HIV in the future NHS

What next for people living with HIV in England?

TRANSFORMING THE UK'S RESPONSE TO HIV

NAT

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INTRODUCTION

For several years, it has been the norm for those working in HIV prevention, testing, treatment and care to describe HIV as a long-term condition. As the UK's HIV policy charity, NAT uses this description in our advocacy to decision-makers, as well as our public awareness and media work. It still has some power to surprise, but this is decreasing as public understanding of the effectiveness of HIV treatment increases.

Despite this, a long-term condition framework for understanding HIV is not yet embedded with the UK public, media, political decision-makers - or the NHS. The framing of HIV as a long-term condition has not replaced the dominant image of HIV as a serious, communicable disease, which is ultimately fatal but for the constant innovation of medical science. (Of course, many long-term conditions are serious and will lead to death in the absence of appropriate treatment).

With around 88,000 people accessing HIV care in England, it is not a common condition compared to the big five conditions named within NHS England strategy for sustainable long-term condition services (cancer, diabetes, dementia, learning disabilities and mental health).[1] HIV may be much less prevalent, but the HIV sector has championed many of the once-radical, person-centred approaches to care which are now being embraced by the NHS.

The absence of HIV and other communicable conditions (such as HCV) from NHS strategies for long-term condition management (or indeed, any content NHS England publishes on the topic) is surprising, given that the health service is increasingly concerned with prevention and early intervention to prevent the development or progression of serious long-term conditions. It is also striking that these strategies for a sustainable health system rely upon concepts such as self-management, treatment literacy, shared decision-making, peer support and other principles of care which have been pioneered and championed in HIV. The Five Year Forward View makes a case for prevention, supported self-management and strong communities. These have been the foundations of the UK's HIV response and there is a lot which the NHS in England could learn from the HIV sector in these areas.

The history of HIV medicine, the location of the HIV specialty within sexual health and/or infectious disease, and the still-stigmatised nature of HIV as a health condition, have created a care system apart from the usual NHS way of doing things. Most notably, and despite significant efforts from HIV specialists to increase the role of general practice in the care of people living with HIV, it is not yet a routine condition from the perspective of most primary care professionals - the NHS's frontline for long-term condition management support. HIV is exceptional in terms of healthcare practice, reinforcing the conviction in the minds of many in the NHS (and indeed people living with HIV) that HIV is an entirely exceptional long-term condition.

This report will not ignore what is special and what is unique about HIV. However, if in a time of major reform we are to retain what is exceptionally good about HIV treatment and care and build upon the

[1] NHS Business Plans, 2015-16 and 2016-17. https://www.england.nhs.uk/publications/business-plan/

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impressive legacy of the past three decades, it is vital that HIV is not absent from more mainstream conversations. The NHS in England can do much more to draw HIV into its vision for long-term condition management, but the HIV sector must also be ready to engage with the policy agenda of the future NHS.

ABOUT THIS REPORT

In January 2016, NAT organised a national conference on HIV in the Future NHS in England.

The goals of the conference were to:

- Increase understanding of drivers of change (the Five Year Forward View, collaborative commissioning and devolution) in the NHS in England within the HIV sector.
- Identify opportunities and threats for HIV long-term condition management arising from these changes.
- Set an agenda for future policy research and analysis on HIV in the future NHS.

NAT ran three focus groups of people living with HIV, in advance of the national conference, to help develop an understanding of how service users feel about the new NHS in England.[2] In this report NAT will build upon what we learnt from the focus groups and conference, with further research and policy case-studies relevant to the topics covered.

The focus groups and conference were concerned only with how the NHS could support the needs of people living with diagnosed HIV. Therefore this report will not address HIV prevention or testing (NAT has previously published a separate report on prevention and testing[3]). Nor will there be extensive consideration of non-NHS support services provided to people living with HIV (for example, by HIV charities), although these clearly are part of the overall HIV care pathway. A thorough analysis of the role of these services, with policy recommendations, will be published by NAT later in 2017.

[2] Three 90 minute focus groups were held, in the following locations: Mixed-age focus group (Manchester, hosted by George House Trust); Young people's focus group (London, hosted by Gilead Young Advocates Advisory Board); Mixed-age focus group (London, hosted by Positive East). Redesigning the NHS, a summary report of the focus group findings is available at: http://www.nat.org.uk/publications

[3] NAT. HIV prevention in England's high prevalence local authorities: 2013/14 and 2014/15. http://www.nat.org.uk/publications

DRIVERS OF CHANGE FOR HIV SERVICES

HIV AS A LONG-TERM CONDITION

Long-term condition management dominates policy discussions about the future NHS in England. Long-term conditions are a major theme in the Five Year Forward View. The NHS Outcomes Framework dedicates one of its five domains of care to enhancing quality of life for people with long-term conditions. This reflects the demand which treating long-term conditions currently places on the NHS. A quarter of the population is currently living with at least one long-term condition.[4] Long-term conditions account for 70% of NHS expenditure in England[5] and a third of GP appointments.[6]

NHS England has not defined 'long-term condition', possibly to avoid unnecessarily restricting what types of diagnoses could fall into the category. Prior to the 2013 restructure of the health services in England, the Department of Health used the following definition: "a condition that cannot, at present be cured; but can be controlled by medication and other therapies."

HIV clearly meets this definition. The most recent research on life expectancy (drawing on the UK-CHIC data set) found people living with HIV on effective treatment had a comparable life expectancy to the overall population.[7] This is not to downplay the seriousness of an HIV diagnosis to an individual or the NHS: a normal life expectancy will only be achieved if the person living with HIV is diagnosed promptly, helped to adhere to their treatment and supported to address leading causes of reduced life-expectancy in the HIV positive population, such as smoking and drug use.[8] Research into the impacts of HIV on an ageing population is inconclusive and ongoing. One study from the Netherlands predicts that by 2030, three-quarters of the Dutch cohort of people living with HIV will be aged over 50.[9] There are also special issues affecting children and young people living with HIV who commence HIV treatment at a younger age and rely upon it for a greater proportion of their lives. Increases in life expectancy depend on continued access to novel therapies following the development of drug resistance; while the development of drug resistance is not inevitable, it is a particular concern for those who start HIV treatment earlier in life.[10]

Aside from regular (3-6 monthly) monitoring appointments with a specialist clinician,[11] the majority of people living with HIV will not need to access acute services to treat the immediate impacts of HIV infection. However, HIV is associated with a range of other conditions, some of which are also long-term. An ageing population means that people living with HIV are likely to develop common long-term conditions, such as diabetes, arthritis and hypertension, which may or may not be related to HIV, but will need to be managed alongside HIV treatment. The prevalence of psychological and psychiatric problems among people living with HIV is substantially higher than in the general population.[12] Two-thirds of respondents to the Positive Voices study (of people accessing HIV

4 https://www.england.nhs.uk/2014/02/martin-mcshane-6/
5 https://www.england.nhs.uk/ourwork/futurenhs/nhs-five-year-forward-view-web-version/5yfv-ch1/
6 J White. 'What matters most? Person-centred co-ordinated care.' Presentation to HIV in the Future NHS conference, 20 January 2016.
7 http://www.aidsmap.com/Life-expectancy-in-older-people-with-HIV-could-exceed-the-average-as-long-as-ART-keeps-working/page/2551483/
8 http://www.aidsmap.com/Life-expectancy-in-older-people-with-HIV-could-exceed-the-average-as-long-as-ART-keeps-working/page/2551483/
9 http://www.aidsmap.com/Geriatric-HIV-living-with-multiple-medical-conditions-will-become-the-norm-as-population-ages/page/2977342/
10 http://www.aidsmap.com/Life-expectancy-in-older-people-with-HIV-could-exceed-the-average-as-long-as-ART-keeps-working/page/2551483/
11 BHIVA. HIV monitoring guidelines 2011. For people who are stable and responding well to treatment, 6 monthly appointments are the norm.

care in England and Wales) reported having at least one long-term condition other than HIV, increasing to three-quarters of respondents aged over 50.[13] The Dutch study quoted above predicted that by 2030, 84% of all people living with HIV will have at least one other medical condition, in addition to HIV – and that 28% will have three or more.

This is all consistent with NHS England's national picture of long-term condition management, which shows that 62% people currently living with a long-term condition have two or more conditions but that on average, people with long-term conditions spend less than 1% of their time directly engaged with NHS services.[14]

But do people living with HIV consider themselves amongst the 16 million currently living with a long-term condition? Does calling HIV a long-term condition help people living with HIV to access the support they need to manage not only their HIV treatment, but other physical, mental and emotional health needs?

We asked these questions of our focus groups of people living with HIV. Participants had mixed opinions about the use of long-term condition to describe HIV. Those who said they personally were happy to use the term saw it as a useful way to normalise HIV, including in discussions with non-specialist healthcare providers who may otherwise view HIV primarily as a communicable disease (or even infection risk). Participants in the young person's focus group were very comfortable with the term; this was in contrast to the views expressed in one of the mixed-age focus groups, where participants had been living with an HIV diagnosis for 10 years or more, in most cases. In this group, most participants did not accept the use of long-term condition management as a useful approach to HIV. They saw it as a re-branding of sorts, to make HIV appear less significant, more generic, and easier to live with than was their experience.[15]

Interestingly, some of the arguments made for why HIV is not a long-term condition like any other, could equally be considered arguments for applying a long-term condition management framework to HIV services: HIV can be difficult or painful to live with; the relentless self-management demanded by an HIV diagnosis; the lack of understanding of HIV displayed in non-specialist services.

One reason some people may object to what they see as a re-branding of HIV as long-term condition management is that it is framed as a positive, compared to how HIV was experienced in the UK prior to the availability of effective treatment (and still is, in resource-poor settings). It is the case that without treatment, HIV is a life-limiting condition. But the same may be said of many long-term conditions which are more common and less stigmatised. We should not expect people living with HIV to feel happy about having a long-term condition! Any such diagnosis is completely life-altering and is the first step on a life-long and difficult journey. For HIV, this is exacerbated by a unique social context and internalised messages someone may have about what it means to be HIV positive.

[12] BPS/BHIVA/MEDFASH. Standards for Psychological Support for People Living with HIV. http://www.bps.org.uk/standards-psychological-support-adults-living-hiv

[13] M Kall et al. 'Self-reported prevalence of co-morbidities and use of non-HIV related medications among people living with HIV in England and Wales: results from the Positive Voices survey'. Abstract presented to the 15th European AIDS Conference. Barcelona, Spain; October 21-24 2015.

[14] J White. 'What matters most? Person-centred co-ordinated care.' Presentation to HIV in the Future NHS conference, 20 January 2016.

[15] For a full discussion see Redesigning the NHS, a summary report of the focus group findings: http://www.nat.org.uk/publications

The opinions expressed in the focus groups give important insights into how the HIV sector in England can most usefully engage with the broader agenda for long-term condition management. HIV undoubtedly aligns well with current models of long-term conditions and, indeed, could be considered an exemplar of a modern long-term condition. NAT also believes that framing health and support services for people living with HIV in the context of long-term condition management will help the clinical and policy case for better support to be heard. However, we must be prepared for -and expect - people living with HIV to engage critically with long-term condition management, in the way many already do with the concept of HIV as a disability. And just as people living with HIV are protected against disability discrimination, whether or not they personally consider themselves to be a disabled person, so can people living with HIV benefit from a health service that meets their long-term condition management needs, regardless of their views on the terminology.

There is room for such difference of opinion within a truly person-centred approach. People living with HIV need not be active advocates of the long-term condition management approach, in order to benefit from it. This is an important distinction, especially given current enthusiasm from NHS England to ask service users to play their part, make their declaration, or otherwise sign up personally to national priorities for long-term condition management (for example, Our Declaration for person-centred care[16]). Efforts to encourage genuine service-user engagement and empowerment are welcome, but service user consensus is simply not possible. People should never feel obliged to join in or sign up, in order to access the care and support they need. HIV is a long-term condition, as understood by the NHS.

People living with HIV need NHS services which meet their life-long support needs.

CASE STUDY: REALISING THE VALUE – LEARNING FROM HIV

NHS England have funded a national project, Realising the Value (lead by Nesta and the Health Foundation), to highlight and further develop the evidence base for person and community-centred approaches to care. Realising the Value is focussing on five areas of practice in person-centred care: Self-management education; Peer support; Health coaching; Group activities that promote health and well-being; and Asset-based approaches in a health and well-being context.

Positively UK, a London-based HIV support organisation, has been selected as the partner site which will demonstrate the value of peer support for people with long-term conditions. Realising the Value will look at Positively UK's peer support programme and its integration within seven NHS Trusts, to evaluate the impact of peer support on well-being and costs to the NHS.

It is an important example of how the NHS can learn from the experiences of people living with HIV and the person- and community-centred approaches which the sector has developed over the past two decades.[17]

THE LEGACY OF THE HEALTH AND SOCIAL CARE ACT

This report will not directly explore the impacts of the Health and Social Care Act 2012 on HIV. This is a topic which has been given significant scrutiny by clinicians and policy experts with an interest

[16] From 1 Sep 2015 to 4 Mar 2016, people were asked to make a 'personal commitment to act' https://www.engage.england.nhs.uk/survey/ltc-declaration

[17] http://www.nesta.org.uk/project/realising-value

[18] All Party Parliamentary Group on Sexual and Reproductive Health. Breaking down the barriers: The need for accountability and integration in sexual health, reproductive health and HIV services in England. July 2015 http://www.fpa.org.uk/all-party-group-uk/accountability-inquiry-standards-sexual-and-reproductive-health Public Health England and MEDFASH. September 2014. Making it work: A guide to whole system commissioning for sexual health, reproductive health and HIV https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/408357/Making_it_work_revised_March_2015.pdf

in effective HIV, sexual health and reproductive health services.[18] However, the policy and commissioning landscape created by the Health and Social Care Act is the backdrop to both the future NHS described in this report and some of the specific challenges which HIV treatment and care must overcome.

The Health and Social Care Act (re-)introduced the principle of localism to the NHS in England. Localism in health has taken root and, as will be illustrated in the next section, has only increased in influence since 2013. At the same time, the redistribution of NHS commissioning responsibilities led to fragmentation of certain services and care pathways. HIV could be considered one of the best examples of this fragmentation and the problems arising from it.

Fragmentation comes about when responsibility for different aspects of treatment and care for a specific condition resides with multiple commissioning bodies. For HIV, treatment and care services are directly commissioned by NHS England through specialised services commissioning. This is an approach which NAT advocated for at the time of the 2010-13 NHS reforms and still supports. However, this locates HIV treatment and care commissioning at the national/regional level, whereas most other secondary care for people living with HIV is commissioned locally, by Clinical Commissioning Groups (CCGs). Primary care for people living with HIV is also directly commissioned by NHS England, but entirely separately from specialised services – although this responsibility is moving to CCGs also, to greater and lesser degrees across England. Crucially, prevention and testing for HIV (and the clinical sexual health services which have historically been inextricable entwined with these services) are the responsibility of local authority public health commissioners.

This fragmentation of responsibility has been observed to have a range of negative impacts for services and therefore the experiences of people living with HIV. The primary concern relates to local authority re-tendering of sexual health services, in which the majority of HIV clinics are situated, separately from and without reference to any future HIV service.[19] This threatens the sustainability of specific HIV clinical services in some locations which do not have the patient numbers to justify a stand-alone HIV service. There is also the question of meeting the sexual health needs of people living with diagnosed HIV, which has been facilitated by co-location of HIV and STI clinics.[20] This arguably applies to some service user groups (such as sexually active men who have sex with men (MSM) with high rates of partner change) more than others.

Another argument raised against fragmentation is that as CCGs do not directly commission the treatment and care of people living with HIV, they are unlikely to consider the needs of people living with HIV when commissioning the services for which they are responsible. This includes psychological services for people with problems that are too complex to manage in primary care, maternity services, and treatment for other long-term conditions which are treated in a hospital setting. The need for better CCG engagement on HIV issues is becoming even more compelling as CCGs also take on responsibility for primary care services.[21]

Finally, some are concerned that the fragmentation of prevention and treatment commissioning creates an incentive problem. The argument is that as commissioners responsible for sexual health and HIV prevention and testing services will not benefit from any positive impact their

[19] J Wilson, D Daniels and R Thompson. BASHH and RCP paper on key threats from tendering of sexual health services, November 2013. http://www.bashh.org/documents/BASHH%20RCP%20paper%20on%20threats%20from%20tendering%202013.pdf

[20] There are also public health for co-commissioning which are more relevant to HIV prevention and testing services, which are not within the remit of this report.

[21] 114 CCGs have taken on full responsibility for primary care commissioning.

efforts have, as any reduction in demand will be experienced by specialised commissioners in NHS England. Some consider this a disincentive to investment – or at the very least, a barrier to measuring the impact of prevention services.

The speed of transition and the very different culture and legal context of local authority commissioning has been highly unsettling for commissioners and providers of HIV services and significant effort has been required to maintain the status quo of treatment and care over the past three years.

The current wave of NHS reforms described in section four of this report - person-centred care, collaborative commissioning, new models of care and devolution of NHS budgets - all propose solutions to fragmentation of health and care services, and increasing demand on acute hospital services. At the same time, all (to a greater or lesser extent), further the localisation of health and care services which the Health and Social Care Act initiated.

FINANCIAL PRESSURE ON NHS SERVICES

This report will not explore or explain the current financial pressures facing NHS services. These budgetary constraints are a fact and one which will shape the future of HIV services in ways which cannot yet be fully anticipated. The NHS is committed to making £22 billion worth of 'productivity improvements' by 2020/2021. NHS England's spending on specialised commissioning, which has increased 6.3% on average per year since 2013 – compared to an increase of 3.5% per year for the overall NHS budget – has come under scrutiny and there are concerns that budgetary pressures will only increase in the near future.[22]

[22] An increase of 6.3% on average per year since 2013 – compared to an increase of 3.5% per year for the overall NHS budget. NAO. The commissioning of specialised services in the NHS. May 2016. https://www.nao.org.uk/press-releases/the-commissioning-of-specialised-services-in-the-nhs/

FUTURE HIV SERVICES

Realising a long-term conditions approach to HIV requires reconsideration of the services which are currently offered to people living with HIV - and how these may need to change.

There are some aspects of existing HIV services which are valued by people living with HIV and are important for achieving good health outcomes. These should be retained.

There are also gaps in current NHS provision for people living with HIV. Specialised HIV services cannot meet all the health needs of people living with HIV and there is variation in how effectively clinics are using networks to provide a holistic service.

A future NHS for people living with HIV must retain what is excellent and improve what is lacking, in current HIV services.

SOME FUNDAMENTALS OF HIV CARE WE CAN'T AFFORD TO LOSE

HIV is a long term condition and the future NHS in England can do more to meet the lifelong needs of people living with HIV. However, HIV is unique and there are fundamental principles of HIV treatment and care which, while not the norm for other long-term conditions, must not be lost as services develop to meet changing needs.

One principle is meaningful involvement of people living with HIV (MIPA). NHS England has prioritised engagement of service users and the general public in all areas of health service reform. However, as the international community's shift in emphasis from greater involvement of people living with HIV (GIPA) to meaningful involvement (MIPA) has shown us, more engagement is not always the same as better engagement. Any decision NHS England makes for specialised services, including HIV, requires proof of stakeholder engagement. However, some consultation exercises are more meaningful than others. As the Chair of the UK Community Advisory Board on HIV said in her address to the conference, people living with HIV who are engaged in consultation should, as a bare minimum, be given full feedback on how their contribution was used and what action was or was not taken as a result of the consultation exercise. The Five Year Forward View recognises the valuable resource that is the voluntary and community sector – and this clearly extends to service users. It must be recognised that while service users have a right to be engaged they also have a right not to respond to such opportunities. Consultation exercises and outcomes responses must show appropriate respect for what it costs service users (in physical, emotional and financial regards) and the community sector to provide this resource.

A second principle is access to best medication for individual clinical needs, for all. This is something which can easily be taken for granted, but is never entirely assured and must be actively promoted in a time of change and severe budgetary restraints.

As with other aspects of HIV services, arrangements for approval and purchasing decisions for antiretroviral therapy are unique within the NHS. HIV drugs are not subject to NICE approval. This has been a boon to HIV treatment over the past two decades, ensuring prompt access to life-saving medications.

Instead of the usual NICE process, decisions around access to HIV drugs are informed by two

sets of guidelines, which align much of the time but at other points come into conflict. The first are the HIV treatment guidelines developed by the British HIV Association (BHIVA), which have been NICE-accredited since 2012 and recommend to HIV clinicians the appropriate course of treatment. The second are the commissioning policies published by NHS England, which describe which drugs will be paid for by the specialised commissioning budget, and in which circumstances.

One complication arising from this unique arrangement is that NICE-recommended treatments and technologies hold a specific status within NHS England budgetary decisions which BHIVA recommendations cannot. When deciding which specialised commissioning policies to approve in a given year (a fixed financial envelope), the Clinical Priorities Advisory Group is obliged to prioritise payment of NICE recommended treatments. The arrangements which have made HIV special over the years could also put continuing access to the best possible medication at risk, given it is not within the NICE system. This must be kept at the forefront of our minds, as we consider how to meet the lifelong needs of people living with HIV in a future NHS which will allow for much more local variation.

A third, basic element which we cannot afford to lose is open access for HIV services. Open access is a concept which can have at least two meanings: access to HIV services without the need for referral from primary care or another specialist; and choice of HIV clinic (which may extend to choice of borough, city or region of access).Public Health England reports that in 2014, 11% of people accessing HIV services in the London were residing outside that PHE centre area. Other PHE centres have lower proportions of out-of-area clinic attendees (all under 10% and most closer to 5%).[23] The principle of open access is not offered for other specialist services. When considering new models of care which promise a more joined-up experience for people with long-term conditions, careful thought needs to be given to how to retain open access.

GAPS IN CARE FOR PEOPLE LIVING WITH HIV

Specialised HIV treatment and care in the UK is of an exceptionally high standard. In 2015 (the most recent statistics available), 96% of people living with diagnosed HIV were accessing antiretroviral treatment.[24] These treatment rates are consistent across all regions of England.[25] Of those on treatment, 94% had achieved viral load suppression, meaning that HIV will not have a negative impact on immune function.[26] Public Health England reports that these outcomes are consistent across time and apply equally regardless of ethnicity, gender and route of HIV acquisition.[27]

Life with HIV is more than antiretroviral treatment, however. This is reflected in the British HIV Association (BHIVA) Standards of Care for People living with HIV, which includes sections on psychological care, sexual health, reproductive health and self-management, in addition to more specialised aspects of HIV treatment. The standards make clear that HIV care requires a multidisciplinary team (MDT) of professionals. This approach to HIV care is also reflected in the NHS England national service specification for HIV treatment and care.[28]

Outcomes for non-ART components of HIV care are not routinely reported on in the same way as

[23] Public Health England. 'Proportion of people living with HIV by PHE centre who reside outside of that centre, 2014'. HIV in the UK: 2015 report slideset. https://www.gov.uk/government/statistics/hiv-in-the-united-kingdom

[24] Public Health England. HIV diagnoses, late diagnoses and numbers accessing treatment and care - 2016 report.' https://www.gov.uk/government/statistics/hiv-annual-data-tables

[25] Public Health England. HIV slideset: 2016. https://www.gov.uk/government/statistics/hiv-annual-data-tables

[26] HIV viral suppression also means that someone is extremely unlikely to transmit the virus – this can also improve some people's sense of wellbeing, e.g. if fear of transmission to partners was affecting their relationship/s and sex life negatively.

[27] Public Health England. HIV slideset: 2016. https://www.gov.uk/government/statistics/hiv-annual-data-tables

[28] Available at https://www.england.nhs.uk/commissioning/spec-services/npc-crg/blood-and-infection-group-f/f03/

ART-outcomes, so we do not have the same national picture of care quality and consistency for all of these measures. The studies and data which are available, however, indicate that for some health needs there is, at best, inconsistent access to provision of services for people living with HIV, especially when they are not routinely offered within the specialist clinic setting.

A recent BHIVA audit of the extent to which HIV clinics are implement HIV monitoring guidelines found that national targets were not being met for a wide range of services.[29] Some findings include: only 45% of current smokers had been offered support to quit; 53.2% of women had been offered annual cervical screening (plus a further 22% of women advised to seek screening from primary care or sexual health clinic); and only 57% had either been offered a flu vaccination or advised to seek one from their GP.

The first national audit of psychological support services for people living with HIV[30] found that in the majority of cases no mental health history or risk assessment had been documented by the HIV clinic. Only a quarter of HIV clinics included in the audit had a psychological support policy (which would facilitate referrals to services) in place and 40% did not have a psychological professional employed within the clinic team. [31]

Similarly, for maternity services, the 2015 BHIVA audit of management of pregnancy for women living with HIV found that a quarter of services did not have either an HIV midwife or women's clinical nurse specialist as part of their multi-disciplinary team, as set out in clinical guidelines.

Annual STI reporting shows that men who have sex with men who are living with HIV experience higher rates of STIs (gonorrhoea, syphilis, LGV chlamydia and other infections such as Shigella) than their HIV negative peers.[32] The Positive Voices study of people living with HIV in England and Wales found that 29% of HIV positive men who have sex with men had engaged in chemsex[33] in the past year and one in ten had engaged in slamsex.[34] This points to specific sexual health, drug user and psychological support needs, which are not yet being met. The BHIVA monitoring audit found that only 73% of MSM patients (65% of patients overall) had been offered an annual sexual health screen.

The most striking and universal gap in provision in services for people living with HIV, though, is in primary care. In a recent study of people living with HIV's experience of stigma, 91% said that their GP was aware of their status.[35] But not all people living with HIV who have disclosed their status are confident in their GP's competency in HIV long-term condition management. Many have experienced stigmatising behaviour from healthcare and/or administrative staff in GP surgeries. In some cases this is recent, in other cases historical – but it has undermined trust in primary care services. These problems are well-known among HIV clinicians and support organisations and many initiatives have been taken to improve the situation with improved GP training, encouraging disclosure of HIV status to GPs and more routine communication between clinics and surgeries. However, primary care in England is now under such pressure as to create what the King's Fund calls a 'feeling of crisis'.[36] Between 2010/11 and 2014/15 there was a 15% increase in the number of GP and primary care nurse

[29] Case-note review of adults attending HIV services. 112 services responded, with 50-100 patients per services. BHIVA Audit and Standards Sub-Committee. Routine monitoring and assessment of adults with HIV. 2015. British HIV Association. http://www.bhiva.org/documents/Conferences/Autumn2015/Presentations/151112/AoifeMolloy.pdf

[30] Conducted by the National HIV Nurses Association. Audit respondents were HIV clinics. Fifty two sites (roughly one-third of those invited) participated in the audit, submitting data on 1,446 patient cases.

[31] NHIVNA. A National Nurse-led Audit of the Standards for Psychological Support for Adults Living with HIV. 2015. http://www.nhivna.org/documents/audit-and-research/2015AuditReport.pdf

[32] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/357451/2014_09_17_STIs_HIV_in_MSM_in_London_v1_0.pdf

[33] Defined by the researchers as "the use of drugs to increase disinhibition and arousal". 15% reported using methamphetamine; 20% GHB or GBL; 11% ketamine; and 23% mephedrone or drugs of its type (cathinones). http://www.aidsmap.com/Very-high-levels-of-chemsex-and-slamsex-seen-in-HIV-positive-men-attending-EnglishWelsh-HIV-clinics/page/3039176/

[34] Injecting or being injected with the drugs. http://www.aidsmap.com/Very-high-levels-of-chemsex-and-slamsex-seen-in-HIV-positive-men-attending-EnglishWelsh-HIV-clinics/page/3039176/

[35] V Delpech, A. Hudson and R Mbewe. HIV Stigma Index. Presentation at British HIV Association Conference. London, November 2015. http://www.bhiva.org/documents/Conferences/Autumn2015/Presentations/151112/ValerieDelpech-AlastairHudson-RebeccaMbew.pdf

36 B Baird et al. Understanding pressures in general practice. The King's Fund. May 2016. http://www.kingsfund.org.uk/publications/pressures-in-general-practice

consultations; over the same period, the primary care budget dropped year on year.[37] The capacity of GP surgeries to meet the needs of patients is over-stretched – and people living with HIV have noticed.

Having a GP who knows about your HIV is not the same thing as having your HIV or other long-term condition needs managed within primary care. The My Care I Care survey of people living with HIV in London asked respondents whether their GP was involved in managing their non-HIV health conditions. It found that for certain conditions (including high cholesterol, neurocognitive disorders, liver problems, kidney problems, problems with drugs and alcohol, ongoing and acute STIs and TB) the patient's HIV clinic was more likely to be involved in management, than a GP. However, GPs were more likely to be involved in managing other conditions, specifically: psychiatric or mental health problems, high blood pressure, diabetes and heart problems.[38] If the NHS is to provide effective support to people living with HIV there needs to be clarity about who is responsible, in partnership with the person living with HIV, for overall oversight of long-term condition management. Is this the responsibility of the HIV clinic? If so, who would be the single point of contact for the person living with HIV? If the NHS view is that responsibility sits within primary care, then how will we ensure a GP involves HIV specialists appropriately in planning and decision-making?

The concept of ping-pong between GP and HIV clinic, where each believes the other is responsible for treatment or care, has been well-known for several years. When combined with a chronic shortage of GP appointments on the one hand, and less-frequent routine HIV monitoring appointments on the other, ping-pong becomes less of an annoyance and more of a serious risk to patient safety.

If primary care is to provide appropriate treatment, care and support to people living with HIV, then a treatment summary will need to be shared with the GP practice. Sharing HIV treatment and care information with GPs is increasingly the norm,[39] but it is still a sticking point for some people living with HIV (and advocates) who would have HIV records kept confidential within the specialist clinic setting. However, as was expressed clearly in conference workshop discussion, HIV treatment and care services have already passed the point at which separation and confidentiality of HIV information from other NHS records is no longer realistic - or even desirable. There is a clear patient safety issue around drug prescribing. But, there is also a broader principle. The HIV sector should not tolerate a situation where stigma and failure to appropriately address unlawful behaviour prevents people with HIV from accessing public services which could improve their quality of life. Primary care is – and will increasingly be, in the future NHS – the lynch pin for long-term condition management support. People living with HIV should expect and be supported to access the same quality of care as their peers with any other condition.

ASPIRATIONS FOR HIV SERVICES IN THE FUTURE NHS

In a future NHS which meets the needs of people living with HIV, every aspect of care and long-term condition management would be provided at the same consistently high standards as specialised treatment is currently provided.

37 B Baird et al. Understanding pressures in general practice. The King's Fund. May 2016. http://www.kingsfund.org.uk/publications/pressures-in-general-practice

38 P Weatherburn et al. My Care, I Care: A study of what people living with HIV value about HIV services in London. 2013. http://sigmaresearch.org.uk/files/report2013f.pdf

39 The BHIVA Standards of Care state that "establishment of clear protocols and pathways for care between both primary and secondary care is essential for safe delivery of care, and regular communication is strongly recommended unless the patient specifically refuses consent." http://www.bhiva.org/standards-of-care-2012.aspx NHS England's service specification for adult HIV services makes clear that the HIV clinic has a responsibility for communicating effectively with other healthcare professionals.

One aspiration we should have from the future NHS is that all people living with HIV have equal access to all aspects of quality care, as set out in relevant standards. Specialised clinicians based within acute sexual health or infectious disease settings are of course deeply committed to the effective care of people living with HIV. But this is not where people living with HIV will get the majority of support needed to live well with HIV.

Sexual health services are very important, especially for most HIV positive MSM, and may well be co-located with the HIV clinic, but are less relevant to many other people with HIV. Other types of care are equally important but not part of the remit of a typical HIV specialist team. Some large HIV clinics in London and other major centres may be able to offer in-house support covering all aspects of the BHIVA Standards of Care, include psychological support and specialist reproductive health advice. This is not the experience of all people living with HIV in England, however, and it is unrealistic to expect this offer of support to expand within specialist care settings in future. Indeed, it is much more likely to shrink, even where available. Clinics already use networked arrangements to provide patient access to a multidisciplinary team (MDT). This approach should be expanded to ensure meaningful involvement of primary care.

To support holistic care, we must aspire to HIV services which are increasingly integrated with HIV-competent primary care. Long-term condition management support requires more than two appointments a year at a specialist HIV clinic, of which possibly only one is with the treating consultant. As the population of people with HIV gets older, and as HIV itself is for most of them increasingly well managed, the balance of contact someone with HIV will have with the NHS is inevitably shifting towards much more frequent contact with other, less complex and less specialist care services. As described in the above section, however, the quality of primary care remains the main issue within the spectrum of care currently offered to people living with HIV by the NHS in England. In the focus groups it was clear that some people living with HIV will save up questions about health issues which are really concerning them between appointments at their HIV clinic. This leads to significant delays in addressing important health issues.

While there are some issues that only specialist clinicians can address, it has been clear for several years that people living with HIV should be getting much more support within primary care. For this to be a reality, primary care needs to become a place where people living with HIV expect (and receive) support to live with a long-term condition. The current ambition for HIV in primary care tends to focus almost exclusively on the current (significant) deficits in the HIV awareness of generalist healthcare professionals. We need to go much further. GP practices and future primary care models must take responsibility for providing competent, non-stigmatising and non-discriminatory care to people living with HIV. Primary and community care providers and providers of specialist HIV care must work together to agree shared care arrangements for people living with HIV, and to determine who has overall responsibility for service users' care pathways and their experience of joined-up care.

THE FUTURE NHS

In the past twelve months a number of new propositions have been made about the form that a future NHS should take. These reforms both continue the move towards local determination present in the Health and Social Care Act 2012; and offer (amongst other proposed benefits) possible solutions to the fragmentation of services which has been attributed to the Act.

The following reforms were considered at NAT's conference and will be explored in more detail below, in terms of what opportunities and threats they present for HIV long-term condition management. Each will be addressed separately, but there is a fair degree of overlap between some of the concepts:

- NHS England's commitment to person-centred coordinated care.
- Collaborative commissioning.
- The Five Year Forward View: New models of care.
- Devolution and local determination.

NHS ENGLAND'S COMMITMENT TO PERSON-CENTRED CARE

NHS England has made a declaration of commitment to person-centred care, as defined by National Voices, the national coalition of health and care charities for England:

"I can plan my care with people who work together to understand me and my carer(s), allow me control, and bring together services to achieve the outcomes important to me."

The vision for person-centred care which NHS England has committed to includes the following elements:

- Improving health outcomes for people with long-term conditions, especially those with complex and multiple conditions.
- Considering both the physical and mental health needs of service users.
- Meeting care needs across the life course.
- Focussing on what personal health outcomes matter to the individual and taking a holistic view of their needs.
- Support for people who self-manage their condition and for family, friends and carers.
- Avoiding over-treatment (for example by treating single conditions without considering co-morbidities or overall pill burden).
- Developing individual treatment and care plans in partnership between services users and clinicians, even if this means deviating from usual guidance.
- Providing support that is 'more than medicine' e.g. signposting to social networks.
- NHS England supporting a person-centred care approach by using the 'House of Care' framework of long-term conditions.[40]

Happily, these themes have significant overlap with what people living with HIV say they want from their care, and with the

[40] NHS England. 'Our declaration: Person-centred care for long-term conditions'. 2015. https://www.england.nhs.uk/wp-content/uploads/2015/09/ltc-our-declaration.pdf

understanding of person-centred care which was expressed by participants in the focus groups.

All focus group participants were asked the question,
What does the term 'patient centred' care mean to you?

- "All about me."
- "Whole-person, and everything is considered in your care."
- "Involvement. I get the final say."
- "Holistic, well-being, rounded."
- "I am an equal partner in the decision-making process. Information is shared to allow me to make my care decisions."
- "A service that fits for me, not making me fit the service."
- "Communication is very good."
- "Financial investment – the bottom line."
- "Being allowed to manage yourself."
- "Choice of where you get care."

These are significant commitments from the NHS, which, if implemented, could meet many of the needs of people living with HIV.

The principles of person-centred care are also expressed in the Standards of Care for People living with HIV,[41] which includes sections on psychological care, complex co-morbidity, safe medicines management and participation of people living with HIV in their care. Specialised HIV services have a strong history of taking a person-centred approach to care.
By contrast, participants in our focus groups (and in other research with people living with HIV) had found that in primary care settings, their HIV positive status was often given more emphasis than was appropriate, given their care needs. People living with HIV talk about GPs who have refused to treat minor ailments in case they are 'HIV-related' or who openly express concerns about whether they are sufficiently expert to treat someone who is living with HIV. If the person-centred care commitment results in a greater focus on the needs and preferred health outcomes of people living with HIV first, and their diagnosis second, then experience of primary care may improve.

NHS England have created commissioning tools to incentivise and support patient-centred care. One which is particularly relevant to people living with HIV is the 2016/2017 CQUIN Scheme for prescribed specialised services GE2: Activation system for patients with long-term conditions. CQUIN (Commissioning for Quality and Innovation) payments are a means for NHS commissioners to encourage healthcare providers to improve services. In a given year, a service will be eligible for payment if they successfully implement the CQUIN scheme/s they have agreed with their commissioner as part of their contract. To be included in the menu of possible CQUIN schemes for a given year, the proposed goal or innovation must meet strict criteria. CQUIN schemes may continue over more than one year, but ultimately they must lead to long-term improvements to care, beyond the life of the contract.

The CQUIN scheme on patient activation is available to all providers of people with complex

[41] BHIVA. Standards of Care for People Living with HIV. 2013. http://www.bhiva.org/standards-of-care-2012.aspx

long-term conditions, including HIV, where adherence to medication is key and self-management is possible, with the right support. Services which take up this CQUIN must use a standard tool, the 'patient activation measure' (PAM), to assess the knowledge, skills and confidence which their patients have in relation to managing their health, and then provide support to improve capacity for self-management. Research (including studies of people living with HIV) has shown that patient activation, as measured by the PAM tool, are closely linked to both individual health outcomes and patient satisfaction with healthcare services. Patient activation has been shown to be a more accurate predictor of health outcomes than socio-demographic factors such as ethnicity and age.[42] A number of interventions have been shown to improve patient activation, including participatory decision-making, coaching, training and completion of one of the Stanford chronic disease self-management programmes (see case study).[43] Providers who adopt the CQUIN would adopt one or more of these approaches for their service users, then re-apply the PAM tool to identify if the support has been successful in improving knowledge and confidence.

As the National Voices model makes clear, though, there is a lot more to person-centred care than people feeling empowered to manage their own health. While improving levels of patient activation will help people living with HIV to identify and assert the goals they have for their care, many need a broader system of support, including social support and social care.

Person-centred care is a concept which resonates with people living with HIV for the same reasons it does for people with other long-term conditions. We are all more than a medical diagnosis and NHS services should meet our health goals in the most holistic sense. However, a greater focus on the individual should not be at the expense of services which foster a community of people living with HIV.

In the midst of person-centred care approaches which focus on individual confidence and patient activation, there must also be acknowledgement

CASE STUDY: POSITIVE SELF-MANAGEMENT PROGRAMME

The Positive Self-Management Programme (PSMP) is one of a suite of condition-specific self-management programmes developed for people with long-term conditions by the Stanford Patient Education Research Centre. It is a group-based programme run over 7 weeks with each session lasing 2.5 hours and covering a wide range of topics, including: managing medication, dealing with difficult emotions, exercise, nutrition and communication skills.

The social enterprise Living Well CIC currently offers the PSMP to people living with HIV in London, provided by accredited facilitators who are themselves living with HIV and were once participants on the programme. Between 2005 and 2012, 438 participants completed Living Well's programme and an evaluation of client outcomes found that the PSMP had helped participants feel more in control of their condition (94%), increased their confidence in coping with the condition (79%) and significantly increased their quality of life (24%).[44]

In addition to the PSMP, Living Well provides a Dual Facilitator Training Programme so that the people they train to become facilitators of the HIV-specific programme are also qualified to deliver the Expert Patients Programme (EPP), a generic version of the PSMP for people living with any chronic condition. This not only gives more scope and opportunities for facilitators to deliver self-management programmes but also raises awareness of HIV in the community, helps to break the cycle of stigma and discrimination and works toward creating improved pathways between HIV and generic health. When delivering to non-HIV groups, Living Well's EPP facilitators often find that disclosing their HIV status allows for a more open and supportive discussion within the group and helps to 'normalise' HIV by helping people to view it the same they view diabetes, arthritis, back pain or any other long-term condition.

[42] J Hibbard and H Gilburt. Supporting people to manage their health: An introduction to patient activation. Kings Fund, May 2014.

[43] J Hibbard and H Gilburt. Supporting people to manage their health: An introduction to patient activation.2014. The King's Fund. http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/supporting-people-manage-health-patient-activation-may14.pdf

[44] Living Well. Positive self-management programme (PSMP) 2005-2012. http://www.livingwellcic.com/wp-content/uploads/2011/01/FINAL-PSMP-Infographic.pdf

of the value many find in solidarity and shared experience. NHS England's commitment to patient-centred care emphasises the importance of support from friends and family. There are frequent mentions of 'the community' but no special attention to the mutually supportive communities which develop among people with a shared health condition or disability, and is especially the case for HIV. The stigma associated with HIV means that support from friends, family and one's immediate community cannot be assumed. The supporting infrastructure for HIV long-term condition management therefore needs to include peer support and other forms of social support, which is not limited to the management of medication and symptoms.

COLLABORATIVE COMMISSIONING

As discussed above, the fragmented nature of HIV prevention, testing and treatment commissioning has created challenges for services, especially when HIV clinics have been left 'orphaned' as a result of sexual health service re-tendering. Lack of joined-up commissioning between specialised services and locally commissioned services is not unique to HIV treatment and care (although the independence of local authority commissioners of clinical sexual health services has created complications which are not present in care pathways involving only CCGs and NHS England). Other specialised condition have observed confusion and gaps in care when commissioning responsibilities are shared between NHS England and CCGs.

Prescribed specialised services which are directly commissioned by NHS England account for 14% of the NHS budget. HIV satisfies, to varying degrees, the four current factors set out in the Health and Social Care Act as defining a 'specialised service'. These are:

- **The number of people accessing the service.** With 88,000 people accessing treatment and care from the NHS in England, HIV is not as rare as other specialised conditions. However, this population is unevenly distributed, ranging from 0 diagnosed cases per 1,000 (Isles of Scilly) to 15 cases per 1,000 (Lambeth)

- **The cost of providing the service or facility.** HIV treatment and care is a high-cost service with estimated lifetime costs of £380,000.[45] While the imminent availability of generic versions of key antiretroviral medications is likely to reduce overall HIV drugs budget, the cost of procurement of HIV treatment remains significant. By negotiating prices regionally, NHS England is able to reduce the total cost of HIV drugs.

- **The financial implications for clinical commissioning gorups if they were required to commission the service or facility.** Given the uneven distribution of HIV, if local areas were to be made responsible for HIV treatment and care commissioning, we would see high-prevalence areas facing a significant financial burden, compared to other areas. At the other end of the scale, even a few additional diagnoses in a low prevalence area could have a dramatic impact on local health budgets.

- **The number of persons able to provide the service or facility.** HIV treatment and care is currently only provided by a limited number of specialist clinics.

At the conference, some delegates questioned whether HIV treatment and care should really

[45] Including the costs of antiretroviral treatment, clinic appointments and monitoring as recommended by BHIVA. F Nakagawa et al. Projected Lifetime Healthcare Costs Associated with HIV Infection. PLoS One. 2015; 10(4). April 22. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4406522/

be considered a 'specialised' service in those geographical areas with high prevalence and multiple clinics, such as London and Manchester. There is arguably a case for consolidating the number of providers, and this will be discussed below in relation to new approaches to specialised commissioning outlined in the Five Year Forward View and NHS England's HIV service reviews. However, the cost of HIV treatment and the extremely uneven distribution of HIV across England creates a significant risk of inequality of access to HIV treatment and care, were CCGs made responsible for commissioning these services. As a specialised service, HIV treatment and care commissioning policies currently apply across England, regardless of the number of patients.

Over 2015/16, NHS England committed to developing a new 'collaborative approach' to specialised commissioning, to encourage a more joined-up experience of specialised services. Collaborative commissioning increases the involvement of CCGs in designing care pathways for people who use specialised services. The national commissioning policies developed by NHS England (for example, access to a particular HIV drug), will be retained, but CCG commissioners will have increasing involvement in implementing these policies and planning the services which will provide access to specialised treatment and care.

As well as encouraging a more holistic approach to service provision for people with specialised conditions, collaborative commissioning aims to "move towards population accountability and lay the groundwork for 'place based' or population budgets and clearer accountability to local populations."[46] NHS England funding for specialised services is now mapped against CCG geography.[47]

This place-based approach is being further developed through Sustainability and Transformation Plans (STPs). STPs are five-year plans developed by all commissioning partners in a geographical area which is larger than the footprint covered by a CCG, but smaller than a region (on average, each STP includes 5 CCGs). STPs are 'blueprint(s) for accelerating implementation of the Five Year Forward View (5YFV).'[48] Those footprints which produce the most compelling STPs will be prioritised for dedicated sustainability and transformation funding.

The STP model clearly relies upon and aims to develop collaboration amongst all commissioners in one location – applying the principles of collaborative commissioning across the local health and care system.

Collaborative commissioning has potential to prevent further fragmentation of the HIV care pathway and to address some of the problems emerging from transition to new commissioning arrangements. NHS England has stated for some time that it considers collaboration a key principle - linking funding to successful production of an STP in partnership with all local decision-makers shows they mean business. However, NHS England's guidance in support of greater local collaboration

[46] NHS England. Developing a more collaborative approach to the commissioning of specialised services. March 2015. https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/03/spec-serv-collabrtv-comms-guid.pdf

[47] NHS England. Technical Guide to Allocation Formulae and Pace of Change For 2016-17 to 2020-21 revenue allocations to Clinical Commissioning Groups and commissioning areas. Spreadsheet I – Specialised Services. https://www.england.nhs.uk/2016/04/allocations-tech-guide-16-17/ NHS England. Allocation of resources to NHS England and the commissioning sector for 2016/17 to 2020/21. Board paper 17.12.15/04. December 2015. https://www.england.nhs.uk/wp-content/uploads/2015/12/04.PB_.17.12.15-Allocations.pdf

[48] https://www.england.nhs.uk/ourwork/futurenhs/deliver-forward-view/stp/

– both in relation to specialised commissioning and in the context of STPs – is built around the assumption that CCGs are the most important local commissioning partners to NHS England.

This is clearly not the case for HIV, where the decisions of local authority sexual health commissioners have a much greater influence on the future sustainability and success of HIV services. For collaborative commissioning to have any positive impact on HIV treatment and care, it must include local authorities as well as NHS England and CCGs.

This is not a simple oversight; NHS England could not simply amend their guidance to include 'local authority commissioners' in addition to references to CCGs. The relationship between NHS England and local authority commissioners (who are not part of the NHS) is entirely unlike that between NHS England and the CCGs (which receive all their funding from NHS England). The Health and Social Care Act made public health the responsibility of local government, and sexual health commissioners will act in accordance with their local authority's priorities. They cannot be compelled to collaborate with NHS England's plans and priorities. Local Government is democratically elected with direct accountability to residents. Local authorities are required by law to balance their budgets and may not go into debt (which NHS Trusts may do, if demand for services outstrips available funding). Local authority commissioners must adhere to specific national and European procurement rules and will draw on a well-developed culture of tendering - now applied to clinical services, in the case of sexual health.

Significant efforts have been made to encourage a more collaborative approach to HIV, sexual health and reproductive health services.[49] Risk-sharing 'section 75' agreements have been used by NHS England and local authority areas as a mechanism for jointly commissioning HIV and sexual health services. This approach helps ensure sustainability of HIV services which have historically been integrated within a GUM clinic. It usually would also maintain co-location of HIV and other sexual health services, which will facilitate access to sexual health support for people living with HIV – a valuable part of long-term condition management for sexually active men who have sex with men, in particular.

Health and Wellbeing Boards, which sit within local authorities, were intended to create a mechanism for collaboration across a local health and care system and have been operational since 2013. However, a Local Government Association analysis has identified only 15 Health and Wellbeing Boards in England which have prioritised sexual health in their plans.[50] Greater involvement of local CCG commissioners in commissioning specialised services may mean that complex and comparatively uncommon conditions, like HIV, gain greater prominence in HWBs' strategic discussions for their area.

Participants at the conference expressed frustration that NHS England give only limited acknowledgement of the role of local authorities in achieving the goals of the Five Year Forward View - and entirely exclude local authorities in their policy guidance on developing collaborative commissioning.

NHS England's expectation for collaborative commissioning for HIV is that the momentum must come from local CCG commissioners, whose proposals could be considered and if necessary supported at a regional or national level by NHS England. While it is important that collaborative commissioning is not imposed on local areas which are not yet prepared to embrace the approach, it

[49] See for example: Public Health England and MEDFASH. September 2014. Making it work: A guide to whole system commissioning for sexual health, reproductive health and HIV https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/408357/Making_it_work_revised_March_2015.pdf ; LGA and MEDFASH. "Sexual health commissioning in local government: building strong relationships, meeting local needs", June 2015. http://www.medfash.org.uk/uploads/files/p19ovbv1tarl8mv5193311uj1mps1.pdf; and the work of the English HIV and Sexual Health Commissioners Group.

[50] The analysis does not provide detail on whether this includes HIV specifically. Local Government Association analysis of Health and Wellbeing Board priorities for England. http://www.local.gov.uk/health-and-wellbeing-boards/-/journal_content/56/10180/6111055/ data published February 2016 and access April 2016.

is hard to see how collaborative commissioning for HIV – involving sexual health commissioners - could develop effectively without leadership from NHS England at a national and regional level.

THE FIVE YEAR FORWARD VIEW: NEW MODELS OF CARE

The overarching principles for NHS reform set out in the Five Year Forward View – investing in prevention, breaking down barriers between different parts of the health and care system and greater involvement and decision-making power for individuals and communities – are expressed in practical terms through the new models of care. These are a limited menu of "radical new care delivery options" which local health and care systems may choose from. Fifty vanguard sites have been approved by NHS England to develop the new models in practice, so that others may learn from their experience.

The Five Year Forward View presents seven new models of care, three of which are particularly relevant to long-term condition management for people living with HIV. These three (presented in bold below) were discussed in greater detail with the focus groups of people living with HIV, and at the conference:

1. Multispecialty Community Providers (MSCP)
2. Primary and Acute Care Systems (PACSs)
3. Urgent and emergency care networks
4. Viable smaller hospitals
5. Specialised care
6. Modern maternity services[51]
7. Enhanced health in care homes.[52]

1. Multispecialty Community Providers (MSCPs)
MSCPs are a care model which reduces the need for people with long-term conditions to access services in a hospital setting. MSCPs are GP-led group practices which may also employ consultants, senior nurses, paediatricians, psychiatrists, therapists, pharmacists, psychologists and social workers, alongside GPs.

The Five Year Forward View suggests that over time, MSCPs may receive delegated responsibility for the NHS budget for their registered patients – and ultimately the pooled health and social care budget allocation for their patient list.

The most obvious potential for MSCPs in relation to long-term condition management of HIV is for certain MSCPs to incorporates or host an HIV clinic (which is in a networked arrangement with other clinics – see point 3 below). MSCPs could help address the frustration people living with HIV can experience with shared care arrangements between their clinic and GP by providing all aspects of the care pathway in one setting. Even if HIV specialised services were not provided at the practice, MSCPs could facilitate better access to mental health services and social care services for people living with HIV, without the need for onwards referral to a separate provider of care.

[51] It is clearly important that maternity services meet the needs of women living with HIV and also support HIV testing and prevention – however, the modern maternity services model is not yet well-developed enough to engage with this level of detail.

[52] The needs of people living with HIV in care homes is also an important issue, one which NAT has recently addressed in our publication HIV: A guide for care providers. As with maternity care, the proposed new model for care homes is not yet at a level of detail where we can helpfully made HIV-specific observations or recommendations. http://www.nat.org.uk/publications

NAT is not yet aware of any examples where HIV services have been incorporated into an MSCP, but this possibility was raised with the focus groups of people living with HIV. Participants saw possible advantages in being able to access HIV specialised services in a primary or community care setting. There was particular interest in attending MSCPs for routine monitoring (blood tests) – which some focus group participants told us is already possible at some GP practices. There was broad support for anything which improved communication between HIV specialists and GPs; and by extension, primary care clinicians' knowledge of HIV.

At the same time, focus group participants expressed significant reservations about moving HIV specialist services into primary and community care settings and for giving GPs greater responsibility for their patient's health and care. This is linked to the common and long-standing concerns about primary care described in the previous section. It is clear that primary care services need to improve their approach to HIV. The development of MSCP models which include access to HIV speciality care is one way of showing how this could be done, by bringing specialist expertise into a generalist setting.

2. Primary and Acute Care Systems (PACSs)

Whereas MSCPs are best understood as expanded versions of a GP group practice, primary and acute care systems (PACSs) go a step further, offering GP, hospital, community, mental health and social care services in one single organisation or partnership. At their most-developed, PACSs would take responsibility for the whole health needs of a registered list of patients, under a devolved, capitated budget. The PACS model promises to provide a more holistic service to this registered list.

PACSs may evolve from MSCPs, in that an MSCP could ultimately take responsibility for running a district hospital. In a different area, a PACS may be set up when a hospital trust opens its own GP surgery.

Unlike MSCPs, which move care out of acute setting into primary and community services, the PACS model does not specify how and where patients will access services. NHS England's public communications about the benefits of new models of care suggest that they would offer patients a single point of access.

As PACS are single organisations or partnerships there is a possibility of providing care in a one-stop-shop approach (although this is not necessarily how all PACSs will develop). For example, the South Somerset Symphony PACS vanguard will be offering three care hubs providing primary and secondary care in one place, for residents living with multiple long-term health conditions. In the focus groups, there was support for the idea of the one-stop-shop model – or, at least, for a more seamless, behind-the-scenes experience of referral from one service to another.

It was clear from the focus groups many people living with HIV still feel more confident in the care provided by their hospital-based HIV doctor, than that provided by their GP. If GP services, mental health services and even social care were available within the same organisation as the HIV clinic there may be more effective communication and referral between clinicians and problems could be resolved more effectively. However, even more than with MSCPs, the PACSs model relies upon a registered patient list. It would not be possible to provide care within a PACS without all services having access to this list and the relevant health-related information it contains.

The MSCP and PACS new models of care are currently being piloted by 23 Vanguard sites[53], intended to provide inspiration to local health

[53] There are 27 further Vanguard sites, piloting enhanced care in care homes, urgent and emergency care and acute cate collaborations.

CASE STUDY: VANGUARDS' RESPONSES TO HIV

NHS England's aims for the Vanguards are to develop "blueprints" for the new models of care and "inspiration" to the rest of the health and care system. The 50 sites selected from the programme are therefore illustrations of what may be possible, but by no means the full expression of how the new models of care may eventually develop.

At this early stage, the Vanguards set up to develop MSCP and PACS models have an emphasis on addressing some of the most urgent issues facing the NHS in England – the care needs of an ageing population and people living with common long-term conditions such as diabetes and hypertension.

Given the comparative rarity of HIV in the general population, NAT did not expect any Vanguards to foreground HIV-related issues in their models. But as people living with HIV are also an ageing population, affected by multiple long-term conditions, it is plausible that the needs of people living with HIV may have been incorporated into models in areas with higher HIV prevalence.

NAT identified all MSCP and PACS Vanguards in areas of high HIV prevalence (diagnosed HIV rate ≥2 per 1,000) and approached the organisations involved to ask if (and how) HIV had been considered in the development of their model. The Vanguards and their responses were as follows:

Tower Hamlets Integrated Provider Partnership MSCP
(diagnosed HIV prevalence: 6.55 per 1,000)*
The Tower Hamlets Integrated Provider Partnership (THIPP) responded that their model focuses on adults at high risk of emergency admission. It had not explicitly considered HIV to date.

Salford Together PACS (integrated care organisation)
(diagnosed HIV prevalence: 4.76 per 1,000)*
Salford Together responded that as "HIV care is not commissioned by the CCG… [and] the Local Authority Public Health team commissions sexual health services", HIV was considered "outside the scope of the Vanguard." This understanding of HIV from a new model of care in a high-prevalence area is disappointing, but not entirely surprising – for much of the NHS, HIV is about prevention and specialist drugs, not long-term condition management.

Modality Birmingham & Sandwell MSCP *(diagnosed HIV prevalence*: 2.65/2.39 per 1,000)*
NAT was unable to get a direct response from Modality. However, the information provided on their website indicates that the focus of their vanguard is on care for people aged over 65. It does not seem likely that the MSCP includes an HIV-specific element.

*At time of NAT approach

and care systems which may want to adopt the models to meet local needs. Even assuming the models will be widely taken up across England, there is of course no guarantee that someone living with HIV will have local access to the model of care that is most relevant to their needs.

This raises questions about how access to new models of care will align with open-access HIV services.

It seems likely that where new models emerge which explicitly address the needs of people living with HIV, these will be in areas of higher prevalence where clinics already have well-developed networks with other specialties.

3. Specialised care
A defining feature of specialised services is that care can only be provided by a limited number of clinical teams. The Five Year Forward View vision for specialised care is that in the case of some specialised services this expertise should be further concentrated to fewer providers. This is based on evidence that clinical teams should aim to achieve a critical mass of services users, in order to develop and retain the skills and expertise needed to provide high quality care to people with specialised conditions.

It is important to note that consolidation would not necessarily mean fewer clinic sites, as specialist services teams would use a networked or hub

CASE STUDY: LONDON HIV SERVICE REVIEW

NHS England's HIV Service Review for London was recommenced in April 2016, looking at all adult HIV outpatient services in London.

The key objectives of the review is "to review the HIV service delivery model, in London, and to implement changes which will streamline pathways and enable better and more efficient services, particularly to:

- Establish the most efficient service model to meet London's growing demand;
- Address critical mass issues for outpatient and inpatient HIV services;
- Develop integrated care pathways that will achieve the best health outcomes;
- Deliver optimum use of staff competencies to support maximum appropriate self – management;
- Work with commissioning partners to secure a coherent set of services for HIV and GUM in London;
- Ensure the service user voice is central to any reconfiguration process;
- Support HIV prevention efforts through collaboration with Local Council commissioners."

The review will explore the potential of new models of care for helping to improve the long-term health and wellbeing of people living with HIV, including their access to primary care.

The need for better-integrated care pathways and meaningful involvement of people living with HIV in any service redesign were emphasised by participants at the conference in relation to all future models of care, so these are welcome inclusions in the London service review's objectives.

In addition, concerns about the impact on HIV services of the London Councils Sexual Health Transformation Programme (SHTP) were expressed by several participants and panellists at the conference, so NHS England's commitment to work closely with the SHTP as part of the HIV service review is an important reassurance.

and spoke approach. There is also potential for the new model of specialised care to be grafted onto MSCPs or PACSs, allowing people living with HIV to access specialised services in primary and community care settings.

Prior to the Health and Social Care Act 2012, HIV specialist commissioners in London embarked on an HIV service review, which drew upon the same concept of critical mass. The review was placed on hold following transition to new commissioning arrangements, but is now being recommenced.

London services currently provide care to just over half of all people living with diagnosed HIV in England – including some who reside outside of the capital. While there are aspects of the review which will be specific to London, the findings and recommendations of the review will be an important indicator of the possible future direction of specialised HIV services for England more broadly.

DEVOLUTION OF HEALTH AND CARE COMMISSIONING

The future NHS is one which promotes local determination and place-based decision-making for health and care services. Collaborative commissioning, STP footprints and the new models of care set out in the Five Year Forward View will all involve delegation of health and social care budgets to local (or at least sub-regional) decision-makers. NHS England proposes that this population-based accountability for NHS funding will support its goals for person-centred care, integrated services and more effective long-term condition management support.

Devolution deals are a further mechanism for increasing local control of the design of NHS

CASE STUDY: GREATER MANCHESTER

On 1 April 2016, Greater Manchester Combined Authority (GMCA) took on devolved responsibility for a £6 billion health and social care budget, to meet the needs of residences of Bolton, Bury, Manchester, Oldham, Rochdale, Salford, Stockport and Tameside, Trafford and Wigan as part of the GM Devolution Agreement.

GMCA states that it will share, with the Secretary of State for Health and GM local councils, the duty to "take any actions it thinks will improve the health of Greater Manchester residents." This will include a comprehensive health and social care plan for Greater Manchester.

In line with the Cities and Local Devolution Act, NHS England commissioning policies for specialised services, including HIV treatment and care, will continue to apply in GM. Any variation to HIV treatment and care services will need to be an augmentation or addition to these national standards.

The GMCA has indicated that adult HIV treatment and care services will undergo service redesign, alongside a range of other specialised services which are provided on a GM footprint.[57]

services. Deals have so far been agreed for eight areas in England: Greater Manchester, Sheffield City Region, West Yorkshire, Cornwall, North-East, Tees Valley, West Midlands, and Liverpool City Region. However, devolution deals are about much more than NHS services, and so far only three appear to include agreements on health and social care integration.[54]

The Cities and Local Government Act 2016 provides the legislative basis for the devolution of budgets to local government. Those parts of the Act which cover health were amended significantly by the Government during the course of the Bill. The resulting approach is more accurately described as a delegation rather than devolution of health budgets and NHS service planning. The Cities and Local Government Act states explicitly that the Secretary of State for Health retains all existing statutory duties (for example, to promote a comprehensive health service and to reduce health inequalities). In addition, the city or region which is receiving devolved/delegated NHS functions must adhere to existing national standards - including NHS England specialised commissioning policies relating to HIV treatment and care.[55]

In other words, it would not be possible for a devolved city or region to refuse to commission an HIV drug which NHS England would commission elsewhere in England. The NHS England service specification for HIV clinical services will continue to apply.

Completely separately to full devolution deals such as Greater Manchester, there are five health and social care 'devolution pilots' underway in London only, as a first step towards more local delegation of responsibility of NHS services in the city.[56] In these pilots, a single local authority or partnerships of local authorities have agreed topic-based plans on issues including integration of primary and secondary care, and health and social care, and using local authority planning and licensing powers to tackle public health concerns.

Although devolution – or delegation – of health and care budgets services sounds radical, in the short-term it will not necessarily lead to any more variation in HIV treatment and care than will already be possible through the other population-based approaches discussed above. The future NHS in England will be one of increasing local variation in HIV care pathways. However, while the specific models may differ, delegation and local control could be used to shape NHS services which are fit for the future of HIV: offering consistent access to high quality specialised care that is fully integrated with long-term condition support, provided in a primary or community care setting.

[54] M Sandford. Cities and Local Government Devolution Bill: progress. Briefing paper Number 07418, 18 December 2015 House of Commons Library.

[55] M Sandford. Cities and Local Government Devolution Bill: progress. Briefing paper Number 07418, 18 December 2015 House of Commons Library.

[56] Participating areas: Haringey; North Central London (Barnet, Camden, Enfield, Haringey, Islington); Lewisham; Hackney; Barking & Dagenham, Havering and Redbridge. https://www.england.nhs.uk/london/2015/12/15/health-and-care-devolution-plans/

[57] GM Devo: Internal delegation by NHS England to GM Chief Officer. 3 March 2016. http://www.gmhsc.org.uk/news/gm-devo-internal-delegation-by-nhs-england-to-gm-chief-officer/

RECOMMENDATIONS

HIV LONG-TERM CONDITION MANAGEMENT

NHS England must take efforts to explicitly include HIV in strategies and programmes related to long-term condition management.
This could include:

- Using HIV as a test case for better commissioning of complex long-term conditions and showing national and local leadership to implement improvements.
- Drawing examples from HIV's history of patient activism, engagement of affected communities, person-centred and holistic care, which other conditions could learn from.
- Including HIV explicitly in data collection about people with long-term conditions (the GP patient survey).

People living with HIV, their networks and advocates should engage with NHS England's framework for long-term condition management.
This could include:

- Developing community models of HIV long-term condition management.
- Sharing examples of good practice from the HIV sector which NHS England could incorporate into their long-term condition management framework.
- Identifying opportunities for improving HIV long-term condition management arising from NHS England's current priorities.

Health and care services for people living with HIV should take a long-term condition management approach to planning treatment and care.
This should include:

- Jointly-produced care and support plans for every person living with HIV, including input from all healthcare professionals involved in the multidisciplinary team (MDT).
- An expanded MDT approach including primary care input as standard, from the point of diagnosis.
- Clarity about which providers are responsible for each aspect of long-term condition management, and who is responsible for overall coordination of the care plan, MDT or care pathway.

PERSON-CENTRED CARE FOR PEOPLE LIVING WITH HIV

Commissioners and providers of HIV treatment and care should build upon a strong history of person-centred HIV care, to ensure that people living with HIV can get the support which is most helpful and meaningful to them. All elements of the HIV Standards of Care are important and should be equally accessible, regardless of which speciality provides the care.

People living with HIV and their advocates should use NHS England's key principles of person-centred care as a benchmark for the care they should be receiving, and ask for improvements from providers and commissioners of services, where these commitments are not being met.

Commissioners and providers of HIV services who invest in patient activation measures (PAM) and other tools to facilitate person-centred care

should not do this at the expense of approaches to long-term condition management which foster a mutually supportive community of people living with HIV, e.g. support services, peer networks and other groups. Both are needed.

COLLABORATIVE COMMISSIONING FOR BETTER HIV SERVICES

NHS England specialist commissioners should engage in collaborative commissioning for HIV treatment, care and long-term condition management.
This should include:

- With **clinical commissioning groups, local authority commissioners and NHS England primary care commissioners** to develop a local HIV care pathway which includes all aspects of the Standards of Care for HIV.
- With **local authority commissioners** as a mechanism for ensuring sustainability of HIV services which are embedded in a locally-commissioned sexual health service.

NEW MODELS OF CARE FOR PEOPLE LIVING WITH HIV

Commissioners and providers of HIV treatment and care should look to the Five Year Forward View New Models of Care Vanguards for inspiration on how HIV specialist care could be provided in settings other than a hospital, sexual health or infectious disease clinic, and take the initiative in developing new approaches to better meet the needs of people living with HIV.

HIV clinicians must normalise involvement of primary care in treatment and care from the point of diagnosis, with all service users. Clinics should provide practical support to overcome barriers to patient engagement with primary care at the earliest possible stage following diagnosis.

Support services and advocates for people living with HIV have a duty to make clear the health and wellbeing benefits of sharing relevant medical information within the NHS, and the risks of not doing so.

The NHS in England must take clear action against HIV stigma, discrimination and harassment in all services, including awareness-raising, education and action against services which act unlawfully.
This should include:

- Investment in anti-stigma interventions within NHS services.
- Guidance to healthcare providers on how to respond to incidents of HIV-related discrimination and harassment (this could be as part of broader guidance on Equality Act duties relating to disability, sexual orientation, gender and transgender discrimination).

NHS England (London region) should use their HIV service review as a means for maintaining and optimising access to specialised services, retaining the principles of open access. The review should also explore possibilities for better integration of specialised HIV services with primary care/ Five Year Forward View new models of care.

CCGs and local authorities in the London region should work collaboratively with the NHS England HIV service review team on the development of integrated care pathways for people living with HIV, including long-term condition management support, primary care links and appropriate connections between sexual health and HIV services.

DEVOLUTION, DELEGATION AND PLACE-BASED COMMISSIONING OF HIV SERVICES

In future place-based agreements for health and care, commissioners should consider all aspects of care outlined in the Standards of Care for People Living with HIV, Psychological Support for People Living with HIV and HIV clinical standards – in addition to providing consistent access to nationally-agreed specialised policies, standards and service specifications.

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