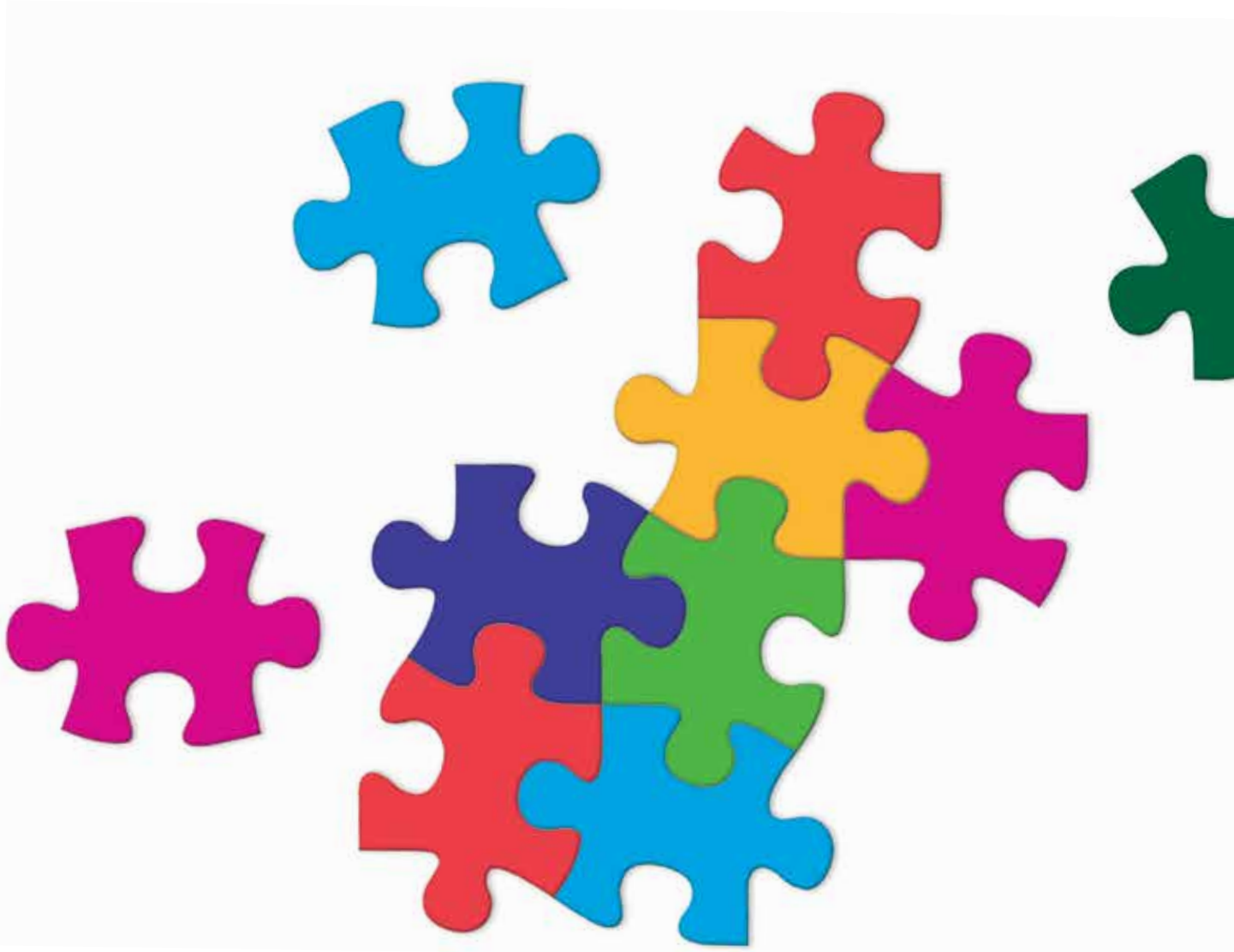




THE ALL-PARTY PARLIAMENTARY GROUP
on HIV & AIDS

The HIV puzzle

Piecing together HIV care since
the Health and Social Care Act



Foreword



Integrating HIV with sexual and reproductive health services is a key aim in the fight against HIV/AIDS globally and integrated services are considered an important factor in the UK's world-leading cascade of care. In 2015, 83% of people living with HIV (PLWH) in the UK were diagnosed, 96% of those diagnosed

were on treatment and 93% of those on treatment were virologically suppressed. The undiagnosed fraction remains too high, but the fact that almost 75% of PLWH are virally suppressed is a genuinely momentous achievement.

However, it is critical not to be complacent. Integrated HIV and sexual health services have historically been how most HIV treatment and care has been delivered in the UK but this is now changing rapidly. The Health and Social Care Act (2012) with its split in commissioning responsibilities, was predicted to risk fragmentation of services in England. This timely report confirms that this is exactly what has transpired.

The report highlights the important areas impacted by these changes; HIV prevention and testing including the vexed and critical issue of pre-exposure prophylaxis (PrEP), destabilisation of HIV services, and reduced provision of social and community support services. These impacts at best threaten further progress in care outcomes and at worse are a harbinger of their decline.

In a key sentence the report identifies that "what seems to be missing in the Health and Social Care Act is an overarching accountability structure at a regional and national level". However, even within the constraints of the existing system there are positive actions that can be taken. This report is very clear on what is required. We hope that it will be the rallying point to more effectively address these issues.

Dr David Asboe

Immediate past Chair,
British HIV Association (BHIVA)



Since I took on the role as Chair of the All Party Parliamentary Group on HIV/AIDS in 2015 I have heard from numerous stakeholders that the changes under the Health and Social Care Act had negatively impacted on HIV services. For that reason, in December 2015 we started to collect written evidence to investigate

whether these concerns were well founded. The inquiry has taken about a year to conclude – we have heard from clinicians, local authorities, public health officials, people living with HIV and the charity sector both through written evidence and oral evidence sessions.

After a year of investigating the impacts of the Health and Social Care Act on HIV services, I think it is fair to say that some degree of fragmentation has occurred. The report demonstrates this quite clearly. The question is where do we go from here? I think most people are agreed that overhauling the new system would be neither desirable nor necessary. We wanted to try and work within the confines of the new system, which is why this report sets out some recommendations that would not require legislative change.

I voted for the Health and Social Care Act and I believe the premise behind it was sound, but we do have to admit where there are areas that need to be improved. That means ensuring that there is clarity and accountability for all aspects of the HIV care pathway. We have seen the effects of lack of clarity in the Act

particularly in the debate surrounding the provision of PREP and the uncertain future for HIV support services. Our report also covers other emerging issues such as lack of integration of sexual health and HIV services and the apparent disincentives for increased testing and prevention, which are so critical to the HIV response.

It is my hope that this report sheds light on these important issues and gives voice to the many concerns that have been raised with the APPG on HIV/AIDS, so that any unintended fragmentation of services is addressed by the Government sooner rather than later.

I want to thank everyone who has participated in the inquiry, particularly those who travelled across the country to attend our oral evidence sessions and all the members of the APPG who took time to give this inquiry the attention it deserved.

Mike Freer MP

Chair of the All Party
Parliamentary Group on HIV/AIDS

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Methodology

In December 2015 the APPG on HIV/AIDS put out a call for written evidence (see terms of reference in the Annex) to address the question, to what extent fragmentation has occurred to HIV services since the implementation of the Health and Social Care Act 2012? In May and June 2016, the APPG held four oral evidence sessions to further interrogate some of the issues raised.

We have received representations from a wide range of stakeholders including sexual health and HIV service providers, advocacy organisations, clinicians, people living with HIV, local authorities and public health in Manchester, Wales and Scotland. Unfortunately, Public Health England and NHS England were unable to provide written evidence or attend oral evidence sessions but we hope this report will provide some insight to them and help inform HIV policies in the future. This report does not however look at HIV services in Wales, Scotland and Northern Ireland. Whilst we did consult with public health officials in the Welsh and Scottish assemblies to gain a broader understanding of how HIV and sexual health services are provided across the UK, this report is only concerned with HIV services in England.

The aim of the inquiry is to identify where fragmentation of HIV services has occurred and to provide potential solutions to those problems. A further piece of work would be needed to look more closely at the constitutional legal framework and what could meaningfully be achieved under the current Act. It may be the case that legislative change is actually required. We hope to work with the Department for Health to ensure whatever can be done under the current legal framework, is taken full advantage of.

While this inquiry looks mainly at HIV and to a certain degree, sexual health, it would certainly be beneficial to do further comparative studies into the impact of the changes in other long-term conditions such as diabetes. It is not clear whether HIV has become particularly fragmented compared with other services and it would go beyond the scope of this inquiry to investigate that point.

Acknowledgements

Thank you to all of the stakeholders who have worked with us throughout the course of the inquiry. Particular thanks go to Halve It for convening the HIV sector response on testing and prevention and to individual organisations for the time and effort you have put into contributing. Thank you to all our witnesses, particularly those who travelled across the country, including Dr Gordon Scott, Dr Marion Lyons and John Dunn. This report was compiled by Susie Pelly, Policy Advisor to the APPG on HIV/AIDS. If you would like further copies please contact pellys@parliament.uk

Executive Summary

There has been significant upheaval to HIV and sexual health services since the Health and Social Care Act 2012 was implemented. Many have complained about the “fragmentation” of the service. The crux of the problem appears to be that the split in commissioning responsibilities between NHS England, Clinical Commissioning Groups (CCGs) and local authorities is unclear and confusing. The lack of a “lead commissioner” or other mechanisms such as an up to date service specification is leading to widely diverging standards in care across the country. This inquiry addresses to what extent fragmentation has occurred to HIV services since the implementation of the Act and what more the Government could be doing to mitigate the impact.

HIV continues to affect a significant minority of people in the UK; over 100,000 people are estimated to have the virus, with 17% of those unaware of their infection and 40% who are diagnosed late. The cost of treating HIV over a lifetime is about £380,000 per person. That money could be saved if more people are prevented from contracting the virus. Currently new diagnoses of HIV continue to rise year on year.

Stigma is still a major barrier to people getting tested for HIV. Support services are designed to help people deal with the subsequent isolation, managing the condition, employment and housing related issues that can arise from an HIV positive diagnosis and others becoming aware of their HIV status. There is a clear economic, social, clinical and public health benefit to encouraging early testing and providing the means for the greatest at risk of contracting HIV, to avoid doing so. The latest discovery that taking Pre Exposure Prophylaxis (PrEP) is highly effective at preventing the spread of HIV could be a ground breaking moment in the fight to end the epidemic, however, conflict over who should be the responsible commissioner is causing delays in access.

There are a number of areas where this fragmentation has had a detrimental impact on patients and healthcare providers. This is clearly visible where HIV services have been separated from sexual health services – an unintended consequence of the Act that will be explored in greater detail later in the report. Furthermore, vital support services are being decommissioned in various parts of the country, including Bexley, Oxfordshire and Portsmouth - to name a few - as local authorities are struggling to pay for them with decreasing budgets and increased responsibilities. Another example is the situation with the provision of PrEP, which is trapped in a legal battle as NHS England attempts to eschew the financial responsibility to commission it.

While the outlook may seem challenging for HIV services, there are a number of actions that the Government could take to mitigate some of the negative effects of the Health and Social Care Act 2012. More detailed recommendations are outlined below but the thrust of the message is that the Government must:

- ensure HIV prevention and testing are not neglected in the wake of decreased local authority budgets and devolved responsibility. Tackling late diagnosis is key to improving HIV outcomes
- clarify commissioning responsibility for HIV support services and ensure they are not summarily cut across the country
- encourage Public Health England to urgently develop a whole-service specification for HIV and sexual health, bringing together the various strands of clinical guidance which already exist, to ensure there is clear, consistent advice available to local authorities, CCGs and NHS England
- NHS England needs to urgently acknowledge its responsibility for commissioning PrEP and assess it accordingly.

Summary of key recommendations

1. HIV support services to be co-commissioned by NHS England and CCGs as part of the patient care pathway provided for long-term condition management. While local authorities do have a responsibility to provide public health and social care services, the ambiguity in the Act and lack of funding is encouraging too many of them to walk away from this responsibility. The sad fact is that people are being denied the right to vital services which could lead to a significant public health failure in the not so distant future. Support services sit comfortably within the mandate which CCGs and NHS England already have to provide HIV treatment and care.
2. Co-commissioning of HIV and sexual health between local authorities and NHS England. NHS England and local authorities need to work together to ensure a service assessment is in place so that whoever the new provider is, they have a responsibility to ensure that the HIV service is maintained and not lost. Local authorities need to be held to account by NHS England.
3. Public Health England needs to urgently develop a whole service specification for HIV and sexual health bringing together the various strands of clinical guidance which already exist, to ensure there is clear, consistent advice available to local authorities, CCGs and NHS England.
4. While public health has been devolved, the Secretary of State must ensure that local authorities have enough guidance to ensure there is a minimum service requirement, which they must provide. At the moment the Act is not providing enough clarity or accountability and it is the Department of Health's responsibility to ensure that it does.
5. The Department of Health needs to ensure that there is mandatory guidance for sexual health service bidders to undertake risk assessments and produce action plans, detailing how the HIV treatment service will be transitioned, and implemented.
6. In order to ensure sustainable commissioning for HIV testing and prevention, the APPG on HIV/AIDS recommends protection of local authority public health grants from further funding cuts, in line with the Government's commitment to ring-fencing the NHS budget.
7. Clinical governance requirements for HIV testing should be clarified by a national body, to ensure that community testing is not limited by local authority interpretation of these requirements.
8. Urgent clarification is needed on PrEP and other areas of HIV treatment and care. The Secretary of State has the power to intervene in the dispute over PrEP and should do so sooner rather than later, to avoid months of wasted time, effort and money through costly court cases, not to mention, needless infections of HIV amongst high-risk populations.

Introduction

Since the 1980s when the HIV epidemic spread fear and caused millions of deaths throughout the globe, the UK has developed a world-leading HIV cascade of care. Since the start of the epidemic 78 million people have been infected with HIV and nearly half of those (35 million) have died from AIDS-related causes.¹ Thankfully the epidemic has changed considerably since those terrifying days – HIV is no longer a death sentence. Antiretroviral treatment is now so effective that someone can expect to live a near-normal life expectancy if they are diagnosed promptly and can obtain a virtually undetectable viral load, which means the virus will not be passed on. New discoveries are always improving our understanding and ability to control the epidemic. In 2013 the START study² proved that starting treatment earlier improves health outcomes and the World Health Organisation (WHO) adopted this as official guidance in 2015.³ The discovery that Pre Exposure Prophylaxis (PrEP) – a drug that can be taken to avoid contracting HIV – is highly effective at preventing onward transmission is also paving the way to ultimately ending the epidemic.

Despite these significant scientific advances however, we are still struggling to control HIV incidence. Infections continue to rise year on year in England, where one of the world's most advanced health systems exists. An estimated 6,151 people were newly diagnosed with HIV in England in 2014 (a slight rise from 2013 but in line with trends for the past few years) and 613 of those people died from AIDS-related causes. Overall an estimated 103,700 people were living with HIV in the UK; 17% (18,100 people) were unaware of their condition,⁴ and 40% (1,975 people) of those diagnosed in 2014 were diagnosed late.

Late HIV diagnosis is not only associated with a higher risk of mortality and morbidity but also with onward transmission; those diagnosed late are likely to have been living with undiagnosed HIV for at least 3-4 years and may have been at risk of passing on their virus. Late diagnoses disproportionately affect black African heterosexuals,

1 UNAIDS Fact Sheet, 2016 <http://www.unaids.org/en/resources/fact-sheet>

2 I-BASE Website <http://i-base.info/start-study/>

“The international START study is one of the most important HIV studies from the last ten years. In May 2015, results showed that HIV treatment has important benefits for your health, even if your CD4 count is still high. These results quickly changed treatment guidelines. This includes UK guidelines (BHIVA) and international guidelines (WHO). Previous guidelines said it was okay to wait until your CD4 counts dropped to a lower level. START included more than 4600 HIV positive people from 35 countries. Everyone entered the study with a CD4 count above 500. Half of participants started ART straight away and half waited until their CD4 count reached 350. Early ART more than halved the risk of a serious illness. Even though the actual risk was low – most people did well in both groups – the difference between the two groups was highly significant. The benefit of treatment was seen for all important sub groups. For example, in older and younger people (above/below 35), in men and women, in people living in both high- and low-income countries, and in people with and without risk for other important illnesses. START showed that early ART was also safe and effective. About 98% of people who started treatment had an undetectable viral load at the end of their first year of treatment.”

3 World Health Organisation 'Guideline on when to start antiretroviral therapy and on pre-exposure prophylaxis for HIV', <http://www.who.int/hiv/pub/guidelines/earlyrelease-arv/en/>

4 Public Health England, 'HIV in the UK – Situation Report 2015: data to end 2014.' November 2015. Public Health England, London https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/477702/HIV_in_the_UK_2015_report.pdf

with 58% diagnosed late in 2014 compared to 29% among gay and bisexual men.⁵ Reducing late HIV diagnoses through frequent HIV testing followed by prompt integration into HIV care and treatment is vital in reducing onward HIV transmission. However, as this report will go on to demonstrate, the current split of responsibilities for HIV testing and treatment is having a detrimental impact on efforts to achieve this goal.

As a long-term chronic condition, treatment for HIV is considerable. It costs the NHS roughly £380,000 per person over the course of a lifetime. Prevention has been shown to be cost effective. We now have new pioneering evidence which is advocated by the World Health Organisation as the gold standard for HIV care: earlier treatment prevents infection and improves health outcomes and giving PrEP to high risk populations will also have a significant impact.⁶ However, the UK unfortunately is not making the most of these advances and some of this is related to changes to the National Health Service (NHS) under the Health and Social Care Act 2012.

The Health and Social Care Act 2012 (hereafter referred to as the Act) was arguably one of the most revolutionary pieces of legislation that the National Health Service (NHS) has undergone since 1945. It was highly controversial for a number of reasons; mainly because the scale of the changes made was unprecedented, and also because local politics became embedded into health decision-making through the delegation of public health to local authorities.

Three years since the implementation of the Act, and following numerous representations and meetings with HIV stakeholders about its implications, the All Party Parliamentary Group (APPG) on HIV/AIDS concluded that it was a good time to take stock of the impact it has had on HIV services. In July 2015 the All Party Parliamentary Group on Sexual and Reproductive Health in the UK produced the report *'The need for accountability and integration in sexual health, reproductive health and HIV services in England'*.⁷ While there is some overlap in the issues covered, this report will deal specifically with the reported "fragmentation" of HIV services and what this means for people living with HIV. Equally, a year on since the APPG on Sexual and Reproductive Health produced their report, there is a growing body of evidence of HIV services that have been impacted by the changes.

The main concern highlighted to the APPG about the new system is that it has caused fragmentation of services. Our inquiry investigates to what degree this is the case and moreover, what can be done about it.

At the time of writing the Health Select Committee has recently reported on its inquiry: 'Public Health post 2013'. The Committee shares our view that sexual health has become fragmented under the new Act. We welcome the recommendation from the committee that a benchmarking framework for local authorities is needed to allow for informed comparison and challenge between local authority areas, and to provide a mechanism for closing the loop so that local authorities can be held to account.

5 Public Health England 'HIV: New diagnosis and treatment in the UK 2015 report', https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/469405/HIV_new_diagnoses_treatment_and_care_2015_report20102015.pdf

6 World Health Organisation, 'Guideline on when to start antiretroviral therapy and on pre-exposure prophylaxis for HIV', <http://www.who.int/hiv/pub/guidelines/earlyrelease-arv/en/>

7 All Party Parliamentary Group on Sexual and Reproductive Health in the UK, *'The need for accountability and integration in sexual health, reproductive health and HIV services in England'*, <http://www.fpa.org.uk/sites/default/files/breaking-down-the-barriers-report-appg-srhuk.pdf>

The report will be divided into the following sections:

Section 1: The Health and Social Care Act 2012 – what changed?

Section 2: Is this the beginning of the end for HIV support services?

Section 3: Integration of HIV and Sexual Health

Section 4: The negative consequences of confusion – testing and prevention

Section 5: The PrEP debacle

Section 6: Conclusion

REPORT FORMAT

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The Health and Social Care Act 2012 – what changed?

Section 2

Is this the beginning of the end for HIV support services?

Section 3

Integration of HIV and Sexual Health

Section 4

The negative consequences of confusion – testing and prevention

Section 5

The PrEP debacle

Section 6

Conclusion

Section 1

The Health and Social Care Act- what changed?

“You cannot encapsulate in one or two sentences the main thrust of this.”⁸

SIMON BURNS, MINISTER OF STATE FOR HEALTH, MARCH 2012

NHS structure pre 2012

Prior to the 2012 Health and Social Care Act, 152 Primary Care Trusts (PCTs) were the administrative body responsible for commissioning most primary, secondary and community care from providers. They were responsible for administering about 80% of the NHS budget. Above PCTs sat ten regional Strategic Health Authorities (SHAs) responsible for overseeing commissioning at a regional level. The Health Protection Agency (HPA), a non-departmental public body, was responsible for protecting the public from threats to their health from environmental or infectious diseases.

The 2012 restructure involved the abolition of PCTs, SHAs and the HPA. Though the exact detail of the structural change was not fully articulated in the Government White Paper *‘Equity and Excellence: Liberating the NHS’*,⁹ the vision of the reform was clearly to create more streamlined, less cumbersome management structures that would enable GPs to commission care for their patients in a more direct way. “We will make the NHS more accountable to patients. We will free staff from excessive bureaucracy and top-down control. We will increase real terms spending on the health service in every year of this Parliament.”¹⁰

NHS structure post 2012

While the original concept of the new structure, as detailed in the Government White Paper, was to place more power into the hands of GPs, with oversight from a national Commissioning Board, the final reality of the Act was somewhat different. What were intended as GP consortia became Clinical Commissioning Groups (CCGs); CCGs are in essence quite similar to what they replaced (PCTs), in that they include many of the same actors. The difference is that they must include a GP from each of their local GP networks, a practice nurse and a specialist doctor.

Beyond that, CCGs also include a practice manager, lay members (with CCG expertise) and the local council. The main difference from PCTs is the emphasis on the involvement of GPs – who, the former Health Secretary, the Rt Hon Andrew Lansley MP believed were best placed to make decisions on behalf of patients.

While the structure may not be revolutionary, the responsibilities and number of stakeholders that the CCGs need to work with has changed considerably. Critically, CCGs must work with the new local authority Health and Wellbeing Boards. Health and Wellbeing Boards are statutory bodies created under the new Act, which were designed to ensure better-integrated health and social care. Local authorities must set up these boards and carry out Joint Strategic Needs Assessments (an assessment of local health and social care needs) to inform a Joint Health and Wellbeing Strategy which is then used to inform commissioning decisions.

CCGs must therefore work closely with local authorities when deciding on which health services to commission. The Act also legislated for the transfer of responsibility for public health to local authorities (most of which was previously commissioned by PCTs). Witnesses to this inquiry have reported most complications with the new structure in this area. The split of responsibilities between local authorities, CCGs and NHS England often overlap, particularly in areas like sexual health, leading to inevitable confusion, and certain aspects of treatment and care falling through the cracks.

The final layer in the new system is the national commissioning board known as NHS England. NHS England is responsible for oversight of the CCGs, however it also directly commissions specialised services. “Specialised services are those provided in relatively few hospitals, accessed by comparatively small numbers of patients but with catchment populations of usually more than one million. These services tend to be located in specialised hospital trusts that can recruit a team of staff with the appropriate expertise and enable them to develop their skills.”¹¹ HIV sits under specialised services and therefore the commissioning of HIV services is split between NHS England, CCGs and local authorities.

Other new bodies created by the Act

The other new key organisation created under the Act is Public Health England, which replaces Health Protection England. Rather than an independent public body receiving government funding, it is now an executive agency of the Department of Health, which is supposed to provide independent public health advice to the Government as well as commissioning of national screening and immunisation for young children. Healthwatch England has also been created as the watchdog for “consumers” of health services. As it states on its website: “Healthwatch England is the national consumer champion in health and care. We have significant statutory powers to ensure the voice of the consumer is strengthened and heard by those who commission, deliver and regulate health and care services.”¹² Healthwatch exists at a national and local level and is the responsibility of local government to set up.

Other bodies intended to provide oversight and to ensure standards are maintained are: Monitor, which is an executive non-departmental public body, sponsored by the Department of Health whose aim is to “support” providers of care “to give patients consistently safe, high quality, compassionate care within local health systems that are financially sustainable.”¹³; the Care Quality Commission, which monitors,

⁸ The Report, BBC Radio 4, 22 March 2012

⁹ Department of Health, *‘Equity and Excellence: Liberating the NHS’*, https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213825/dh_119109.pdf

¹⁰ Department of Health, *‘Equity and Excellence: Liberating the NHS’* Foreword

¹¹ NHS England website, <https://www.england.nhs.uk/commissioning/spec-services/>

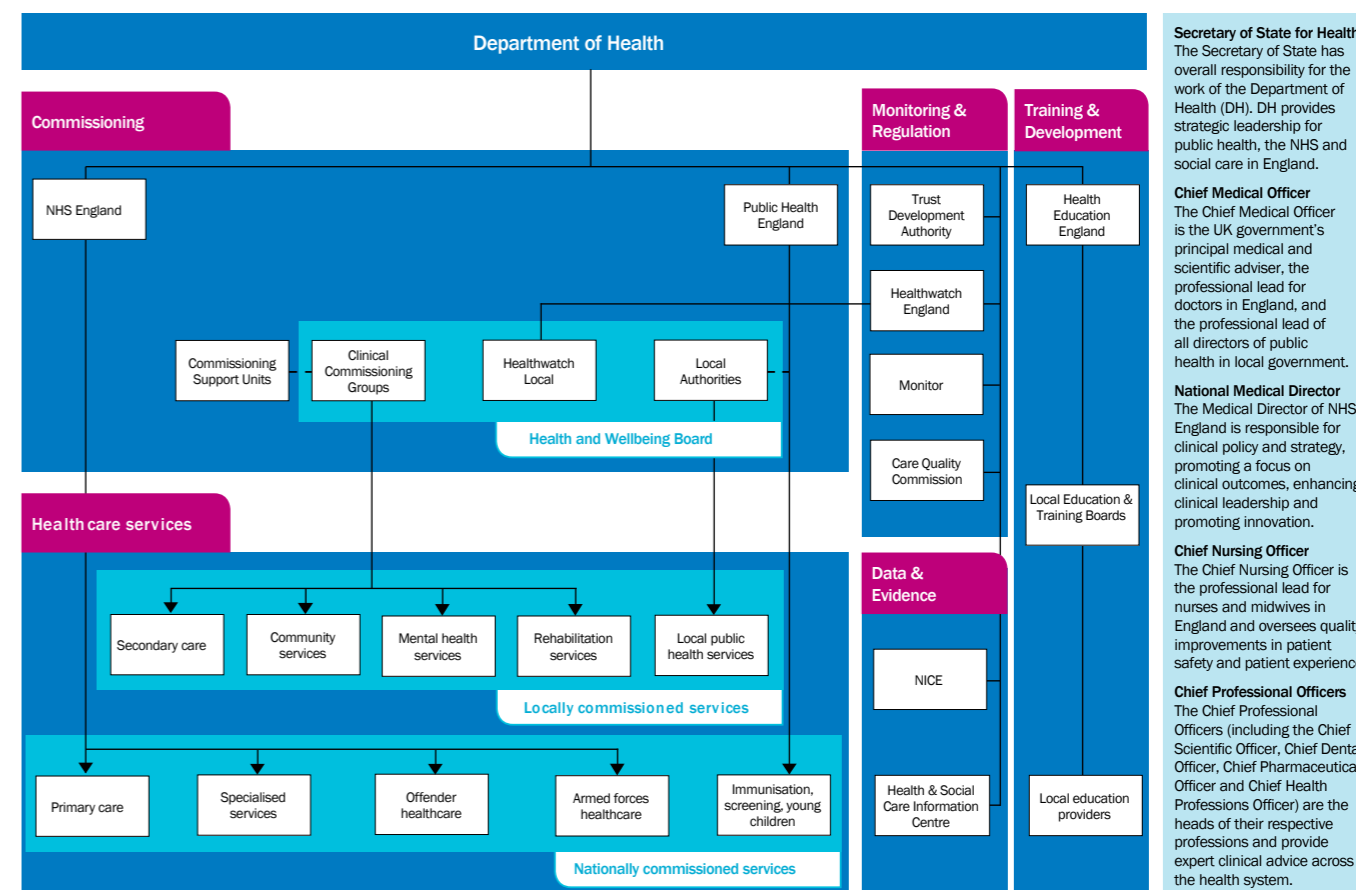
¹² Healthwatch England website, <http://www.healthwatch.co.uk/about-us>

¹³ Monitor website, <https://www.gov.uk/government/organisations/monitor/about>

inspects and regulates health and social care services. They publish what they find, including ratings to help people choose care;¹⁴ and finally, the National Institute for Care and Excellence (NICE), which, although previously in existence, has been given a greater mandate to provide service specifications for the main care pathways, as detailed in the Government White Paper 'Equity and Excellence: Liberating the NHS'.¹⁵ There are a number of other bodies, which have been created under the new system, however, for the sake of being succinct, we will not detail all of them here. The Kings Fund has an excellent animated video that explains the changes in six minutes.¹⁶ Please see the NHS England diagram below for a graphic illustration.

The key structure, which does not seem to have been replaced in any form, is comprised of the ten Strategic Health Authorities. While there is oversight at local authority level, there is no regional oversight of health care provision. In some areas local authorities are working together to improve public health beyond their local areas, as it is more cost efficient and is necessary to overcome some of the challenges in the new legislation, for example that sexual health services should be "open access". This means that patients can attend sexual health services in any local authority. The problem then arises of how to manage cross-charging and referrals etc. Regional cooperation is also important for the collection of data. With service provision now split between three different commissioners, the previous systems for collecting data on patient uptake of services, retention in care and other important indicators like these, are being lost. Currently, local authorities are under no legal obligation to work together, however, this may prove to be an obstacle to improved healthcare in the future.

STRUCTURE OF THE NHS IN ENGLAND



Taken from the NHS England Website¹⁷

Summary

Under the Health and Social Care Act 2012, far reaching reforms changed the entire structure of the NHS. While not all of the structural change was outlined in the Government White Paper, the intent was clear: to streamline management structures and create a more patient-centred health service. While this may have been the objective, in practice, as this report will go on to demonstrate, the changes have in fact lead to an *increase* in complexity and the subsequent fragmentation of HIV services. The dramatic abolition of Strategic Health Authorities has left a considerable gap where regional oversight once existed. The shift from PCTs to CCGs is not as revolutionary, however the re-organisation of health responsibilities which would have previously fallen to PCTs but are now divided between CCGs, NHS England and local authorities, all add up to a considerable level of change which the system it still struggling to manage.

14 Care Quality Commission website, <http://www.cqc.org.uk/>
 15 Department for Health, 'Equity and Excellence: Liberating the NHS', https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213825/dh_119109.pdf p32
 16 The Kings Fund website, <http://www.kingsfund.org.uk/projects/nhs-65/alternative-guide-new-nhs-england>

17 NHS England website, <https://www.england.nhs.uk/wp-content/uploads/2014/06/simple-nhs-guide.pdf>

Section 2

Is this the beginning of the end for HIV support services?

Fragmentation in the Oxford dictionary is outlined as “the process or state of breaking or being broken into fragments.”¹⁸ The question that this inquiry seeks to address is whether services have become more disparate or broken, and less integrated than they were prior to the Act.

The APPG received numerous representations which all highlighted where HIV services are becoming more fragmented. The following sections will summarise some of the key concerns raised, including HIV support services; the separation of sexual health and HIV; barriers to testing and prevention; and finally the conflict over PrEP. As described above however, the main problem derives from the splitting of responsibilities between three different bodies - NHS England, CCGs and local authorities - and the subsequent confusion and conflict this has created.

Clinicians and the HIV community have long seen HIV support services as a vital part of the care pathway for people living with HIV. Moreover, the British HIV Association (BHIVA) which is accredited by NICE as the official guidance for HIV treatment and care, states that the following are necessary for effective long-term condition management: “peer support, support and information about HIV treatment, healthy living with HIV, diet and lifestyle, and optimisation of general health, support around access to health services, financial, housing and employment support”.¹⁹ Given the NICE accreditation of these guidelines, it is surprising that no provision was made in the Health and Social Care Act to ensure that they were clearly embedded into the commissioning landscape.

Support services include a mixture of professional and peer support. Not everyone living with HIV requires support and most will only need to use the services periodically when they are newly diagnosed; experiencing employment issues; during pregnancy; when they need to think about disclosure; and if they are experiencing discrimination. Psychological support is particularly important for people living with HIV as any mental health issues can impact on treatment adherence. It is telling that NHS England recognises the importance of support services when it states that:

“The effectiveness of HIV specialised services depends on other elements of the HIV care pathway being in place and effectively coordinated... [including] third sector HIV care and support services for treatment adherence, peer support, and self-management... [and] social care, mental health and community services for rehabilitation, personal care or housing”.²⁰

In a recent briefing produced by the National AIDS Trust and Terrence Higgins Trust, they highlight some key findings from their survey:

“100% of clinicians said that they advise their patients to use HIV support services. Identified patient outcomes include coping better with diagnosis (reported by 91% of clinicians), improved emotional well-being and/or reduced isolation (89%), and improved confidence around disclosure (80%), and improved treatment adherence (65%). All clinicians thought that information, advice and advocacy; sex and relationships support; and psychosocial support are essential services for people living with HIV, and well over 90% stated that self-management support and peer-support services are essential.”²¹

Given the clear medical and social grounds for maintaining HIV support services, it may be surprising to hear that some of these services are being cut and de-commissioned in Slough, Bracknell Forest, Portsmouth, Oxfordshire County Council, Bexley and Bromley. Other councils, including Lambeth, Southwark and Lewisham where the highest rates of HIV in the country exist, are planning to de-commission some aspects of the HIV support service, such as counselling. Unfortunately, they seem to be one of the major victims of the new system. No clearly defined commissioning responsibility was assigned to local authorities and due to extreme financial pressure, they are proving highly vulnerable to cuts.

Why are HIV support services vulnerable under the new Act?

HIV support services are vulnerable under the new Act mainly because commissioning responsibility was not clearly defined. Despite clear expert guidance, it is evident from Public Health England’s guidance to commissioners that HIV support services are the only part of the care pathway which has been left “to be determined locally”. This means that either the CCG or the local authority could provide them. The diagram below from the Public Health commissioning guide ‘*Making it work: A guide to whole system commissioning for sexual health, reproductive health and HIV*’ outlines the slightly confused split of responsibilities:²²

¹⁸ The Oxford Dictionary online <http://www.oxforddictionaries.com/definition/english/fragmentation>

¹⁹ Standards of Care for People Living with HIV, British HIV Association, 2013

²⁰ NHS England HIV adult service specification 2.2, 2.5

²¹ Parliamentary briefing paper ‘Services supporting people living with HIV’ September 2016 National AIDS Trust and Terrence Higgins Trust:

²² Making it work: A guide to whole system commissioning for sexual health, reproductive health and HIV, Public Health England http://www.medfash.org.uk/uploads/images/file/Making_it_work_FULL%20DOCUMENT_revised%20March_2015.pdf p.54

Services shared between all three commissioning bodies
<p>5 Support services for people living with HIV (PLWH)^{viii}</p> <p>Community-based HIV clinical nurse specialists (<i>determined locally</i>)</p> <p>Hospital-based HIV clinical nurse specialists (<i>NHS England</i>)</p> <p>Community-based psychological, social and peer support for PLWH (<i>determined locally</i>)</p> <p>Treatment information for PLWH (<i>determined locally</i>)</p> <p>Psychological support for PLWH as part of routine patient care in general practice (<i>NHS England</i>)</p> <p>Mental health services for PLWH with complex or severe psychological difficulties (<i>CCGs</i>)</p>
<p>LOCAL SOLUTIONS:</p> <p>CCGs and NHS England review the role of HIV clinical nurse specialists at a local level to ensure it is integrated with the pathway in the national service specification for specialised HIV services.</p> <p>CCGs, LAs and NHS England jointly agree commissioning arrangements for psychological and social support and treatment information for PLWH.</p> <p>NHS England, CCGs and LAs jointly agree pathways for PLWH between specialised HIV treatment and care, community-based psychological, social and peer support (including voluntary sector and general practice) and specialist mental health services.</p>

The public health mandate that was entrusted to local authorities does not outline a clear responsibility to provide HIV support services. While the mandate for public health funding within local authorities is to prevent the spread of sexually transmitted infections including treating, testing and caring for people with such infections, as well as partner notification, they were not given any legal mandate to provide services for People Living with HIV (PLHIV), while of course they can still legally provide these.²³

Secondly, local authorities were subject to a £200 million in-year cut. While the public health budget may have been ring-fenced for 2015/2016, this cut to local authorities ultimately completely undermined that commitment. The anger at this move is succinctly described by the King’s Fund in their submission to the Health Select Committee inquiry into Public Health post 2013 - Structures, Organisation, Funding and Delivery.

“The recent in-year cut to English local authority budgets of £200 million, and the announcement of an average 3.9 per cent real cut every year to local authority allocations throughout the course of this Spending Review period suggests that the government (despite its rhetoric) is not sufficiently committed to the public health agenda.”²⁴

23 Point 6.5 of the ‘The Local Authorities (Public Health Functions and Entry to Premises by Local Healthwatch Representatives) Regulations’ states: ‘The duty of the local authority under paragraph (1)(b) does not include a requirement to offer services for treating or caring for people infected with Human Immunodeficiency Virus’

24 Written evidence submitted by the King’s Fund to the Health Select Committee <http://data.parliament.uk/writtenevidence/committeeevidence.svc/evidencedocument/health-committee/public-health-post2013-structures-organisation-funding-and-delivery/written/25526.html>

What is happening to HIV support services on the ground?

As previously outlined some HIV support services have already been completely de-commissioned in Slough, Bracknell Forest, Portsmouth, Oxfordshire County Council, Bexley and Bromley.²⁵ Other councils, including Lambeth, Southwark and Lewisham where the highest rates of HIV in the country exist, are planning to de-commission some aspects of the HIV support service, such as counselling. In written evidence to the inquiry, Positively UK – a support service provider – explained some of their concerns with the current threats to services:

“Interpretation of how the mandate should be enacted in terms of social care support for people living with HIV varies. For some boroughs they interpret this as having no responsibility once the person tests positive for HIV, for others it entails support for people newly diagnosed up to 6 months from point of diagnosis.”

“Public health funding is being used to address shortfalls in social care services. As a result HIV prevention, testing and social care services are not only competing against other public health priorities for funding, but are competing against all services provided by local authorities.”²⁶

The overriding message we have heard throughout the inquiry is that it is a postcode lottery. In one of the inquiry oral evidence sessions we heard from Robbie Currie who is the sexual health programme lead for the London borough of Bexley. Robbie previously worked in sexual health under the NHS and has therefore had experience of both the old and new systems. Bexley, as previously mentioned has completely de-commissioned HIV support and care services including counselling. From Robbie’s perspective the services are very important and he fought to maintain them, however the pressure to reduce spending was too great. Another challenge that he highlighted is that local authorities don’t have any systems in place to collect data on who is using support services over a long period of time, so it is difficult to prove their value.

25 Slough / Bracknell Forest – peer support, drop-in, workshops on confidence, disclosure etc.
 Portsmouth – peer support and advice services
 Oxfordshire County Council (these were decommissioned by County Council, but subsequently picked up by the CCG; although with no long-term commitment to funding)
 Bexley – peer support services
 Bromley – peer support services

26 Written evidence from Positively UK

In response to a question on what the consequences would be of decommissioning services, Robbie said:

“It’s really tough, to be very honest, it’s really very tough to actually know what the consequences of that will be. Obviously I think the real consequences of that will be that people will face hardship alone, they will not get access to a range of welfare benefits or advocacy that they previously would have enjoyed. I think their isolation and social stigma will increase through that decommissioning process.”

Chief Executive of Positively UK, Allan Anderson, also pointed out that HIV seems to be the only “long-term condition” which is subject to such extensive cuts:

“If you look at long-term condition management and HIV, in one sense it’s termed a long-term condition, but actually it doesn’t quite sit within the long-term conditions framework, and actually all other long-term conditions are commissioned by the NHS. You can get cancer care, peer support for mental health services, the Desmond self-management model for diabetes, and of course actually the government have said they prioritise diabetes care, then it’s questionable why HIV alone should be sitting in local authorities and not sitting within the NHS.”

While a comparison of HIV with other long-term conditions would go beyond the scope of this inquiry, it is worth noting that specialists view support services as an essential element of HIV treatment and care. It would therefore make sense for them to be co-commissioned by NHS England and CCGs. Ultimately there needs to be one lead commissioner who can be held accountable for maintaining the HIV care pathway. CCGs would probably be best placed to do this as they already commission for other long-term conditions. Local authorities should not, however, walk away from their current responsibility but should work with CCGs to encourage a smooth transition of commissioning home.

CASE STUDY

National Aids Trust have compiled a number of case studies of support services that are under threat or have been de-commissioned, here is one example:

THAMES VALLEY POSITIVE SUPPORT: INTRODUCTION

In January 2015 Slough Borough Council withdrew funding from Thames Valley Positive Support. They were the only charity in Slough that offered support to HIV positive people. It is worth noting that 97% of their client base were not willing to disclose their HIV status to other agencies or individuals and therefore would not be able to access support from non-HIV specific services. Supporting someone with HIV requires expert knowledge regarding their rights surrounding employment, benefits, housing, immigration as well as the myriad of health issues, both physical and mental, that exist alongside this complicated virus.

The case study below from Thames Valley Positive Support is one recent example of a client they provided support to.

C.1

F, 43-year-old female

This lady has been known to our service for many years. She had ongoing mental health issues and a heart condition. In 2013 she was evicted from her property due to non-payment of rent and along with her partner she moved away from the area. She returned in October this year and shortly after her return was admitted to hospital after having a heart attack. Her mental health condition means she is suspicious of anyone in authority and she initially refused to engage with health professionals or social services as she knew neither, we were able to visit her in hospital and offer her reassurance and emotional support. She discharged herself from hospital but shortly afterwards was readmitted having had another heart attack which left her in intensive care, at this point it became clear that she and her partner (who is also positive) were living in a car. We were able to support her husband and liaised with social services regarding their housing situation. After 10 days she was well enough to leave hospital and was discharged, she returned to living in her car whilst her housing application was considered, we were able to help with food, and offer them both a safe and warm environment at our drop in centre. A couple of days later she died, following another massive heart attack. We have helped her partner organise the funeral.

With continued funding we would:

- offer him counselling to help him come to terms with his bereavement
- support him to pursue his housing application
- help him access benefits or support him to return to work
- ensure his was coping during this difficult time
- ensure he remained healthy by supporting him with his HIV medication adherence, something people struggle with in times of extreme hardship
- encourage him to attend our drop-in and create his own support network and friends to ensure he is not isolated.

Summary

Support services are being systematically de-commissioned as a consequence of the Health and Social Care Act. Commissioning responsibility for support services was not clearly defined in the Act and the mandate given to local authorities leaves this point notably ambiguous. The BHIVA guidelines state that support services are an important part of the HIV care pathway. BHIVA provide the only comprehensive guidelines for HIV and are formally accredited by NICE; their voice on HIV should therefore hold considerable weight with the Government. Despite expert advice however, as evidence to the APPG demonstrates there is now a postcode lottery on HIV support services. The future for HIV support services does not look good unless this failure to appoint commissioning responsibility is addressed.

Recommendation

- HIV support services to be co-commissioned by NHS England and CCGs as part of the patient care pathway provided for long-term condition management. While local authorities do have a responsibility to provide public health and social care services, the ambiguity in the Act and lack of funding is encouraging too many of them to walk away from this responsibility. The sad fact is that people are being denied the right to vital services which could lead to a significant public health failure in the not so distant future. Support services sit comfortably within the mandate which CCGs and NHS England already have to provide HIV treatment and care.

Section 3

Integration of HIV and sexual health

One particular area of concern that has been brought to the APPG's attention is the separation of some HIV services from sexual health services, which seems to have been an unintended consequence of the Act. The problem has occurred because while local authorities are responsible for commissioning sexual health services, they are not responsible for all aspects of the HIV service. HIV clinical services are commissioned by NHS England. HIV clinics have traditionally sat within, or next to, sexual health or genitourinary medicine (GUM) clinics because it is a logical place for them to reside and helps with referrals and the continuation of care. Most HIV diagnoses are picked up during routine sexual health check ups. In some cases, the HIV service has remained intact with the sexual health service, in other cases it has been relocated or discontinued. This disruption of care presents real problems for keeping track of patients and ensuring they remain in the care pathway.

The British Association for Sexual Health and HIV Services (BASSH), the lead professional representative body for those managing STIs and HIV in the UK, believe this has been a genuine oversight:

“I think it just wasn't thought about... I think there is a great deal of logic in having sexual health, STIs, contraception, health promotion and prevention together... I don't think the connection of what would happen if, particularly in a small service, the sexual health element of the tender was won by another provider. I don't think anybody thought what would happen to the HIV service that was there. I think they thought it would just continue to be provided... and of course that may well be the case if it's a large HIV unit, but in many cases it isn't and it's financially not viable, and that's where the problem lies and that's why I think there has to be something within local authority tenders for sexual health services that mandates the bidders to have a plan for what is going to happen to the HIV service – how they are going to ensure that that is still provided.”

ELIZABETH CARLIN PRESIDENT OF BASSH²⁷

²⁷ Oral evidence to the inquiry from Elizabeth Carlin President of BASSH

In written evidence BASSH outlines a number of case studies where this has happened and the subsequent fallout:

“Example B: A Sexual Health service was put out to tender and this was won by another large Sexual Health service provider leaving no local HIV service provision. Subsequently, the Sexual Health site identified for the new Sexual Health provider has fallen through leaving all elements of the previously integrated service in an uncertain position. NHSE are yet to decide who will be commissioned to provide an HIV service or how that decision will be made. There is no coherent plan to share with HIV service users, no planned consultation and several staff have left due to unacceptable uncertainty around their posts.

“Example E: In a SH service that went out to tender a few years ago the contract was awarded to a community NHS provider. The outreach HIV clinic that had been well established was not sustainable and the service was discontinued. The majority of the service users transferred their care to other HIV providers some miles away but 9% were presumed to have disengaged in care.”

BHIVA, which is the leading UK association representing professionals in HIV care, also shared a number of anonymised quotes about some of the fall out since the implementation of the Act which mirrors the examples given by BASSH, and reflects some seriously concerning issues arising from split commissioning.

“Essentially, our joint Sexual Health and HIV service was split in April 2012 after a competitive tendering and procurement process where as a result of TUPE, myself and a nurse specialist were left to look after 450+ HIV patients i.e. we had no receptionist, phlebotomist, health adviser, consultant colleague.”

“The result of tendering of the GU and HIV services has been disastrous for the patients. Our Trust did not wish to bid for the service as there was no money in it.”

“There are no GU or HIV physicians now at the Hospital in the event that a patient is admitted. There is no agreement for their “ex HIV Physicians” to see such patients despite pleading from these physicians for such an agreement in advance of leaving the Trust.”

Aside from the split of commissioning responsibilities that is leading to this unintended separation of services, another contributing factor was also identified by the inquiry; there is no whole service specification for HIV and sexual health, and this is further contributing to its de-prioritisation amongst health professionals. NICE is limited to recommendations on promoting testing amongst Black Africans²⁸ and Men who have sex with Men (MSM),²⁹ and reducing STIs and HIV in young people.³⁰ The service specifications that do exist are ‘Integrated Sexual Health Services: National Service Specification’³¹ and the NHS England Service Specification for Adult HIV Services and the same for paediatric HIV.³² While all of these guidelines are useful, what is really lacking is a comprehensive service specification for HIV and sexual health. Public Health England would be the best organisation to produce this.

Summary

The separation of HIV from sexual health clinics is an unintended consequence of the Health and Social Care Act but it needs to be addressed urgently. The split responsibility for HIV between local authorities and NHS England is leading to confusion in commissioning. Local authorities are entirely responsible for providing sexual health services but they are not responsible for the entire HIV care pathway. This has resulted in sexual health services being put out to tender without a plan for the HIV service. Sexual health is the more profitable service and therefore many providers have only purchased the sexual health service, leaving no place for HIV. The result of this has been different in different areas but ultimately it is leading to a huge divergence in the quality of care. Anecdotal evidence suggests that a significant proportion of HIV patients have fallen out of the care pathway as a result. Previously sexual health was all commissioned by PCTs and the separation of HIV from sexual health services was unheard of. The importance of a clear service specification for HIV and sexual health should also not be underestimated. Currently, the different strands of guidance from different bodies mean that there is no “one stop shop” for local authorities or CCGs and this is not helping the sense of fragmentation experienced by patients and health professionals.

28 NICE Guidance PH33

29 NICE Guidance PH34

30 NICE Guidance PH3

31 Department for Health website

32 NHS England website

Recommendations

- Co-commissioning of HIV and sexual health between local authorities and NHS England. NHS England and local authorities need to work together to ensure a service assessment is in place so that whoever the new provider is, they have a responsibility to ensure that the HIV service is maintained and not lost. Local authorities need to be held to account by NHS England.
- The Government should encourage Public Health England to urgently develop a whole service specification for HIV and sexual health bringing together the various strands of clinical guidance which already exist, to ensure there is clear, consistent advice available to local authorities, CCGs and NHS England.
- While public health has been devolved, the Secretary of State must ensure that local authorities have enough guidance to ensure there is a minimum service requirement that they must provide. At the moment the Act is not providing enough clarity or accountability and it is the Department of Health's responsibility to ensure that it does.
- The Department of Health needs to ensure that there is mandatory guidance for sexual health service bidders to undertake risk assessments and produce action plans, detailing how the HIV treatment service will be transitioned, and implemented.

Section 4 The negative consequences of confusion – testing and prevention

The commissioning split between local authorities, CCGs and NHS England is not just leading to the illogical separation of sexual health and HIV services, it is also having a knock-on effect on prevention and testing. Lack of oversight and clear lines of responsibility are leading to a fragmented service. Ultimately the reasons these issues are occurring are the same reasons previously outlined. The commissioning split is complicated. Local authorities are responsible for HIV prevention, but prevention also includes testing and testing is also commissioned by CCGs and NHS England. Many of the HIV services (including prevention) were traditionally available in sexual health clinic settings but the separate commissioning of sexual health and HIV services creates a further layer of complication. Fundamentally, commissioners aren't entirely sure which bit of the HIV service they are supposed to be providing and paying for and this is causing fragmentation.

Public Health England's report on HIV in England for 2015 revealed all but one borough in London by the end of 2014 had surpassed the threshold for expanded testing in general practice new registrants and hospital admissions.³³ The report states: "there is an urgent need to increase HIV testing opportunities and uptake for people living in these areas, in line with the HIV national testing guidelines." With this in mind, evidence provided to the APPG that this is not happening, that in fact, testing is decreasing as a result of the Act, is extremely concerning. As Public Health England data also shows, late diagnosis of HIV is a real problem in the UK. At the end of 2014, an estimated 103,700 people were living with HIV in the UK; 17% (18,100 people) were unaware of their condition,³⁴ and 40% (1,975 people) of those diagnosed in 2014 were diagnosed late. Public Health England clearly advises that addressing late diagnosis is key to improving HIV outcomes. Furthermore, as previously outlined in the introduction, late diagnosis disproportionately affects the Black African community. Unfortunately, however, as this section will go on to demonstrate, the current system is not facilitating increased testing within this particular community.

³³ NICE Guidelines PH34

The threshold for increased testing according to NICE guidelines is when there are 2 or more HIV diagnoses in 1000 people. These areas are called high prevalence areas. The guidelines state that high risk groups should be offered routine testing in primary and secondary care.

³⁴ 'HIV in the UK – Situation Report 2015: data to end 2014.' November 2015. Public Health England, London https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/477702/HIV_in_the_UK_2015_report.pdf

According to the NICE testing guidelines, testing should be available in a variety of settings. This is because not all high-risk groups are comfortable with attending a sexual health clinic. Black African communities for example are reportedly more likely to attend their GP, others will only access testing if an outreach service comes directly to them. In high prevalence areas (where more than 2 in 1000 people in the general population have diagnosed HIV) "...the guidelines recommend an HIV test is considered for everyone at GP registration and hospital admission."³⁵ Community outreach services are often provided by small, niche charities catering to a particular minority group. The inquiry has heard that these charities are struggling to survive under the new, more competitive market conditions. As the next section will go on to demonstrate, challenges are being seen at all levels where testing should be taking place.

Examples of fragmentation in testing and prevention at sexual health clinics

Below are various examples that the APPG has heard throughout the inquiry where prevention and testing within a sexual health clinic setting have been adversely affected by the Act:

BASSH have reported concerning trends with regard to testing:

“Some services have reported that commissioners have limited service development and promotion:

Example A: A large GUM service was not allowed to expand their opening hours by their commissioner. The service believes this was because the commissioner feared increased activity and increased costs.

Cuts to public health spending have reduced HIV testing opportunities, limiting the scope for increased testing and early detection of HIV. Due to Sexual Health falling outside of ‘core NHS services’ and with the prospect of further cuts to public health funding, we have real concerns there will be a further detrimental impact on the availability of HIV testing services.”

The overriding message that we have heard throughout the inquiry is that the commissioning landscape is just too complicated and is leading to problems across the board. We took oral evidence from Public Health in Greater Manchester where the health budget has been devolved. Its opinion is aligned with everyone else on this matter:

³⁵ Public Health Guidance PH34, <https://www.nice.org.uk/guidance/ph34/chapter/1-Recommendations>

“The transfer of power to local authorities has worked well in some areas but the funding of sexual and reproductive health services doesn’t sit well with local authorities. The tension between achieving open access at the same time as being restricted to funding services only for residents is the problem. We have tried to reduce the risk of fragmentation but it has happened.” If one organisation is going to take responsibility in the future it shouldn’t be local authorities, it should be the NHS. The changes have made our jobs much harder as we are focusing on who’s doing what rather than addressing the health of our populations”.

JOHN DUNN, PUBLIC HEALTH MANCHESTER

Fragmentation of HIV testing and prevention outside of sexual health clinics

PRIMARY AND SECONDARY CARE

While testing within GUM clinics is critical to the HIV response, it does not necessarily capture all demographics of people living with HIV (PLHIV) or at highest risk of contracting HIV. As data from Public Health England suggests,³⁶ certain population groups - such as black African communities - are less likely to get tested at a sexual health clinic than men who have sex with men (MSM). Another key group who are less likely to get tested at a GUM clinic are those infected through heterosexual sex that represent nearly half of people living with HIV (48%, 40,842). Among heterosexuals 15,383 are men and 25,459 women; 60% of people were of black African ethnicity, 24% white, 4% black Caribbean, 3% other black ethnicity, 2% Indian/Pakistani/Bangladeshi, and 2% of other Asian ethnicity.³⁷

The demographics of people diagnosed late is also interesting, with 58% (568/978) recorded as black Africans, 61% (488/805) heterosexual men, and 65% (66/101) people who inject drugs (PWID).³⁸ The large proportion of late diagnosis amongst non MSM groups is a clear indicator that testing must take place in a variety of settings, not just in GUM clinics where MSM are most likely to attend.

³⁶ HIV in the UK – Situation Report 2015: data to end 2014.’ November 2015.

Public Health England, London https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/477702/HIV_in_the_UK_2015_report.pdf

³⁷ Public Health England ‘HIV: New diagnosis and treatment in the UK 2015 report’, https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/469405/HIV_new_diagnoses_treatment_and_care_2015_report20102015.pdf

³⁸ Public Health England ‘HIV: New diagnosis and treatment in the UK 2015 report’, https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/469405/HIV_new_diagnoses_treatment_and_care_2015_report20102015.pdf

Halve It is a national campaign comprising 30 national and international organisations from the voluntary, private and public sectors committed to halving late and undiagnosed HIV by 2020. As preparation for this inquiry, Halve It conducted a survey of over 50 HIV community stakeholders from across a variety of different sectors and regions within England.³⁹ Their aim was to understand respondents' individual and organisational experience of adapting to the changes to health commissioning as they relate to HIV testing.

Based on the evidence collected from these 50 HIV community stakeholders, Halve It concluded that the Act poses further challenges to the provision of HIV testing in both primary and secondary care. Their research demonstrates that prior to the Act GPs were already reluctant to offer HIV tests⁴⁰ and that this has not improved under the Act. The responsibility for testing in high prevalence areas has now shifted to local authorities, therefore there is little incentive for GPs to encourage increased testing within their practices. Local authorities are also subject to funding cuts, which makes the service even more vulnerable.

Halve It members are also concerned about the impact on certain minority groups:

“The data is clear that other high risk communities, particularly black African communities, are far less likely to access sexual health clinics and much more likely to access primary care.⁴¹ The challenges to providing HIV testing in primary care as described above therefore risk entrenching existing inequalities in late diagnosis between MSM and Black African communities.”

With regard to testing in secondary care, the problem is very similar to that which is seen in primary care. With no lead commissioner, incentives to encourage testing in line with NICE guidelines are significantly reduced. With the main responsibility ostensibly sitting with local authorities, some key opportunities to improve late diagnosis will certainly be lost unless there is a strong governmental push to improve testing in primary and secondary care settings.

39 Halve It stakeholders surveyed were in some cases anonymous. Named participants include: BHIVA, English Sexual Health Commissioners' Network, NAT, MEDFASH, Positively UK, Positive East, the Association of Directors of Public Health and the LGBT Foundation

40 Halve It GP survey on HIV testing in primary care 2012 <http://www.halveit.org.uk/resources/Halve%20It%20GP%20survey%20at%202012%20RCGP%20conference%20report.pdf>

Halve It GP survey on HIV testing in primary care 2013

Halve It GP survey on HIV testing in primary care 2014

Halve It GP survey on HIV testing in primary care 2015

41 National AIDS Trust 'HIV and Black African Communities in the UK' 2014 P.19

'There is a reported unwillingness amongst many Black African men and women to use GU services, which makes their GP practice an even more important opportunity for HIV testing. And in fact many more Black Africans are diagnosed in primary care than gay men. Mayisha II [HPA's 2005 study into the sexual attitudes and lifestyles of Black Africans] found that a quarter of women who had previously tested in the UK and a third of men had tested in GP practices. So the evidence is both that this is a setting where Black Africans are willing to test, and do so, but that there is still much more we could do to increase testing through engagement of primary care. It is depressing in this context that NAT has heard of two instances recently where local African HIV support organisations have approached local GP practices offering to discuss how best to support Black African men and women around HIV testing and got no response.'

Evidence collected by the National AIDS Trust further highlights this point:

“NICE guidelines for HIV testing, which emphasises testing outside the sexual health clinic, are not being consistently commissioned and implemented. Our own evidence from our national survey in March 2015 highlighted that this was the case in the majority of local authorities...35 out of 58 surveyed, and this includes recommendations on HIV testing in primary care, secondary care in high prevalence areas, as well as around community testing...

“In terms of current investment in HIV prevention, the survey that I mentioned, which was in 2014-2015, found £1 pound spent for prevention for every £55 spent on treatment, no correlation between how much local authorities spend on prevention and testing and their level of HIV prevalence, and out of 58 high-prevalence authorities, 7 spent nothing on HIV prevention. A further 13 spent less than £25,000 which is just not enough money realistically to have an impact.”⁴²

COMMUNITY SETTINGS

Testing in community settings has also been impacted by the changes in a number of ways. Marion Wadibia, the Chief Executive of NAZ, a sexual health agency which provides support predominantly to Black, Asian and minority ethnic (BAME) groups, described in oral evidence to the inquiry that one of the major challenges is an emerging criteria which organisations need to meet in order to apply for a contract, namely that you would need a minimum spend or turnover of £1 million to be the lead agency.⁴³ For smaller organisations providing a niche service, this is unattainable. While local authorities should in theory be best placed to provide services for their communities, they are essentially taking on a new role that requires knowledge and expertise. As witnesses to the inquiry have highlighted however, there is considerable concern that the local authorities simply do not understand the HIV community's needs and pressure on budgets is having a detrimental impact.

A further complication arising from the devolution of public health commissioning to local authorities has been the inconsistent interpretation of clinical governance on HIV testing across different local authorities. Some local authorities require a registered nurse to administer an HIV test, whereas others do not. In areas where clinical expertise is required, the operations of community testing providers can be limited. Halve It recommends clearer guidance from a national body such as PHE, to ensure consistency in practice across the country. It is also vital that once someone has tested positive, they are swiftly moved into treatment and care. With separate commissioning bodies for testing and care, the transition is not currently as quick or smooth as it needs to be.

42 Oral evidence to the inquiry from Deborah Gold, Executive Director, NAT
The NAT survey 'HIV prevention in England's high prevalence local authorities 2013/2014 and 2014/2015' looks at all high prevalence local authorities.

43 Oral evidence to the inquiry from Marion Wadibia, Chief Executive, Naz

Summary

Testing and prevention are now largely the responsibility of local authorities, however CCGs and NHS England do still have commissioning responsibilities. This is causing significant confusion and fragmentation of services. Within sexual health clinics it has been reported that some commissioners are refusing to extend opening hours for fear of increased testing and therefore increased cost. Testing in primary and secondary care settings is historically not particularly high; evidence to the inquiry suggests that the legislative changes have made this situation even worse. Community setting testing is also under threat as many smaller organisations, which have been delivering HIV testing and care to minority groups for years, are unable to bid for contracts. Cuts to local authority budgets means that the future for HIV testing and prevention is vulnerable. Late diagnosis of HIV has been recognised as a real problem in the UK. Increased testing and prompt referral into care are key to addressing this issue. The changes under the Health and Social Care Act are unfortunately not helping to achieve this goal, and are potentially creating barriers to increased testing and patient referral into care.

Recommendations

- In order to ensure sustainable commissioning for HIV testing and prevention, the APPG on HIV/AIDS recommends protection of local authority public health grants from further funding cuts, in line with the Government's commitment to ring-fencing the NHS budget.
- Clinical governance requirements for HIV testing should be clarified by a national body, to ensure that community testing is not limited by local authority interpretation of these requirements.
- Whilst clinician knowledge of when to offer an HIV test is not directly related to the Act, increased pressure on primary and secondary care as a result of the Act means that educating healthcare professionals on the subject in line with NICE public health guidance must be a priority.

Section 5

The PrEP debacle

Background

Pre-exposure prophylaxis (PrEP) has caused a major headache for NHS England over the past few months and epitomises the problems created by lack of clarity in the Health and Social Care Act. PrEP is game changing drug, which, if taken correctly, provides almost complete immunity to HIV.

“PrEP is exciting, new, and currently, unique. It is not a vaccine, although it has a similar impact. We can draw comparisons to statins, in terms of preventing illness, or contraception, in terms of preventing unwanted consequences of sex. But actually, there is nothing quite like it. It is the definition of healthcare innovation.”

NATIONAL AIDS TRUST

So why has this major medical discovery caused the NHS such great problems? There are a number of reasons. First, PrEP is a preventative drug and with the main responsibility for public health and prevention lying with local authorities, the scope of NHS England's role in HIV prevention was as yet not firmly established. Secondly, the drug for PrEP - Truvada - is currently on patent and therefore quite expensive, though it should be noted that the patent expires in 2018. Moreover, PrEP has been shown to be cost-effective in the long-term, as while the cost of HIV treatment over a lifetime is estimated at £380,000 per person, PrEP would normally only be required for a much shorter time period and therefore the costs would be greatly reduced. The problem however, is that politically it is sometimes difficult to justify short-term cost for long-term benefit, particularly when budgets are squeezed.

Thus, PrEP presents a dilemma to NHS England, while on the one hand the cost is considerable, on the other, they have a potential get-out clause under the new Act. The recent judgement by the High Court however, has now repudiated that viewpoint. As we have demonstrated throughout the report, there are many areas where commissioning responsibilities overlap, and this is one of those areas. The friction over PrEP has escalated so far that the National AIDS Trust (NAT) challenged NHS England in a judicial review. At the beginning of August 2016 the High Court ruled in NAT's favour, stating that NHS England is legally able to commission PrEP. The judge, Mr Justice Green stated at the hearing:

“No one doubts that preventative medicine makes powerful sense. But one governmental body says it has no power to provide the service and the local authorities say that they have no money. The Claimant is caught between the two and the potential victims of this disagreement are those who will contract HIV/AIDs but who would not, were the preventative policy to be fully implemented.”

MR JUSTICE GREEN⁴⁴

Previously NHS England had stated that “local authorities are the responsible commissioner for HIV prevention services” and that “NHS England is not responsible for commissioning HIV prevention services.”⁴⁵ The reason given, is the fear that if PrEP is funded, advocates for other conditions which lose out in the next funding round might take legal action, arguing that the specialised commissioning budget is not there for prevention but for treatment.

The legal battle continued as NHS England decided to appeal the decision, much to the disappointment of PrEP advocates who fear that this was yet another delaying tactic. On 10th November the Court of Appeal ruled against NHS England.⁴⁶ However, while the High Court has ruled that NHS England is legally able to commission PrEP, it doesn't mean they have to. The drug still needs to go through consultation and then the formal decision making process within NHS England for any new drugs. The longer the legal battle has continued, the greater the delay for new, potentially life saving treatments for a whole range of different conditions. This is one example of where the Health and Social Care Act has failed patients. If commissioning responsibilities are the cause of such great contention that they end up in the High Court, then the Act has clearly not achieved what it set out to do. Moreover, it is a terrible waste of taxpayers' money and NHS time.

Breaking down the arguments for who should be responsible for commissioning PrEP

When NHS England decided to exclude PrEP from the commissioning decision-making process in March 2016, it came as a big surprise to those working on it. In 2014 NHS England convened a formal working group including doctors, patient groups, Public Health England (PHE), NHS England and the Department of Health (DH), to investigate the role that PrEP could play in preventing HIV in those at the highest risk. Those involved in the working group believed their purpose was to look into whether NHS England should commission PrEP, not local authorities. NHS England issued a press release in March 2016, highlighting the findings of the working group – that PrEP is in fact very effective. Curiously the press release then outlines the legal commissioning framework and points out that it is not responsible:

“Commissioning PrEP – the legal framework

As set out in the Local Authorities (Public Health Functions and Entry to Premises by Local Healthwatch Representatives) Regulations 2013, local authorities are the responsible commissioner for HIV prevention services. Including PrEP for consideration in competition with specialised commissioning treatments as part of the annual CPAG [Clinical Priorities Advisory Group] prioritisation process could present risk of legal challenge from proponents of other ‘candidate’ treatments and interventions that could be displaced by PrEP if NHS England were to commission it.”⁴⁷

This came as quite a surprise, particularly to those who had been part of the working group for the past eighteen months and caused understandable anger. The timing of the press release seems particularly bad. Just as advocates were expecting a decision to be made in June 2016, they were informed that they had effectively been working with the wrong commissioning body. While they state the legal responsibility lies with local authorities in a very matter of fact manner, it was obviously a point they felt needed clarified – hence the press release. It also begs the question, why did they not point this out eighteen months earlier when the working group was set up, rather than at the end of their work when expectations were extremely high?

Regardless of the somewhat tactless nature of the press release, the confidence with which local authority responsibility is defined is misplaced for the following reasons:

- while local authorities are responsible for commissioning prevention, NHS England also has a clear role; it commissions immunisation and vaccines, for example
- the drug which is used in PrEP (Truvada) is already commissioned by NHS England for HIV treatment
- NHS England also commissions PEP (post-exposure prophylaxis)
- HIV is considered a specialised condition partly because of the high treatment costs, which is why NHS England is the responsible commissioner for HIV clinical treatment. Any decision not to commission an expensive treatment like PrEP at a national level, would be financially unwise.

Fundamentally, local authorities would not be able to afford the drug for PrEP. Equally however, it would not make financial sense for them to do so. NHS England is an experienced commissioner of drugs and would be able to secure the best price for PrEP at a national scale rather than local level. The outcome of the debate is still to be determined.

⁴⁴ Mr Justice Green quote taken from NAT press release, 2 August 2016, http://www.nat.org.uk/Media-and-Blog/Press-Releases/2016/August/Historic_win_NAT_PrEP_judicial_review.aspx

⁴⁵ NHS England website <https://www.england.nhs.uk/2016/03/prep/>. NHS England Press release, 21 March 2016

⁴⁶ National AIDS Trust website <http://www.nat.org.uk/press-release/final-prep-hiv-drug-case-win-national-aids-trust-court-appeal> NAT Press Release, 10 November 2016

⁴⁷ *ibid*

Summary

The issues around PrEP are just one example of where conflict over commissioning responsibility has escalated and no doubt there will be more. The lack of clarity in the Act allows for this kind of discrepancy, and as budgets (both NHS and local authority) are constrained the problems are likely to continue. It is very impractical to have an intervention where NHS England needs to commission the drug (PrEP) because of its purchasing power, but where the service has to be commissioned by local authorities. It risks a postcode lottery in the implementation; local authorities will vary in terms of whether they actually provide the drug at all, and how quickly they make it available to residents.

More broadly, the downside of fragmentation is most apparent when budgets are cut or under immense pressure. In such circumstances, instead of collaboration and sharing of responsibilities, we see all the different parts of the system saying that a particular intervention is somebody else's job so they don't have to pay for it. PrEP is just one example of this. Thus the problem is that with responsibility shared across the health system no one is volunteering or willing to pay for what is so greatly needed. PrEP is yet to be resolved, however the view of this inquiry is that NHS England does have the power to commission the drug and should make that decision based on the cost-benefit arguments for and against it and nothing else.

Recommendation

- Urgent clarification is needed on PrEP and other areas of HIV treatment and care. The Secretary of State has the power to intervene in the dispute over PrEP and should do so sooner rather than later to avoid months of wasted time, effort and money through costly court cases, not to mention, needless infections of HIV amongst high-risk populations.

Section 6 Conclusion – finding a way forward

It has become clear throughout this inquiry that HIV treatment and services have become more fragmented since the Act was implemented. This is demonstrated by some key examples: support services have no commissioning home and are therefore the first major casualties of the Act, as they are summarily cut across an ever increasing number of local authorities. The groundbreaking drug PrEP, which has the potential to bring numbers of new infections down to an unprecedented level is caught up in a legal battle, as the only body that could afford to commission it, desperately tries to find legal loopholes to renege on their responsibility. HIV services are being senselessly separated from sexual health services, while testing and prevention of HIV are also taking a hit. As local authorities struggle to make ends meet with decreasing budgets, lack of clear commissioning guidelines makes it easy for them to justify lack of investment.

The outlook may seem bleak but there are some clear ways the Government could address these issues created by the new Act. With regard to support services for HIV, the current Public Health England advice “to be determined locally” is not good enough. There needs to be a very clear service specification for all aspects of the HIV care pathway, and currently this is not in place. Ideally, the Government would also outline a lead commissioner for each area of care. In oral evidence to the inquiry the APPG heard from public health representatives from Wales and Scotland, where health and social care is integrated with local authorities. Their advice was very clear. Marion Lyons from Public Health Wales stated that a good service specification is crucial, even more important than legislation. In Scotland sexual health sits under Blood Borne Viruses in the health system, which Dr Gordon Scott argues makes it easier to set priorities. This is something the Department may also want to look into as a potential solution.

Sexual health and HIV services should be provided in one service in the same location. The unintended split of services is not good for patients or HIV healthcare professionals. While there is some benefit to local authority oversight of sexual health, the negative consequences seem to be outweighing the positive. To avoid system overhaul once again however, and legislative change, the negative effects of these changes could be mitigated by taking some important steps. The Secretary of State must ensure that Public Health England produces a comprehensive HIV and sexual health service specification. Local authorities should be obligated to provide mandatory risk assessments and action plans from bidders which outline how the HIV service will be transitioned. The Government should prioritise the initiation of a formal dialogue between NHS England and local authorities about co-commissioning. Unless these steps are taken, HIV and sexual health services are in danger of seriously deteriorating in the not too distant future.

It is shortsighted to neglect HIV prevention and testing. While this may not have been the intention, with prevention now sitting in local authorities and commissioning responsibilities for testing split between 3 very different organisations, the outlook does not seem promising. Testing and prevention are now subject to local authority cuts and a whole host of competing priorities. While primary and secondary care still have some responsibility for testing, evidence to the inquiry demonstrates

that the commissioning split is confusing and acting as a deterrent to increased testing. Testing within community settings is also under threat as long-standing outreach organisations are unable to meet local authority contract requirements because they are too small. Differing interpretations of clinical guidance in local authorities are also leading to an inconsistency in delivery standards on testing.

To address some of these issues, the APPG HIV/AIDS recommends protection of local authority public health grants from further funding cuts, in line with the Government's commitment to ring-fencing the NHS budget. A national body such as PHE should clarify clinical governance requirements for HIV testing, to ensure that community testing is not limited by local authority interpretation of these requirements. While clinician knowledge of when to offer an HIV test is not directly related to the Act, increased pressure on primary and secondary care as a result of the Act means that educating healthcare professionals on the subject in line with NICE public health guidance must also be a priority.

The PrEP debate needs an urgent resolution and it is down to the Health Secretary to intervene and ensure NHS England is able to do what it was set up to do - provide specialised treatment for HIV. This kind of legal dispute should not be repeated. It stands as an indictment of the Health and Social Care Act and the Government should take all necessary steps to ensure there is enough clarity in commissioning responsibilities so that it does not happen again. Numbers of new HIV infections have steadily increased over the past few years and it is time to halt that trend. As HIV treatment has improved, more people living with HIV are reaching old age and that puts pressure on the health system. Prevention makes economic sense and it is time that the Government put their money where their mouth is.

HIV should really be a thing of the past, but it continues to affect people's lives adversely. The stigma associated with an HIV diagnosis is unlike any other life-long manageable condition. The media coverage of the PrEP debate aptly demonstrates this, as Daily Mail headlines called into question the "morality" of providing preventative treatment and pitted HIV against other conditions like cystic fibrosis.⁴⁸ It is cynical and it is wrong to do so but it is the reality that we live in.

The Government has a responsibility to ensure that people who live with the virus, or who are at risk of contracting HIV, have the same rights as any other person accessing the health service. Stigma, even within the health service, needs to be tackled. Support services should be recognised as a crucial part of the HIV care pathway. While treatment may have improved, the challenges of living with an HIV diagnosis have not disappeared. Support services provide many benefits to the health system, including ensuring better adherence to treatment, and should not be de-prioritised because of budget constraints. Sexual health and HIV are inextricably linked and should be provided in the same location. Ultimately, we cannot allow shortsighted planning and over ambitious reform to negatively affect our efforts to end the HIV epidemic.

⁴⁸ Daily Mail website, <http://www.dailymail.co.uk/news/article-3720706/What-skewed-sense-values-NHS-told-5-000-year-lifestyle-drug-prevent-HIV-vital-cataract-surgery-rationed.html>

Annex 1

Organisations who gave written evidence

Terrence Higgins Trust
 National AIDS Trust
 British Association for Sexual Health and HIV Services (BASSH)
 British HIV Association (BHIVA)
 Halve It
 Stigma Index and Family Planning Association (FPA)
 Positively UK
 London Councils
 LGBT Foundation
 Cepheid
 Chelsea and Westminster Trust
 MSD
 National LGBT Partnership
 Naz Foundation
 National HIV Nurses Association (NHIVNA)

Oral Evidence witnesses

Ian Green – CEO Terrence Higgins Trust
 Rob Walton – Secretariat for Halve It
 Marion Wadibia – CEO NAZ
 Dr Gordon Scott – Public Health Scotland
 Dr Marion Lyons – Public Health Wales
 John Dunn – Public Health Manchester
 Robbie Currie – Sexual Health lead for Bexley Council
 Deborah Gold – Executive Director National AIDS Trust
 Allan Anderson – Executive Director Positively UK
 Cristian Sandulescu – Peer representative Mortimer Market
 Andrew Gwynne MP – Former Shadow Secretary of State for Health
 Dr David Asboe – Immediate past Chair, British HIV Association (BHIVA)
 Dr Elizabeth Carlin – President, British Association for Sexual Health & HIV (BASHH)

Members of the APPG Inquiry Committee

Mike Freer MP
 Ben Howlett MP
 Stephen Doughty MP
 Baroness Gould
 Baroness Barker
 Baroness Masham

Annex 2

Inquiry terms of reference

BACKGROUND TO THE INQUIRY

In April 2013 the Health and Social Care Act (2012) came into force. Implementation of the act resulted in significant changes to the commissioning of key HIV services with responsibility being shared between local authorities, clinical commissioning groups and NHS England. This has given rise to concerns about the practical implications of the Act, including:

- the potential fragmentation of services
- the lack of accountability in local authorities tasked with maintaining treatment and prevention programmes
- the impacts of budget constraints on provision of services
- geographical differences in service quality and availability
- the lack of specialised HIV expertise within local authority commissioning bodies.

Now that the Act has been in force for two years, the APPG would like to take stock of its consequences. We would like to investigate whether the changes have benefitted or hindered HIV services and treatment. Anecdotal evidence to date implies that the quality of services has declined in many areas. Taken alongside the increased prevalence of HIV within key demographics, this suggests that there is a very real risk that the changes could be impacting on the effectiveness of services and putting the NHS under greater strain through increasing treatment costs.

The inquiry aims to identify what changes may be necessary to ensure the highest quality of HIV services are delivered, whilst ensuring that the appropriate bodies have clearly defined budget responsibility, and other accountability measures are in place to ensure that public funds are utilised most effectively. We are also keen to identify examples of best practice that could become potential templates for success.

PROCESS

Written submissions will be invited and considered in late 2015.

Further field research and oral evidence sessions will be conducted in early 2016.

Findings and recommendations will be published spring/summer of 2016.

QUESTIONS FOR THE INQUIRY

1. What has been the impact of the changes to health commissioning, introduced in April 2013 by the Health and Social Care Act (2012), on the provision of the following services:
 - a. HIV testing
 - b. HIV prevention
 - c. HIV treatment
 - d. HIV related social care
2. Is an adequate level of clinical expertise present within the relevant commissioning bodies?

3. Which body or bodies should be responsible for the commissioning of each of the services?
4. Which body should be responsible for oversight and ensuring standards of provision are met?
5. What impact have the changes had on the implementation of NICE guidance in relation to the HIV prevention and care pathway? (Please include examples of good or bad implementation and/or examples of innovation or good practice developed as a result of the act)
6. What steps could be taken to adapt the current arrangement to ensure that measures are in place to achieve the highest standard of services whilst ensuring public funds are most effectively spent?
7. Please share any other relevant information.

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Further Reading

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