to identify.

5. BHIVA believes that there should be transparency throughout the entire specialist commissioning pathway and clarity about the ways in which decisions may be influenced by service providers and users.

   RECOMMENDATION: NHS-E strategic approach to specialised commissioning should set out clear lines of accountability and responsibility. This should include accountability for integration across the entire patient pathway and accountability for decision making. Specialised Service specifications should include measurable and auditable outcomes together with clear lines of accountability.

MONEY

6. BHIVA recognises the financial pressures associated with specialist care for a growing and ageing population of people living with specialist conditions, together with the cost

pressures brought to bear by innovation, advances in treatment and care and associated costs. The introduction of NHS-E specialised commissioning brings new opportunities for national and regional approaches to procurement of high cost drugs and interventions that were previously unavailable. However setting specialist services together within programme of care boards (PoCBs) means that perverse incentives are now in place as potential savings made by one specialist service will be applied to other specialities within the PoCB.

7. With different players within a single system, cost saving in one part of the system may not be appreciated by those who instigate the intervention. For example prevention initiatives instigated through the public health function of local government are likely to save acute providers and NHE-E substantial amounts in longer term acute and possibly intensive clinical care. This saving will not accrue to the local authorities, and the initial intervention is likely to be a cost pressure for them, leading to a possible reluctance to invest in such an area.

RECOMMENDATION: **NHS-E strategic approach to specialised commissioning should ensure that cost improvement including new opportunities for economies of scale are ploughed back into investment in the speciality.**

INTEGRATION

8. Although integration across and between services, commissioners, providers and users is critical to best outcomes, the post April 2013 situation mitigates against a joined up approach. Multiple commissioners across each patient pathway, 75 CRGs in “silos” of specialisation, 211 CCGs with local agendas, localism in public health and social care commissioning and provision across 326 local authorities, the separation of research and education into new bodies all combine to make for a fragmented, parochial and fractured environment. Yet the local links between populations and local government and the establishment of health and wellbeing boards has real potential to ameliorate some of this damage. Nonetheless, for specialised services the risks for pathway disintegration have never been higher. The NHS-E strategic approach must address this issue if current standards are to be sustained, let alone improvements delivered in the new environment.

9. A regular, public coming together of leaders of NHS-E, PHE, local government and the department of health would be a simple first step in demonstrating commitment to joined-up working and commissioning.

10. The inclusion of integration, with measurable auditable outcomes within service specifications and contracts could be a helpful step, using financial incentives to secure an appropriate approach.

RECOMMENDATION: **NHS-E strategic approach to specialised commissioning must ensure that integrated care is a priority.**

QUALITY AND SAFETY

11. Assessing and ensuring quality and safety must form a core part of commissioning for specialist services.

12. A fundamental part of this will include ensuring timely and consistent access to the specialist service which will require clear pathways as well as sufficient capacity within the service.

13. The establishment of new and the further development of existing clinical networks will help ensure safety and quality but must involve careful discussion with key stakeholders and will involve some degree of funding to ensure effective communication of policies, guidelines and the provision of educational events within them, in order to ensure that there are consistent and high standards of clinical

governance across the clinical network. Many such networks exist for specialist services including HIV.

14. Consistent measurements of quality both relating to clinical outcome, patient pathways and patient satisfaction should be applied across specialist services regardless of their geographical position. Regular audit will be essential. BHIVA benefits from robust nationally recognised guidelines with auditable outcomes and a strong national audit programme.

    RECOMMENDATION: NHS-E strategic approach to specialised commissioning should ensure that there is a standardised approach to the assessment of access, quality and safety across clinical networks.

INNOVATION

15. The management of patients with HIV has changed rapidly over the last 2 decades to transform the condition from a once universally fatal condition, to a long-term manageable condition with almost normal life expectancy. This has involved the rapid evolution of a number of new drugs and some laboratory techniques. BHIVA has a great deal of experience in the pathway of a new drug from initial assessment to evaluation of the evidence base for the drug and its introduction into practice and this involves significant input from patient advocates.

16. The introduction of generic drugs is a situation faced by many specialties including HIV. It is crucial that strategic planning ensures consistent approaches to generic drugs and that the potential fragmenting of funding and care does not result in differential access to either new drugs or generic drugs across geographical sites. Where generic drugs are available, savings resulting from their use should be reinvested in services in order both to incentivise the use of generics and also to fund the use of newer, better drugs when these become available, since this is one way in which services can potentially be improved without increasing overall costs.

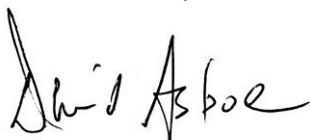
17. An early focus on the link between NHS England and research with regard to specialist commissioning is crucial. This will again require consistency and communication within and between networks. Robust mechanisms are required to evaluate the findings of research projects whether they involve clinical issues or innovative service developments to ensure efficient roll out across the specialty at a national level.

    RECOMMENDATION: NHS-E strategic approach to specialised commissioning should ensure that there is a robust and consistent approach to the funding of innovative medication, techniques and research.

Please do not hesitate to contact me if you have any queries.

With kind regards

Yours sincerely



Dr David Asboe
Chair, British HIV Association (BHIVA)