

Integration and Innovation: working together to improve health and social care for all; the Department of Health and Social Care's legislative proposals for a Health and Care Bill. Comments from the British HIV Association (BHIVA), 23 March 2021

The British HIV Association (BHIVA) is the leading UK association representing professionals in HIV care. Since 1995, it has been committed to providing excellent care for people living with and affected by HIV. BHIVA is a national advisory body on all aspects of HIV care and provides a national platform for HIV care issues. Its representatives contribute to international, national and local committees dealing with HIV care. In addition, it promotes undergraduate, postgraduate and continuing medical education within HIV care. Contact: Laura Waters (lwaters@nhs.net) & BHIVA (bhiva@bhiva.org)

The Department of Health and Social Care's legislative proposals for a Health and Care Bill published on 11th February 2021 (the White Paper) lay down the Government's proposed structural changes, and supporting legislation, to implement the NHS long-term plan. Whilst we support the key elements of the Government's ambition, including better integration, less bureaucracy, and enhanced accountability, we have several concerns, both general and related to the potential impact on HIV care in England.

General comments

Social Care and Public Health

Robust Social Care and Public Health are crucial for safe and effective NHS care; to propose better integration in a paper so scant on detail about these seems counter-productive. We join calls for the Government to commit to a radical 10-year plan for adult social care, ideally before major NHS restructure.

Sexual Health services, the largest providers of HIV care in England, bore the brunt of significant Public Health cuts, the consequences of which may take years to emerge. A medical focus risks perpetuating a culture of spending millions managing preventable illness whilst neglecting underlying root causes and health inequalities. Though advances in modern medicine are welcome, a cash-strapped system must make tough spending decisions. The White Paper must address this head on. Strong foundations of health and wellbeing are essential for medical innovation and reform to deliver at population level.

Bureaucracy and cost

While the White Paper assures us that reform will reduce bureaucracy there is also a risk of increased bureaucracy, given the multiple agencies involved.

- What work has been undertaken to ensure ICSs will indeed be 'leaner'?
- Considering the costs of reform, what modelling, and cost projections have been undertaken? Can this be shared with stakeholders?

Inequality

COVID has highlighted unacceptable health inequalities, and drivers of poor health outcomes are experienced disproportionately by people living with HIV. Although the White Paper mentions addressing inequalities, there is a concerning lack of detail about:

- How inequalities will be measured and addressed
- Which body will do this?
- How will the communities with the poorest health outcomes be engaged and heard?

ICS-based commissioning could undoubtedly reduce variation for high-volume services managing common conditions. For services currently commissioned across footprints larger than ICSs, including nationally, important questions include:

- How will NHS England and NHS Improvement ensure devolution does not widen inequalities?
- If ICSs are accountable for minimising variation within ICSs, who is accountable for variation *between* ICSs? Or *between* regions?
- Who will be accountable if local outcomes for devolved specialised services don't meet national standards?

Timing

Is this the right time? There is never a perfect time for major reform, but it is hard to think of more challenging circumstances than those in which we find ourselves currently.

Dismantling Public Health England (PHE), particularly during a pandemic, risks destabilising care as BHIVA has already expressed in a joint statement with specialist and community colleagues [1]. PHE monitors HIV diagnoses and care outcomes, data essential for commissioning, but we risk serious knowledge gaps during the transition to a new body. The National Institute for Health Protection (NIHP) is not yet established, and this would ideally precede major NHS restructure.

Many workers and service users across NHSE, local government, public health, social care and the third sector remain tied up with the ongoing challenges of COVID, despite exhausted resilience reserves. It is therefore unfair to push through major reform when the attention of those most affected is focused elsewhere, and consequently the capacity of staff to deal with upheaval markedly restricted. After Sexual Health, most HIV care is provided by Infectious Diseases, a speciality particularly impacted by COVID.

Workforce planning

Workforce planning across health and social care is a major concern yet is not adequately addressed in the current proposals. Addressing under-recruitment in several specialties, staff retention and Brexit, on a background of pre-existing understaffing, must be central to care reforms.

IT & data

IT investment is crucial but integrated approaches have previously failed, at spectacular expense. More granularity is required about better exploiting 'the potential of digital and data'. Is this by bespoke, NHS developed approaches, or is it the intention to look at external providers?

Currently services can use any electronic patient record system, with no obligation to use one of the eight NHS Digital recommended providers, a missed opportunity to harmonise systems. A clearer blueprint for a digital structure to support reform, with clear governance and oversight is essential, some of which could sit under an expanded remit for the CQC.

Accountability

Having experienced the barriers to implementing NICE HIV testing guidelines due to fragmentation of responsibilities across CCGs and Local Authorities, with no clear overarching accountability, we welcome this focus. However, the White Paper lacks detail on the precise structure, responsibilities, and mechanisms of accountability for Integrated Care Systems, and without that detail it is impossible to see in what way, and to what degree, things will improve.

Secretary of State powers

Intervention by The Secretary of State, particularly in staff appointments and local decisions about reconfiguration, must be controlled carefully. Local leaders need freedom to make decisions in the best interests of their local populations. Politicising decisions is a risk and granting the NHS more independence is widely recognised as successful. Any intervention must be fully transparent, independently overseen, and subject to consultation.

HIV specific comments

England enjoys outstanding HIV outcomes which are amongst the best in the world, against a background of major reductions in total spending (unlike most other specialised services). This was achieved despite major disruption to sexual health care following the 2012 Health and Social Care Act (HSCA).

We absolutely support moving towards integration, but strongly believe that for HIV care this should be deferred until some of the major uncertainties related to the proposed reforms have been addressed and the system has had an opportunity to settle.

We support the proposed duty for NHSE and Local authorities to collaborate. This is of primary importance for Sexual Health and HIV services, which were split between Local Authorities and NHSE, respectively, after the HSCA. It took five years to implement a national HIV pre-exposure prophylaxis (PrEP) programme, a highly effective and cost-effective tool to reduce HIV transmission, and there is no integrated commissioning pathway for new PrEP agents. The problems of fragmented HIV testing commissioning mentioned above could also be alleviated by better collaboration between local authorities, primary and secondary care.

Unlike some conditions, such as alcohol-related liver disease where outcomes are poor and better integration is likely to produce real benefits, with HIV we are in a position where destabilisation could risk our effectiveness, efficiency, and ability to navigate the post-COVID landscape. Specific concerns include:

Meeting the HIV Commission targets

In December 2020, The HIV Commission published a blueprint to end new transmissions in England by 2030. The Government has committed to enacting its recommendations, with the Health Secretary committing to an 80% reduction of new cases of HIV by 2025.

We are on track to achieve these ambitious targets, but the concerns outlined below, including disruption to services and data collection, could limit our ability to eradicate new HIV transmission and may even reverse some of the gains made.

Devolution of HIV care to ICS level

HIV is commissioned directly by NHS England. Its specialised service status was based partly on its specialist care model but relates primarily to the relatively high costs of HIV treatment. Since being given specialised service status, despite an increased number of people accessing HIV services, total drug spends have declined dramatically. This is partly thanks to generic drugs but also to targeted, nationally co-ordinated drug switch programmes.

A single paragraph in the White Paper addresses specialised services:

“[Collaborative Commissioning proposals...will] enable NHS England to delegate or transfer the commissioning of certain specialised services to ICSs singly or jointly, or for NHS England to jointly commission these services with ICSs if these functions are considered suitable for delegation or joint commissioning subject to certain safeguards. Specialised commissioning policy and service specifications will continue to be led at a national level ensuring patients have equal access to services across the country.”

This suggests that plans will vary by specialised service, which is eminently sensible. HIV is not a rare condition, so we support a move towards more localised HIV commissioning. The HIV Clinical Reference Group (CRG) already includes representation from key stakeholders, including community representatives, so should be central to any changes to HIV commissioning. Whilst the success of CRGs has varied, the HIV CRG has functioned effectively in delivering key innovations, particularly to reduce drug spending. Any proposed changes to commissioning and care pathways must undergo stakeholder consultation, including people living with HIV.

Despite commitment that *“specialised commissioning policy and service specifications will continue to be led at a national level”* there is a lack of detail about the actual role of national standards and specifications, and how their implementation will be managed, especially for services that might move from national to ICS level commissioning:

- Will the appropriate structures be in place for 2022?
- How will ICSs be held accountable?

Several HIV services were seriously destabilised by post-HSCA sexual health service reconfigurations. The sudden requirement for some patients to transfer to other services was not necessarily undertaken in a way that mitigated risk since some local authority commissioners acted independently of NHS England. This risk of further destabilisation must be robustly accounted for in the new legislation, particularly given the uncertainty around which specialised services will be devolved to single or several ICSs.

Some national elements of HIV care must be protected:

- The imminent move to national HIV drug procurement has the potential to drive prescribing costs lower, in a climate where the UK already pays amongst the lowest prices in Europe.
- Localised targets and monitoring of outcomes will be important but must not replace national standards and data monitoring, which are essential to support standardised care and equitable patient experience.

Data

To monitor HIV outcomes, PHE collates regular data submissions from individual services to monitor trends and compare units through a national dashboard. Since close monitoring will be essential to assess any impact of changes to commissioning and care models, we ask that major change to HIV services is deferred until the ability of NIHP to provide accurate and timely data has been confirmed.

PHE also plays a key role in collecting patient reported outcomes (including the Positive Voices survey) and psychosocial data. This data is highly relevant to, and provides rich information for, the more co-ordinated, integrated approach to patient care which is the aim of the White Paper. An inability to monitor health inequalities or to detect any deterioration in HIV outcomes could create several risks:

- Widening health inequalities
- A negative impact on the health of individuals living with HIV
- Public health and spending consequences of onward HIV transmission
- Excess NHS costs: complications of poorly treated HIV, more costly drugs for second-line treatment.

Confidentiality & data sharing

We applaud any innovation allowing sharing of data and medical records to support seamless care. Indeed, we believe that stricter NHS Digital guidance in terms of which electronic patient record systems organisations use would support standardisation and sharing, reduce duplication and improve patient experience. Sharing blood results, vaccination records and up-to-date medication information are just some areas that could improve care.

Although most people with HIV are happy to share their HIV status and care details with other care professionals, a significant minority are not, which is often the result of previous poor experience. Stigma is still an important barrier to HIV testing and care, and people with HIV continue to experience discrimination within health services.

The General Medical Council still consider HIV to be “a serious communicable disease” and on that basis:

*“If the patient continues to refuse to allow you to tell other members of the healthcare team about their infection status, you **must abide by their wishes...**”*

Digitalisation of health care makes it challenging to fulfil GMC guidance; anecdotally some services find it difficult or impossible to fulfil patient wishes, so provision must be made to enable them to do so.

Accessing care out of area

A cornerstone of HIV care is the ability of patients to access any service of their choice, regardless of location. Reasons include:

- Confidentiality: people may avoid services staffed and used by people from their own community
- Convenience: people may prefer to access care close to their place of work
- Previous history: people may want to continue to access a service that knows them well although they have moved from the area
- Expertise: some services offer ‘super-specialised’ support not uniformly accessible.

Whilst impossible to quantify, freedom to choose a service has undoubtedly contributed to our excellent outcomes. People with HIV rate and trust their HIV clinics very highly, higher than primary care, as highlighted by the Positive Voices survey.

The White Paper seems reassuring in regard to patient choice, but we require more detail about how this would work in practice. Sexual Health offers examples where patient choice is not supported through place-based commissioning because some Local Authorities will only fund local care provision.

Some of the discussions during the Health Select Committee interviews suggest that an ICS will support ‘within ICS choice’, and out of area care where that best suits local population needs; this does not necessarily translate to out of area care based solely on patient preference.

We support people accessing their local HIV service to best provide holistic care and seamless local referrals. Indeed, anecdotally COVID has ‘forced’ some people to access HIV care closer to home, which has been a positive experience for many. However, it will take time for others to make that transition and we must therefore preserve the right to choose HIV care outside an ICS or region.

Moreover, there are several HIV services, particularly in urban areas, for whom a significant proportion of their cohort is from out of area. Some operate in a ‘hub and spoke’ model and how these arrangements can be supported within the proposed reforms is not clear. Decisions as to which elements of HIV care can be provided locally, regionally, or nationally must engage the HIV CRG and other stakeholders, and there must be sufficient flexibility to support different arrangements across the country.

Board balance

Two ICS Boards are proposed: an NHS Board, plus a Health and Care Partnership Board including a wider group of organisations. Many elements crucial for good care provision to an ageing HIV population (public health, social care, community engagement) will sit under the latter. We seek clarity on:

- How the power of the two boards will be balanced
- How the HIV sector will be represented, particularly where the population of people with HIV is small
- How the ‘imbalance’ in ICSs where the current provision of HIV care is disproportionate to local population prevalence will be managed
- The mechanisms by which ICSs will be accountable to people who access their services but do not reside within their geographic footprint
- How the needs of HIV services and their users will be met if their priorities do not align with those of the ICS.

Patient representation

HIV care has a strong legacy of engaging people with HIV at all levels of decision making, and some of our huge success in driving down drug spend is thanks to early community engagement and support. With little detail on membership of either board, or how people from vulnerable communities will be engaged, we are concerned that the voices of people most affected by HIV will not be heard.

Removal of procurement obligations

Sexual health services suffered thanks to the HSCA, the move of sexual health from the NHS to local authorities, and procurement obligations. The impact on service provision and staff morale, and the costs of bids, redundancies, and consultations, were significant. We therefore naturally support removal of this requirement. However, how will existing providers be judged and what freedom will commissioners have to change providers when deemed necessary?

Beyond CQC inspections and grades, more frequent and individualised assessment of services and appropriate levers to review and change providers are required. Presumably the proposed “health services provider selection regime” will cover these issues. Where private companies tender successfully for services, this must also include the provision of the appropriate training, education, research, and data collection that NHS organisations offer.

Closing statement

We raised several issues in our response to the January ICS consultation, some of which are also outlined above, but many of which have not been addressed in the White Paper:

<https://www.bhiva.org/file/602d2a7033c42/ICS-consultation-response.pdf>.

We welcome the direction of travel of the NHS long-term plan and the current White Paper, particularly regarding better integration across health and social care. However, we believe a phased approach will be the best approach. As Amanda Pritchard stated during her interview with the Health Select Committee, “there are some examples where things are working incredibly well now and we don’t want to stop people getting on and building on that success”.

We believe that HIV care is one such example of things “working incredibly well now”. Whilst ICSs are being established and mobilised, we feel that the specialised service structure for HIV care should be left in place for a period of time. There will be much disruption while the huge volume of services already co-ordinated at local and sub-regional level settle into the new system, so deferring devolution of high-performing specialised services makes sense. This will allow some of our major concerns, as outlined above, to be addressed, such as sensitive issues around data-sharing and the impact of the transition of PHE to NIHP. We can then approach devolution and local integration of care with confidence and full community engagement.

References

- 1) <https://www.bhiva.org/joint-response-to-the-announcement-of-the-NIHP-and-the-future-of-public-health>