

“No decision about me, without me: Liberating the NHS: Further consultation on proposals to secure shared decision-making”. Consultation Response from the British HIV Association

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1. The British HIV Association (BHIVA) is the leading UK association representing professionals in HIV care. The current membership of the association is over 1,000 across a wide range of healthcare professionals. BHIVA is committed to providing excellence in the care of those living with and affected by HIV. BHIVA is an NHS information accredited body, producing evidence based clinical guidelines on the prevention, treatment and management of HIV infection and has established national standards for the care of people living with HIV in the UK. The Association acts as a national advisory body to professions and other organisations on all aspects of HIV care. BHIVA provides a national platform for HIV care and contributes representatives for international, national and local committees with an interest in HIV care. The Association’s work promotes undergraduate, postgraduate and continuing medical education about HIV and research.

2. People living with HIV are involved in all BHIVA work streams, are represented within the board of Trustees and the Association’s external scrutineers.

3. From the earliest days of the HIV epidemic in the UK when much was unknown and levels of uncertainty for both clinicians and patients were extremely high, sharing information and decision making about all aspects of diagnosis, treatment and care became central to the provision of high quality care for people living with HIV. It is from this perspective that we are responding to the consultation document “No decision about me, without me: Liberating the NHS: Further consultation on proposals to secure shared decision-making”.

*Q1. Will the proposals provide patients with more opportunities to make shared decisions about their care and treatment in the following areas?*

*a) In primary care? b) Before a diagnosis? c) At referral? d) After a diagnosis?*

4. Choice alone is not enough. Although we welcome the increased emphasis that is being given to patient choice and shared decision making, the document focuses largely on giving people a wider choice about who provides care at various stages. . This is not the same as ensuring people have real opportunities to be active participants in their own care. Without a shift in emphasis to embrace greater engagement and shared decision making people will indeed have a greater choice in finding providers, but will get the same sort of health care provision as they have now. The detailed “nuts and bolts” of how greater engagement between service users and providers will happen are essentially absent from the document.

5. There is an ongoing need for high calibre clinical leadership and advice for people who are ill and in need of support and care. If there is to be a greater choice of providers and services then there must be clear, understandable evidence about the quality of these services. This data must be in a form that is accessible and relevant to the person seeking help. People who are seeking healthcare or are acutely unwell may be less able to exercise choice due to the very situation in which they find themselves.

6. Making sure that care is “joined up” and the diverse array of potential providers are able to share appropriate and relevant clinical information with service users in a secure and useable way will be even more important than it is at the moment. Inadequate details are provided about how this will work in real life. HIV remains a stigmatised condition in the UK and for some disclosure of the diagnosis is difficult, yet many are taking complex medication with potential for drug – drug interactions. Using “drop in “primary care services without adequate information being shared in both directions may bring potential risks in conditions such as HIV.

7. It is important to remember that for a significant number of people the GP is unlikely to be the first point of NHS contact. In the case of HIV many people will have used open access GUM clinics or HIV services as the place of screening and/or diagnosis. They may already have secondary care in place. This may change the relationship between primary care clinician and patient if hospital services are already involved before the GP is aware of the diagnosis. This point is not made adequately in the document.

8. We welcome the proposal that people may retain a general practitioner with whom they have a good working relationship if they relocate. We recommend that people with HIV have a GP who is aware of their diagnosis and fully engaged in their care, and yet we know that for some people this can be a difficult process. Maintaining a long term relationship with a GP who is aware of the diagnosis and the complexities of the management plan will be helpful in providing quality care.

9. The ways in which diagnostic testing is chosen with a greater range of providers being involved, is an important issue for HIV management. There is clear evidence that HIV is under diagnosed in a variety of clinical settings. This contributes to late diagnosis and avoidable morbidity and mortality. Without the offer / recommendation of an HIV test an HIV positive diagnosis will be missed and those who are HIV negative will not have the opportunity to maximise their chances of avoiding acquisition of HIV. Providers of primary care and of diagnostic tests must be competent to offer and perform HIV testing and to deal appropriately with the results –positive or negative. National guidelines on HIV testing should be followed by all those involved in delivering diagnostic tests.

10. We welcome the proposal to increase choice in the provision of mental health care. People with HIV have higher rates of mental health morbidity than people who are HIV negative. HIV services are not subject to geographical boundaries and people may choose where to base their HIV care. Mental health care, currently highly geographically bounded, means that these two aspects of care for someone living with HIV are frequently divorced from one another, to the detriment of integrated care for the person concerned. .

*Q3. Looking at the proposals collectively, are there any specific areas that we have not recognised appropriately in the consultation document?*

*Q4. Have we identified the right means of making sure that patients will have an opportunity to make shared decisions, to be more involved in decisions about their care across the majority of NHS funded services?*

11. No matter how much choice is available if there are barriers to understanding and to access then there will be no difference for the individual. Some of these barriers are language, differences in health beliefs and socioeconomic factors including: age, gender, income, relationship status, housing status, food security and immigration status. Financial constraints have led to a diminution in translation and health advocacy services within the NHS, and without such resources real communication between some patients and their health care teams is fatally compromised. No choice can be exercised if the person concerned (clinician or patient) is without knowledge or understanding of what is being discussed. These issues are inadequately addressed and will hinder the proposals, particularly in a worsening economic climate with rising levels of poverty.

12. The issue of language in the wider sense is not mentioned within the document, but it is a very important issue for people using health care services. Identification of the person with the condition is unhelpful and disempowering, and puts obstacles in the way of fluent communication. Making language person – centred rather than disease centred facilitates partnership. For example, using the term “people with HIV” rather than “HIV infected individuals” immediately makes the person the centre of the conversation. Phrases such as “bed 6 is the new HIV diagnosis” used between clinical team members immediately puts the person into the background and makes shared working very problematic. This needs to be systematically addressed across clinical practice if shared decision making is to become part of routine clinical care. This is not mentioned in the consultation document.

13. Becoming an active agent in one’s own health care requires certain skills and understanding. Capacity building will be required to provide people with the necessary attributes to participate effectively. In the field of HIV, specialist NGOs, peer supporters and peer educators together with NHS clinical teams all work to help people with HIV to become proficient within the health economy. Even with this sort of support and experience being widely available a significant number of people with HIV are lost to follow-up. There is no evidence within the consultation document to explain what resources will be available to a wider public to make this happen.

*Q5. Do you feel that these proposals go far enough and fast enough in extending choice and making “no decision about me, without me” a reality?*

14. The proposals are limited in their scope, and although providing opportunities for greater choice of provider and geographical location of services there is far too little on the actual process of engagement with and partnership in care. There is minimal mention of peer support, peer navigators through services, decision making aids or patient related outcome measures. Including people with particular conditions in the design and delivery of services as well as in decisions about their own personal health care is an important component which is inadequately covered in the proposals. Ensuring real community engagement within treatment guidelines, research protocol development and audit programmes needs more attention.