Growing older positively

The challenge of ageing with HIV

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Contents

Foreword

That this report can be written at all is testament to the extraordinary progress of HIV treatment in the UK over the last twenty years. The disease has gone from a death sentence to a manageable chronic condition that, as these pages highlight, need not threaten normal life expectancy if managed carefully. Those successes have been realized with more than advances in clinical diagnostics and drug regimens. From the outset, HIV has challenged doctors and patients to work together; has pushed public health to see prevention and care as two sides of the same coin and, given the unparalleled degree of stigma that still clings to it, has called for a 'whole patient' approach, particularly to social care, that keeps people strong enough in spirit to be well in body.

Today, as is so clearly demonstrated by this timely report, HIV is again leading the challenge to health and social care to appropriately and collaboratively manage a range of chronic health conditions, including diabetes, heart disease and hypertension, in an ageing population which will almost double by 2037 (ONS 2013). As such, many of its findings, including confusion over multiple sources for funding of services, lack of understanding on the most effective way for GPs and specialist services to work together, and perceived poor communication between primary and secondary care will resonate beyond HIV.

Gail Beer, Matt James and Sean Summers have worked through these findings, giving clear recommendations throughout the report on steps to address specific or structural problems and the appropriate body to lead such changes. A clear-eyed analysis of the strengths and weaknesses of different models for HIV service delivery is well framed against the complex and largely untried commissioning arrangements that have come in as part of the Health and Social Care Act 2013. These arrangements, and the pathways of care that flow from them, must be carefully monitored to determine their strengths and ensure they deliver real impact.

Above all what is clear from this document is that people over 50 are newly contracting HIV in higher numbers and, once diagnosed, the complex and changing needs of this growing but diverse group are not and will not be adequately addressed without filling what the report describes as a 'vacuum of strategic leadership around HIV'. In order to be efficiently and properly responsive to those needs, enabling patients to manage their condition whilst making sure knowledge of the complexities of treating HIV and co-morbidities is shared across specialist boundaries, there must be a centralized leadership of services. For HIV, as for so many life-threatening conditions, medical science is now enabling us to live longer, but this is not enough. We need also to be able to live well. The kind of analysis into how that can be achieved that this report delivers is an essential part of the next chapter of HIV in the UK.

Anne Aslett
EXECUTIVE DIRECTOR
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About this Publication

Gilead Sciences has funded this review and the report. 2020health is conducting the review on Gilead's behalf in a consultancy capacity. 2020health is an independent, social enterprise think tank working to improve health through research, campaigning, networking and relationships. We do not lobby on behalf of companies, organisations or individuals and retain editorial control of all our publications.

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Matt has a particular interest in the intersection of values, health, technology and public policy. As an independent consultant, he has a wide ranging portfolio of expertise which spans the arenas of public policy, academia and third sector, including working in Parliament as a parliamentary researcher for a MP and shadow minister. Skilled in research, administration and new media development, Matt has convened numerous series of public symposia which have helped initiate and bring together key stakeholder groups to discuss the ethical, social and legal implications of new technologies and health. Matt has an undergraduate degree in political history and sociology as well as a Master's degree in bioethics and medical law. He is a Fellow of the Royal Society of Arts and Commerce (FRSA).

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1. Executive Summary

For many people, age 50 may not seem to be 'old', but increasingly 50 is being used to record and analyse statistics on older people living with HIV. In 2012 one in four adults living with diagnosed HIV in England were aged 50 years and over (PHE 2013:5). Older people are the fastest-growing group in the UK living with HIV. It is estimated that 24,510 people living with HIV in the UK in 2012 were aged 50 or over. These numbers are set to double over the next five years.

The two groups most affected by HIV in the UK are:

- Gay and bisexual men – the group at highest risk of being infected in the UK
- People who have migrated from regions of the world where HIV is common, such as sub-Saharan Africa.

Research also indicates that white heterosexuals living with HIV are often neglected in HIV studies (Terrence Higgins Trust 2014).

Due to advances in effective HIV treatment more people than ever before are living to older age with HIV. Despite the tremendous advances in effective treatments for HIV, which have resulted in the disease being considered chronic rather than acute, older people with HIV remain at a disadvantage in comparison to their peers, particularly in terms of quality of life. From poor levels of health to access to social care and financial security, the older person living with HIV faces significant challenges.

For the first time we have a significant cohort of those living with HIV aged over 50, which presents new challenges to the way HIV care and treatment are designed, managed and delivered.

This report reviews how HIV is strategically planned for and managed in the UK today and develops recommendations for Government and the NHS in light of changes in the patient profile. The goal must be to ensure that with appropriate care and support everyone with HIV can live a long and fulfilled life. From our research we have identified the following key issues which effectively help to meet this goal:

- **Treatment and prevention** – The separation of services of treatment and prevention is clearly an unhelpful distinction. An effective system demands close monitoring and regular reporting on key performance indicators (KPIs) for treatment and prevention, together with dialogue between commissioners and third sector and voluntary sector organisations.
- **Primary care and specialist services** – Improving the quality of primary care for people with HIV and establishing better interaction between HIV specialists and other community clinicians, is essential to providing good quality patient centred care, particularly when managing complex long terms conditions due to ageing and being older with HIV.
- **Training and education** – These are essential to greater levels of competence and confidence among all healthcare professionals in caring for the older patient with HIV infection and co-morbidities.

1. Executive Summary

- **HIV and the ageing process** – Multi-disciplinary team involvement is critical to the sharing of knowledge and expertise in treating older patients with HIV. HIV clinicians need to work together with specialist clinicians and with geriatricians in helping patients manage common co-morbidities.

- **Targeted support** for the two main groups of older people living with HIV in the UK:

    - Specific mental health and social support, especially among men who have sex with men (MSM) who report particular concerns in this area triggered by fears of homophobia as they consider their need of social care support.

    - Educating and supporting those from Black African communities who often have problems in navigating the health system – thus the extent to which they are able to understand and take responsibility for their own care.

    - Identifying the needs of white heterosexuals living with HIV and empowering them to live their lives confidently without feeling isolated and neglected.

- **Care provision** – Care service providers need to be better informed and equipped to help care for those living longer with HIV. Many providers have not needed to respond to the care needs of the older person living with HIV, so they currently have very limited experience. Skills and training need to be improved in this area. Here is an opportunity to establish what a good care provider should offer in terms of services and facilities for long term conditions.

- **Confidentiality** – Previously those living with HIV will have been familiar with working with specialist healthcare professionals who have maintained confidentiality. As the group widens to include care providers (such as care workers and personal assistants) there is the fear of other people becoming aware of their condition and the risk of confidentiality being compromised. Reassuring patients of the importance placed upon confidentiality and the procedures in place to uphold this throughout the health and social care system is essential to help build trust and confidence between patient and professional.

Underpinning all of this is the need for any refashioning and redesign of services to focus on empowering older patients to live a life with HIV. Rather than providing for older patients, services now need to work with the patient, balancing good HIV treatment with treatment for co-morbidities, and integrating social care support.

1. Executive Summary

Based upon our analysis the following recommendations are proposed:

Recommendation:	Action to be taken by:
A map of funding routes for HIV should be published as part of the development of PHE's national framework.	PHE
Evaluate the effectiveness of separating commissioning responsibilities for treatment and prevention.	Department of Health
Create a reporting process to feed back KPIs to the HIV CRG.	NAT CRG
PHE's national framework should aim to fill the vacuum of strategic leadership around HIV which currently exists.	Public Health England
Ongoing support for peer support networks needs to continue.	Local authorities CCGs
Specialist training relating to HIV and AIDS should be a mandatory part of GPs' ongoing professional development. Training and education in HIV and AIDS should also form a core part of undergraduate teaching for all new medical students.	Royal Colleges Medical Schools
Evaluate existing models of care involving primary care and specialised services, identifying key criteria and drivers for effective implementation and improvement.	Domain 2 lead, NHS England
The opportunities presented by the personal health record should be explored in further detail by HIV patient groups. Whilst it is important that information about a patient's HIV status remains separate to wider NHS information flows, appropriate steps should be taken to secure the informed consent of patients who might benefit from the greater transferability of their information.	Charities & third sector organisations
Commission a review of training given to professionals on HIV with an emphasis on the older person.	Royal Colleges Professional bodies NHS Deaneries
Establish greater opportunities for multidisciplinary learning and knowledge exchange on managing co-morbidities in the lives of those people who are living longer with HIV.	Royal Colleges BHIVA BASHH
Promote further long-term research into people with HIV, so as to better understand the cumulative effect of HIV as they grow older, and develop a profiling tool.	Royal Colleges NHS England
Targeted advice and information on matters such as nutrition, exercise and smoking cessation should be made available to empower patients to maximise healthy choices.	GPs Local public health
Bring together groups and charities working with the elderly and those living with HIV to help meet the needs of the ageing cohort.	Patient groups and charities

1. Executive Summary

Recommendation:	Action to be taken by:
Mental health support programmes need to be fit for purpose and designed with the needs of the older person in mind.	NHS Mental Health Trusts Social services GPs
A national patient experience survey of people living with HIV should be funded by NHS England to help ensure independence is maintained.	NHS England
Review of the social care needs assessment, including the introduction of questions which help to identify and capture the true extent of the patient's needs.	Local authorities
Provide adequate training for staff who undertake the social care assessment so they can better understand and capture the needs of the older patient living with HIV.	Local authorities, independent organisations and charities
Mandatory basic training in HIV to be brought in for all those working in health and social care, helping to increase confidence and competence.	Skills for Care NHS England
Minimise stigmatisation through the promotion of life-enhancing and positive language and behaviour in the training of social care services.	Skills for Care
Establish best practice for care homes that commissioners can follow and adhere to when commissioning services.	CQC
Develop the use of personal health budgets (PHB) among HIV patients	Patient Patient groups and charities
All HIV clinics and GP practices should provide the NAT resource (or comparable ones) to their patients living with HIV, and accompany it with a verbal explanation and an opportunity to ask questions.	Service providers

2. Introduction

Defining at what age a person becomes an 'older' person is not easy. While there are commonly used definitions of old age, no general agreement has been reached as to what age a person becomes an older person. Taking a calendar age and using it as a marker of old age assumes that there is a corresponding link with biological age, but it is generally accepted that the two are not synonymous (WHO 2014). The age of 60 or 65, roughly equivalent to retirement ages in most developed countries, is often a common marker. In the United States 50 years and above has been used, while the UK has traditionally used 65 years.

To many people, age 50 may not seem to be 'old', but increasingly 50 is being used to record and analyse statistics on older people living with HIV. In 2012 one in four adults living with diagnosed HIV in England were aged 50 years and over (PHE 2013:5). Older people are the fastest-growing group in the UK living with HIV. It is estimated that 24,510 people living with HIV in the UK in 2012 were aged 50 or over. These numbers are set to double over the next five years.

Due to advances in effective HIV treatment more people than ever before are living to older age with HIV. The latest UK Collaborative HIV Cohort (UK CHIC) study found that life expectancy for HIV-positive people on successful treatment in the UK is now considered 'normal' (May et al 2014; 2012).

Despite the tremendous advances in effective treatments for HIV, which have resulted in the disease being considered chronic rather than acute, older people with HIV remain at a disadvantage in comparison to their peers, particularly in terms of quality of life. From poor levels of health to access to social care and financial security, the older person living with HIV faces significant challenges.

This report reviews how HIV is strategically planned for and managed in the UK today and develops recommendations for Government and the NHS in light of changes in the patient profile. The research had the following objectives:

- Explore the implications of redesigned services for a changing patient profile, with particular reference to those older patients who acquired HIV early on and who are living longer as well as those older patients who have recently acquired HIV (also referred to as late diagnosis).

- Explore new settings for managing care, given advances in technology, the commitment to give patients choice as to where and when they are treated and the care they receive.

- Develop new insights and proposals for treating HIV alongside co-morbidities brought on through the ageing process.

The research responds to these objectives with a focus on treatment pathways and reference to the increased costs as numbers of people with HIV rise.

This research does not cover prevention, testing and public health initiatives.

2. Introduction

2.1 Methodology

A selection of research methods were employed to gather evidence and perspectives for the project. The work was undertaken between June and December 2013 and consisted of three key strands:

- **Desk-based literature review and research** – Reviewing and evaluating the development of HIV policy, care and treatment over recent years, with specific regard to the older person living longer with HIV. This research was used to inform the telephone interviews and stakeholder discussion.

- **Series of expert telephone interviews** – In-depth telephone interviews were conducted with 14 key stakeholders from across the UK. Participants included consultants, nurses, commissioners, patients and representatives from professional bodies. A semi-structured schedule was used to establish a basic interview framework, whilst also allowing opportunities for respondents to explore specific issues in depth, drawing upon their areas of expertise and experience. Interviewees were assured that their comments would remain unattributed and were encouraged to offer their own personal opinions.

The interviews prompted thoughts and opinions on the following issues:

a) The commissioning process for HIV treatment and care from diagnosis onwards

b) The management of co-morbidities and HIV

c) The skills, expertise and multidisciplinary approach required in the delivery of services for an ageing cohort

d) The social care needs of older HIV patients

e) New technologies and strategies that could help to empower the patient and provide new settings to manage their care and access specialised services

f) The current strengths and weaknesses of the system in terms of patient experience and choice

g) How best to promote innovation and best practice

h) HIV-related stigma among healthcare professionals, including stigma among social care workers and wider society

- **A stakeholder discussion** – This discussion was convened in order to gather different perspectives on the state of patient experience and care of HIV, and to assess what action may be needed in the future to improve service provision. With a variety of key stakeholders in attendance (including consultants, GPs, representatives from the Royal Colleges and patient groups), space was given for open dialogue and the exchange of ideas and opinions.

The research has had the support of an external steering group of unpaid experts. 2020health discussed the emerging themes, findings and recommendations from the research with these experts in a number of meetings.

3. HIV: An Overview

Nearly 30 years have passed since HIV was first identified as the primary cause of Acquired Immune Deficiency Syndrome (AIDS) and it remains a significant and critical issue for public health.

Human immunodeficiency virus (HIV) attacks the body's immune system, the body's defence against disease. The first cases are now known to have occurred in 1959, after a pathologist noted a highly unusual type of pneumonia in a deceased Jamaican-American and retained the lungs for further research. In most known early incidences of HIV, the deceased had prior contact with West Africa. It was 1980 before the first AIDS case in the United States was actually recognised at the time and reported to the US Center for Disease Control, with immuno-deficiency being suspected in 1981. The terminology 'AIDS' was agreed in 1982, as by then it was known that there were a variety of routes to infection. After initial severe flu-like symptoms in most people, in all cases of HIV infection, the immune system eventually becomes very weak and no longer able to fight off illnesses without effective treatment intervention (NAT 2013). Key facts on HIV are noted in Table 1.

Table 1
Key Facts: HIV

Prevalence

In 2012 there were approximately 100,000 people living with HIV in the UK.

77,610	21,900	6,360	490
people diagnosed and accessing HIV care	people undiagnosed	new diagnoses	deaths among people living with HIV

Two groups most affected by HIV in the UK are:

- A) **Gay and bisexual men** – the group at highest risk of being infected in the UK.
    - Men who have sex with Men (MSM) remain the group most affected by HIV with 47 per 1,000 living with the infection
    - New diagnoses among MSM continue to rise and reached an all-time high of 3,250 in 2012
    - One in nine gay and bisexual men diagnosed with HIV are 50 years or older
- B) People who have migrated from regions of the world where HIV is common, such as sub-Saharan Africa.
    - In 2012, an estimated 31,800 African born heterosexuals were living with HIV in the UK, of whom about 23% remained undiagnosed
- Research also indicates that white heterosexuals are often neglected in HIV studies. This group of people report considerable isolation, financial concerns and a sense that existing services do not prioritise their needs.

3. HIV: An Overview

Life expectancy & changing patient profile

- It is estimated that 24,510 people living with HIV in the UK in 2012 were aged 50 or over.
- Estimates are that by 2015, half of people living with HIV will be aged 50 plus.
- In 2012 one in four adults living with diagnosed HIV in England were aged 50 years and over.
- Improvements to antiretroviral treatment were cited as the main reason for the increase in life expectancy.

Late diagnoses and mortality

- Late diagnosis is the most important predictor of morbidity and one-year mortality among people with HIV infection.
- A late diagnosis is defined as having a CD4* count <350 cells/mm3 within three months of diagnosis; <350 cells/mm3 is the threshold at which antiretroviral therapy (ART) should begin.
- In 2012, a higher proportion of older adults, aged 50 years and over was diagnosed late compared to adults aged under 50 (63 percent vs. 44 percent).
- The lowest proportion of late diagnosis was among MSM, with 34 per cent (1,110/3,250) diagnosed late. This is a result of more frequent testing among MSM.

Transmission

HIV can be passed on through infected:

1. **Blood**
2. **Semen**
3. **Vaginal fluids**
4. **Breast milk**

The most common ways HIV is passed on are:

- **Unprotected anal or vaginal sex**
- **By sharing injecting equipment**
- **From a mother to her baby during pregnancy or birth, or when breastfeeding**

Sources: PHE 2013: 4-5, 13; May et al 2011; Rosenfeld et al 2012; Avert 2014; NAT 2014.

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* CD4 cells are an essential part of the human immune system. The more CD4 cells there are in the immune system, the better.

3. HIV: An Overview

There has been undeniable progress and improvement in the field of clinical care and understanding of antiretroviral therapy, clinical outcomes and public support for research. Nevertheless the fact remains that HIV is a condition that is heavily stigmatised.

Despite generating less media attention today than it has previously, the epidemic shows no sign of abating. The annual number of new HIV diagnoses nearly tripled between 1996 and 2005, when the annual rate peaked at almost 8,000 diagnoses. Annual diagnoses have slightly declined since then with 6,360 new diagnoses in 2012 (PHE 2013).

The general public's knowledge and awareness of HIV and AIDS appears to have decreased over recent years. Research conducted by National AIDS Trust (NAT) revealed that in the year 2000, 91 percent of people in the UK knew that HIV could be transmitted through unprotected heterosexual sex; by 2010 this figure had fallen to 80 percent (NAT 2011). This decline in public awareness was also highlighted by the House of Lords Select Committee 2011 report into HIV and AIDS , which stated that 'awareness of HIV and AIDS in Britain has fallen below the public radar' (House of Lords 2011).

Four decades

Experts have split the first three decades of HIV awareness into key stages of development:

- ***First decade –*** Activism, energy and understanding. The overarching aim was to increase public awareness of the condition.

- ***Second decade –*** Intervention and medication. Advances in medicine began to help gain biological control over the disease.

- ***Third decade*** – Stabilisation of the condition. Simpler regimens became the norm and helped eradicate what had been a death sentence to so many living with HIV.

As we enter the fourth decade, much of the focus is beginning to fall on how to care for patients, and the questions of how and where people with HIV should receive their care.

Standards of care

In 2007 the British HIV Association (BHIVA) working in partnership with other key stakeholders including those living with HIV, produced the first set of quality standards for the care of people with HIV in the UK. Since the drafting of the first set of standards the commissioning of HIV services along with the financial climate have changed. Those living with HIV are likely to access many different health services and organisations delivering health care. The standards have therefore been recently revised and updated to reflect these changes and to ensure that appropriate quality of care is set out for all adults living with HIV in the UK, so they are aware of what they should expect to receive (cf BHIVA Standards 2013 (BHIVA 2012)).

Critical to supporting standards of care needs to be a national strategy for HIV, in particular to minimise regional variation. Following a three-year hiatus the government published its renewed sexual health framework in 2013, entitled Framework for Sexual Health Improvement in England. The document commits 'to continue to tackle HIV through prevention and increased access to testing to enable early diagnosis and treatment; and joined-up provision that enables seamless patient journeys across a range of sexual health and other services – this will include community gynaecology, antenatal and HIV treatment and care services in primary, secondary and community settings' (Department of Health 2013: 5).

While the government's renewed framework is to be welcomed, the report does not give adequate focus and attention to the ongoing needs of those living with HIV. It cannot be underestimated the extent to which growing older with HIV presents new and novel challenges to how models of HIV care and treatment are designed, managed and delivered.

4. Positively Ageing

As the data in Table 1 indicates there has been a huge step change in the number of adults over the age of 50 living with HIV. Estimates are that by 2015, half of people living with HIV will be aged 50 plus (Rosenfeld et al 2012).

Looking beyond the UK, people aged 50 and older are an increasing proportion of the population of persons living with AIDS in the USA. Of the 9,796 people living with AIDS in San Francisco in 2010, more than half (5112 or 52 per cent) were 50-years old or older (O'Keefe et al 2013). In contrast to younger people, those aged 50 or older were more likely to be white (69 per cent, in comparison to 56 percent of those under 50) and to have acquired HIV as a result of sex with another man (75 contra 68 per cent) (O'Keefe et al 2013). This case study from San Francisco demonstrates the need for HIV medicine to overlap with other medical specialties in order to provide effective care of the older patient who already has complex medical needs as a result of a HIV diagnosis.

Those people aged 50 plus who are living longer fall into two general groups:

- Those people who acquired HIV early on in their life and are living longer as a result of effective therapies and treatment

- Those people who are acquiring HIV later in life

Currently there appears to be no reason to suggest that those over 50 diagnosed before and after the introduction of effective ART have needs that are categorically different to one another, although some data suggests that this might be the case (Cooper et al 2001). A full explanation for the growing number of new diagnoses in the over 50s is not yet apparent (PHE 2013) and should form the focus of future research.

There are a number of factors that have greater implications for older people with HIV, including:

a) **Stereotypes** – It is assumed that older people do not continue to be sexually active in later life. Therefore GPs and other healthcare professionals are less likely to be asking those over 50 years of age about their sexual behaviour. 'Routine' testing pilots also show that older people are less likely to be offered a test (HPA 2011: 19-22).

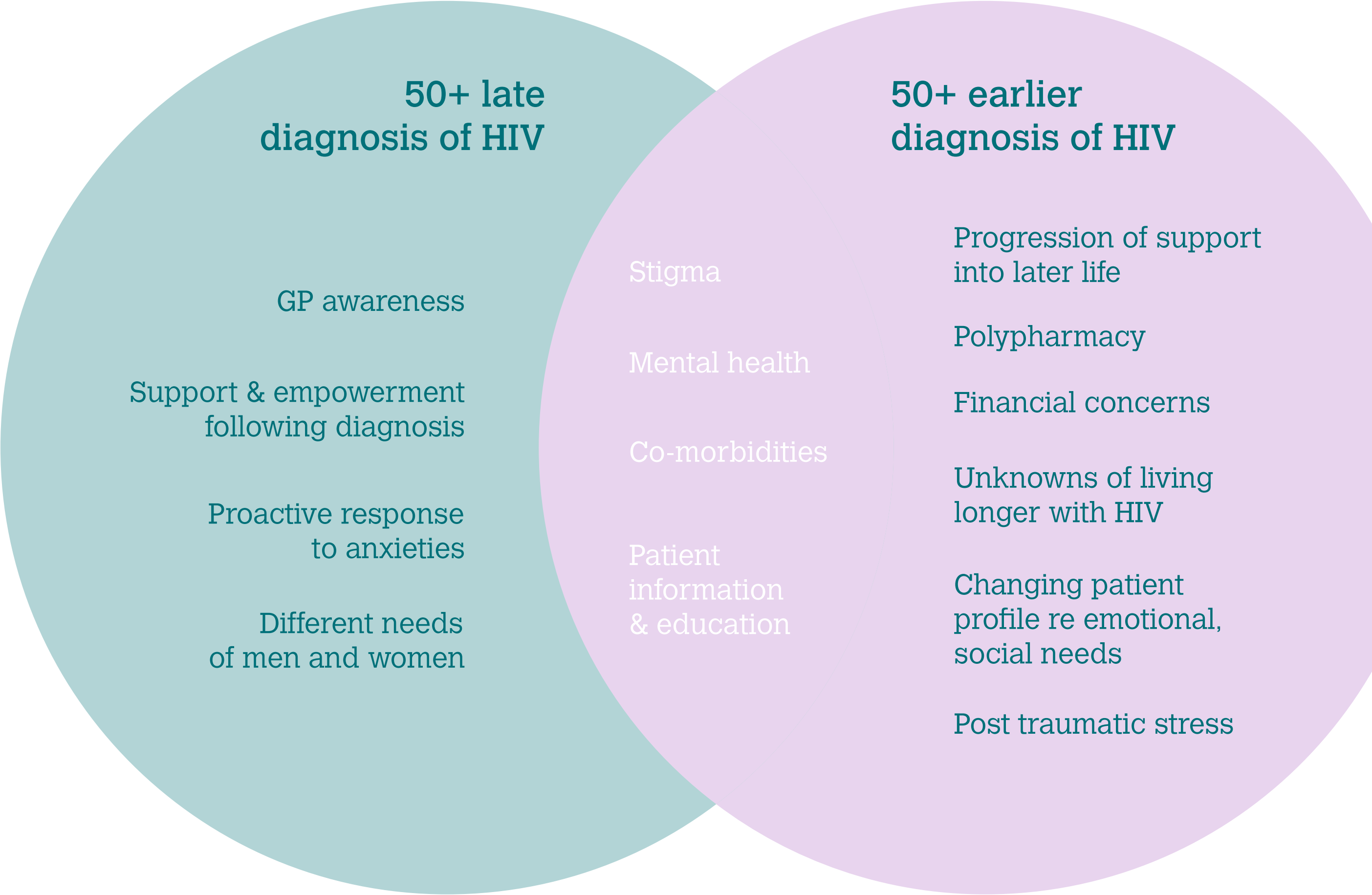
b) **Use of contraception** – Those within the 50-plus age bracket are not as familiar with the public health messages on contraception and condom use as younger generations. The use of contraception does not resonate as much with older generations.

c) **Biological reasons** – Erectile dysfunction (ED) is more common in older men resulting in condom use being more difficult. The availability of newer treatments for ED over the last decade has transformed the sexual lifestyle of older men. For women around the time of the menopause the vagina becomes much more fragile. Recent research seems to indicate that post-menopausal women perhaps have greater susceptibility in the cervix with cells that are likely to be more HIV receptive than younger women (Anderson 2011).

4. Positively Ageing

When reviewing the challenges of treating older patients diagnosed with HIV in later life and those diagnosed in earlier years, there appear common challenges as well as specific issues of particular concern for each group. (While some interviewees were keen not to make a clear distinction between the two groups, there was general agreement that there were some challenges affecting one group more than the other.) Figure 1 reflects this, illustrating the overlap between the two while still highlighting the perceived challenges to each group.

Figure 1



4. Positively Ageing

When considering the range of care and treatment required by those aged over 50 and living with HIV, it is necessary to not only think about specialised HIV treatment but also the various co-morbidities they are likely to experience as they enter later life. As Table 2 shows, while some of the conditions may be linked to the long term effects of HIV and treatment, these are also typical conditions associated with the ageing process. Increasingly, research points to the fact that the interaction between HIV and ageing presents highly complex clinical challenges and that the diseases and conditions of ageing present earlier or more severely in people who also have HIV (Power et al 2010). There is good data available to suggest that older patients are more likely to experience side-effects from antiretroviral therapy (May et al 2011; May, Gompels & Sabin 2012).

Table 2

HIV and Co morbidities	
Cardiovascular disease	Untreated HIV can increase the risk of cardiovascular disease.
Diabetes	HIV treatments may increase the chances of developing diabetes.
High blood pressure	Some HIV drugs can cause increases in blood fats, similar to those caused by a fatty diet.
Osteoporosis	Research suggests that there may be a greater risk of bone fractures in men and women who are treated for HIV (Mallon 2010; Post et al 2011).
Cognitive functioning	Some drugs may penetrate the blood-brain barrier and could lead to the possibility of cognitive impairment.
Poly-pharmacy	The known and unknown effects of taking multiple medications. This remains an issue for older people with complex needs, particularly those living longer with HIV.

The direct consequence of this to the older patient who acquired HIV early in life is that while advances in HIV therapies and treatment have helped extend their anticipated life span, their general health and quality of life is at higher risk of impairment.

A compound effect is therefore taking place. Increased life expectancy with the associated above-average risk for cardiovascular, metabolic, bone and neurological problems are layered on top of a HIV diagnosis which is already a complex medical condition to manage and treat.

4. Positively Ageing

It is clear that the challenges of growing older with HIV arise from a layering of six significant factors which impact upon the life of those living with HIV:

1. **HIV treatment** – The complexities and nuances of treating and caring for those patients with HIV.

2. **Co morbidities** – On top of an already complex condition are layered the complications and co morbidities arising from increased life expectancy.

3. **Mental health** – The uncertain long-term prognosis for HIV, the changing estimates of life expectancy and level of health, as well as the amount of public prejudice and stigma surrounding the condition, can all have a negative impact upon the mental health of someone living with HIV.

4. **Social care** – As people living with HIV live longer they will increasingly require the same range of social care support that many require in later life. How this works in practice and is accessed by someone living with HIV (with the associated risks linked to disclosure and stigma) is a concern for many.

5. **Work and finance** – Many who were diagnosed with HIV early on in their lives were not able to secure mortgages and pensions. Others cashed in pensions early expecting reduced life expectancy. Support from family may be less as often there is no partner and/or no children. Now facing later life with the prospect of having to pay for aspects of their care, finding the money to help pay for this is a real concern and source of anxiety.

6. **Stigma** – A common strand running throughout the above factors, as well as the result of the culmination of those factors, is the stigmatisation of HIV itself. This contributes to a culture of secrecy and fear among many patients.

Although common to the HIV population at large, these factors appear to affect certain subgroups of the older population with HIV to varying degrees. As the key facts given in Table 1 indicate, those most affected by HIV in the UK are:

- Men who have Sex with Men (MSM)

- Black Africans – particularly women

- White heterosexuals

Research suggests that these subgroups have particular concerns about growing older with HIV. Table 3 indicates the top five concerns for each of these subgroups (Power et al 2010: 10).

4. Positively Ageing

Table 3

MSM	%
Difficulties with self care	83.3
Mental health/depression	79.4
Financial difficulties	78.0
Inability to get healthcare	76.0
Social stigma/discrimination	67.9

Black African Women	%
Financial difficulties	72.2
Employment	72.2
Difficulties with self care	58.3
Social stigma/discrimination	52.7
Inability to get healthcare	44.4

White heterosexuals	%
Financial difficulties	90.0
Inability to get healthcare	72.0
Mental health/depression	68.0
Loneliness	68.0
Difficulties with self care	66.0

In the next chapter each of the key factors summarised will be addressed with the intention of giving a voice to the specific needs and challenges of the older person living with HIV.

5. Challenges of living with HIV for the older person

For the first time we have a significant cohort of over 50s living with HIV, which demands consideration of new challenges as already summarised. This section scrutinises challenges and proposes solutions under the following topics:

- Age-specific HIV treatment
- Commissioning of services
- Service design
- Managing co-morbidities
- Meeting mental health needs
- Meeting social care needs
- Putting the patient at the centre of healthcare

5.1 Age-specific HIV treatment

Following many years of medical research resulting in the development of effective treatment for HIV, the majority of people diagnosed in the UK can now anticipate a very good prognosis and long life expectancy. However there remains some key challenges surrounding delivering age-specific HIV treatment which are summarised in Table 4.

5. Challenges of living with HIV for the older person

Table 4

KEY challenges for HIV treatment

Present situation:	Response:
• Confusion over multiple sources for funding of services and where to sign-post people to • Lack of understanding on the most effective way for GPs and specialist services to work together • Perceived poor communication between primary and secondary care. Lack of education and awareness of HIV affects levels of care and treatment. • Perceived lack of knowledge exchange across specialist boundaries of the complexities of treating HIV and co-morbidities • Lack of a form of leadership that helps coordination and collaboration	• Need to develop a more joined up, integrated approach involving primary care and specialist services with clearly defined roles • Introduction of an integrated IT communication system • Introduction of personal health records which the patient holds • A widespread and revitalised educating and 'tooling up' process in HIV for all those involved in health and social care as per BHIVA Standards 2013 (BHIVA 2012) • The need for strategic leadership • A national forum/conference to promote best practice and foster knowledge exchange

5.2 Commissioning services

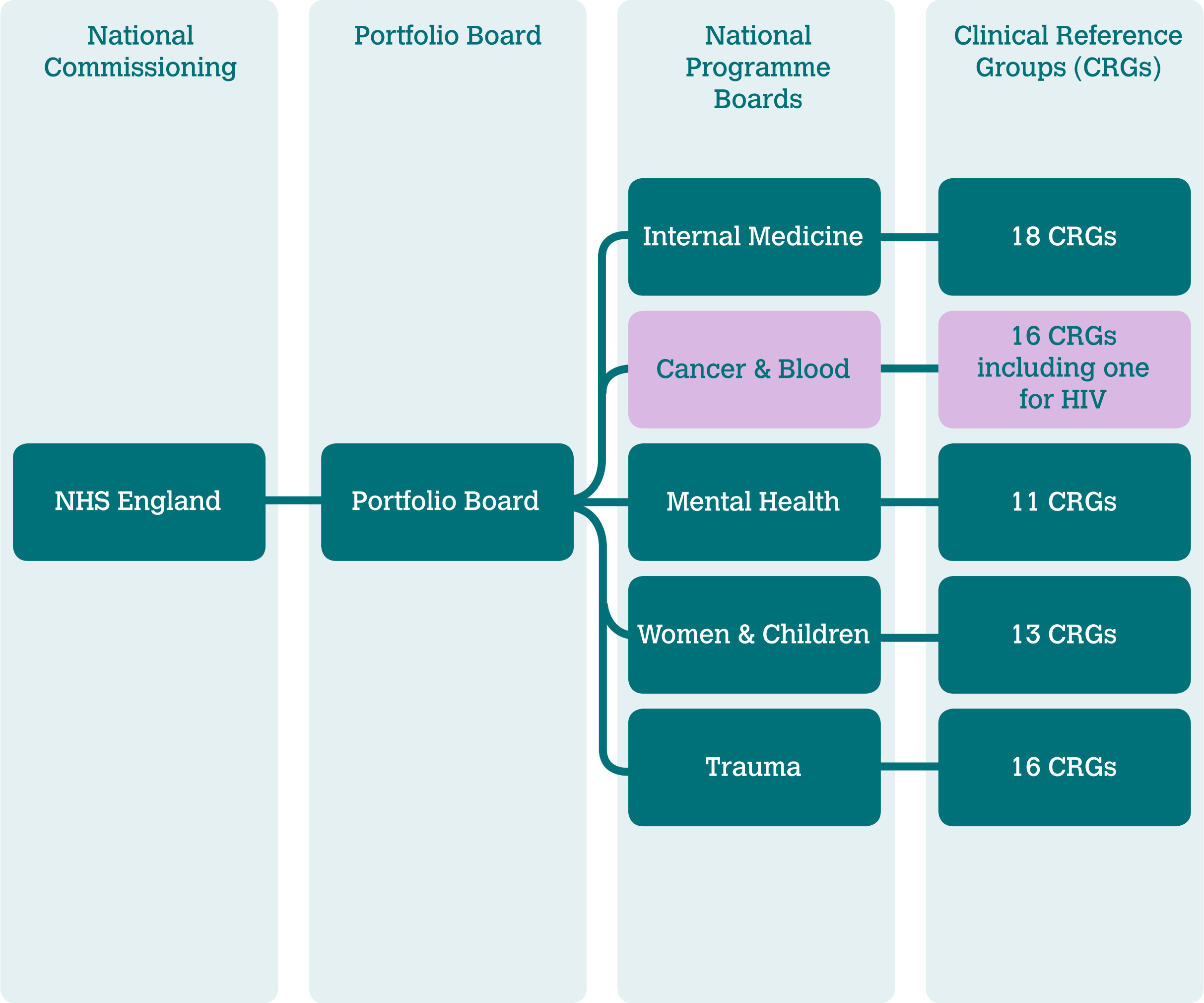
Commissioning involves buying in services from a range of health service providers (including GPs, dentists, community pharmacists, NHS and private hospitals, and voluntary sector organisations) to meet the health needs of local people, and monitoring how well they are being delivered. There was the perception that the commissioning of care for HIV patients focused on the HIV element of the disease and did not included the co-morbidities. HIV is a condition that necessitates a multidisciplinary approach to care and commissioning.

The Health and Social Care Act 2013 created new commissioning arrangements which came into existence on 1 April 2013 and included the provision of sexual health services. Commissioning is now split between:

- **Local authorities** (as public health is overseen by them)
- **Clinical Commissioning Groups** (CCGs), led by General Practice
- **Clinical Reference Groups for Specialised Commissioning** (CRG) which sit within NHS England

These changes were made to try and ensure that commissioning is a clinically-led process that delivers equity to the population of England. HIV sits within the cancer and blood National Programme Board and has its own Clinical Reference Group (CRG). CRG membership is drawn from each of the 12 geographical areas covered by the 12 senates (regional, strategic teams) and represents a model of devolved clinical leadership which acts as a source of clinical advice to NHS England (NHS Commissioning Board 2013: 5).

Figure 2 - Governance of Clinical Reference Groups



It is too early to tell just how well the system will work in practice, recognising that the new system requires time to bed down and establish itself. Nevertheless, at this early stage perceived strengths and weaknesses have been articulated. Table 5 sets out commissioning responsibilities of the three main bodies and summarises key strengths and weaknesses.

The main strengths of the new arrangements are perceived to be that there is now a national and robust service specification for HIV and that specialised services are now clinician led. This allows for expert and professional input to help feed into and shape decision making as well as theoretically offering standardisation of care across England.

5. Challenges of living with HIV for the older person

In contrast, there is a perception that the commissioning process has been fractured by distinguishing between treatment and prevention. As a result, antiretroviral therapy will reduce transmission at an individual level and may in turn have a significant public health impact (BHIVA 2012: 1; 44). By dividing up the commissioning of treatment and prevention and assigning responsibility to different bodies, there is concern that the two will not work in tandem and support one another. Consequently the general feeling is that prevention measures, be they based on social or biomedical research, need to have a more clearly defined place in the current commissioning structure, aside from the immediate value they bring to the NHS in terms of prevention measures.

Perhaps in recognition of these weaknesses, Public Health England has announced its intention to publish in the summer of 2014 a national framework for HIV, sexual and reproductive health commissioning, aiming to bring together the commissioning responsibilities of local government, CCGs and NHS England.

Payment for treatment services can either be through payment by results, block contract or integrated tariffs, with a trend emerging towards using more block contracts. Due to multiple sources of funding for services (NHS England, CCGs and local authorities) accountability confusion can arise; greater clarity is needed as to how the different strands of commissioning are to work together effectively. A map of how the various funding routes work and relate to one another should be provided to clinicians.

Recommendation:	Action to be taken by:
A map of funding routes for HIV should be published as part of the development of PHE's national framework.	PHE

The new arrangements need to be given time and an appropriate evaluation must take place before any conclusions are drawn, but consideration needs to be given to coordinating the separate services of treatment and prevention as this is clearly an unhelpful division. There is a risk that splitting responsibilities according to treatment and prevention could create a gap in the provision of services.

In order to allay concerns, close monitoring and regular reporting on key performance indicators (KPIs) for treatment and prevention need to be developed quickly. Increased dialogue between commissioners and third sector and voluntary sector organisations is required. The National AIDS Trust (NAT) currently provides administrative support for the English HIV and Sexual Health Commissioners Group. This is a professional forum for those engaged in undertaking Sexual Health & HIV commissioning activities in England. The aim is to help ensure consistent and high quality services (prevention, treatment, care and support) are delivered across the country in partnership with the Department of Health. This forum could be the natural place to see dialogue and reporting with commissioners, which itself needs to become a priority of the forum's work and activity.

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Recommendation:	**Action to be taken by:**
Evaluate the effectiveness of separating commissioning responsibilities for treatment and prevention.	Department of Health
Create a reporting process to feed back KPIs to the HIV CRG.	NAT CRG

While BHIVA is providing clinical leadership (BHIVA Standards 2013) and the CRG is trying (as best it can) to provide strategic leadership, effective dissemination and sharing of information and best practice among all key stakeholders is currently lacking. This does not help the full range of medical and care services to move forward together. A centralised form of strategic leadership is required, charged with bringing all the various strands of HIV care and treatment together and taking it forward in a clear and collaborative way.

Recommendation:	**Action to be taken by:**
PHE's national framework should aim to fill the vacuum of strategic leadership around HIV which currently exists.	Public Health England

5. Challenges of living with HIV for the older person

Table 5 - Commissioning responsibilities for HIV

Body	Commissioning Responsibilities	Services Provided	Strengths	Weaknesses
Local authorities	HIV prevention Contraception (outside of the GP contract) Sexually Transmitted Infection (STI) testing and treatment (including sexual health clinics, community settings, primary care and drug treatment services) Sexual health promotion	Public health	Tailors HIV prevention services according to local need Includes HIV prevention measures (based on social or biomedical research) in the commissioning process	Could become less concerned with long term intensive care as early diagnosis and prevention becomes the priority Likely that the sexual health needs of the 50+ age group will not be focused on Separates treatment and prevention Confusion over payment of services Obligation to pay for Post exposure prophylaxis (PEP) and Pre-exposure prophylaxis (PrEP) is unclear Unclear how local authority initiatives will work with national campaigns instigated by Public Health England

5. Challenges of living with HIV for the older person

Body	Commissioning Responsibilities	Services Provided	Strengths	Weaknesses
Clinical Commissioning Groups	Some community-based sexual health services including termination of pregnancy services	Secondary care (excluding specialised services)	Prioritisation of services according to local need	Lack of incentivisation for CCGs to be involved, so unclear as to what will really change Confusion over payment of services
NHS England	Specialist clinical treatment of HIV including HIV treatment and care	Primary care Specialised services	Robust and clear national specification for services Clinician led National procurement of drugs leading to potential financial savings	'Fracturing' of commissioning system Separates treatment and prevention Confusion over payment of services Does little to build capacity in primary care and GP regarding HIV care and services Lack of patient empowerment

5. Challenges of living with HIV for the older person

5.3 Service design

Any refashioning and redesign of services needs to focus on empowering older patients to live a life with HIV. Rather than providing for the patients, services need to work with the patient. Clinical services are already focused on helping the patient live with HIV but very often the supporting specialist services are working to older models of care and treatment. The reality is with older patients, service design now needs to balance good HIV treatment with treatment for other co-morbidities and social care support. Service provision therefore needs to involve both:

- HIV care
- Care of other co-morbidities

What new models of care should be adopted is the subject of much discussion and debate. Currently many people living with HIV have fears and experiences of receiving poor treatment in primary and generalist healthcare settings. This indicates the need to consider two key points when looking to the future:

- To improve the quality of primary care for people with HIV, and for better interaction between HIV specialists and other community clinicians
- To identify the best place for treatment to be delivered

The government has decided to shift the emphasis of care from acute hospitals to primary care, thus bringing services closer to the patient allowing them to stay in their community. If this is the model to be adopted, then how this affects those living with HIV and how it can be practically outworked needs to be assessed, with consideration being given to the following:

1. **Patient empowerment:** As with many other long term conditions, a model for care for those living with HIV should focus on helping patients to manage their condition.

2. **Location:** The best location needs to be found for the delivery of optimum levels of all care without undue inconvenience to the patient.

3. **Specialist services:** Specialist services are important in treating HIV and need to be involved appropriately.

Some excellent work has been undertaken in terms of advice, advocacy and ‘buddy’ programmes which have proved invaluable in supporting patients post-diagnosis. It is widely recognised that voluntary sector organisations lead the way in this area, providing local support programmes, acting as a respected and authoritative source of information and working to help reduce stigma and discrimination. Over the years through their engagement with those living with HIV, these organisations have built up a wealth of skills, expertise and insights. They have proved themselves strong and adaptable in responding to change and supporting those living with HIV in ways which perhaps health and social care services have not been able to do. As the challenges of caring and treating the older patient with HIV become more acute, it is crucial that the role voluntary organisations can play is championed and supported. However many community and voluntary based organisations have lost funding following budget reviews and cuts.

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There are no immediate solutions to this problem, with many worthwhile initiatives continuing to try and exist on limited funding.

Recommendation:	Action to be taken by:
Ongoing support for peer support networks needs to continue.	Local authorities CCGs

Multi-disciplinary team involvement is absolutely critical to help share and increase knowledge of treating the older patient with HIV. HIV clinicians need to work together with specialist clinicians, geriatricians and other non-medical specialists for common co-morbidities. Developing joint care arrangements presents a number of benefits:

- Provides opportunity for knowledge exchange between disciplines
- Encourages multi-disciplinary input as to how best to manage the patient living with HIV
- Facilitates workforce planning, helping to maximise resources and patient experience
- Assists prevention as well as treatment of long term conditions
- Enhances support around co-morbidities
- Addresses both the health and social care needs of the older person living with HIV

How best to involve HIV specialists needs to be carefully considered. The development of sub specialities (for instance HIV and cardiovascular disease) may be worth pursuing in order to build up knowledge and expertise within a particular area. Alternatively, it might be better to develop HIV specialists that liaise across specialities. This approach could help create a more adaptable model that can respond to the specific needs of patients, above what may appear to work from an organisational perspective. The role and responsibilities of primary and secondary services and the way in which they interact with HIV specialist services needs to be documented through defined algorithms. This will avoid confusion and help ensure equity of care for patients across the country.

The role of the GP

Concerns have been raised as to whether or not GPs are sufficiently educated and informed to lead on the delivery of care and treatment of HIV. Both GPs and HIV specialist services appear to share a desire to see awareness and education of HIV increase amongst general practice and primary care. The House of Lords Select Committee report on HIV and Aids in the UK (2011) strongly recommended that GPs must become more involved in the care of their HIV-positive patients. Building up GP confidence and competence in this area should therefore be made a key priority.

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Recommendation:	Action to be taken by:
Specialist training relating to HIV and AIDS should be a mandatory part of GPs' ongoing professional development. Training and education in HIV and AIDS should also form a core part of undergraduate teaching for all new medical students.	Royal Colleges Medical Schools

The flow of communication between primary and secondary care can very often break down, leading to resources being wasted through duplication of services and a lack of understanding of the patient's treatment programme. For instance, routine patient tests are often duplicated as GP surgeries may undertake blood tests to fulfil QOF objectives, replicating work undertaken by specialists and wasting patient's time. Moreover, owing to limited understanding of HIV, GPs often refer patients with HIV back to their HIV clinic for unnecessary reasons. The advantages and disadvantages of different models of care including GP-led, specialist-led, integrated and accountable lead provider are considered in Table 6.

Table 6

	GP-led care model	Specialist only model	Integrated care model	Accountable lead provider
Potential benefits	Knowledge of the older patient. Older patients acquiring HIV later tend to have stronger connection with their GP. GPs are experienced in the management of long term conditions Helps to build capacity of HIV education and awareness within general practice and primary care	Optimum levels of care provided by specialist services Older patients have access to specialist centres and services Ready access to diagnosis and treatment	Builds on the level of trust already commonly established between HIV specialist and the patient Empowers GPs to be what they are good at – 'expert generalists' and management of long term conditions Builds synergy between primary care, specialist services and the third sector Allows for knowledge exchange and capacity building in HIV care and treatment across services	Single organisation is contracted to take responsibility for the whole patient pathway, and then involves other providers in the delivery of services Avoids confusion over who is responsible and for what regarding care and treatment Builds on the skills and competencies of specific providers

5. Challenges of living with HIV for the older person

Table 6 (continued)

	GP-led care model	Specialist only model	Integrated care model	Accountable lead provider
Potential benefits			Helps empower the older patients to manage their own conditions, supported by both their GP and specialist services closer to home Improved long term follow up and management of co-morbidities Assists regular monitoring and assessment, linking in with annual health check Better levels of communication, exchange of patient notes between clinicians Enhances levels of confidence in the system between older patient and professional Minimises waste of resources and time	

5. Challenges of living with HIV for the older person

Table 6 (continued)

	GP-led care model	**Specialist only model**	**Integrated care model**	**Accountable lead provider**
Potential risks	Limited experience and capability in care & treatment of HIV Increased risk of communication breakdown between primary and secondary care Duplication of work and time wasted in resolving communication breakdown issues Continuity of care is reduced	Awareness and understanding of HIV in primary care does not increase Demands on specialist services increase Increased risk of communication breakdown between primary and secondary care Duplication of work and time wasted in resolving communication breakdown issues Continuity of care is reduced	GPs can remain under informed of HIV Division of responsibilities are not clearly understood which results in sub-standard care Continuity of care breaks down due to changes of clinician	Less opportunity to build capacity of HIV education and awareness within general practice and primary care Continuity of care is reduced

To try and develop greater GP involvement various models have been piloted. Consideration needs to be given to what elements of best practise can be learnt from these models and how this might then be applied and replicated nationally. At the very least, a national pilot could then be undertaken on a wider scale.

Recommendation:	**Action to be taken by:**
Evaluate existing models of care involving primary care and specialised services, identifying key criteria and drivers for effective implementation and improvement.	Domain 2 lead, NHS England

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Developing a model where the GP takes lead responsibility is clearly some way off. A recent Penn study has found that multi-centred care does not work. Receiving care at several sites may increase medication errors, duplicate services and contribute to higher care costs. Continuous care with one provider provides the optimal conditions for outcomes and reduces transmission (Yehia et al 2013). However a personal health record (PHR) – either facilitated by specialist services or compiled by the patient using existing platforms – would enable much clearer information exchange, GP involvement and understanding of care. The NHS's Information Strategy sets out the vision of patients being able to access and share their own health and care records, thereby empowering the patient to take part in decision making in partnership with professionals (Department of Health 2012: 25). Based on nationally set information standards, the strategy is a way to encourage fully joined-up systems, facilitating the sharing and communication of information and data in an efficient and swift manner across the health and social care system.

Recommendation:	Action to be taken by:
The opportunities presented by the personal health record should be explored in further detail by HIV patient groups. Whilst it is important that information about a patient's HIV status remains separate to wider NHS information flows, appropriate steps should be taken to secure the informed consent of patients who might benefit from the greater transferability of their information.	Charities & third sector organisations

Having a single repository of all information relevant to the patient overcomes concerns about fragmentation of services and can essentially put the patient in the driving seat, should this be their preference. For older patients too, most PHR platforms allow for the inclusion of social care records and personally entered data, all of which will facilitate information exchange and accuracy.

Role of nurse-led clinics

There is considerable scope for developing nurse-led clinics in line with the management of older patients living with HIV. Nurse-led clinics have proven to be successful in a number of ways:

- Reducing pressure on specialist services by working with older patients with complex medical needs over the long term
- Early detection and treatment of co-morbidities through full assessment of all medical problems and medications; ensuring that cholesterol and blood pressure medications are optimised and checking for any drug interactions, in partnership with HIV specialist pharmacists
- Creating pathways for onward referral to specialists in care of the elderly when required
- Bringing services closer to the patient

While these clinics have been proven to work in the effective management of complex conditions, they can be expensive to run. Therefore, to help make the economic case to commissioners, a strong evidence base is required to help demonstrate the need for this kind of service. This may also help ensure the removal of deterrents to the setting up of these services, thus helping to minimise regional variation and improving equity of access.

5. Challenges of living with HIV for the older person

The role of nursing in HIV care has developed over the years, varying in the focus and range of responsibilities covered (see Table 7). The role continues to evolve, more recently including a care coordinator's role which:

- Helps the older patient with HIV to navigate the system and access the services they require, which can often be confusing and difficult to understand
- Sets up regular case meetings with specialists to support complex decision making and case management
- Develops individual care programmes in partnership with the older patient

These tasks naturally fall under the job description of community matrons. Introducing these responsibilities to the community matron's role should be considered and evaluated.

Table 7 – Nursing and HIV treatment

1990	1996	2002	2011	2025
Nurse-led	**Combination therapy**	**Medically-led**	**Demand / Capacity driven**	**Case management**
Palliative care Patient IV admin IV Line care Chemotherapy Endoscopy MDT approach	New skills for all Care and treatment Change in patient relationships	Treatment driven Nurse led Triage Adherence Co-infection roles	Nurse-led clinics STI screening New patient clinics Patients on ARVs CNS and Consultant roles Complex disease management	Long term chronic disease management Assessment Care coordination Patient empowerment

Education & culture

Training and education are essential to greater levels of competence and confidence in caring for the older patient with HIV infection and co-morbidities. Knowledge of HIV amongst healthcare professionals needs to be expanded and is something that Ministers have acknowledged must sit along educating the public at large (House of Lords 2011: 52). BHIVA have taken steps to try and build across professional boundaries and help educate and inform other specialities about HIV, thereby helping to fill the current knowledge gaps. Rather than wait for other specialities to approach them for insights and knowledge, BHIVA have followed a proactive strategy and gone to them offering to share learning.

5. Challenges of living with HIV for the older person

Understanding of HIV in primary care needs to be improved across all service areas. The Royal Colleges should commission a review of training given to professionals on HIV with an emphasis on the older person. The findings and conclusion should be offered to their membership and shared with the voluntary sector.

Recommendation:	**Action to be taken by:**
Commission a review of training given to professionals on HIV with an emphasis on the older person.	Royal Colleges Professional bodies NHS Deaneries

5.4 Managing co-morbidities

On top of the complexities of HIV treatment and long term conditions are further complications brought on through the ageing process. This is of great concern to older people. The particular challenges faced by the older patient living with HIV are show in Table 8.

Table 8

KEY challenges for managing co-morbidities

Present situation:	**Response:**
Uncertainty over how best to track and monitor diseases and conditions of ageing that can present earlier or more severely in people with HIV	Need for ongoing long-term research into the interrelationship between ageing and HIV
Lack of understanding of the inter relationship between HIV and the ageing process	Long-term condition management is critical for future care and support for those living with HIV
No clear understanding as to how best to manage and treat co morbidities in older people living with HIV	Patient empowerment and self management must form part of counteracting or minimising multiple co-morbidities

While diseases and conditions of ageing can present earlier or more severely in people with HIV, it remains unclear as to precisely how much of this relates to HIV disease itself damaging the body and initiating premature ageing, and how much relates to the side effects of earlier, more toxic treatments (Power et al 2010). For instance non-AIDS-related co-morbidities were more frequent in HIV-infected individuals at an earlier age than for those who were HIV-negative. HIV-positive people in their 40s had multiple co-morbidities as often as HIV-negative people in their 60s (House of Lords 2011: 119).

In general, managing care for the older person is complex because the ageing process represents physical, psychological and social change. Whereas a bone fracture in a younger person may not present too many added complications, in someone older this can lead to dehydration, bruising, pneumonia and immobility. This restriction of activity can then lead to feelings of isolation, depression and loss of confidence. An already challenging situation is made more complex in the case of an older person living with HIV.

5. Challenges of living with HIV for the older person

The need for effective long-term condition management is becoming an increasingly relevant component to caring for those living with HIV. The best models and approaches to fulfil this are still a matter of debate. Research and engagement in this area will require the active sharing of information, insights and findings between different groups, supported by effective commissioning of services and appropriate service design.

Regardless of the complications HIV brings, informed decision making on the part of the patient in terms of lifestyle choices can make a positive impact upon general health. Therefore, appropriately targeted advice and information on matters such as nutrition, exercise and smoking cessation should be given to the older person living with HIV so as to empower them to maximise healthy choices.

Recommendation:	Action to be taken by:
Establish greater opportunities for multidisciplinary learning and knowledge exchange on managing co-morbidities in the lives of those people who are living longer with HIV.	Royal Colleges BHIVA BASHH
Promote further long-term research into people with HIV, so as to better understand the cumulative effect of HIV as they grow older, and develop a profiling tool.	Royal Colleges NHS England
Targeted advice and information on matters such as nutrition, exercise and smoking cessation should be made available to empower patients to maximise healthy choices.	GPs Local public health

5.5 Meeting mental health needs

Many older people living with HIV report concerns over their mental health. While both long term diagnosed and late diagnosed can be affected, those long term diagnosed can experience particularly high levels of stress and anxiety associated with living with a life-threatening condition, public stigma and frequent complex information change. Concerns over mental health and depression are of particular concern to older gay and bisexual men. Table 9 summarises some of the core mental health themes.

5. Challenges of living with HIV for the older person

Table 9 - Core mental health themes

	Common	Distinct	
		Late diagnosed	**Long term diagnosed**
Trauma & depression	Many do not have families around to offer care and support Uncertainty about the future. Clinically, the future remains unknown as to the impact of HIV on ageing. Concern about how others may react	A new diagnosis of HIV can be very traumatic for people due to a poor understanding of HIV. The perception of HIV is of a quick and painful death.	Many never expected to live this long with HIV and so are not prepared for what lies ahead Some may well have seen close friends die from AIDS and question why they have been able to survive
Rejection and disempowerment	Socially and sexually From social care services, carers and care homes If living within a care home setting, the potential for discrimination from staff and fellow residents From family members	Concern about how others may react, including children and grandchildren How do they go about building new relationships with partners?	Many have suffered rejection in the past and fear it will happen again in the future Poor healthcare experiences Financial disadvantage owing to poor employment prospects, unable to secure mortgage and a pension
Loneliness, guilt and isolation	Disclosure Perpetuating cycle of loneliness and isolation for some patients who still feel as though they cannot disclose their condition	Concern over how family will react Perception of other people of age inappropriate promiscuity	Many never expected to live this long with HIV and yet have seen close friends die as a result of the condition Perception of others that those with HIV are 'too old' to have HIV; that they 'should have known better'

5. Challenges of living with HIV for the older person

Advances in clinical practice means that there is now high quality care for the physical management of HIV, but it is the provision of HIV specific mental health and social care support that requires further development. This is about funding, but also identifying and accepting that this kind of support is required. Specific support programmes can then be developed with appropriate funding. Key elements to support programmes need to include:

- Access to mental health services and therapies
- Space and opportunity to meet with others for peer support

Keeping abreast of new mental health techniques and programmes such as cognitive behaviour therapy (CBT) is important in assisting those living with HIV to manage long term conditions. There is also scope for third sector involvement, which is often already active and engaged in providing peer level support. One example of this is the Health, Wealth & Happiness Project developed by the Terrence Higgins Trust, which provides opportunities for older people to participate as active members of their community by supporting them to take charge of their lives, tackle challenges and access services (Terrence Higgins Trust 2014). Specific group work initiatives for older Black Africans and gay and bisexual men have proven particularly effective in creating a sense of belonging and opportunity to develop and strengthen good social relationships.

Further consideration needs to be given to how these groups and networks could partner and integrate with other later life groups and activities. For instance, collaborating to provide exercise and healthy eating programmes, as well as sessions on supporting those with age-related illnesses, including heart disease, dementia and diabetes. These groups could:

- Decrease stigma
- Empower individuals to live a life with HIV as opposed to merely treating the condition
- Utilise resources and build on existing knowledge and best practice

Recommendation:	Action to be taken by:
Bring together groups and charities working with the elderly and those living with HIV to help meet the needs of the ageing cohort.	Patient groups and charities
Mental health support programmes need to be fit for purpose and designed with the needs of the older person in mind.	NHS Mental Health Trusts Social services GPs

Maintaining independence

Concerns over work and money, have a real impact on mental well-being. Being engaged in work provides an income and a pension but also helps to build self-esteem, give a sense of purpose, prevent isolation and positively affect mental well-being and health.

5. Challenges of living with HIV for the older person

Work and money issues are a particular concern amongst those older people living with HIV and who were diagnosed early in life. They have serious fears and concerns about how they are going to remain independent and manage financially in the future. Table 10 summarises some of these concerns.

Table 10

	Long term diagnosed	Late diagnosed
Employment status	Older people living with HIV are significantly less likely to be economically active than their peers	More likely to have been in work for most of their lives but may have to retire early due to ill health
Level of income	Depending on employment status, likely to see a direct impact upon levels of support entitlement Unlikely to have been able to secure a private pension plan or life insurance to draw upon	Been in work for longer so more likely to have some savings to draw upon Concerns may arise from: (a) having to stop work earlier than expected and (b) how they prepare for the future in light of the unknown impact of HIV
Access to financial services	Represent the generation who were refused mortgages, life insurance and pension schemes. Deemed to be too high a risk to be offered such products. No financial reserves to draw upon to help support them in later life	Not so much of a concern as many may have either a private pension or employer-funded pension
Housing	Owning their own home has been a problem for many in light of not being able to secure a mortgage Concerns arise over how they are going to be able to afford to pay rent	May own their home but have concerns over how they may continue to pay mortgage in subsequent years along with added care costs
Social care	How are they going to afford to pay for home care or sheltered housing or a care home (depending on their needs)? How are they going to manage and deal with potential discrimination and stigma of care staff, fellow residents?	How are they going to afford to pay for home care or sheltered housing or a care home (depending on their needs)? How are they going to manage and deal with potential discrimination and stigma of care staff, fellow residents?

5. Challenges of living with HIV for the older person

Given the current economic climate and the government's aim to reduce the number of people claiming benefits, there is understandable concern among those older people living with HIV about benefits and support. In many cases they are not out of work out of choice, having had to stop work due to ill health, perhaps also stigma and discrimination and increased fatigue. Consequently they look to the future with uncertainty and fear as to how they are going to manage financially and meet even their basic needs. Fear of what the future holds is one of the key concerns for gay and bisexual men.

Very often older people living with HIV describe a lack of awareness and understanding as to what is available in terms of benefits and support. Those who are aware have to engage in an intense battle to make their voice heard and to present their case. While specialist HIV social workers have been able to assist, this is not the experience of many.

More needs to be done to help support and encourage those people living with HIV aged 50 plus to return to some form of work. Not only would this yield financial benefits but also help improve their mental well-being. In a further step to help eradicate stigma and discrimination, HIV third sector and voluntary sector organisations should work closely with existing 'back to work' schemes and programmes. As well as providing opportunity for the exchange of best practice and expertise, such an approach would be a further step to making HIV a more 'routine' condition. This is not without its challenges for those out of work for many years.

Improving levels of awareness and understanding of financial benefits and entitlements for the older person living with HIV should be a key priority area for voluntary sector organisations and statutory agencies. One of the priorities of the Health, Wealth and Happiness project has been to build the financial resilience of older people with HIV, helping to ease the transition to later life by empowering them to better manage their day-to-day finances, rights and entitlements, and plan for their future (Terrence Higgins Trust 2014).

To build on this further, an annual survey of patients' experience of their HIV care should be instituted by NHS England, which would allow the support and provision of advice to older people to be audited on a regular basis – and for gaps to be addressed. Practical and sustainable solutions can then be devised to help fill the gaps.

Recommendation:	**Action to be taken by:**
A national patient experience survey of people living with HIV should be funded by NHS England to help ensure independence is maintained.	NHS England

For those from black African groups it is particularly challenging to secure health and social care support. Notably black African women experience significant hardship, having to cope with poverty, poor housing, treatment access and migration issues, as well as major HIV stigma within their cultures (Power et al 2010: 5). Interviewees indicated that this is largely because many have immigrant status and have no money to pay for care, nor have entitlement to services through public funds. Many also have no family in this country to offer support, so very often the only place for them to find some sort of social support is at the local hospital.

5. Challenges of living with HIV for the older person

5.6 Meeting social care needs

We have known from the start of the HIV epidemic in the 1980s that those living with HIV have a high level of social care need. As advances in clinical interventions are helping to improve prognosis, so the need also arises to ensure appropriate social care is provided for the older person living with HIV. The key challenges surrounding social care are given in Table 11.

Table 11

KEY challenges for managing social care needs

Present situation:	Response:
Generic social services lack awareness and understanding of the social care needs of older people living with HIV	Build capacity of HIV awareness within social care
Inadequacy of the process to assess the social care needs of the older person living with HIV	Improve the assessment process to better capture the social needs of the person living with HIV
Lack of understanding of and training on HIV among the care professions	Introduce basic mandatory training for care staff in the management of the older person with HIV
Uncertainty among those living with HIV of the benefits and support available to them	Establish standards for social care provision for the older patient living with HIV

Social care for those living longer with HIV can encompass many things, including:

- Support in daily living
- Psychological and emotional support
- Counselling
- Peer support
- Finance related issues – housing and employment benefits.

This form of support has been typically provided through local authorities, either directly or by funding voluntary organisations or through private care providers offering residential and home help.

Funding for social care

One HIV transmission in the UK is estimated to result in direct lifetime healthcare costs of between £280,000 and £360,000 (NAT 2011b:2). Not included in this figure are the associated social and economic costs of that person's ill-health (or the costs incurred by other people who that person passes HIV onto). A breakdown in social care and failure to adequately meet the social needs of those people living with HIV is more likely to result in increased rates of HIV transmission. Interestingly this reinforces the view that treatment and prevention need to go together, as discussed in the 'Commissioning of services' section.

5. Challenges of living with HIV for the older person

In the past, funding for specialist services for people living with HIV, such as specialist social workers, counselling, home helps and management of long term conditions, has come from the use of a ring-fenced grant, the AIDS Support Grant (ASG). In 2010, arrangements were altered and money rolled into the Formula Grant and the ring fence removed (see appendices – 'Funding HIV Social Care'). All councils have allocated monies and it is at their discretion how they spend it.

At present it appears that social care provision for people with HIV of any age will be reduced (NAT 2012: 7) or at worse removed entirely. Consequently generic services will be used to meet the needs of the older person living with HIV. It will therefore be crucial that these services are both accessible and appropriate to the needs of those with HIV.

Social Care Assessment

There was a strong belief that the current assessment process does not capture the needs of those living with HIV. The assessment process undertaken by local authorities to determine the level of social care need for all clients is set out in Table 12.

Table 12

Fair Access to Care Services (FACS) Framework

Stage 1	Stage 2	Stage 3
National framework which sets out broad principles of social care need Each authority develops own assessment based on these principles Opportunity for variation across the country	Assessment is carried out by a social worker	Person's need assessed as either: • Critical • Substantial • Moderate • Low

NAT reports that recently the threshold for each level of care has shifted. In 2012 a survey conducted by NAT found that 81 percent of local councils set the threshold for accessing any care at the level of 'substantial', with a further 4 percent setting their threshold at 'critical' (NAT 2013: 1) . This presents a challenge for the older patient with HIV because social care assessments do not adequately assess their needs. Questions focus on physical disability as opposed to mental disability and the social care/financial needs which are more prevalent in HIV.

How best to address mental health need is one of the core themes raised by older people living with HIV. There is a greater prevalence of extreme 'good' and 'bad' days and so they never quite know how they are going to feel physically and mentally (Rosenfeld et al. 2012). Trying to capture this adequately through an assessment can be challenging.

5. Challenges of living with HIV for the older person

Components of a good social care strategy

The social care requirements of those living longer with HIV needs to become a key component of a national strategy for HIV. This should make appropriate consideration of the following key factors:

- HIV ready
- Treatment management
- Home care and care homes

HIV ready

The needs of an older person living with HIV will change over time as symptoms fluctuate. To manage this effectively, a successful strategy will make sure there is:

- Ongoing assessment and review
- Assessment that adequately captures the needs of the older person living with HIV
- A named lead contact who can coordinate the care; this could be the responsibility of a GP or nurse fulfilling a care coordinator's role
- Building up of capacity and improved levels of education and awareness among those delivering care
- Appropriately trained assessors attuned to the complexities of HIV and sensitive to the patient's emotional and social needs

Treatment management

With the growing recognition that HIV, in and of itself, is a long term condition (LTC), steps needs to be taken to see it better integrated into care pathways. Greater opportunity should be made for multidisciplinary working to take place beyond specialist boundaries.

Any social care strategy must have strong focus on medical management. For instance, assessing the support needs of the older person living with HIV and dementia, who also needs to maintain medical adherence to their HIV medication. Emotional and social support may also be necessary to help the older patient with HIV manage the transition from independent living to moving into a care home or supported living environment. They may well have fears and concerns over loss of independence and discrimination from staff and other residents.

5. Challenges of living with HIV for the older person

Recommendation:	Action to be taken by:
Review of the social care needs assessment, including the introduction of questions which help to identify and capture the true extent of the patient's needs.	Local authorities
Provide adequate training for staff who undertake the social care assessment so they can better understand and capture the needs of the older patient living with HIV.	Local authorities, independent organisations and charities

Housing

Home ownership is less likely for the older person living with HIV. A survey conducted into those aged 50 plus living with HIV found that just over half (52.7 per cent) of respondents were home-owners, with gay and bisexual men the most likely group to have this form of tenure (62.4 per cent) (Power et al 2010: 35). This is in contrast to four out of five people in the UK (81.2 per cent) who were 50 and over and owned or part-owned their home at the same point in time (Department for Communities and Local Government 2008).

The older person with HIV is thus more likely to be living in council or housing association stock or in private rented accommodation; a reflection perhaps of income levels and poverty overall, but this may point to the difficulties those living with HIV have faced in securing a mortgage. Substantial financial difficulties and penalties have been a barrier for many. Black African women have been found to be the most likely group to be in insecure housing, including asylum support housing, private sector renting and renting a room in a house with other tenants (Power et al 2010: 35).

For some, their housing situation prevents them from trying to return to work. Faced with having to pay high rentals in both private and social housing, they find it difficult to return to work at the same time as remaining eligible for housing and council tax benefits. This causes uncertainty about where they may live in the future should they need to move into some form of supported living or care home environment, and how they might afford to pay for it.

Home care and care homes

As older people living with HIV encounter problems with mobility and self care, they will inevitably need to start accessing home care services or will need to consider moving into a residential care home. This is something that causes great concern, centring on two main themes:

- **Training** – Will staff have the sufficient training and education in order to help care for and support someone living with HIV?

- **Culture** – How will an older person living with HIV be received and treated either in their own home (cared for) or within a residential care home?

Particularly amongst gay and bisexual men there are concerns about homophobia.

5. Challenges of living with HIV for the older person

Many care staff who provide home care services or work within residential care homes have not needed to undergo specific training in caring for patients with HIV. This is because previously people living with HIV have not reached the later stages of life where they have needed such services. Lack of training can result in:

- Unnecessary procedures being adopted (for instance double gloving for basic tasks)
- The right kind of support not being provided (for those suffering with HIV and dementia, making sure they continue to take their HIV medication is crucial)
- Refusal to provide any support services at all because the person has HIV
- The individual unnecessarily treated and cared for in isolation from other residents

There is now an opportunity to establish what a good care provider (in a patient's home or in a care home) of the future should offer in terms of services and facilities. Some examples are:

- Basic mandatory training in HIV for those working in care homes, to be incorporated as part of Skills for Care's Code of Conduct and national minimum training standards for healthcare support workers and adult social care workers in England. This would help to ensure that care provided for those with HIV is appropriate and adequate.
- Development of best practice guidelines to establish the standards of care provision for those living with HIV. This could drive change in two ways. First, these guidelines can be followed by care providers, and commissioners can use them to guide commissioning decisions. Second, older people living with HIV can be empowered to stipulate care from a provider who can demonstrate they are sensitive to the needs of those living with HIV.
- A change in the use of language with and about patients to reduce stigma and prevent ignorance (Dilmitis et al 2012). Being mindful of the language used in the training and education of care staff can help to build a culturally-sensitive workforce that recognises the person first and foremost, helps to break down barriers and build bridges of mutual respect and understanding.

There is divided opinion on whether there should be specialised care homes for older people living with HIV, or whether they should be cared for within the wider community of care homes. The former could be seen to be perpetuating stigma and discrimination towards individuals with HIV and be expensive. Many felt that integration was important if we are to de-stigmatise HIV. Having reviewed the evidence it is recommended that steps are taken to integrate individuals with HIV following the points highlighted above.

5. Challenges of living with HIV for the older person

Recommendation:	Action to be taken by:
Mandatory basic training in HIV to be brought in for all those working in health and social care, helping to increase confidence and competence.	Skills for Care NHS England
Minimise stigmatisation through the promotion of life-enhancing and positive language and behaviour in the training of social care services.	Skills for Care
Establish best practice for care homes that commissioners can follow and adhere to when commissioning services.	CQC

Personal health budgets

One solution to the problem of stigma may be to broaden the use of personal health budgets (PHBs). A PHB can help empower the person living with HIV to make their own decisions about how to spend NHS funds allocated to their care, and maintain themselves in their own homes for as long as possible. PHBs allow the person freedom to employ a personal care assistant of their own choice. For patients with HIV, concerns over lack of confidentiality and stigma could therefore be assuaged by control over who cares for them. This may also help act as a driver of change to see more care providers become HIV sensitive and aware.

The necessary practical support and advice should be made available to help those living with HIV secure a PHB. This fits in well with the NHS drive to enable people with long term conditions to have greater choice, flexibility and control over the health care and support they receive.

Recommendation:	Action to be taken by:
Develop the use of personal health budgets (PHB) among HIV patients	Patient Patient groups and charities

Telehealth

New technologies could also be used to help alleviate isolation and boost patient empowerment. Telehealth options could assist in monitoring and supporting patients with long term conditions such as HIV, allowing them to stay in their preferred home setting for longer. Being able to engage online with specialist services helps to minimise time taken in ‘physical’ appointments and consultations. Virtual clinics which allow patients to access services remotely, particularly from outside urban areas, save on travel time and increase patient involvement in access to data and information. Using online counselling and resources in relation to mental health programmes can be an effective way of maximising access. Nevertheless, several key points need to be considered:

- Technological solutions should always augment and support face-to-face appointments, never replace

- Given the sensitivity surrounding HIV, patient concerns over information confidentiality and handling of data would need to be adequately addressed

- While IT skills and awareness are becoming more commonplace, those in the later stages of life may not be as competent or at ease with technology. Therefore appropriate consideration is needed as to how they can access services without being marginalised by relying too heavily on technology.

As discussed earlier in 'Service redesign', personal health records (PHR) can help play a part in achieving clearer information exchange of health information and data. Because the patient can compile and maintain their own PHR they are able to take an active role in managing the quality of their healthcare, perhaps complimented by managing their own PHB. Naturally some people will want more power, some will want less. Flexibility is therefore needed to ensure decisions can be made on a case by case basis. An early indication of how this could work in the future is the MyHIV website and its free app which can be downloaded onto a smartphone (Terrence Higgins Trust 2013). The app gives access to a suite of tools which includes:

- Free and discrete reminders for medication and appointments

- Logging and tracking of blood counts

- Storing of up-to-date information about medication

- Links to key information and support resources on myHIV

- Full access to the facilities of myHIV, including the community forums

5.7 Putting the patient at the centre of care

PHBs and telehealth are key strategies in the government's commitment to place the patient at the centre of their own care. The government acknowledges in its report Liberating the NHS: No decision about me, without me, that in order to create a patient-centred NHS, embedding care planning, shared decision-making and providing the information and support necessary to enable people to manage their own condition, where they wish to do so, should be actively pursued (Department of Health 2012: 26). Over the last thirty years, those living with HIV have as a group championed patient empowerment. This needs to continue as they go on to experience many of the same issues that an ageing population will face. There are challenges that need to be resolved before the older patient living with HIV can feel empowered to live out their latter years. Table 13 helps to summarise these challenges.

5. Challenges of living with HIV for the older person

Table 13

KEY challenges for putting the patient at the centre

Present situation:	Response:
Limited choice for the person living with HIV to manage and make healthy choices and decisions on self-care Lack of opportunity for people living with HIV to choose who provides their social care Uncertainty and concerns surrounding patient confidentiality	Develop and strengthen peer support networks which can support and provide counsel, information and advice on many aspects of living with HIV Develop the use of technology to empower the patient to better manage their condition

Empowering all patients, regardless of their HIV status, must be the principle which drives forward change.

Particularly for those diagnosed late with HIV, a need has been identified to ensure communication is clear and reliable between clinicians and patients. Signposting the patient to relevant, reliable and accessible sources of information for self-education is important.

Searching and accessing information on the internet without any appropriate guidance can result in spurious information being accessed. The work of third sector organisations is invaluable in this area. For example the MyHIV online service facilitated by Terrence Higgins Trust, which provides information, advice and support for those living with HIV as well as discussion boards by and for people with HIV. Examples like this indicate the scope there is to develop further e-learning resources which could feed into the national NHS Choice Framework.

There is also a need to allow time for the patient to discuss the information with a healthcare professional to ensure appropriate understanding. Linked to this is the ability of patients to navigate their way through the administrative process of accessing services. It is recognised that people with multiple health and social care needs often receive a very fragmented service, resulting in less than optimal care experiences, outcomes and costs (Goodwin, Sonola, Thiel & Kodner 2013:ix).

The role of care coordinators has been found to provide a holistic focus that supports patients and carers to become more functional, independent and resilient as opposed to focusing solely on managing or treating symptoms (Goodwin, Sonola, Thiel & Kodner 2013: 16,25). Acting as a patient advocate, the coordinator can help navigate the patient's journey across multiple services and settings.

This helps to address the particular concerns of MSM over self care and those older patients from black ethnic minority (BEM) groups. Not having English as a first language can present problems in fully understanding aspects of care and treatment the person is receiving. The role of nurses as care coordinators has been seen to help with this, as have peer support and community networks, which have achieved significant successes (AHPN 2013). Although poorly funded to begin with, African-led peer support networks have proved effective in providing a care coordinator's role but the numbers of networks have depleted over recent years due to budget cuts made by local authorities. A solution may be to utilise the patient representative role which most HIV clinics have. That the role is fulfilled by a patient is perceived to be a strength to build upon and earns the trust and support of patients. With appropriate training and recognition from other professionals, this role could help to navigate the patient through the system and make them aware of the support and assistance to which they are entitled.

5.8 Confidentiality

Confidentiality is a theme which runs throughout this report as it is an important issue for patients living with HIV. For those newly diagnosed older patients in particular, there is the fear of disclosure and how it will be received. Those earlier diagnosed with HIV will likely be familiar with working with specialist healthcare professionals who recognise the need to maintain confidentiality. As the group widens to include social care providers (such as care workers and personal assistants) there is the fear of other people becoming aware of their condition and the risk of confidentiality being compromised.

To help build trust and confidence between patient and professional, patients need to be reassured of the importance placed upon confidentiality and the procedures in place to uphold this throughout the health and social care system. The National Aids Trust is supporting this process of reassurance by publishing a written resource explaining how the personal confidential information of people with HIV is handled and shared in the NHS. Good governance in this area needs to be continually reinforced and is important for all patients.

Recommendation:	Action to be taken by:
All HIV clinics and GP practices should provide the NAT resource (or comparable ones) to their patients living with HIV, and accompany it with a verbal explanation and an opportunity to ask questions.	Service providers

Those who have been living with HIV for many years have been trail blazers in increasing engagement and patient empowerment. They bring a wealth of experience in creating dialogue with professionals, demanding and developing new services and creating a partnership of care. As they age it is important that they continue to trail blaze; and perhaps by their example and with their leadership improvements can be made to the care received by older people in our society. If the aim is to truly have patients at the centre of care, then this group should be recognised for their experience of meeting this challenge head on and changing things for the better.

6. Conclusion

Many years of medical research has resulted in the development of effective treatment for HIV, with the majority of people diagnosed in the UK now able to expect a very good prognosis and long life. For the first time we have a significant cohort of those living with HIV aged over 50, which presents new challenges to the way HIV care and treatment are designed, managed and delivered.

The goal is to ensure that with appropriate care and support everyone with HIV can live a long and fulfilled life. From our research we have identified the following key issues which effectively help to meet this goal:

- **Treatment and prevention** – The separation of services of treatment and prevention is clearly an unhelpful distinction. An effective system demands close monitoring and regular reporting on key performance indicators (KPIs) for treatment and prevention, together with dialogue between commissioners and third sector and voluntary sector organisations.

- **Primary care and specialist services** – Improving the quality of primary care for people with HIV and establishing better interaction between HIV specialists and other community clinicians, is essential to providing good quality patient centred care, particularly when managing complex long terms conditions due to ageing and being older with HIV.

- **Training and education** – These are essential to greater levels of competence and confidence among all healthcare professionals in caring for the older patient with HIV infection and co-morbidities.

- **HIV and the ageing process** – Multi-disciplinary team involvement is critical to the sharing of knowledge and expertise in treating older patients with HIV. HIV clinicians need to work together with specialist clinicians and with geriatricians in helping patients manage common co-morbidities.

- **Targeted support for the two main groups of older people living with HIV in the UK:**

    - Specific mental health and social support, especially among MSM who report particular concerns in this area triggered by fears of homophobia as they consider their need of social care support.

    - Educating and supporting those from Black African communities who often have problems in navigating the health system – thus the extent to which they are able to understand and take responsibility for their own care. Support needs to continue for African-led peer support networks, which have proved effective in providing a care coordinator's role and supporting those with HIV through the system. Women from these communities, particularly, need to be more aware of their rights and access to services.

    - Identifying the needs of white heterosexuals living with HIV and empowering them to live their lives confidently without feeling isolated and neglected.

- **Care provision** – Care service providers need to be better informed and equipped to help care for those living longer with HIV. Many providers have not needed to respond to the care needs of the older person living with HIV, so they currently have very limited experience. Skills and training need to be improved in this area. Here is an opportunity to establish what a good care provider should offer in terms of services and facilities for long term conditions.

6. Conclusion

- **Confidentiality** – Previously those living with HIV will have been familiar with working with specialist healthcare professionals who have maintained confidentiality. As the group widens to include care providers (such as care workers and personal assistants) there is the fear of other people becoming aware of their condition and the risk of confidentiality being compromised. Reassuring patients of the importance placed upon confidentiality and the procedures in place to uphold this throughout the health and social care system is essential to help build trust and confidence between patient and professional.

Underpinning all of this is the need for any refashioning and redesign of services to focus on empowering older patients to live a life with HIV. Rather than providing for older patients, services now need to work with the patient, balancing good HIV treatment with treatment for co-morbidities, and integrating social care support.

This report has highlighted challenges and obstacles that those living with HIV (both early and late diagnosis) face and have to overcome. The voice of this group has effected many changes and we must harness this not only to improve the quality of later life of those with HIV, but of all older people.

7. Appendices

Steering Group Members
Chair: **David Walden**

Name	Position	Organisation
Gail Beer	Director of Operations	2020health
Mark Davis	Director of Government Affairs	Gilead
Prof Martin Fisher	HIV medicine at Brighton & Sussex Medical School; Executive member British HIV Association	Brighton & Sussex Medical School
Matt James	Research Fellow	2020health
Deborah Jack	Chief Executive	National Aids Trust
Dr Karen Lowton	Senior Lecturer in Ageing & Health, Institute of Gerontology	King's College London
Lisa Power	Policy Director	Terrence Higgins Trust
Paul Steinberg	Sexual Health and HIV commissioning Manager	NHS Lambeth and Southwark
David Walden CBE	Board member	2020health

List of interviewees

Name	Position	Organisation
Prof Jane Anderson	Consultant Physician (Interviewed in a personal capacity)	Homerton University Hospital, London
Garry Brough	Membership & Involvement Officer	Terrence Higgins Trust
Prof Philippa Easterbrooke	Senior Scientist, HIV department	World Health Organisation
Philip Glanville	Policy & Parliamentary Officer	National AIDS Trust
Andy Hilton	Chair	National Long Term Survivors Group
Jo Josh	Chair	Body & Soul Patient Group
Dr Margaret Johnson	Clinical director of HIV/AIDS services	Royal Free London NHS Foundation Trust

7. Appendices

List of interviewees (continued)

Name	Position	Organisation
Dr Philippa Matthews	GP	Royal College of General Practitioners (RCGP)
Eileen Nixon	HIV Nurse Consultant	Brighton and Sussex University Hospitals NHS Trust
Nicky Perry	Research Manager, Department of HIV and Genitourinary Medicine	Brighton and Sussex University Hospital NHS Trust
Paul Steinberg	HIV Prevention and Sexual Health Commissioning Manager	London Borough of Lambeth
Jacqueline Stevenson	Acting Chief Executive Officer	African Health Policy Network
Prof Anthea Tinker	Professor of Social Gerontology	King's College London
Dr Juliet Wright	Senior Lecturer and Honorary Consultant Elderly Medicine	Brighton and Sussex University Hospital NHS Trust

Stakeholder Discussion Participants
Chair: **David Walden**
The discussion took place under the Chatham House Rule.

Name	Position	Organisation
Gail Beer	Director of Operations	2020health
Russell Brown MP	Vice Chair	All Party Parliamentary Group on HIV & AIDS
Garry Brough	MyHIV, Terrence Higgins Trust	Terrence Higgins Trust
Mark Davis	Director of Government Affairs, UK & Ireland	Gilead Sciences
Dr Valerie Delpech (invited)	Consultant Epidemiologist	Health Protection Agency
Dr Will Ford-Young	Sex, Drugs & Blood Borne Virus group	Royal College of General Practitioners (RCGP)
Phil Glanville	Policy and Parliamentary Officer	National Aids Trust
Cham Herath	UK & Eire Medical Director	Gilead Sciences

7. Appendices

Stakeholder Discussion Participants (continued)
Chair: **David Walden**
The discussion took place under the Chatham House Rule.

Name	Position	Organisation
Matt James	Research Fellow	2020health
Jo Josh	Chair	Body and Soul
Andrew Kaye	Head of Policy and Campaigns	Independent Age
Murad Ruf	Associate Director of Community Affairs and Public Health Strategy	Gilead Sciences
Christopher Sandford	Patient Representative	Mortimer Market Centre, Bloomsbury Patient Network, Bloomsbury
Jacqueline Stevenson	Acting Chief Executive Officer	African Health Policy Network
Paul Steinberg	HIV Prevention and Sexual Health Commissioning Manager (LSL)	Lambeth
Sean Summers	Researcher and Projects Assistant	2020health
David Walden CBE	Board Member	2020health
Simon Wilkinson	Age Action Alliance Secretariat	Age Action Alliance, Department of Work and Pensions

7. Appendices

Funding HIV Social Care

Key Facts (NAT 2009: 7)

Aids Support Grant

- Started in 1989 by Department of Health
- Important funding resource for people living with HIV, facilitating access to appropriate mainstream social care
- The grant had the following aims:
  - To enable Social Services Departments to draw up strategic plans, based on local population needs assessments, for commissioning social care for people living with HIV and AIDS
  - To enable Social Services Departments to finance the provision of social care for people with HIV and AIDS and where appropriate, their partners, carers and families.

Evidence

- No evidence of strategic planning required despite the stated aims mentioning the need for planning
- No need for local authorities to provide detailed expenditure plans. The need for expenditure plans were abolished from 2003.

Planning and regulating

- Previously, Comprehensive Performance Assessments (CPA) were undertaken by the Commission for Social Care Inspection (CSCI); local authorities were allocated a performance rating (the star rating) for adult social care, based on the quality of their services and their management
- The CPA system has now been replaced by the Comprehensive Area Assessment (CAA) where local authorities are assessed on their performance against outcome-focused national indicators
- Local authorities and partner stakeholders select and agree 35 indicators from a list of 198, which set out their priorities for action. This forms the basis of a three year Local Area Agreement (LAA) between the local authority and central Government
- LAA involves local authorities bringing together local stakeholders in a Local Strategic Partnership (LSP)
- The LSP work together with the local authority to carry out a Joint Strategic Needs Assessment (JSNA)
- JSNA should then inform and shape the commissioning of services.

Incentives

- Under CPA assessment process, well performing authorities received a set of freedoms design to act as an incentive to others
- Local authorities with a CPA score of three or four have no conditions attached to their ASG payment. In 2008, 83 per cent of local authorities achieved a CPA score of three or four.

7. Appendices

Funding HIV Social Care (continued)

Key Facts (NAT 2009: 7)

Formula Grant

- 2010 – Ring-fencing removed from funding and money rolled into the Formula Grant
- Formula Grant is the large sum of money given to local councils to fund all their activities
- There remains funding named and allocated to each local council for 'HIV/AIDS Support'

7. Appendices

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2020health's mission

Making health personal

2020health is an independent, social enterprise think tank whose purpose is to both improve individual health and create the conditions for a healthy society, through research, evaluation, campaigning and relationships.

2020health research and activity includes the following workstreams

Fit-for-school:
To create a holistic picture of wellbeing and what children need in order to thrive at school, and identify ways of enabling more children to flourish and break the cycle of failure.

Fit-for-work:
To continue looking at the importance of work for health and health for work, and ensure that those who experience illness receive timely and appropriate support, understanding that worklessness impacts on economies and society as a whole.

Fit-for-later life:
To look from active retirement, to increasing dependency and end-of-life care and consider new models of provision, raise the status of caring, embed respect for ageing and ensure inclusion.

Forgotten conditions:
To ensure that people with rare or unusual health conditions have their needs met by the NHS.

Integration:
To promote integrated care that uses technology to empower people and enable management of their healthcare and wellbeing.

International:
To ensure that we continue to share our knowledge of healthcare and learn from those countries that care for people better than we do.

Innovation:
To ensure that people have access to innovation in all of its forms and keep the UK at the forefront of R&D.

Social Care:
To find sustainable solutions to ensure people's vulnerable or final years are the best they can be.

"Passionate about patient power and won't flinch from promoting their interests."

**Dr. Mark Britnell, Chairman and Partner,
Global Health Practice, KPMG**

"Always striving to keep people's needs at the centre of what the NHS delivers."

**Dr. Johnny Marshall, GP, Head of Policy,
NHS Confederation**

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