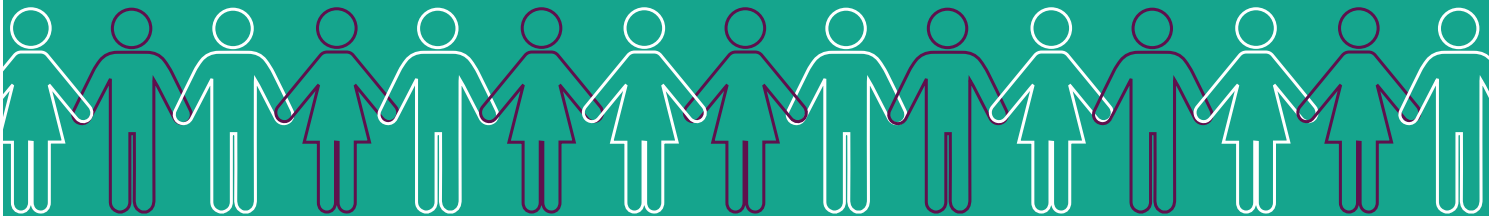


Why we need HIV support services



A REVIEW OF THE EVIDENCE

March 2017

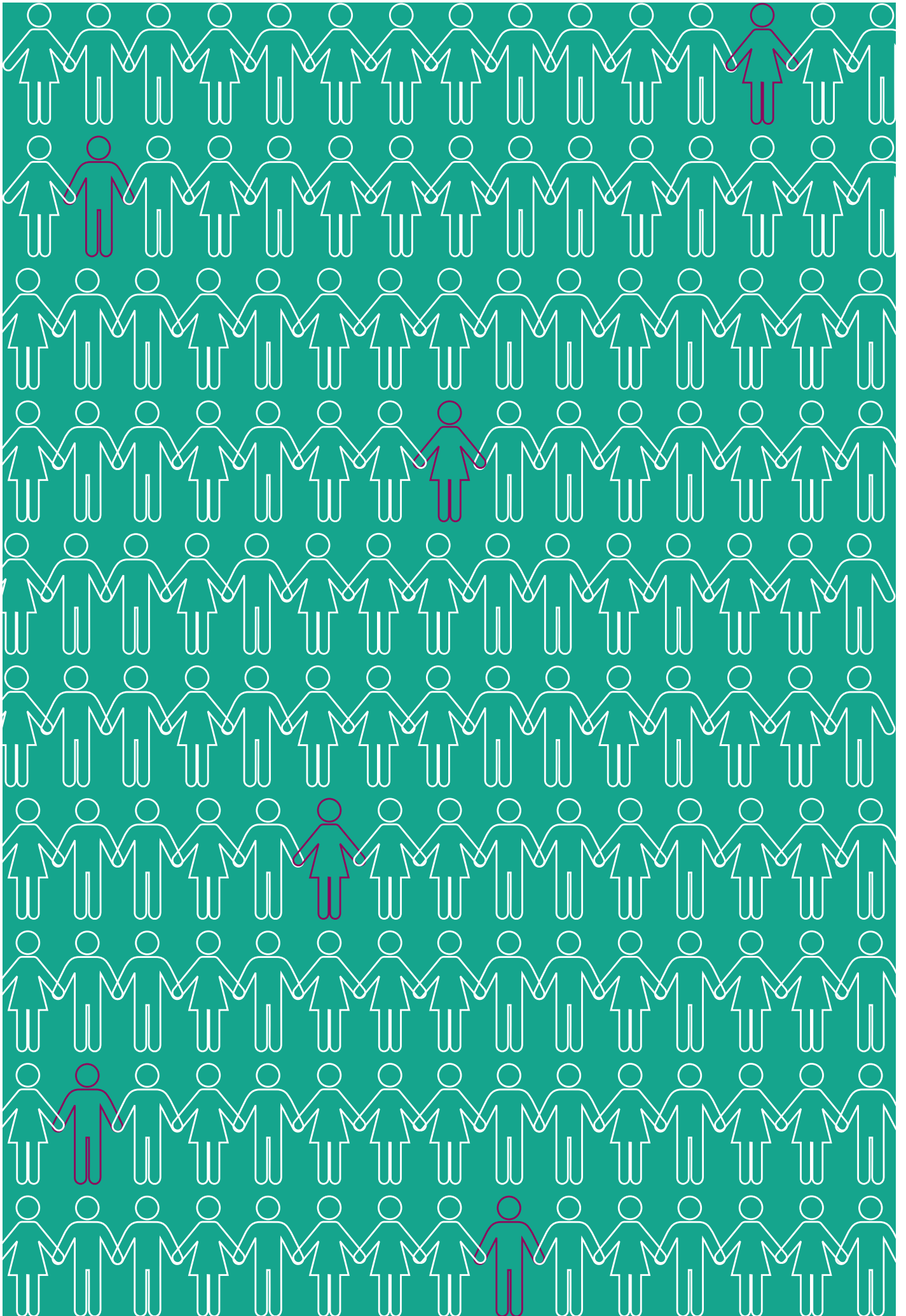


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CONTENTS

EXECUTIVE SUMMARY	05	PART 5 – EVIDENCE ON OUTCOMES AND EFFECTIVENESS	38
PART 1 – INTRODUCTION	10	Community-based approaches for people with long-term conditions	38
PART 2 – CURRENT PROVISION AND USE	13	Evidence of impact	40
What are HIV support services?	13	Developing outcome measures	42
What is provided and by whom?	13	Recommendations	44
How many use HIV support services?	16	PART 6 – CURRENT POLICY PRIORITIES, GUIDELINES AND STANDARDS	45
PART 3 – THE NEEDS OF PEOPLE LIVING WITH HIV	18	National health policy for long-term conditions	45
Context	18	Supporting the local voluntary and community sector	48
HIV and co-morbidities	19	The Care Act 2014	49
Ageing	20	HIV-specific policy	50
Treatment information	22	Modernising HIV support services	51
Mental health and neurocognitive needs	23	Recommendations	53
Drug and alcohol-related needs	24	ENDNOTES	54
Stigma	25		
Poverty and social inequalities	26		
Women living with HIV	28		
Different people – different needs	29		
PART 4 – DOES SPECIALIST PROVISION MATTER?	31		
Specialist v generic provision	31		
Current capacity within generic services	35		
Retaining a 'mixed economy'	36		
Recommendations	36		





EXECUTIVE SUMMARY

INTRODUCTION

KEY MESSAGES

The case for commissioning support services for people with HIV is overwhelmingly strong – support services which complement specialised HIV clinical care.

HIV support services are still needed and accessed by a majority of people with HIV. They are an essential part of the HIV care pathway and commissioners have an obligation to ensure these services are in place to meet those needs.

HIV specialist provision continues to be necessary to provide many of these support services if they are to be of a quality and expertise to secure trust and good outcomes.

The HIV community sector is a precious local asset and resource which should be supported and fostered.

HIV support services reflect perfectly the current ambitions of our health and social care system for person-centred, holistic long-term condition management. Far from being phased out, they should be maintained, modernised and used as a service model from which many other conditions can learn and benefit.

CURRENT PROVISION AND USE

KEY MESSAGES

HIV support services are provided both by suitably qualified professionals and by peers also living with HIV (and of course many professionals will be peers).

HIV support services both provide information (and this includes advice services, advocacy, signposting and

referral), and support change (such as psychological support and behaviour change interventions).

HIV support services address psychological and emotional (psychosocial) needs; condition self-management; sex and relationships needs; and social needs – as they relate to, affect and are affected by HIV.

HIV support services are accessed over time by a majority of the HIV positive population (and about a third in any one year). They are an integral part of the HIV care pathway. They are particularly important to people with HIV during times of significant need such as when newly diagnosed or when experiencing poor mental health. The excellent high-level clinical outcomes for people with HIV in England should be attributed as much to the availability of such support services as to specialised clinical care.

THE NEEDS OF PEOPLE LIVING WITH HIV

HIV and co-morbidities

KEY MESSAGES

People living with HIV experience higher rates of co-morbidity than the general population. The significant impacts of these co-morbidities, in such areas as employment, social isolation and self-care, all underline the need for local commissioners to plan support services to meet these needs and to prevent serious deterioration in wellbeing.

Ageing

KEY MESSAGES

Older people with HIV access, value and rely on HIV support services to ensure a good quality of life. Needs relate to finances, sex and relationships, stigma, mental health, co-morbidities, and the physical challenges and unknowns of living with HIV.



Treatment information

KEY MESSAGES

Treatment information is a key need for people with long-term conditions. It ensures patient empowerment, supports physical, mental and emotional wellbeing, and reduces health and social care costs. HIV support services have a long and well-established track record of meeting such needs, complementing clinic provision.

Mental health and neurocognitive needs

KEY MESSAGES

There are high rates of poor mental health amongst people with HIV, which is a harm in and of itself, and should be addressed with a ‘parity of esteem’ from commissioners. Such poor mental health can undermine clinic attendance and so have an impact on mortality and morbidity, as well as onward transmission. It also adversely affects self-care, social contact, employment and finances.

Drug and alcohol-related needs

KEY MESSAGES

There is a particularly high rate of problematic drug and alcohol use among HIV positive men who have sex with men, which risks other serious health harms including overdose and death, blood-borne virus transmission, STI transmission, mental health harms, and loss of employment, amongst others. This needs to be urgently addressed.

Stigma

KEY MESSAGES

HIV stigma, both external and internalised, significantly affects people living with HIV in the UK. There is robust evidence it can compromise adherence to HIV medication. There is international evidence that support services for people with HIV which combine skills-

building activities, peer support and opportunities to discuss stigma and its effects, can all build resilience and reduce the harms arising from HIV stigma.

Poverty and social inequalities

KEY MESSAGES

Poverty, unemployment and social inequality are significantly higher among people with HIV than the general population. This has an impact on retention in care, adherence to medication and viral load suppression, and thus on mortality and morbidity as well as rates of HIV transmission in the community.

Women living with HIV

KEY MESSAGES

Women living with HIV have particular needs which should be met by support services. There are, for example, treatment information needs relevant specifically to women. Women also experience elevated levels of intimate partner violence and poverty. For many women their needs intersect with their experience as migrants living within African communities. Support services must be competent and literate around the gendered experience of living with HIV.

Different people – different needs

KEY MESSAGES

People with HIV very often come from communities already significantly affected by social and health-related disadvantage. Needs assessments should recognise the diverse experiences and needs of people with HIV and be sensitive to the way HIV interacts with other structural needs and inequalities.



DOES SPECIALIST PROVISION MATTER?

KEY MESSAGES

Many HIV support interventions cannot be replicated by generic services. These include, almost by definition, peer support. But they also include services to help people deal with HIV stigma, to cope with a diagnosis, to understand HIV treatment and the importance of adherence, to practise safer sex, and to disclose, when appropriate, one's HIV status.

There is an important place for generic services meeting some of the information, advice and advocacy needs of people living with HIV. But HIV support services will remain necessary to help many people with HIV access such generic provision confidently and effectively, to provide HIV training for generic services and assist with complex cases, and to help ensure the services accessed by the person with HIV are as joined up and integrated as possible.

Clinical standards for psychological support for HIV, including for community-based support, require a degree of HIV knowledge and experience not usually found in generic mental health provision such as IAPT.

RECOMMENDATIONS

HIV specialist support should be retained locally both to meet needs which generic services are unable to provide appropriately (for example peer support), and also to complement, train and work alongside generic provision.

Both Clinical Commissioning Groups (CCGs) and local authorities should monitor the experience, acceptability and use of the generic services they commission for people with HIV. They should identify and agree with people with HIV living locally what makes a generic service useful and acceptable.

Generic services should never be proposed as an acceptable alternative to HIV-specific services when those generic services are under-resourced, failing to meet demand appropriately even without HIV positive

service users, and where staff of such services have not been meaningfully and effectively trained on HIV issues.

EVIDENCE ON OUTCOMES AND EFFECTIVENESS

KEY MESSAGES

There is considerable research evidence of the effectiveness of the kinds of intervention provided by HIV support services, for example peer support, advice and information services, and self-management education.

Many HIV support providers have impressive evidence of the success and impact of their services.

Gaps in the evidence cannot be an excuse not to commission services to meet need.

Current initiatives to agree outcomes measures nationally around HIV support services and more generally for long-term condition support are welcome. They have the potential to assist commissioners and providers and to build a stronger evidence-base around what does and does not work in service provision.

RECOMMENDATIONS

Best available evidence of effectiveness should be used to commission and provide HIV support services. Services and their outcome measures should be planned to contribute optimally to further research on evidence of impact.

All HIV support services should be agreeing outcome measures, monitoring impacts and publicising their results.

The current NHS England support for Patient Activation Measures is an opportunity to frame HIV support services as a key contributor to such activation. Discussions should take place between the HIV Clinical Reference Group, BHIVA and HIV support service providers to agree how best to promote patient activation for people with HIV, drawing on and developing current clinical and voluntary sector infrastructure and capacity.



Support services for people with HIV, and for people with long-term conditions generally, should be consistently classified, to an agreed taxonomy, to assist research, consistent commissioning and provision. Discussion should take place across HIV and other long-term condition charities with the NHS and Public Health England to initiate this project.

CURRENT POLICY PRIORITIES, GUIDELINES AND STANDARDS

KEY MESSAGES

There is an overwhelming policy case for the commissioning of HIV support services. National policy on long-term condition management, as set out, for example, in the House of Care model, and as emphasised in the NHS Five Year Forward View, prioritises support in self-management and a focus 'beyond medicine' on wider mental health and social elements to wellbeing, as well as the key role of the voluntary and community sector in the delivery of relevant services. HIV support services have over more than 30 years modelled such provision and care. It is extraordinary and unacceptable for anyone to consider entirely decommissioning such HIV services just at the moment the wider health system is waking up to the relevance of this sort of support for all long-term conditions.

Commissioning services from the HIV voluntary and community organisations meets explicit policy expectations on the social value of such organisations' reach with marginalised groups, their impact on health and social care engagement, their employment of HIV positive staff and volunteers, and their ability to provide advice and expertise to the local health and care system.

HIV support services are also clearly set out in NHS England's national service specification for HIV specialised services as an essential part of the care pathway, as well as in clinical guidelines.

Local health and care systems must identify the needs of people with HIV and plan and commission appropriate support services. Not to do so is to neglect their responsibilities.

HIV support services have constantly adapted to changes in clinical treatment, in epidemiology and in healthcare. Further modernisation is now needed to meet current developments in need and commissioning practice. Commissioners should work in partnership with HIV support services to identify new models of support, ensuring needs are consistently and appropriately met.

RECOMMENDATIONS

Clinical Commissioning Groups (CCGs) must recognise, as part of their commissioning responsibility for people with long-term conditions, their obligation to meet the long-term condition needs of people living with HIV.

CCG commissioning responsibility for HIV support services should also be explicitly recognised at the national level by the relevant bodies with a policy interest – the Department of Health, NHS England, Public Health England, the Local Government Association and NHS Clinical Commissioning. It should be explicitly acknowledged as lead commissioning responsibility – in other words, a responsibility for coordinating the involvement of other commissioning bodies to ensure needs are met, as well as commissioning directly much of the provision.

'Making It Work' should be amended as soon as possible to provide clear recommendations of responsibility at the local level for treatment information, clinical nurse specialists and HIV support services.

Where numbers with HIV are relatively low within a particular CCG boundary, there should be proactive discussion with other local CCGs for joint commissioning of HIV support services at an appropriate scale.

CCGs should be using STPs (sustainability and transformation plans) and place-based commissioning to secure collaboration across CCGs, local authorities



and NHS England in the commissioning of HIV support services.

NHS England should both advocate for HIV support services to be in place locally and revisit its own commissioning practice and HIV service specification to identify how it can commission an appropriate element of such services.

Local authorities continue to have significant commissioning responsibilities for HIV support services, even if CCGs have a lead commissioning role. In particular, they have a public health interest in people with HIV being supported in safer sex, healthcare engagement and adherence to medication in order to minimise the onward transmission of HIV in their area. Their social care duty, and especially its preventive focus, also means local authorities should consider a commissioning contribution to local HIV support services and their promotion of wellbeing. There should be formal discussions between CCGs and local authorities about how they can work together to support people with HIV in their area.

Any transfer of commissioning responsibility for HIV support services from local authorities to CCGs must be properly agreed and managed to ensure no break or gap in service provision.



INTRODUCTION

KEY MESSAGES

- The case for commissioning support services for people with HIV is overwhelmingly strong – support services which complement specialised HIV clinical care.
- HIV support services are still needed and accessed by a majority of people with HIV. They are an essential part of the HIV care pathway and commissioners have an obligation to ensure these services are in place to meet those needs.
- HIV specialist provision continues to be necessary to provide many of these support services if they are to be of a quality and expertise to secure trust and good outcomes.
- The HIV community sector is a precious local asset and resource which should be supported and fostered.
- HIV support services reflect perfectly the current ambitions of our health and social care system for person-centred, holistic long-term condition management. Far from being phased out, they should be maintained, modernised and used as a service model from which many other conditions can learn and benefit.

There is an urgent need for this report in the current financial climate where commissioners are being forced to make savings and decommission services considered unnecessary or a low priority. The All Party Parliamentary Group on HIV and AIDS, in its recent report 'The HIV puzzle', which looks at the current state of HIV provision in England following the Health and Social Care Act 2012, raises serious concerns about the future of HIV support services.¹ We hear from various parts of the country of moves either to end HIV support services completely or so significantly cut them as to render them ineffectual.

For example, a recent survey report 'Cutting the Ribbon?' which looks at the health of HIV support organisations in the UK found that 50% of organisations had had to draw on their reserves in the previous financial year and 69% expected to use their reserves in order to survive in the coming financial year. A third of respondents reported the planned closure of services over the coming year.²

Such financial pressures are made worse by a lack of clarity as to who is responsible for commissioning these services. Historically, HIV support services had, prior to 2013, been commissioned by a mix of Primary Care Trusts (PCTs), given their public health and healthcare responsibilities, and local authorities, given their social care functions.

Under the system brought in from 2013 by the Health and Social Care Act 2012, local authorities are now responsible not just for social care but also for public health commissioning whilst Clinical Commissioning Groups (CCGs) commission most NHS secondary care services (including long-term condition management). NHS England retains responsibility for HIV clinic services as part of its specialised commissioning responsibilities. There is, however, no clarity or agreement as to who, within this new structure, should commission HIV support services.

Public Health England (PHE), in their publication 'Making It Work', state:

‘Current commissioning arrangements for community-based support services for people living with HIV are often determined by historical decisions. While some were always commissioned by local government, the budgets for others were transferred in April 2013 from primary care trusts to either CCGs or local authorities. In the case of these services, as with HIV community nurse specialists and the provision of HIV treatment information, there is no centrally determined allocation of commissioning responsibility and arrangements should be locally determined between commissioning bodies to ensure services are provided to meet assessed need.’

It is true that before 2013 arrangements for the funding of HIV support services had developed historically as a result of local agreement and collaboration and there was no national stipulation as to which commissioner should be responsible for which elements in HIV support. But in a time of relative plenty funding-wise, this was not a problem. With funds now scarce and commissioning responsibility unclear, and with all services being looked at afresh given new commissioning structures, HIV support services are extremely vulnerable to cuts.

NAT has joined with other HIV organisations in the #StopHIVCuts campaign. Throughout this report we include quotations from individuals who have sent comments in to the campaign on the importance they attach to HIV support services.³

This report looks at the continuing need for HIV support services in England. Our focus on England is because of the particular challenge around clear commissioning responsibilities for HIV support services in the English health and social care system. But much of this report – the descriptions of services, of the needs of people with HIV, and of the interventions necessary – are applicable across the UK. We also drew on learning from across the UK, and indeed internationally, in drafting this report.

In preparation for this report NAT surveyed the views of the 32 larger HIV support service providers in the UK, and the views of HIV clinicians. Three focus groups were held to inform our thinking. One in London at NAT’s offices; one in Birmingham hosted by the local service provider, ABplus; and one in Scotland organised for us by Waverley Care and HIV Scotland, and held in THT Scotland’s offices. We are very grateful to all those who contributed to our work and thinking on this vital subject. It is sad to note that since the focus group, AB Plus has been forced to close because of precisely the sort of local cuts highlighted in this report.

We focus mainly on community-based HIV support services and on treatment information (where again community organisations play a key role). Whilst we do not discuss in detail the role of clinical nurse specialists in this report, we must emphasise that they also are an essential component of effective HIV care, especially for patients living in marginalised, vulnerable and/or chaotic circumstances. We are arguing also for a clear nationally agreed vision for the place and value of the clinical nurse specialist within HIV clinical teams.

In addition to this policy report, NAT is also surveying all local areas in the UK to find out what support services are currently being commissioned for people living with HIV. A report of our findings will be published early in 2017. But it is already evident, in England, that there is a patchwork of commissioning approaches across the country (where services are commissioned at all) – some services are commissioned and funded by local authorities – either from public health budgets or sometimes from social care budgets – some, though far fewer, by Clinical Commissioning Groups (CCGs) given their long-term condition management responsibilities, some in effect by NHS England specialised commissioning through monies provided to the HIV clinic.

This patchwork reflects to some degree the spectrum of need which support services meet – from services



which amplify those provided by the HIV clinic (e.g. treatment information) through social care (e.g. home visits) and public health interventions (e.g. safer sex support) to long-term condition management (e.g. nutrition advice). But as PHE states in 'Making It Work', this patchwork is as much a result of historical accident, and, we would add, the presence or absence of local champions, and the relative capacities of various local commissioning budgets.

This report aims to support greater national consistency in the commissioning of HIV support services, with a shared analysis of the needs of people with HIV and the services necessary to meet those needs. Support services are an essential part of the HIV care pathway and should not be lost simply as a result of a policy vacuum.



CURRENT PROVISION AND USE

KEY MESSAGES

- HIV support services are provided both by suitably qualified professionals and by peers also living with HIV (and of course many professionals will be peers).
- HIV support services both provide information (and this includes advice services, advocacy, signposting and referral), and support change (such as psychological support and behaviour change interventions).
- HIV support services address psychological and emotional (psychosocial) needs; condition self-management; sex and relationships needs; and social needs – as they relate to, affect and are affected by HIV.
- HIV support services are accessed over time by a majority of the HIV positive population (and about a third in any one year). They are an integral part of the HIV care pathway. They are particularly important to people with HIV during times of significant need such as when newly diagnosed or when experiencing poor mental health. The excellent high-level clinical outcomes for people with HIV in England should be attributed as much to the availability of such support services as to specialised clinical care.

WHAT ARE HIV SUPPORT SERVICES?

By 'HIV support services' we mean any service provided to meet HIV-relevant needs of people living with HIV, other than those provided as part of primary or secondary clinical care.⁴

HIV support services have been an integral part of the national response to HIV since the beginning of the epidemic in the 1980s. They are richly varied and might include, for example:

- a peer-support group for people who are newly diagnosed with HIV
- trained advice workers who link people with HIV up with more specialist support, for example mental health services, or who advocate for the client with benefits,

housing or social care providers

- counselling using cognitive behavioural therapy approaches to address anxiety and depression
- educational programmes on HIV treatments and getting the best out of your HIV clinic
- opportunities to socialise and engage in activity, reducing social isolation and loneliness.

WHAT IS PROVIDED, AND BY WHOM?

There are no current comprehensive data available on who is providing HIV support services across the UK. It is, however, known that the greater part of HIV support services has historically been provided by the HIV voluntary and community sector. The HIV voluntary and community sector consists mainly of charities which have a strong focus on involvement of people



living with HIV in their work, as both paid employees and volunteers. The sector may also employ clinical professionals such as psychologists or nurses as part of their service provision, as well as other professionals such as trained social workers.

We should not confuse the provider of a service with the setting for that service. A local HIV charity, for example, may provide a service on its own premises or other community setting, in a service user's home or from within an HIV clinic or other NHS setting.

Whilst the bulk of HIV support services are provided by the voluntary sector, it is also possible for some elements of HIV support services to be provided by the HIV clinic, even though the service is not included within the specification for HIV specialised services. The Bloomsbury Patients Network at the Mortimer Market Clinic is a well-known example.

NAT surveyed providers of HIV support services to get a more detailed and accurate sense of what is being provided. We received responses from 32 service providers who between them constitute the majority of voluntary sector services commissioned to support people with HIV. We asked them both

what HIV support services they were providing and also, more generally, what services they considered 'must be available for people living with HIV to establish health and wellbeing' (irrespective of whether or not they were providing them).

It is helpful to step back and get a bird's eye view of the sorts of HIV support services identified by respondents from a drop-down menu as essential for the health and wellbeing of people with HIV.⁵ They can be summarised as follows in terms of who provides them, what is provided and the needs they meet:

- HIV support services are provided both by suitably qualified professionals and by peers also living with HIV (and of course many professionals will be peers).
- HIV support services both provide information (and this includes advice services, advocacy, signposting and referral), and support change (such as psychological support and behaviour change interventions).
- HIV support services address psychological and emotional (psychosocial) needs; condition self-management; sex and relationships needs; and social needs – as they relate to, affect and are affected by HIV.

Services considered essential for people living with HIV⁶

Peer support	Information, advice and advocacy, including legal advocacy/referrals	Self-management	Sex and relationships support	Psychosocial support
<ul style="list-style-type: none"> • 1-2-1 support • group support 	<ul style="list-style-type: none"> • housing • finances • benefits • employment • social care support and care planning • immigration⁷ 	<ul style="list-style-type: none"> • treatment information • adherence support • long-term condition management • healthcare engagement 	<ul style="list-style-type: none"> • sexual health support • disclosure support • relationships support • pregnancy and parenting support 	<ul style="list-style-type: none"> • counselling • mental health • general social support (<i>which covers various emotional support services including befriending, and social activities that help with isolation and anxiety</i>)



The box opposite contains a more detailed list of the kinds of service that respondents felt had to be available for people with HIV.

There was a very high degree of consensus in the results. Every service identified was deemed to be essential by 90% or more of respondents (1-2-1 peer support was thought essential by 100% of respondents) – the only exceptions were healthcare engagement (88%) and mental health services (88%).

NAT also surveyed HIV clinicians (69 responses) for their views on support services. All clinicians responding considered information, advice and advocacy, sex and relationships support, and psychosocial support to be essential for their patients. Only 1% said 'not essential' for self-management support. For peer support only 7% of clinicians reported such services as not essential.

Not only was there a high degree of consensus amongst providers as to what should be available for people with HIV, there was also, perhaps expectedly, a high degree of provision of these services from those who responded to the survey:

- 29 out of 32 respondents provided peer support.
- 25 out of 32 respondents provided information, advice and advocacy.
- 24 out of 32 respondents provided self-management programmes.
- 25 out of 32 respondents provided sex and relationships support.
- 19 out of 32 respondents provided psychosocial support.

HIV support services therefore model a person-centred approach to provision where a variety of needs are all met holistically from the same organisation, and often via the same intervention. Many respondents, for example, reported that sexual health needs were mainstreamed into most activities and services.

We did ask whether there were specific sub-groups of people with HIV especially in need of services and

in general the response was that the services outlined should be generally accessible by all people with HIV. Some respondents did, however, highlight particular subgroups who especially benefit from particular services. Newly diagnosed people, women, black African people, migrants, older people, and younger people, all were mentioned.

These responses underline how important it is to recognise the diversity of the population of people living with HIV, and specific elements of acute need, when planning, commissioning and providing services at a local level.

Within these broad service categories, there was interesting detail provided on service content.

Peer support – This is of course less a category about what is provided and more about by whom, and as a result there is considerable variation in services described. Both 1-2-1 and group peer support are offered, sometimes open to all and sometimes targeted at specific groups (for example, MSM, the newly diagnosed, women, mothers) or at specific issues (parenting, patient participation, pain management, life coaching). Services were provided by patient representatives and trained peer staff and volunteers. Provision could be by appointment, drop-in, by phone, or online.

Information, advice and advocacy – A wide range of topics are covered within these services including housing, immigration, employment, benefits, treatment and care, and independent living. Services include legal advocacy, case work, staff trained to offer advice and attend appointments with the service user as advocates, as well as signposting and referrals. Staff were a mix of paid staff, trained volunteers and peers, pro bono solicitors, in-house CAB workers and social workers.

Self-management services – Provision focuses on health and treatment literacy, including specific issues such as nutritional support. The service is provided by a mix of professional and peers, in a wide variety of ways – workshops, courses, 1-2-1 work, practical support in the home and transport, information materials, counselling and accredited training.



“ I AM HIV POSITIVE AND HAVE RECEIVED GREAT SUPPORT THAT HAS HELPED ME OVERCOME THE EMOTIONAL DIFFICULTIES OF ACCEPTING THE DIAGNOSIS. I TAKE MY MEDS AND PROGRESS IN MY LIFE AND CAREER AND TRULY HOPE THAT MEN AND WOMEN WHO BECOME DIAGNOSED IN THE FUTURE MAY BE ABLE TO ACCESS THE SAME KIND OF HIGH QUALITY CARING SUPPORT THAT I DID. NOT EVERYONE WILL NEED SUCH GREAT SUPPORT BUT FOR THOSE WHO DO, THESE SERVICES ARE ESSENTIAL.”

PATRICK #STOPHIVCUTS

Sex and relationships support – A number of respondents said this support was integral to all aspects of their services for people living with HIV. There was a range of formats and media for this service provision. Sexual health (including reduction in risks of transmission and risk-taking behaviour), HIV status disclosure and the law, knowledge, confidence and self-empowerment in sexual relationships, are all covered.

Psychosocial support – Services include cognitive behavioural therapy and counselling (mentioned by most respondents), but also psychotherapy, life coaching, and practical workshops around themes such as coping skills and developing resilience. Provision was from a mix of professionals and trained volunteers, and including a specialist therapist, psychologists, health advisers and counsellors.

HOW MANY USE HIV SUPPORT SERVICES?

There is recent and reliable data on the proportion of people with HIV who use HIV support services. The Positive Voices survey undertaken by Public Health England found in 2014 that 35% of its weighted representative sample had accessed HIV support services in the previous 12 months. The most common services accessed were:

- information about living with HIV
- treatment advice
- peer support or social contact with other HIV positive people, and
- counselling.

We should note that many people access such support services episodically, around specific and time-limited needs. So over a few years we would expect to see a majority of people with HIV accessing support services.



It is also worth emphasising that the services used were not only peer support and counselling but also information and advice.

The UK Stigma Survey 2015 shows similar results for the use of HIV support services. Overall 59% had sought support in the previous 12 months, with nearly a third of respondents (30%) receiving this support from a local HIV support organisation (other sources of support were listed as online, peer group, NHS patient support group, local policy organisation, faith group and community group). Certain groups of people living with HIV particularly depend on these services. Among their sample, 46% of those recently diagnosed, 43% of those feeling suicidal and 37% of those who had experienced HIV-related discrimination had accessed local HIV support services.⁸

The REACH study asked participants whether they had attended a local HIV support group and of those who attend their clinic appointments regularly (the vast majority), 31.8% had attended such a local service and a further 14.3% said they had not but would like to.⁹

There are high levels of service use from these national surveys, especially given the fact that not every area will have accessible local HIV support services.

The Clinical Quality Dashboard for the care of people with HIV in England measures the proportion of people diagnosed with HIV who are accessing care, the proportion who commence ART when clinically indicated and the proportion of those on ART who are virally suppressed after six months. On every measure the UK does impressively well. It is perverse to argue, as some appear to, that these excellent outcomes are a reason for us no longer to invest in HIV support services. These outcomes have been achieved with the majority of people with HIV accessing HIV support services. If those services had not been available, it is by no means certain people with HIV would be doing as well as they are currently.



THE NEEDS OF PEOPLE LIVING WITH HIV

This section of the report outlines the evidence for the needs of people living with HIV which are addressed by HIV support services. We also provide evidence of the harms that accrue if such needs are not met.

CONTEXT

Two initial points should be made for context, when thinking about the needs of people living with HIV. First, adherence to daily HIV medication is of absolute importance to people living with HIV on treatment. Interruption to medication risks development of drug resistance and viral load rebound, both of which may severely affect future health outcomes. Furthermore, viral load rebound resulting from non-adherence may mean the individual is at risk of transmitting HIV to

sexual partners (the vast majority of people diagnosed with HIV cannot pass HIV on because their viral load is suppressed). Many of the needs we refer to will result, if not addressed, in such serious failures in adherence and clinic engagement.

Secondly, the needs described below are in many instances linked to poverty and social marginalisation. Financial austerity is often cited by local authorities as a reason for closure of support services. But this same austerity is in fact substantially increasing the need and demand for HIV support services – both directly because poverty and social need are increasing and also because the closure or contraction of other public services seriously limits where else people can go for help. In the ‘Cutting the Ribbon?’ survey two thirds of organisations had experienced an increase in demand for services in the previous 12 months and a third expected an increase in the next twelve months.¹⁰

“PEOPLE WITH HIV STILL SUFFER FROM STIGMA, ISOLATION, INEQUALITIES, IMMIGRATION, MORE MENTAL HEALTH ISSUES AND LOWER SOCIAL SUPPORT. THEY NEED MORE THAN MEDICAL CARE ALONE CAN PROVIDE. OTHER SERVICES ARE ESSENTIAL FOR KEEPING THEM WELL.”

LUCIANA #STOPHIVCUTS

HIV AND CO-MORBIDITIES

KEY MESSAGES

People living with HIV experience higher rates of co-morbidity than the general population. The significant impacts of these co-morbidities, in such areas as employment, social isolation and self-care, all underline the need for local commissioners to plan support services to meet these needs and to prevent serious deterioration in wellbeing.

For many people living with HIV, their HIV is not the only challenge in their lives to their wellbeing. People living with HIV are disproportionately affected by co-morbidities.

The Positive Voices survey for 2014 found high rates of co-morbidities amongst people living with HIV. Overall 64% of people with HIV had at least one other co-morbidity (60% for those aged between 18 and 49, and 77% for those aged 50 and above).¹¹ 38% had multiple co-morbidities.¹²

Depression/anxiety was the most common co-morbidity across all ages (30% overall prevalence, compared with 20% in the general population). High cholesterol and hypertension were the most common age-associated co-morbidities (20% and 14% respectively), and prevalence was two times higher amongst those aged over 50. Prevalence of rheumatoid arthritis, diabetes and heart conditions were also strongly associated with age.¹³

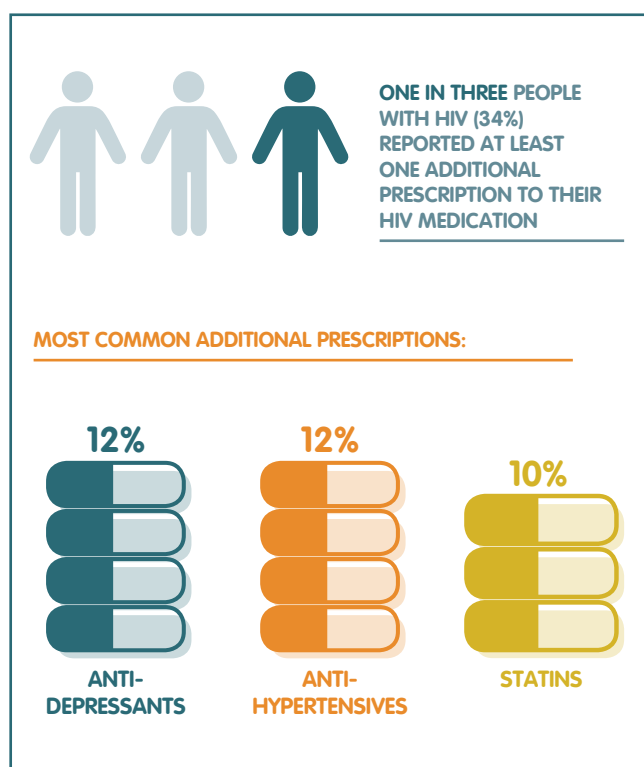
Amongst people living with HIV, men who have sex with men are particularly affected by co-morbidities. 69.6% had at least one co-morbidity, and 42.1% more than one, with high rates of depression/anxiety (36.5%) high cholesterol (26.3%) and hypertension (15.5%).¹⁴

There were also high rates of multiple medication prescriptions ('polypharmacy'). One in three people

with HIV (34%) reported at least one additional prescription to their HIV medication, most commonly anti-depressants (12%), anti-hypertensives (12%) and statins (10%). Nearly half of those 50 or over experienced polypharmacy (46%) with 29% on statins and 22% on anti-hypertensives.¹⁵

Positive Voices, on the basis of the age profile of the population of people with HIV in the UK, also made projections on the burden of long-term conditions by 2028.¹⁶ By 2028, when over half of the UK HIV cohort will be aged 50 or over, rates for long-term conditions other than HIV are expected to have risen dramatically.

For example high cholesterol will increase from 19% (2013) to 29% (2028); hypertension will increase from 13% to 19%; diabetes from 4% to 7%; and heart condition from 3% to 7%. They conclude, 'this suggests the need to develop interventions to reduce lifestyle risk factors, as well as less resource intensive models of managing long-term conditions in people with HIV'.





In 2011 NAT surveyed people with HIV around experience of symptoms and their fluctuation.¹⁷ The findings provide insight into how HIV interrelates with co-morbidities. The co-morbidities surveyed were ones known to be in many cases linked to underlying HIV positive status or to the medication taken to combat the virus – hence their description as ‘symptoms’.

Whilst the survey was a convenience, rather than a representative, sample of people with HIV, and probably to some degree overestimated the overall prevalence of the various symptoms in the population of people with HIV, it nevertheless does point to significant needs which commissioners must consider when planning services.

Commonly reported symptoms included fatigue/exhaustion/lack of energy (57%), depression/anxiety (55%), gastro-intestinal problems (48%), insomnia (46%) and neuropathy (nerve pain) (33%). There were high rates of co-morbidity. Symptoms fluctuated and were often unpredictable. Such symptoms had a significant impact on quality of life. There was a particular impact on work, both in terms of ability to get into employment or, for those in work, difficulties and disruptions to one’s working life. More broadly, these symptoms had an impact on exercise, leisure and social occasions, on getting out of the house, shopping, preparing food, basic housework and personal care.

The NHS Outcomes Framework 2016-17 has as one of its improvement areas, ‘Health-related quality of life for people with three or more long-term conditions’ – 38% of people with HIV according to Positive Voices are in that category. This underlines how important it is for local NHS commissioners to consider explicitly the support needs of people living with HIV.

AGEING

KEY MESSAGES

Older people with HIV access, value and rely on HIV support services to ensure a good quality of life. Needs relate to finances, sex and relationships, stigma, mental health, co-morbidities, and the physical challenges and unknowns of living with HIV.

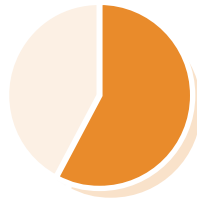
The population of people with HIV in the UK is getting older. In 2015, there were 29,960 people living with diagnosed HIV and aged 50 and over, or about 34% of the total population living with diagnosed HIV in the UK. This percentage has been increasing in recent years as people with HIV live into old age as a result of the effectiveness of treatment. It is not only, however, a function of people diagnosed in earlier years getting older. The numbers newly diagnosed at and after the age of 50 are also increasing. In 2015 1,018 people aged 50 and over were newly diagnosed with HIV (17% of all new diagnoses), whilst in 2004 there had been 609 such diagnoses (8% of all new diagnoses).¹⁸

There are challenges specific to ageing with HIV. THT have recently published ‘Uncharted Territory’, the report of a survey they undertook of 246 people living with HIV over 50, as well as the findings of 30 interviews and six workshops.¹⁹ Over a third of respondents were solely reliant on welfare benefits to live. 58% of respondents were defined as living on or below the poverty line (twice the level of poverty in the general population). 84% were concerned about future financial difficulties and 88% had not made financial plans to fund future care needs. Some of the harms arising from poverty in relation to management of HIV are set out later in this section of the report.

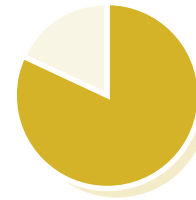
A third were socially isolated and 82% experienced moderate to high levels of loneliness. 22% rated their current wellbeing as bad or very bad. They



OVER A THIRD
OF RESPONDENTS WERE
SOLELY RELIANT ON WELFARE
BENEFITS TO LIVE.



58%
OF RESPONDENTS WERE DEFINED
AS LIVING ON OR BELOW THE
POVERTY LINE (TWICE THE LEVEL
OF POVERTY IN THE GENERAL
POPULATION).



84%
WERE CONCERNED ABOUT
FUTURE FINANCIAL DIFFICULTIES
AND 88% HAD NOT MADE
FINANCIAL PLANS TO FUND
FUTURE CARE NEEDS.

have on average three times as many long-term health conditions as the general population. There was experience of discrimination from social care professionals and a high level of concern (82%) as to whether they would be able to access social care to meet needs in the future.

These findings mirror those of an earlier report published by THT, AgeUK and the Joseph Rowntree Foundation in 2010.²⁰ That report concluded 'there is a real need for a range of services to address these issues and avert or minimise later poverty problems. These include support to stay in or re-enter the workplace, benefits advice and access to debt management and financial planning skills as part of long-term condition management'.

The HALL (HIV in Later Life) study, led by Keele University, reported on the high degree of concern around prospects for future support into old age and over the long-term effects of ARVs.²¹ There was also considered to be additional and specific stigma and discrimination in relation to being older with HIV, linked for example to negative views about older people and sex. Emotional and sexual relationships proved challenging for those older people currently single in this context of stigma, which of course contributes significantly to isolation and poorer mental health.

The study found that two thirds of participants reported a good or moderately good quality of life, with one fifth reporting a poor quality of life (QoL). Very importantly, 'For all participants regardless of how they rated their QoL, good QoL was an ongoing project that required active work. Examples of the active work needed to achieve good QoL were seeking appropriate support, attending and volunteering for HIV specific organisations, declining to identify with HIV groups, and rethinking HIV to lessen its impact on their lives'.

There was an emphasis on the need for support for good mental health and quality of life from other people living with HIV, which was not replicable from HIV negative friends and family. 'Participants stated that the support they gained from attending and volunteering in HIV organisations and groups was an important element in reducing isolation, providing a 'safe space', and allowing opportunities to 'give back' and support others'. In particular, 'Heterosexual people, both black African and white, sought out these connections through HIV specific organisations and support groups. The benefits of HIV support groups were most pronounced among those in receipt of statutory benefits. HIV support groups lessened the negative impact on QoL and mental health that resulted from being on benefits'.



I HAVE BEEN HIV POSITIVE SINCE 2002 AND I DON'T KNOW WHAT GETTING OLD WITH THE VIRUS WILL BE LIKE. HOW CAN I ACCESS THE SUPPORT I MAY NEED IF IT ISN'T THERE?"

PAUL #STOPHIVCUTS



TREATMENT INFORMATION

KEY MESSAGES

Treatment information is a key need for people with long-term conditions. It ensures patient empowerment, supports physical, mental and emotional wellbeing, and reduces health and social care costs. HIV support services have a long and well-established track record of meeting such needs, complementing clinic provision.

People with HIV need treatment information, given the need to adhere to daily antiretroviral medication. Such information should explain the importance of adherence, the effectiveness of treatment, the various antiretroviral regimens, possible side-effects and how to manage them, possible contra-indications with other medication, as well as wider health issues affecting people living with HIV (for example, mental health, nutrition, smoking).

The NHS Five Year Forward View prioritises the empowering of patients in the management of their condition 'staying healthy, making informed choices of treatment, managing conditions and avoiding complications. With the help of voluntary sector partners, we will invest significantly in evidence-based approaches such as group-based education for people with specific conditions and self-management educational courses, as well as encouraging independent peer-to-peer communities to emerge'.

Given this need and the NHS commitment, it is disturbing to see that treatment information is another element of HIV service provision which does not have a clear commissioning home since April 2013. Of course some information is provided within the HIV clinic. But the majority of people with HIV have only one or two appointments with their HIV clinic each year. HIV support services play a key role in supplementing clinic information and working in depth with different communities.

50% OF ATTENDEES AT EXPERT PATIENT GROUPS SUBSEQUENTLY REPORTED FEWER GP VISITS. FOR AN INVESTMENT OF £400 PER ATTENDEE, THERE WAS AN AVERAGE NET SAVING TO THE NHS FOR EACH PATIENT WITH A LONG-TERM CONDITION OF £1,800. HEALTH INEQUALITIES ARE ALSO REDUCED AND THE PATIENT EXPERIENCE SUBSTANTIALLY ENHANCED

Sigma Research surveyed people with HIV in 2007/08 around their needs and found then that 14% of respondents felt unhappy about their ability currently to access information about HIV, 11% had had difficulties accessing information in the previous 12 months, and 64% wanted to learn more about living well with HIV. Difficulties sometimes related to the quality of service available locally, or access to computers, or translation issues – but in addition 'Many respondents reported problems based on where they lived – some felt there was little or no specialist support in their local area, including some that had seen organisations they valued close or severely curtail their services'.²² This was at a time when there was much more funding available for support services than is now the case – we can only speculate that the need has accordingly increased.



More recently in 2011 Sigma Research's report 'Plus One' on people from African communities in sero-different relationships had a strong focus on the central importance of good information on HIV and prognosis when on treatment. Poor understanding of HIV meant significant anxiety and difficulty managing safer sex, relationships and disclosure.²³

The Patient Information Forum summarises powerfully the case for treatment information.²⁴ High quality information reduces demand for primary and secondary care services, and ensures the demand that does exist is more appropriate. Such impacts reduce NHS costs. To give just one example, 50% of attendees at expert patient groups subsequently reported fewer GP visits. For an investment of £400 per attendee, there was an average net saving to the NHS for each patient with a long-term condition of £1,800. Health inequalities are also reduced and the patient experience substantially enhanced.

MENTAL HEALTH AND NEUROCOGNITIVE NEEDS

KEY MESSAGES

There are high rates of poor mental health amongst people with HIV, which is a harm in and of itself, and should be addressed with a 'parity of esteem' from commissioners. Such poor mental health can undermine clinic attendance and so have an impact on mortality and morbidity, as well as onward transmission. It also adversely affects self-care, social contact, employment and finances.

People living with HIV have higher rates of poor mental health. People with HIV are about twice as likely to be diagnosed with depression as matched controls in the general population.²⁵

A systematic review found that anxiety prevalence was three-times higher in HIV positive groups

than among HIV negative controls.²⁶ More broadly, the prevalence of psychological and psychiatric problems is substantially higher than in the general population.²⁷

In the Positive Voices survey 29.6% of people with HIV reported depression/anxiety (and 36.5% of HIV positive MSM), significantly higher rates than in the general population (20%).²⁸ Similarly, in the Stigma Survey UK 2015, 18% of participants reported suicidal ideation in the last 12 months (with that percentage rising to 28% among those diagnosed in the last 12 months).²⁹ A recent Lancet paper has found a suicide rate for HIV positive men in the first year after diagnosis over five times higher than that for men in the general population.³⁰

The early years of the HIV epidemic before ART saw many people affected by HIV-associated dementia (HAD). Whilst this has decreased in incidence since the introduction of HIV treatment, numerous studies in the era of ART have shown continuing high levels of neurocognitive impairment, in particular milder impairment which nevertheless affects daily living. A US cohort study looking at patients between 2003 and 2007 found that whilst only 2% had HAD, 25% had neurocognitive impairment that interfered with their daily activities at least mildly.³¹ Factors now associated with HIV-related neurocognitive impairment include nadir CD4 count, co-infection with hepatitis C and drug use. Ageing influences the development of neurocognitive impairment amongst those with HIV and high rates are also seen in HIV positive adolescents who acquired HIV from maternal transmission.

Poor mental health results in worse engagement with and retention in healthcare. The REACH study found that both a diagnosis of depression and symptoms of neurocognitive impairment were associated with irregular HIV clinic attendance.³² Poor adherence or increasingly erratic clinic attendance are often indicators to a provider of possible neurocognitive impairment.³³ Such impairment impacts managing household finances, washing, driving, job performance/employment, attention, information processing, motor skills, for example.³⁴



IT SAVED MY LIFE. I ATTEMPTED SUICIDE TWICE ... IF IT WASN'T FOR THAT [THE NEWLY DIAGNOSED GROUP] I MIGHT NOT BE HERE TODAY."

NAT FOCUS GROUP PARTICIPANT

There is of course also an obligation on our health system to address poor mental health in its own right and apply to mental health problems a 'parity of esteem' with physical ill-health. The mental health charity MIND are currently running a campaign called 'Life Support' making the case for local charity and voluntary support for people with mental health problems as a key aspect of care. Their briefing for councillors and local commissioners also sets out the harms arising from poor mental health – for example, unemployment is three times as high amongst those with mild to moderate mental health problems; people with poor mental health are over 50% more likely to be isolated from friends and family; they are three times more likely to be in debt than the general population.³⁵

DRUG AND ALCOHOL-RELATED NEEDS

KEY MESSAGES

There is a particularly high rate of problematic drug and alcohol use among HIV positive men who have sex with men (MSM), which risks other serious health harms including overdose and death, blood borne virus transmission, STI transmission, mental health harms, and loss of employment, amongst others. This needs to be urgently addressed.

There are high rates of drug and alcohol use amongst people living with HIV. This is particularly well-evidenced amongst HIV positive gay men, with especial concern recently around 'chemsex'. Chemsex is a term to describe sexualised use of newer drugs, in particular crystal methamphetamine, GHB/GBL and mephedrone. Drug use can include injecting and is associated with extended sex sessions, often involving multiple partners and risky sexual behaviours. Harms cited include transmission of HIV and hepatitis C, as well as other often serious STIs, drugs overdose, mental health harms, sexual assault when unconscious, and even death.

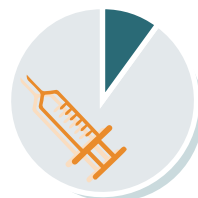
The Positive Voices survey found that 29% of sexually active HIV positive MSM engaged in chemsex in the previous year and 10% in 'slam sex' (i.e. injecting drugs during sex sessions).³⁶ There was a particularly high prevalence in London and an association with smoking and with a diagnosis of depression or anxiety. The Gay Men's Sex Survey (GMSS) 2014 found that 1.8% of respondents had injected drugs in the previous 12 months but this proportion rose to 11.3% of all men living with diagnosed HIV in England and 14.4% of men living with diagnosed HIV in London. In relation to broader use of the three main chemsex drugs (GHB/GBL, crystal meth and mephedrone), in the previous four weeks, 6.6% of MSM in England had used one or more of those drugs, rising to 21.9% of all MSM living with diagnosed HIV and 32.7% of men with HIV in London.³⁷

The Positive Voices survey found that chemsex was associated with increased odds of sexual behaviour with a risk of onwards transmission (i.e. sero-discordant unprotected anal intercourse with a detectable

THE POSITIVE VOICES SURVEY FOUND DURING THE PREVIOUS YEAR THAT, OF SEXUALLY ACTIVE HIV POSITIVE MSM:



29% ENGAGED IN CHEMSEX



10% ENGAGED IN 'SLAM SEX' (I.E. INJECTING DRUGS DURING SEX SESSIONS)

viral load). It was also associated with risky sexual behaviour, STI diagnoses and greatly increased odds of hepatitis C infection.³⁸

STIGMA

KEY MESSAGES

HIV stigma, both external and internalised, significantly affects people living with HIV in the UK. There is robust evidence it can compromise adherence to HIV medication. There is international evidence that support services for people with HIV which combine skills-building activities, peer support and opportunities to discuss stigma and its effects, can all build resilience and reduce the harms arising from HIV stigma.³⁹

Since the beginning of the epidemic, HIV, and people living with HIV, have been subject to societal stigma, which in turn generates self-stigma (also called 'internalised stigma') in many people living with this condition.

NAT has since 2000 been regularly working with Ipsos MORI to survey a representative sample of the British population to gather information on knowledge of HIV, and attitudes towards HIV. These surveys provide us with robust data on the prevalence of stigma within the British population.

The 2014 NAT survey found that stigmatising attitudes were held by a minority of people, but that minority was substantial enough to remain a cause for concern. For example, 15% of people thought that their relationship with a family member would be damaged if they found that family member was HIV positive, and 18% thought that the relationship would be damaged in the case of a neighbour found to be HIV positive. Twenty-three percent of people agreed that they did not have much

sympathy for those who got HIV through unprotected sex (a further 20% were neutral on this statement, with 51% disagreeing).⁴⁰ The good news is that HIV stigma is a minority attitude and slowly on the decline. The bad news is that HIV stigma remains common enough for people with HIV to experience it with some frequency.

The Stigma Survey UK 2015 found high levels of concern amongst people with HIV about stigma in health services. In the previous 12 months, 32% and 39% of participants worried about being treated differently from other patients in general practice and dental care respectively. 13% and 14% avoided seeking care from GPs and dentists respectively when it was required.⁴¹ The significant impact of stigma in deterring people from accessing public services should be noted.

Unfortunately this apprehension and fear of stigma in healthcare can be borne out in reality. In NAT's survey of people with HIV around confidentiality and the NHS, 22% of respondents reported experiencing breaches of confidentiality from healthcare staff. Even more worrying was the 40% of respondents who said they had ever been treated differently or badly by a healthcare worker because of their HIV status. Examples cited included healthcare workers asking patients how they got HIV, blaming people for becoming HIV positive, inappropriate discussions around lifestyle, being made to feel inferior or different, refusal to operate/provide treatment, treatment being postponed to the end of the day after all other patients were seen, and accusations of posing a health threat to the healthcare worker and colleagues.⁴² In the Stigma Survey UK 2015 5% of participants reported treatment being refused or delayed in GPs, Dentists and outpatient settings in the previous 12 months.⁴³

In NAT's survey of gay men living with HIV in work⁴⁴, just over a fifth of men (21%) who had disclosed their HIV status in the workplace had experienced HIV discrimination in their job, either their current job (7%) or a previous one (14%). In NAT's survey of attitudes to HIV among the general public, conducted by Ipsos MORI, 37% of the public think an employer should tell them if one of their colleagues has HIV.⁴⁵



Experience of stigma can result in isolation, poor access to services and also affect adherence to medication. A systematic review and meta-synthesis found that HIV-related stigma compromised patients' abilities to successfully adhere to ART. Internalised stigma and concealment in particular contributed to this effect.⁴⁶

There is international evidence that support services for people with HIV which combine skills-building activities, peer support and opportunities to discuss stigma and its effects, can all build resilience and reduce the harms arising from HIV stigma.⁴⁷

POVERTY AND SOCIAL INEQUALITIES

Key messages

Poverty, unemployment and social inequality are significantly higher among people with HIV than the general population. This has an impact on retention in care, adherence to medication and viral load suppression, and thus on mortality and morbidity as well as rates of HIV transmission in the community.

People living with HIV are disproportionately affected by poverty, hardship and inequalities. The Positive Voices Survey found that there are far fewer people with HIV in employment than in the general population (63.8% v 73.0%) and a much higher percentage of people with HIV are unemployed (17.4% v 6.4%). Unemployment

“HIV SADLY REMAINS A HIGHLY STIGMATISED CONDITION. FRIENDS, FAMILIES AND PARTNERS AREN'T ALWAYS SUPPORTIVE. PEOPLE END UP LIVING IN ISOLATION. DESPITE THE POSITIVE OUTCOMES OF MEDICATION - MENTAL HEALTH, WELLBEING, COMMUNITY AND FAMILY SUPPORT NETWORKS REMAIN A CRITICAL ISSUE FOR PEOPLE LIVING WITH HIV. CUTTING THE SERVICES THAT SUPPORT THESE, WILL EVENTUALLY UNDERMINE THE PROGRESS FROM MEDICATION AND WILL COST MORE MONEY IN THE LONG RUN.”

MARCELA #STOPHIVCUTS



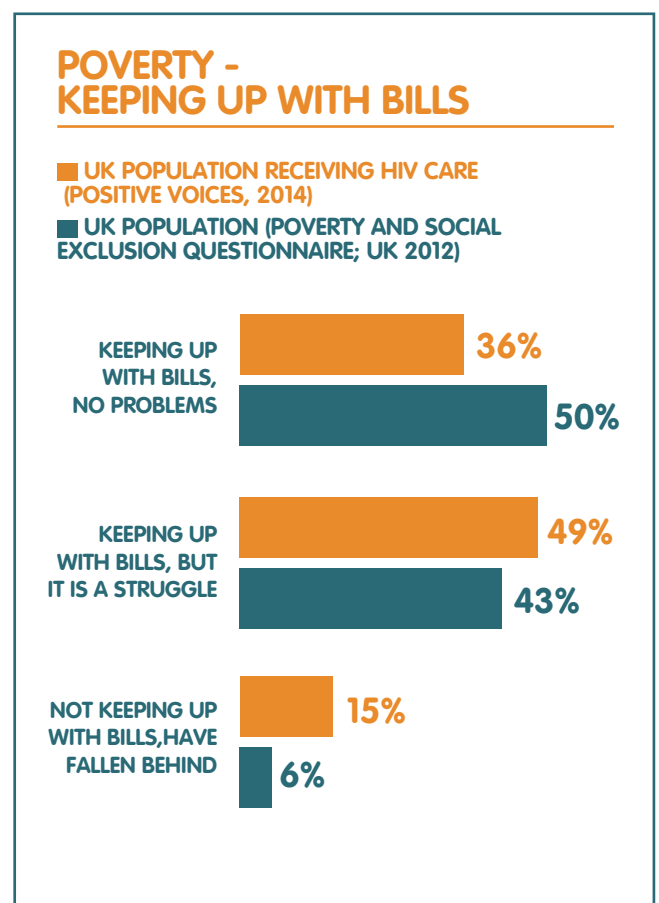
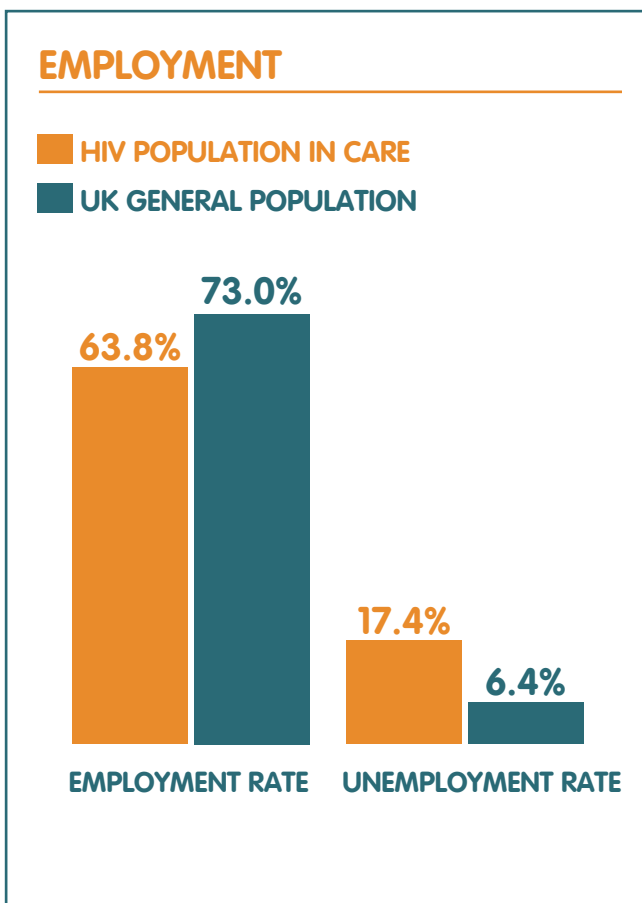
is especially elevated within the HIV positive population amongst women (25%), heterosexual men (22%), and amongst black African people (29%), 'black other' people (53%) and Asian (26%).

Positive Voices also found that whilst 6% of the general population report that they are not keeping up with bills and have fallen behind, this rises to 15% among people with HIV. A third of people (33%) with HIV report sometimes skimping on food because of poverty and a further 17% report doing so often. Twenty-nine percent (29%) of people with HIV report being in receipt of benefits (excluding child benefit).⁴⁸

The Positive Voices survey findings reflect the results of previous surveys and analysis, all of which conclude that

people with HIV experience significantly higher rates of unemployment and poverty when compared with the general population.

There is important data available on the harms which result from poverty for the health of people with HIV and for public health more widely. The ASTRA study was a cross-sectional questionnaire study in 2011/12 of over 3,000 people with HIV from eight clinics in the UK. After adjusting for demographic factors, the study found that non-fluent English, not being employed, not home owning, education below university level and increasing financial hardship were each associated with higher prevalence of a viral load which was not suppressed by HIV treatment. Much (though not all) of the impact was mediated via a failure to adhere to medication.⁴⁹ Failure





to suppress viral load results in increased morbidity to the patient and means that s/he is more likely to be infectious and pass HIV on to sexual partners.

The REACH study (2014/15) looked at engagement and retention in healthcare for people with HIV in the UK. Irregular attendance and non-attendance were associated among other things with not having money for basic needs, as well as other markers of social disadvantage such as not being a home-owner and having lower educational qualifications.⁵⁰

All support services report high levels of stress and need for advice around benefits assessments such as the Work Capability Assessment for Employment Support Allowance and the new assessments for Personal Independence Payments which have replaced Disability Living Allowance (DLA - when DLA ended 10% of people with diagnosed HIV were accessing this benefit).

WOMEN LIVING WITH HIV

KEY MESSAGES

Women living with HIV have particular needs which should be met by support services. There are, for example, treatment information needs relevant specifically to women. Women also experience elevated levels of intimate partner violence and poverty. For many women their needs intersect with their experience as migrants living within African communities. Support services must be competent and literate around the gendered experience of living with HIV.

Women make up one third of all people with HIV being seen for care in England (25,671 women in 2015⁵¹) and have a range of specific experiences and needs where support services can play a vital role. There is evidence of a high rate of intimate partner violence affecting both cis-gendered and trans women living with HIV. A

study in east London of HIV positive women conducted in Homerton Hospital found that 52% of women living with HIV had ever experienced intimate partner violence, 14% in the previous year and 14% during pregnancy. These rates are higher than those found in women attending general practice in east London. There was a strong association with mental health problems.⁵² In this context there are also concerns around the disproportionate impact of criminalisation of HIV transmission on women living with HIV, where legal expectations around condom use and disclosure of status take no account of the fact women do not wear the condom and may very sensibly not disclose as an act of self-protection.⁵³

There are treatment information needs specific to women, for example around reproductive health and contraception choices, as well as pregnancy and maternity. More broadly, women may want to know about any differences between men and women in their response to specific antiretroviral regimens. Trans women have specific treatment information needs also, for example around the interaction between hormones and antiretroviral treatment.⁵⁴ Care responsibilities for children and others often fall disproportionately on women in families and this is another area where advice and support can be crucial.

The Positive Voices survey found elevated rates of poverty amongst women living with HIV, compared not only with the general population but also with other people living with HIV. For example, 21% of women reported often having to skimp on food because of poverty (compared with 17% of all people with HIV), 36% were in receipt of benefits, excluding child benefit (compared with 29% of all people with HIV), and 25% were unemployed (compared with 17.4% among all people with HIV). There were also significantly higher rates of obesity at 46% (compared with 26% overall) and lower rates of disclosure of HIV status outside healthcare settings at 79% (compared with 84% overall).⁵⁵ Support services need therefore to be designed with the needs of women explicitly in mind.

Women make up about two-thirds of African people living with HIV in the UK and African women make up two thirds of women living with HIV in the UK. There



is therefore an interface between the needs of women living with HIV and the needs of African people with HIV – stigma and discrimination, poverty, benefits, housing and immigration issues, for example are highly gendered in experience given how many African-born people with HIV are women. NAT in its report on ‘HIV and Black African Communities in the UK’ 2014 notes that many of these issues are common to men and women but adds, ‘They are all, however, experienced by black African women as black African women – with, for example, specific beliefs and expectations for women around religious example, family roles, relationships, responsibility for children, the obligation to be resilient. Support services have to be literate in the gender-related dimensions of these many needs, offering spaces for women to help each other, providing support around family life and disclosure (or non-disclosure) in intimate relationships’.⁵⁶

DIFFERENT PEOPLE – DIFFERENT NEEDS

KEY MESSAGES

People with HIV very often come from communities already significantly affected by social and health-related disadvantage. Needs assessments should recognise the diverse experiences and needs of people with HIV and be sensitive to the way HIV interacts with other structural needs and inequalities.

The population of people living with HIV is very diverse. We have focussed above mainly on needs distributed across the whole population living with HIV. But then looked at one group of people living with HIV – women – in more detail, to make clear that such needs are experienced in the context of other specific identities.

Every individual of course has his or her own set of circumstances, experiences and needs. But there are also

specific groups within the overall cohort of people living with HIV who share particular characteristics and needs.

As demonstrated above, there are higher drugs-related needs, co-morbidities and suicide rates amongst MSM with HIV.

Children and younger people living with HIV, and living in families affected by HIV, have a range of very specific and well-documented needs which support services can help address.⁵⁷ They include support around disclosure; sexual relationships and reproductive education; adherence to medication and the long-term effects of medication; transitioning from paediatric to adult HIV care; and caring responsibilities.

Studies have shown greater stigma-related need amongst black African communities. NAT’s report on ‘HIV and Black African Communities in the UK’ noted ‘The importance of HIV support organisations and services to address the needs of black African men and women in the context of such isolation and community stigma, supplying often the only safe place where people can be themselves and discuss relevant concerns and issues’.⁵⁸

HIV support services should be designed and provided so as to meet the significant ethnic and religious diversity of the population of people living with HIV in the UK. There are many examples of such services across the UK, often having particular expertise in addressing the intersection of physical and mental health need with complex immigration issues.

People with HIV who inject drugs also have elevated needs. NAT’s report ‘HIV and Injecting Drug Use’ July 2013 found very high mortality rates amongst people with HIV who inject drugs, linked less directly to their HIV and more to the complex associated social and health needs, which includes homelessness and experience of prison. In that context, services and peer support can be immensely important.⁵⁹

There are also specific needs for trans people living with HIV.⁶⁰ Health services are too often transphobic and ignorant of trans healthcare needs. There is also a wider context of social and institutional discrimination



MOST OF US HAVE IMMIGRATION ISSUES AND IF THE HOME OFFICE HAS TREATED YOU IN A WAY THAT IS NOT APPROPRIATE, WAVERLEY CARE GIVE SUPPORT FOR THAT.”

PARTICIPANT IN NAT FOCUS GROUP, SCOTLAND

and elevated levels of poverty and deprivation. ClinicQ at 56 Dean Street is an example of a trans-led community initiative which combines sexual health clinical provision with wider support, including for trans people living with HIV. Such provision and support needs to be replicated, commissioned and fully funded across the UK in accessible centres of excellence and expertise. Further research and data are needed around trans people living with HIV, their wellbeing and needs to inform support service planning.



DOES SPECIALIST PROVISION MATTER?

KEY MESSAGES

- Many HIV support interventions cannot be replicated by generic services. These include, almost by definition, peer support. But they also include services to help people deal with HIV stigma, to cope with a diagnosis, to understand HIV treatment and the importance of adherence, to practise safer sex, and to disclose, when appropriate, one's HIV status.
- There is an important place for generic services meeting some of the information, advice and advocacy needs of people living with HIV. But HIV support services will remain necessary to help many people with HIV access such generic provision confidently and effectively, to provide HIV training for generic services and assist with complex cases, and to help ensure the services accessed by the person with HIV are as joined up and integrated as possible.
- Clinical standards for psychological support for HIV, including for community-based support, require a degree of HIV knowledge and experience not usually found in generic mental health provision such as IAPT.

SPECIALIST V GENERIC PROVISION

A number of councils have proposed decommissioning of HIV specialist support services, stating that the needs of people with HIV can be met instead by generic providers. Examples of generic provision recommended for people with HIV have included Citizens Advice, generic mental health provision (including IAPT), and local council/third sector advice services such as Law Centres and benefits/financial planning services (e.g. Lambeth's 'Every pound counts service').

In our surveys of HIV service providers and HIV clinicians there was strong support for HIV specialist provision. The degree to which such specialism was deemed essential varied by type of service – for example information, advice and advocacy had a lower

percentage considering specialism to be essential than other types of service such as peer support, self-management and sex and relationship support. Importantly, it was accepted that for most services generic provision could possibly meet some of the need. There was though a strong message that there would be significant numbers of people with HIV who would not bring HIV-specific needs to generic providers.

HIV clinicians, for example, said in response to our survey that barriers to access to support included concerns about stigma from generic services (54%) and patients wanting HIV-specialist services but only generic services being available (32%).

It is clear, looking at the range of needs and services outlined in this report, that some needs are more readily met by generic services than others. And conversely that some needs more obviously and consistently require HIV specialist provision.



“IT CAN BE VERY DIFFICULT TO FIND THE TRUST AND COURAGE TO DESCRIBE HOW HIV AFFECTS YOUR LIFE, PARTICULARLY WHEN DEALING WITH MAINSTREAM LOCAL SERVICE-PROVIDERS WHO HAVE HAD NO TRAINING IN HIV AWARENESS. FORCING PEOPLE INTO INADEQUATE SERVICES WILL LEAVE MANY WITHOUT THE SUPPORT THEY NEED.”

CHARLIE #STOPHIVCUTS

Self-management, sex and relationships, and peer support

Self-management support around HIV treatment information, adherence to HIV medication, and nutritional advice for the person with HIV, or sex and relationships support around disclosure of HIV status, sexual health and parenting of HIV positive/affected children, all demand such a detailed knowledge of the specifics of HIV, both medically and socially, that HIV specialist competence is essential. Peer support, by definition, means specialist support from other people living with HIV.

Information, advice and advocacy services

Information, advice and advocacy on the other hand – especially relating to benefits, employment, housing and immigration – deal with generic rules and systems. In theory these services should be able to support someone living with HIV just as well as anyone else. Indeed many people with HIV no doubt use such services without any need to disclose their HIV status. The difficulty arises where the individual feels that their HIV status is relevant to the support they want. For example, in relation to benefits someone might want to explain how HIV affects them differently on different days, or in relation to employment someone might want to complain about discrimination linked to their HIV status.

Where HIV has to be disclosed to an information/advice service, it is essential that the service is free from stigma and discrimination, has strong and clear confidentiality protocols (for example, private spaces for discussion so no one overhears, and clear controls over access to records and information sharing within the organisation) and an appropriate degree of core knowledge of HIV amongst all frontline staff. As importantly, the service must have the resourcing, capacity and quality to provide the service promptly, accessibly and to a high standard. We heard in our focus groups of good as well as bad experiences from generic services – so provision can be high quality and meet appropriate needs if commissioned and planned effectively.

HIV specialist services could well have a role in providing training on an ongoing basis for generic services staff, acting as a ‘friend’ and advocate with generic services, and also being somewhere for people with more complex and intersecting needs to be referred.

Psychosocial support

The Standards for psychological support for adults living with HIV were published in 2011 by MEDFASH, the British HIV Association and the British Psychological Society, and are endorsed by a range of other bodies including the RCN and the RCGP. They are also the basis for Standard 6 (Psychological care) of BHIVA’s Standards of Care for People Living with HIV (2013).



The national service specification for adults living with HIV, from NHS England, cites the Standards for psychological support as ‘key standards relevant to the specification’.

The Standards advocate a ‘stepped care approach’ to the psychological needs of people living with HIV, involving four levels from Level 1, the most generic, to Level 4, the most specialised. Reading the Standards, it is clear that the majority of mental health care at all four Levels requires significant HIV-related knowledge and specialism.

At Level 1 (‘provided by all practitioners directly responsible for the care of PLWH in statutory and non-statutory services’) there is a requirement to ‘understand cultural issues pertaining to HIV, health beliefs, sexuality and stigma’ and interventions include ‘talking about sexual matters’. At Level 2 assessment is required at various key HIV-related events such as HIV diagnosis, onset of symptoms, starting or switching medication, non-adherence to medication, when experiencing HIV stigma, at times of co-infection with TB or hepatitis C, to name just a few which are cited. The interventions likewise revolve around such provision as post-test discussion, adherence support, sexual risk reduction, support around adaptation to living with



WE HEARD IN OUR FOCUS GROUPS OF GOOD AS WELL AS BAD EXPERIENCES FROM GENERIC SERVICES – SO PROVISION CAN BE HIGH QUALITY AND MEET APPROPRIATE NEEDS IF COMMISSIONED AND PLANNED EFFECTIVELY.

HIV, education around coping with and understanding mental health problems, and substance misuse support. In other words, for Level 2 psychological support the national Standards require a significant degree of HIV-related experience and knowledge.

“GENERIC PROVIDERS OFTEN HAVE VERY LIMITED UNDERSTANDING OF THE SPECIFIC NEEDS AND CONCERNS OF HIV POSITIVE PEOPLE AROUND ISSUES SUCH AS CONFIDENTIALITY, DISCLOSURE AND IMPACT OF STIGMA. INDEED SOME GENERIC SERVICES ARE RESPONSIBLE FOR EXPRESSING ILL-INFORMED, STIGMATISING AND DISCRIMINATORY ATTITUDES.”

HIV CLINICIAN RESPONDENT TO NAT 2015 SURVEY



“ I’M LIVING WITH HIV MYSELF AND HAVE BEEN LUCKY ENOUGH TO ACCESS SERVICES IN THE PAST IN LONDON, ESSEX AND SUFFOLK, AND I’M SURE I WILL BE IN NEED OF SUPPORT IN THE FUTURE... A WORRYING TREND IS THE BELIEF THAT EVERYTHING WE EVER NEED CAN BE FOUND ONLINE, THAT THERE’S NOT A NEED FOR HUMAN CONTACT. THERE ABSOLUTELY IS A NEED FOR HUMAN CONTACT, A FACE TO A NAME, A SMILE, SOMEONE TO EXPLAIN IN NORMAL LANGUAGE. THOSE IN RURAL AREAS SOMETIMES STRUGGLE THE MOST, AND ARE EXPECTED TO TRAVEL MILES TO ACCESS SUPPORT. IF THOSE SERVICES WHICH ARE MILES AWAY ARE CUT, WHERE DO THOSE PEOPLE IN THOSE RURAL LOCATIONS GO? EVERY CUT HAS A WIDER REACHING EFFECT THAN PEOPLE THINK.”

ANDY #STOPHIVCUTS

This continues for Level 3 services, ‘Counselling and psychological therapies’, which are described in the Standards as ‘HIV-specialist’. It is only at Level 4, where there are severe and complex needs, where generalists are cited as professionals to whom referrals could be made.

HIV support services will often provide counselling and psychological support especially at Levels 2 and 3. It is clear that their detailed knowledge of the lived experience and challenges of HIV is an essential element of their competence and effectiveness. Very few generic providers will also have that degree of HIV specialism.

IAPT services have been proposed by some commissioners as an appropriate alternative to HIV

support services around psychological need. There is not much evidence of the acceptability or effectiveness of IAPT for people living with HIV. Whilst IAPT can meet low level adjustment needs, for example in relation to diabetes or CVD diagnoses, it is less suited to complexity and risk. It is not, for example, designed to address co-morbidities around stigma, drug and alcohol use and sexual risk, and these matters do not form part of the IAPT curriculum. One clinician in responding to our survey did mention successful use of IAPT. We have also heard more sceptical views. There is urgent need for further evidence on acceptability of IAPT for people with HIV and on outcomes.



CURRENT CAPACITY WITHIN GENERIC SERVICES

Some councils present the decommissioning of specialist support and the proposal that instead people with HIV access generic services as a way of securing efficiencies to meet need and also destigmatising and normalising HIV. The reality, however, is in too many instances very different. People with HIV are not being referred to well-resourced generic providers fully trained on HIV, but to services which are themselves facing massive cuts, too often demoralised and unable even to meet current need promptly and well, let alone new service users living with HIV.

This is not the fault of local authorities. It is a result of austerity and cuts to local authority and legal aid budgets, as well as constraints on NHS budgets which make it hard for health services to meet increases in need.

In relation to mental health, in 2013 the We Need To Talk coalition found that over half the people needing IAPT had been waiting over three months to receive their treatment, and of those who had accessed IAPT half felt there were insufficient sessions.⁶¹ Media reports present a similar picture with *Pulse* stating that 'Talking therapies are "bursting at the seams", with GPs turning to prescribe more antidepressants to combat the long waiting times'.⁶²

As of March 2015, almost 100 Citizens Advice branches have been closed or lost to merger since 2009 as a result of cuts to local authority and legal aid budgets.⁶³ There is a random geographical variation in Citizens Advice provision depending on the different approaches of often neighbouring local authorities. Citizens Advice have secured some national government contracts around specific advice, for example the Pension Wise service. In response to criticism from some pensions experts on the content of their advice, Citizens Advice CEO Gillian Guy has made clear that they will not be able to provide specialist pensions advice but only deliver guidance. This interestingly highlights both the great value of Citizens Advice but also their limitations. Generic and specialist provision must work hand in hand.

PEOPLE WITH HIV ARE NOT BEING REFERRED TO WELL-RESOURCED GENERIC PROVIDERS FULLY TRAINED ON HIV, BUT TO SERVICES WHICH ARE THEMSELVES FACING MASSIVE CUTS, TOO OFTEN DEMORALISED AND UNABLE EVEN TO MEET CURRENT NEED PROMPTLY AND WELL, LET ALONE NEW SERVICE USERS LIVING WITH HIV.

In 2014 the Low Commission estimated at least a 20% shortfall in funding for advice and legal support services from 2015 for even the 'basic level of provision of information, advice and legal support on social welfare law'.⁶⁴ Shelter has closed nine of its advice centres as a result of cuts to legal aid funding.⁶⁵ Cuts to advice centre funding mean according to the Low Commission 'many advice centres being cut in the face of unprecedented demand. Reducing financial support places pressure on services, reduces the number of advice agencies and their capacity to proactively respond to people's issues over the longer term'.⁶⁶ Law centres similarly saw cuts in revenue of 40% in the last parliament, with some centres closing altogether as a result and others reducing services and the numbers they can help, at a time of rising need.⁶⁷ This trend appears to be continuing



THERE'S NO BACK UP INFORMATION SUPPORT FOR THEM [GENERIC SERVICES] SO THEY KNOW HOW TO PROVIDE THEIR SERVICES WHILE DEALING WITH A PERSON'S UNDERLYING CONDITION."

PARTICIPANT AT NAT FOCUS GROUP, SCOTLAND

with the Law Centres network noting in the 2015 legal aid statistics a decrease in housing cases on legal aid despite increasing homelessness and a 61% decrease in help for debt despite the escalating problem of household debt.⁶⁸

RETAINING A 'MIXED ECONOMY'

The debate over 'specialist' v 'generic' services can be pitched as a binary either/or choice. But that is a mistake. A key function of HIV specialist support services is to signpost and enable people to access generic services and make the most of them. Whether it is applying for benefits or housing, or accessing mental health or addiction services, the support of the HIV organisation can make such generic access possible and help ensure it is effective. A well prepared service user, equipped by HIV specialist support to be as clear as possible on their circumstances and needs and motivated to remain in contact with the generic service, ensures that generic service monies are well spent and have the desired impact.

Conversely, the HIV specialist support can be a place of referral by generic services of people with HIV with particularly complex needs and problems.

Finally, the HIV support service fulfils a key role in integration of services, beginning with the needs of the

'whole person', meeting many of those interconnected needs within the organisation but also acting as a hub and coordinator, in partnership with the person with HIV, as they access a range of separate generic services.

RECOMMENDATIONS

HIV specialist support should be retained locally both to meet needs which generic services are unable to provide appropriately (for example peer support), and also to complement, train and work alongside generic provision.

Both CCGs and local authorities should monitor the experience, acceptability and use of the generic services they commission for people with HIV. They should identify and agree with people with HIV living locally what makes a generic service useful and acceptable.

Generic services should never be proposed as an acceptable alternative to HIV-specific services when those generic services are under-resourced, failing to meet demand appropriately even without HIV positive service users, and where staff of such services have not been meaningfully and effectively trained on HIV issues.



CASE STUDY FROM SAHIR HOUSE, HIV VOLUNTARY SECTOR ORGANISATION, LIVERPOOL

A man in his late 40s with physical and mental health issues was referred to Sahir House by a local sexual health clinic due to concerns about his mental health. At assessment a range of issues were identified and twice weekly visits from the Sahir House support worker were agreed with the service user.

He was experiencing financial and debt problems with mortgage arrears. As a result of the support provided, his home is no longer at risk of repossession and his mortgage arrears are being managed. He is managing his finances better – he received benefits advice and his benefits have been maximised for his situation. As a result, he is able to pay his bills and a debt management plan has been established.

He and his partner were experiencing HIV-related stigma, homophobic abuse and hate crime in their local area. The support provided by Sahir House included arranging police involvement and improving his home security and as a result his safety has increased. He and his partner have also been supported to access local support groups, addressing the isolation they were experiencing.

His physical and mental health are being addressed. The Sahir House support worker arranged multi-professional meetings to coordinate his healthcare and a social services assessment was arranged. His decline in physical health is now being managed. He has been referred to external support agencies and is now receiving support from a local mental health charity.

CASE STUDY FROM SAHIR HOUSE, HIV VOLUNTARY SECTOR ORGANISATION, LIVERPOOL

B is a gay male who has been receiving support from Sahir House for the last four months. He presented with quite complex needs: ongoing mental health issues (relating to a long-term mental health diagnosis) had affected his motivation and willingness to take and adhere to both mental health medication and antiretroviral treatment for his HIV. The client was also experiencing ongoing debt problems which he had attempted to tackle with a local support service – but again his mental health issues had meant engagement with this service was sporadic. Compounding everything, B had been the victim of a homophobic attack and sustained homophobic abuse from his neighbours.

He was supported by Sahir House to report this to the police. He was also supported to find new, suitable accommodation where he felt safe and provided a letter in support of his application to his social landlord. He also received welfare rights support at Sahir House to apply for a community care grant. This application was successful and the client was awarded £1,000 to purchase or replace (faulty) appliances and other essential items. Sahir House has provided ongoing advocacy for B and calls have been made to his debt worker who continues to progress this work and alleviate some of the emotional stress he faces. B has also shown some progress with adherence to medication as he reports fewer missed doses and he has recently re-engaged with taking mental health medication.



EVIDENCE ON OUTCOMES AND EFFECTIVENESS

KEY MESSAGES

- There is considerable research evidence of the effectiveness of the kinds of intervention provided by HIV support services, for example peer support, advice and information services, and self-management education.
- Many HIV support providers have impressive evidence of the success and impact of their services.
- Gaps in the evidence cannot be an excuse not to commission services to meet need.
- Current initiatives to agree outcomes measures nationally around HIV support services and more generally for long-term condition support are welcome. They have the potential to assist commissioners and providers and to build a stronger evidence-base around what does and does not work in service provision.

COMMUNITY-BASED APPROACHES FOR PEOPLE WITH LONG-TERM CONDITIONS

There is considerable evidence of the effectiveness of community-based support services for people with long-term conditions.

There is, for example, good evidence that peer support provides significant benefits to people with long-term conditions. National Voices and Nesta summarised evidence from over 1,000 studies in 'Peer support: What is it and does it work?'. Whilst the report identifies evidence gaps and the need for further research, it found that peer support has the potential to improve experience, psychosocial outcomes, behaviour, health outcomes and service use among people with long-term physical and mental health conditions.⁶⁹

The importance of advice services has recently been powerfully demonstrated in the June 2015 report from the Advice Services Alliance and the Low Commission,

'The Role of Advice Services in Health Outcomes'. Looking at 140 research studies in the field, it concludes that 'welfare advice provided in health care settings results in better individual health and wellbeing and lower demand for health services'. Benefits include 'lower stress and anxiety, better sleeping patterns, more effective use of medication, smoking cessation and improved diet and physical activity'.⁷⁰ The Report notes the need for stakeholders to work together to develop agreed outcome measures and evaluation tools (see more below) but certainly the evidence of benefit is already there.

The 'Realising the Value' programme is a partnership led by Nesta and the Health Foundation and funded by NHS England to develop the evidence-base around person- and community-centred care, taking its cue from the ambitions of the NHS Five Year Forward View. Their report 'At the heart of health: Realising the value of people and communities' summarises the evidence for effectiveness around five types of approach to people with long-term conditions – peer support; self-management education; health coaching; group activities to support health and

wellbeing; and asset-based approaches in a health and wellbeing context.

There is good evidence for positive outcomes from such approaches especially for mental and physical health and wellbeing. This is particularly true for peer support and self-management education. Benefits of peer support include individuals' knowledge, skills and confidence to manage their health condition; physical functioning and ability to self-care; quality of life; and social functioning and perceived support.⁷¹ The greater perceived empathy and respect gained through support from a peer is a key benefit. Importantly, 'groups work well when they are not time-limited or tied to the delivery of particular training content, but can offer a mechanism for responsive, sustained support'.⁷²

Benefits of self-management education include health outcomes such as self-efficacy (that is, belief in one's ability to complete tasks and reach goals), knowledge, skills and confidence to manage one's condition ('patient activation'), self-rated health; clinical or biomedical outcomes; and social outcomes such as improved communication and relationships. Furthermore, 'there is some evidence that disease specific self-management education programmes may be more effective than generic courses ...'.⁷³

In relation to patient activation measures (PAMs), a King's Fund report states, 'A study of HIV patients found that every five-point increase in PAM scores was associated with a significant improvement in CD4 counts, adherence to drug regimens and viral suppression (Marshall et al 2013)'.⁷⁴

It is also worth noting, however, the repeated emphasis in the 'At the heart of health' report on the fact that in many areas the evidence base 'is still at a much earlier stage of maturity'. This applies both to particular interventions, and also to cost-effectiveness analyses. Some of the evidence is 'mixed or inconclusive'. An intervention may bring particular benefits to people with one condition but have a different set of benefits for those with a different condition – which underlines the need for far more evidence around the specific impacts of these services on people living with HIV.

BENEFITS OF PEER SUPPORT INCLUDE INDIVIDUALS' KNOWLEDGE, SKILLS AND CONFIDENCE TO MANAGE THEIR HEALTH CONDITION; PHYSICAL FUNCTIONING AND ABILITY TO SELF-CARE; QUALITY OF LIFE; AND SOCIAL FUNCTIONING AND PERCEIVED SUPPORT. THE GREATER PERCEIVED EMPATHY AND RESPECT GAINED THROUGH SUPPORT FROM A PEER IS A KEY BENEFIT.

Importantly, the incompleteness of the evidence base is not a reason for inaction – the report goes on to say, 'we strongly believe that we need to combine a continued focus on building the research evidence along with implementing, testing and evaluating these approaches in practice ... While we should continue to strive to improve the evidence of the impact of these approaches, we believe a compelling case has been made to adopt and implement them now'.⁷⁵



EVIDENCE OF IMPACT

Peer support

Positively UK is a charity which has provided significant peer support services over many years. Their report 'Improving well-being: The effectiveness of peer support' January 2014 sets out outcomes for their services:

- 89% said that peer support improved their emotional wellbeing
- 88% said that peer support improved their understanding and management of HIV
- 84% said that peer support helped them access all the services they need.⁷⁶

Similarly, 95.2% of respondents said that peer support had slightly (18.1%), significantly (36.2%) or very significantly (40.9%) improved their wellbeing.⁷⁷ Positively UK point to the NHS Outcomes Framework and Domain 2 'Enhancing quality of life for people with long-term conditions', and in particular the parameter, 'Ensuring people feel supported to manage their condition'. The effectiveness of peer support for people with HIV is directly relevant to this ambition of the NHS Outcomes Framework. The report also shows

substantial improvement (of 12%) from peer support as measured by the Warwick Edinburgh Mental Well-being Scale. A variety of peer support services were included in the assessment – one-to-one, group, by email and by telephone.

The Bloomsbury Clinic support group at Mortimer Market reports that in 2014 they saw 2,000 patients roughly split 50/50 between one-to-one and group peer support. There was for their newly diagnosed course a 98% satisfaction rate with reporting of marked improvements against measured criteria such as confidence in disclosure, feeling able to get more information about HIV and HIV medications, understanding of how HIV is transmitted and of how to access PEP.

One important finding is that mentors as well as recipients of the services often report benefits, for example in an independent evaluation of Positively UK's 'Mentor Mothers' programme.

Advice, information and advocacy

The impact of HIV support services around advice, information and advocacy is also evident from much of the peer support work cited above, which



89%

OF RESPONDENTS SAID THAT PEER SUPPORT IMPROVED THEIR EMOTIONAL WELLBEING



88%

OF RESPONDENTS SAID THAT PEER SUPPORT IMPROVED THEIR UNDERSTANDING AND MANAGEMENT OF HIV



84%

OF RESPONDENTS SAID THAT PEER SUPPORT HELPED THEM ACCESS ALL THE SERVICES THEY NEED.



“AS A GROUP THE BENEFIT IS IMMENSE. I NOW FEEL I BELONG SOMEWHERE. I CAN SHARE MY FEELINGS WITHOUT FEAR. I AM NOW IN A POSITION TO SUPPORT OTHERS WISHING TO KNOW THEIR STATUS. I RELATE BETTER ... SHARING EXPERIENCES WITH PEOPLE IN SIMILAR SITUATIONS IS REWARDING. I HAVE GAINED SO MUCH CONFIDENCE AND EVEN SHARED MY EXPERIENCE OF LIVING WITH HIV. I FEEL EMPOWERED TO DISTRIBUTE HIV/AIDS MATERIALS AND INFORMATION IN THE COMMUNITY. SOMEHOW I FEEL GREAT.”

PARTICIPANT IN THE PEER SUPPORT PROGRAMME OF THE AFRICAN ADVOCACY FOUNDATION

often includes such interventions. For example, the peer support provided by the Bloomsbury Network includes advice on immigration, employment, benefits and housing, as well as on such issues as starting medication, disclosure and confidentiality issues.⁷⁸

Many of the providers we heard from reported good outcomes from their advice and information services. To take one example, the Brigstowe Project in Bristol reports for 2014/15 providing housing advice to 27 clients with 94% achieving a positive outcome, including 10 of them being able to establish or renew a tenancy or have a housing duty accepted by the local council. Financial advice to 56 clients had a 72% positive outcome and advice to 35 clients on other entitlements and services had an 83% positive outcome. Their Migrant Advice and Support service supported 17 clients in that year, with all achieving two or more positive outcomes around access to legal advice, increased skills and knowledge, improved housing situation, improved access to community care and healthcare, improved financial situation, improved

self-management, improved relationships management and community participation.

Psychosocial support and behavioural interventions

THT's Life Plus project involving local health trainers for people with HIV showed that 79% of participants responding to their questionnaire reported an improvement in emotional wellbeing. Body and Soul reported that 80% of their service users said that as a result of the service they were happier, had improved confidence levels and were better able to express thoughts and feelings.

Views of HIV clinicians

In our 2015 survey of HIV clinicians on their experience of and views on the impact of HIV support services on their patients' wellbeing, 97% agreed that HIV support services produced positive outcomes for their patients. A range of outcomes were cited by clinicians as being



attributable to the use of support services (the percentage of clinicians responding who cited the relevant outcome is included in parentheses). These included:

- Coping better with diagnosis (91%)
- Improved emotional wellbeing and/or reduced isolation (89%)
- Improving various social factors which indirectly but significantly affect patients' health – employment, housing, finances etc (82%)
- Improving confidence around disclosure (80%)
- Improved mental health (71%)
- Improved treatment adherence (62%).

This 2015 survey mirrored a similar survey of clinicians' views on social care support we published in 2011 and to which 149 healthcare professionals responded.⁸⁰ There was particular mention by clinicians in that 2011 survey of the benefits of specialist social work support (77%), peer support (77%) and counselling (74%).

DEVELOPING OUTCOME MEASURES

There is an understandable focus at the moment to ensure public money is effectively and productively spent. Activity has to be clear as to the outcomes which are aimed at and measure the extent to which those outcomes are achieved. Despite the examples above of effectiveness of support services, more could be done to develop this evidence base. There is now an emphasis from the NHS on identifying measures which can be replicated nationally across the health system to achieve some consistency in commissioning, provision and benchmarking/assessment of impact.

Patient Activation Measures

NHS England has a system of financial incentives known as CQUINs linked to service improvements to be

“ I’M AN NHS CONSULTANT WHO SEES THE FIRST HAND BENEFITS TO PATIENTS OF COMMUNITY-BASED SUPPORT SERVICES. THESE SERVICES ARE PARTICULARLY ACCESSED BY THE MOST VULNERABLE. THE CONSEQUENCE OF ‘SAVINGS’ AT LOCAL AUTHORITY LEVEL ARE SHORT-SIGHTED AND WILL HAVE ADVERSE HEALTH AND WELLBEING IMPACTS ON PATIENTS WHICH WILL DRIVE UP OVERALL COSTS (VIA NHS AND OTHER AGENCIES).”

MARK #STOPHIVCUTS



HIV CLINICAL NURSE SPECIALISTS (CNS) – AN ECONOMIC ASSESSMENT OF THEIR IMPACT

The role of the clinical nurse specialist is often provided out of the HIV clinic, rather than from a voluntary sector organisation, and is commissioned by local authorities or CCGs. This role has also been affected by uncertainty on commissioning responsibility and by budget cuts. Work has been undertaken by Shaun Watson, Community HIV Clinical Nurse Specialist, Chelsea & Westminster NHS Foundation Trust, to assess the economic benefits of this support service.⁷⁹

The HIV CNS engages in complex case management (vigilance and rescue work around safeguarding and vulnerabilities), adherence management and support, symptom control management and support,

assessment and care planning and multi-disciplinary liaison and team approach to care delivery.

With an active caseload of between 60 and 70 patients in Westminster, it is estimated that between £162,500 to £260,000 is saved in a year from avoidance of ARV wastage (assuming 50% wasted without intervention). To that must be added the far greater savings from onward transmissions prevented (since non-adherence means people with HIV can pass HIV on). Significant costs are also avoided elsewhere in the health and care system from prevention of calls on ambulance services, A&E departments, hospital bed days, GP appointments and mental health services.

delivered by providers. One of the current CQUINs is around 'Activation for patients with long-term conditions' with people with HIV specifically mentioned as a patient group who can benefit. A standard tool, the 'patient activation measure', or PAM, licensed from Insignia, must be used by all participants in this CQUIN scheme.

The rationale is described as follows, 'There is a substantial body of evidence demonstrating that patients with long-term conditions with higher levels of activation (the knowledge, skills and capacity to manage their own condition) have better outcomes including reduced frequency of exacerbations and associated high cost interventions. There is also evidence that information about activation levels can be used effectively to focus intervention on patients groups more effectively. There is currently no regular and consistent systematic assessment of activation levels for PSS patient groups who are likely to benefit from implementation of an activation system'.⁸¹

Effective interventions tend to focus on development of skills and building of confidence; use peer support,

changes in social environment, health coaching and educational classes; and take place in a variety of settings including community, workplace, secondary and primary care. HIV support services certainly deliver around patient activation – 'the knowledge, skills and capacity to manage their own condition' – and the rolling out of PAMs offers the prospect of this being consistently captured across our health system.

Work on HIV-related outcome measures

HIV-specific outcome measures are also being developed. BHIVA is working on Patient Reported Experience Measures (PREMS) for people with HIV which have the potential to capture not just experience of their specialised healthcare but also broader indicators of wellbeing where HIV support services have a definite role. Past work can also feed into outcomes development, for example the 'measurable and auditable outcomes' in BHIVA's Standards of Care for People Living with HIV 2013. Positively UK are launching Standards for HIV peer support with outcome



measures which can be used across local areas by commissioners and providers to identify relevant outcomes and assess effectiveness.

All these national initiatives are welcome. It will be important for outcome measures for people with HIV to map on to each other and have a degree of consistency. It is as important for there to be agreed generic outcome measures relevant across long-term conditions and linked to an agreed taxonomy of interventions.

Over the years HIV service providers have complained of the variety and scale of reporting requirements made of them by some commissioners and their sense that when the information was provided it was not then used to inform commissioning going forward. Agreed national outcomes around the long-term condition management of people with HIV, as part of a wider set of outcomes for all people with long-term conditions, would support effective commissioning and provision of services, as well as develop the essential evidence-base for impact and service improvement.

RECOMMENDATIONS

Best available evidence of effectiveness should be used to commission and provide HIV support services. Services and their outcome measures should be planned to contribute optimally to further research on evidence of impact.

All HIV support services should be agreeing outcome measures, monitoring impacts and publicising their results.

The current NHS England support for Patient Activation Measures is an opportunity to frame HIV support services as a key contributor to such activation. Discussions should take place between the HIV Clinical Reference Group, BHIVA and HIV support service providers to agree how best to promote patient activation for people with HIV, drawing on and developing current clinical and voluntary sector infrastructure and capacity.

Support services for people with HIV, and for people with long-term conditions generally, should be consistently classified, to an agreed taxonomy, to assist research, consistent commissioning and provision. Discussion should take place across HIV and other long-term condition charities with the NHS and Public Health England to initiate this project.



CURRENT POLICY PRIORITIES, GUIDELINES AND STANDARDS

KEY MESSAGES

- There is an overwhelming policy case for the commissioning of HIV support services. National policy on long-term condition management, as set out, for example, in the House of Care model, and as emphasised in the NHS Five Year Forward View, prioritises support in self-management and a focus ‘beyond medicine’ on wider mental health and social elements to wellbeing, as well as the key role of the voluntary and community sector in the delivery of relevant services. HIV support services have over more than 30 years modelled such provision and care. It is extraordinary and unacceptable for anyone to consider entirely decommissioning such HIV services just at the moment the wider health system is waking up to the relevance of this sort of support for all long-term conditions.
- Commissioning services from the HIV voluntary and community organisations meets explicit policy expectations on the social value of such organisations’ reach with marginalised groups, their impact on health and social care engagement, their employment of HIV positive staff and volunteers, and their ability to provide advice and expertise to the local health and care system.
- HIV support services are clearly set out in NHS England’s national service specification for HIV specialised services as an essential part of the care pathway, as well as in clinical guidelines.
- Local health and care systems must identify the needs of people with HIV and plan and commission appropriate support services. Not to do so is to neglect their responsibilities.
- HIV support services have constantly adapted to changes in clinical treatment, in epidemiology and in healthcare. Further modernisation is now needed to meet current developments in need and commissioning practice. Commissioners should work in partnership with HIV support services to identify new models of support, ensuring needs are consistently and appropriately met.

NATIONAL HEALTH POLICY FOR LONG-TERM CONDITIONS

HIV is without doubt a long-term condition and HIV support services align perfectly with the ambitions of the NHS and the Department of Health around long-term condition management.⁸²

The NHS Five Year Forward View

The most significant current policy framework for healthcare is that set out in the **NHS Five Year Forward View** which notes that long-term conditions now take up 70% of the health service budget. Its vision for those with long-term conditions such as HIV is one of person-centred care and supported self-care:



‘.. we will do more to support people to manage their own health – staying healthy, making informed choices of treatment, managing conditions and avoiding complications. With the help of the voluntary sector partners, we will invest significantly in evidence-based approaches such as group-based education for people with specific conditions and self-management educational courses, as well as encouraging independent peer-to-peer communities to emerge.’⁸³

There is a clear emphasis on the role of the voluntary sector to partner with the NHS in delivering effective care, and a commitment to develop more straightforward and multiyear funding arrangements:

‘Stronger partnerships with charitable and voluntary sector organisations: When funding is tight, NHS, local authority and central government support for charities and voluntary organisations is put under pressure. However, these voluntary organisations often have an impact well beyond what statutory services alone can achieve ... these organisations provide a rich range of activities, including information, advice, advocacy and they deliver vital services with paid expert staff. Often they are better able to reach underserved groups, and are a source of advice for commissioners on particular needs.’⁸⁴

The House of Care

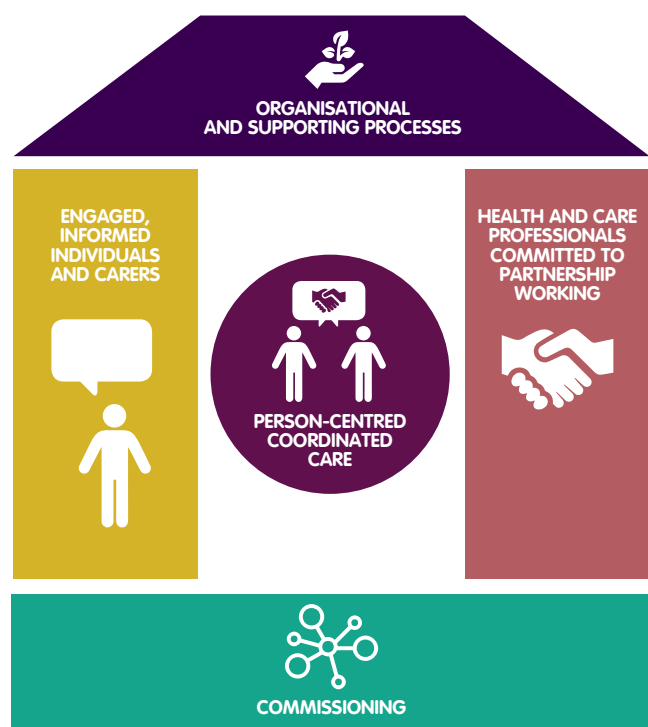
NHS policy in England focuses in particular on the House of Care model⁸⁵ which aims to address long-term conditions by moving away from a ‘medical model’ towards ‘a model of care which takes into account the expertise and resources of the people with long-term conditions (LTCs) and their communities to provide a holistic approach to their lives and help them achieve the best outcomes possible’.

Barriers to great care include ‘a lack of attention to the mental health and wellbeing of people with ‘physical’ health problems’; ‘failure to support people with ‘more than medicine’ offers as provided by, for example, third and voluntary sectors’; ‘failure to identify vulnerable people who might then be given extra help to avoid hospital admission or deterioration/complications of their condition(s)’; and ‘services which treat people as

passive recipients of care rather than encouraging self-care and recognising the person as the expert on how his/her condition affects their life’.⁸⁶

One of the ‘walls’ in the House of Care is ‘Engaged, informed individuals and carers’ and within that, one of the components is ‘Group and peer support’ where peer support, structured education programmes and community champions are all mentioned as important and helpful services – again often in fact provided by HIV support services at a local level. It also includes ‘services provided through voluntary and community services, schools, Local Authorities and other public services’ supporting people ‘to more confidently manage their health and wellbeing’.⁸⁷ The House of Care model is central to the NHS vision of personalised care and support.

Importantly, Clinical Commissioning Groups (CCGs) are seen as the key commissioners responsible for ensuring such a House of Care is established for people with long-term conditions in their local area. Whilst some





CCGs are involved in the commissioning of HIV support services, NAT's ongoing research suggests they are very much in the minority. This despite the fact that HIV support services are obvious examples of long-term condition management and 'House of Care' provision.

The Outcomes Frameworks

The current emphasis on addressing long-term conditions is reflected in the three Outcomes Frameworks, for the NHS, Adult Social Care and Public Health.⁸⁸ **The NHS Outcomes Framework** has its Domain 2 'Enhancing quality of life for people with long-term conditions'. Improvement areas include people feeling supported to manage their condition, employment, and quality of life for people with multiple long-term conditions. Given the challenge of managing a stigmatised condition such as HIV, as well as the low rates of employment and high rates of co-morbidity with other long-term conditions, HIV support services can clearly contribute to meeting relevant indicators in the NHS Outcomes Framework.

Similarly, **the Adult Social Care Outcomes Framework People** within its Domain 1, 'Enhancing quality of life for people with care and support needs', has an outcome measure that 'people are able to find employment when they want, maintain a family and social life and contribute to community life, and avoid loneliness or isolation'. Again these indicators are very relevant to HIV with its impact on employment and family/social relations. **The Public Health Outcomes Framework** has a measure on the employment of people with long-term conditions, as well as a domain relating to the prevention of premature mortality.

Legal Duties

Public bodies often have a legal duty to perform their functions and make their decisions in a certain way. Two legal duties are of especial relevance to commissioners when considering the needs of people living with HIV locally and the role of HIV support services.⁸⁹

One is the Public Sector Equality Duty (PSED) under section 149 of the Equality Act 2010. The PSED

applies to the 'protected characteristics' under the Act, one of which is disability. Under the same Act, all people living with HIV are considered to have a disability for the purposes of discrimination law. Furthermore, the majority of people living with HIV share other characteristics which are protected under the Act – for example, many will be MSM protected on the basis of sexual orientation and many will be of black African ethnicity protected on the basis of race.

The PSED places public bodies under a duty to have due regard to the need to 'eliminate discrimination, harassment, victimisation and any other conduct that is prohibited by or under this Act'. Given the stigma and discrimination experienced by people living with HIV, support services' role and advocacy in enabling people to address discrimination, and to complain and challenge it when it is experienced, is extremely important. Similarly, there should be due regard to the need to 'encourage persons who share a relevant protected characteristic to participate in public life or in any other activity in which participation by such persons is disproportionately low'. Again, HIV support services are for many people vitally important in equipping them to disclose, to access mainstream services, to get back into work and to take part in wider social activity.

These are just two examples of how the PSED might be relevant to the case locally for HIV support services – there are others. A public body, including local commissioners, will need to show that they have considered relevant inequalities and needs, consulted on how to address them, and acted reasonably and proportionately in coming to their decisions in the light of these equality considerations.

The second legal duty, under the National Health Service Act 2006, as amended by the Health and Social Care Act 2012, is for NHS England (s 13G) and CCGs (s 14T) to have due regard to the need to reduce inequalities between patients in access to health services and outcomes achieved. We have shown earlier both how people with HIV can have difficulty accessing healthcare services confidently given issues of disclosure and stigma; and also that they experience in many areas of physical and mental health worse health outcomes than others. Support services play a vital role in addressing the health inequalities experienced by people living with HIV.



Particular mention should be made of the duties on both CCGs (s 14Z1) and on NHS England (s 13N) to exercise their functions in relation to health inequalities ‘with a view to securing that health services are provided in an integrated way, and are integrated with health-related and social care services, where they consider that this would improve quality, reduce inequalities in access to those services or reduce inequalities in the outcomes achieved’. Given the overlapping commissioning responsibilities around HIV support services, this duty around integration across organisational boundaries (including with local authority social care functions) is especially important.

There is also the duty under s 2 of the Health Act 2009 to have due regard to the NHS Constitution which again includes values and commitments around health inequalities, as well as other issues relevant to people with HIV.

SUPPORTING THE LOCAL VOLUNTARY AND COMMUNITY SECTOR

Whilst HIV support services can be provided by a range of providers, in practice a high proportion are provided by HIV-specific voluntary and community organisations. Consideration of the case for HIV support services links to consideration of the value of local patient and community organisations existing and thriving.

The recent ‘**Joint review of partnerships and investment in voluntary, community and social enterprise organisations [VCSE] in the health and care sector**’, produced by representatives of the VCSE sector, the DH, NHS England and PHE, stresses the key role of the VCSE sector in ‘helping marginalised people to have their voices heard’.⁹⁰ The review emphasises the role of the sector in engaging with local health and care decision-making and ensuring, from a health equalities perspective, that all voices are heard – for example, in the JSNA (Joint Strategic Needs Assessment) process. Targeted support for smaller community organisations is encouraged ‘as fewer people will be left unsupported where there is a wide

range of community-based and innovative interventions from which to choose’.⁹¹

The **market-shaping duty** for local authorities under section 5 of the Care Act 2014 is especially relevant to commissioning decisions affecting HIV support services. This new duty requires local authorities ‘to facilitate and shape their market for adult care and support as a whole, so that it meets the needs of all people in their area who need care and support, whether arranged or funded by the state, by the individual themselves, or in other ways’.⁹³ One key element to such market shaping is ‘supporting sustainability’.

Local authorities ‘must work to develop markets for care and support that – whilst recognising that individual providers may exit the market from time to time – ensure the overall provision of services remains healthy in terms of the sufficiency of adequate provision of high quality care and support needed to meet expected needs. This will ensure that there are a range of appropriate and high quality providers and services for people to choose from’.⁹⁴

There is an obligation under this duty to ensure choice through different types of service provision and provider, and to facilitate information and advice services to support people’s choices for care and support. Market-shaping strategies should be co-produced with local communities and stakeholders (including health bodies) which should be linked to the local Joint Strategic Needs Assessment (JSNA).

The significance of the market-shaping duty is its requirement for local authorities to think about the availability of services, including those which they do not commission themselves, which promote the wellbeing of their residents. That means for a start that when decommissioning a service there should be consideration of the impacts of such a move for the sustainability of the organisation concerned and the ongoing availability of choice for service users. It is difficult to believe that people with HIV will not want some access to HIV specialist services locally (especially for those elements described above which in effect require specialist provision), in addition to high quality generic services.



“THE VOLUNTARY COMMUNITY AND SOCIAL ENTERPRISE SECTOR PLAYS A VITAL ROLE IN AMPLIFYING THE VOICES OF PEOPLE FROM COMMUNITIES WHOSE VOICES ARE SELDOM HEARD, HELPING THEM TO ENGAGE WITH THE HEALTH AND CARE SYSTEM.”⁹²

Local authorities may well want to discuss their commissioning and market-shaping arrangements with neighbouring local authorities since for the relatively smaller population of people with HIV, market shaping might be more effectively done on a larger geographical footprint. People with HIV should be involved in market shaping. HIV support organisations may have a role both in providing elements of care and support and also in facilitating access for people with HIV to other care and support services.

The Public Services (Social Value) Act 2012

which places a legal duty on NHS and local authority commissioners to have regard to economic, social and environmental wellbeing in connection with public services contracts. The social value of awarding a contract to a local organisation which employs people with HIV or engages people with HIV as volunteers should be considered when awarding contracts for services for people with HIV.

There is also significant interest now in ‘**social prescribing**’ which involves GPs referring patients with a variety of social, emotional or practical needs to a range of non-clinical services, very often the local voluntary sector.⁹⁵ Services can be around, for example, social interaction, volunteering, exercise, or advice on debt, benefits and housing. The referral process, and the service referred to, is commissioned and funded.

Of course, since the beginning of the epidemic HIV clinics have routinely referred patients on to local support services for further and essential elements

of care. But this referral process and the package of care accessed has not been specifically and discretely commissioned. The social prescribing model suggests an option of commissioners funding discrete packages of support for referral from either HIV clinics or GPs. There is, however, little point in championing social prescribing if no efforts are made to ensure the voluntary sector infrastructure is in place locally to receive such referrals.

THE CARE ACT 2014

Another key policy context for HIV support services is social care and in particular the **Care Act 2014** and its general duty for local authorities to promote the individual’s wellbeing. Wellbeing is broadly defined and covers many of the needs of people with HIV. For example, it includes personal dignity, including the treatment of the individual with respect. This has a clear relationship to stigma and supporting people in resilience to stigma both external and internalised. Wellbeing also includes physical and mental health and emotional wellbeing; domestic, family and personal relationships; participation in work, education, training or recreation; social and economic wellbeing – just to name some of the elements explicitly mentioned.

There is also a duty under the Care Act 2014 to arrange provision of services, facilities or resources, or take steps, to prevent the development of the need for care and support. This preventive focus is especially important. Such preventive social care can



range from 'wide-scale whole-population measures aimed at promoting health to more targeted, individual interventions aimed at improving skills or functioning for one person or a particular group'.⁹⁶ There is an expectation that local authorities identify unmet needs, and the range of local providers who might meet those needs – 'Local approaches to prevention should be built on the resources of the local community, including local support networks and facilities provided by other partners and voluntary organisations'.⁹⁷

There is also an explicit warning around de-commissioning, 'Local authorities should consider the potential impact and consequences of ending the provision of preventative services. Poorly considered exit strategies can negate the positive outcomes of preventative services, facilities or resources, and ongoing low-level care and support can have significant impact on preventing, reducing and delaying need'.⁹⁸

HIV-SPECIFIC POLICY

HIV support services are frequently cited in national guidelines as an essential component of HIV care.

The **NHS England service specification for adult HIV services** makes clear repeatedly that specialised clinical care needs to be complemented by other provision:

'In addition to specialised HIV services, meeting the needs of HIV infected individuals relies on access to other services

including sexual health and reproductive health, mental health, antenatal and third sector support services'.⁹⁹

There is a strong emphasis throughout the service specification on referral pathways to other services, including community and third sector support ('These services can provide important support on long-term condition management'¹⁰⁰), and the importance of self-management. Service element requirements include:

'Access to health advisor/counsellor and other forms of emotional and psychological support (e.g. peer support) as required to address psychological and emotional difficulties associated with HIV diagnosis, disease, treatment and prevention of HIV. These services are sometimes provided by community or third sector providers.'

'Access to treatment support including patient education, delivered in partnership with community or voluntary providers.'

The service specification also refers to adherence support, 'non-specialised HIV care and support needs and services', 'access to behavioural interventions, peer support, support for self-management and information', 'third sector support services to support adherence, peer support and self-management programmes'.

Crucially, the service specification states that 'The effectiveness of specialised HIV services depends on other elements of the HIV care pathway being in place and effectively coordinated'.¹⁰¹



SPECIALIST HIV SERVICES ARE VITAL TO PEOPLE LIVING WITH HIV. WE MUST NOT LOSE THE EXPERTISE AND CARE THAT WE HAVE BUILT UP OVER THE PAST 30 YEARS."

KATHRYN #STOPHIVCUTS



As was mentioned earlier, in the Specialised Commissioning CQUINS 2017-18/2018-19, one of the CQUINS is 'GE2: Activation System for Patients with Long-Term Conditions'. HIV is explicitly mentioned as one of the 'suggested conditions' which would benefit from such patient activation measures, or PAMs.

The **NHS England service specification for children HIV services** also stresses the importance of provision of peer support, community and voluntary sector providers, and non-specialised HIV care and support.

The **BHIVA Standards of Care for People Living with HIV 2013** are cited as a key standard in the NHS England service specification and are endorsed by a wide range of bodies including the Local Government Association (LGA) and the Social Care Institute for Excellence (SCIE). The most important Standard from the perspective of HIV support service provision is Standard 9 'Self-management'. This Standard is striking in positioning support services within a paradigm of self-management – such services are there ultimately not to foster dependency but confidence, competency, knowledge, skills, responsibility, allowing professional resources to be focussed where most needed. 'Evidence shows that limited health literacy contributes to sub-optimal care, poorer health status of affected individuals and avoidable costs within health systems'.

HIV support services are also cited as important to achieve Standard 10 'Participation of people with HIV in their care'. Such participation helps address readiness for and adherence to treatment, in particular concerns over disclosure, adverse reactions as well as psychological, cognitive, socio-economic and cultural factors. The Standard recommends 'A range of information resources and peer-support services, including printed and web-based information, telephone advice lines, treatment advocates and peer-support groups' as 'an important complement to clinical services'.

The **Standards for psychological support for adults living with HIV (BHIVA, British Psychological Society, MEDFASH 2011)** are also cited as a key standard in the service specification.¹⁰² Psychological support is defined as 'any form of support which is aimed at helping people living with HIV to enhance their mental health and their

cognitive, emotional and behavioural wellbeing'. It is 'provided at different levels of complexity by a wide range of professional groups, peers and informal providers, in clinical settings and in the community. Psychological support includes, but is not limited to, emotional support and the provision of a variety of talking therapies, cognitive rehabilitation and appropriate medication'.

The Standards adopt a stepped care approach. Level 1 (Information and support) is provided by anyone in statutory and on-statutory services providing care for people with HIV. It focuses on general supportive emotional care, supported self-help, signposting and the identification of more serious problems for onward referral. Level 2 (Enhanced support) is provided by practitioners with additional expertise through training and experience and includes brief interventions that are standardised in manuals such as motivational interviewing and post-test discussion. Level 3 (Counselling and psychological therapies (HIV-specialist)) is provided by qualified, professionally registered practitioners in counselling and psychological therapies who receive appropriate supervision. Level 4 is provided by psychological and mental health specialists who have clear pathways developed from HIV services.

HIV support services provide psychological support at Levels 1, 2 and, in many cases, at 3. The Standards make clear that all people with HIV should have access on the basis of assessment of need to services at all four levels.

MODERNISING HIV SUPPORT SERVICES

This report argues for the continuing vital role of HIV support services in the wellbeing of people living with HIV. That does not mean that HIV support services should remain unchanged. Over three decades they have adapted as the HIV epidemic has changed both in treatment and prognosis, but also in those affected. They will continue to change as new challenges and needs emerge and others subside.



THE QUALITY STATEMENTS FOR STANDARD 9 IN THE BHIVA STANDARDS OF CARE:

‘People living with HIV should have access to services which promote self-management of HIV including:

- Provision of practical and empowering support and information about HIV, treatment, healthy living with HIV, diet and lifestyle, and optimisation of general health.
- Provision of support and information on maximisation of entitlement to health services and support.
- Provision of support and information to enable people to optimise their entitlement and access to financial and housing support, and to optimise their ability to gain/regain employment.
- Self-management services including access to peer-support opportunities should be available in a choice of modalities, and should be accessible both via HIV specialist clinical services and by direct access.
- HIV services should have referral arrangements in place to enable people living with HIV to access services delivered by HIV support services either locally or by remote access (e.g. online or via telephone).
- Services should be delivered by providers with appropriate expertise and competencies. Wherever appropriate and relevant, providers should have the requisite professional qualifications and be appropriately accredited.’

An ageing population living with HIV and problematic chemsex behaviours are just two examples of currently developing needs which HIV support services must now address.

Change will be necessary not only in the services made available and the needs to be met, but also in how such services are designed and delivered. The implications for support provision of fewer consultations with the HIV clinic should be assessed (more access to HIV support services could well be required). The opportunities of new technologies to provide information, virtual community, and face-to-face counselling and advice should be exploited. New models of interaction and co-working between generic and HIV specialised provision could be developed. Different ‘footprints’ for different services can be agreed – from very local peer support to highly specialised advice on a more regional (or even national) scale.

We know HIV support providers are ready to think freshly about how HIV support services can be effectively provided in today’s context. But they can only do so in

partnership with an engaged NHS England, CCGs and local authorities, who understand how essential these services are and who are willing to think flexibly and collaboratively on how to meet need.

For example, NHS England specialised commissioners for HIV should be asking what support services are available locally to complement specialised clinical provision, given their service specification describes such support services as ‘essential’. It is an abrogation of their responsibility not to advocate with CCGs and local authorities for such services to be in place. They should also be looking at how specialised clinical provision can meet some of these needs – treatment information, for example, or peer support and patient activation. An inflexible insistence that a particular service does not qualify as specialised provision when it could be provided so sensibly and helpfully from within the HIV clinic, is the opposite of patient-centred care, and quite possibly unlawful under the ‘integration’ duty cited earlier in this report.



It is also essential not just that a CCG and local authority collaborate in one specific area but, to secure economies of scale and excellence, local commissioners work together with the voluntary and community sector across wider areas (rural communities, cities) to commission accessible high quality services. The current move to place-based commissioning via STPs (sustainability and transformation plans) is a key opportunity to make this happen¹⁰³.

In addition to collaboration, we need leadership and accountability for the system to work. Public Health England and the Department of Health, as well as NHS England, cannot ignore this issue. There needs to be national agreement on who the lead commissioner should be in the health and social care system to ensure that system is working coherently and to its full potential to meet HIV needs. We believe CCGs, being responsible for meeting long-term condition needs, are the appropriate commissioners for this role.

Current financial challenges facing the health and social care system are coinciding dangerously with a fragmented commissioning landscape for HIV. Instead of redesigning HIV support services and collaborating across commissioning silos to ensure needs are met, we are seeing in too many areas commissioners agreeing short-sighted and short-termist cuts ending HIV support entirely. This trend must be reversed before it is too late. If it is not, we will see a serious deterioration in health and wellbeing outcomes for people living with HIV.

RECOMMENDATIONS

Clinical Commissioning Groups must recognise, as part of their commissioning responsibility for people with long-term conditions, their obligation to meet the long-term condition needs of people living with HIV.

CCG commissioning responsibility for HIV support services should also be explicitly recognised at the national level by the relevant bodies with a policy interest – the Department of Health, NHS England, Public Health England, the Local Government Association and NHS Clinical Commissioning.

It should be explicitly acknowledged as lead commissioning responsibility – in other words, a responsibility for coordinating the involvement of other commissioning bodies to ensure needs are met, as well as commissioning directly much of the provision.

'Making It Work' should be amended as soon as possible to provide clear recommendations of responsibility at the local level for treatment information, clinical nurse specialists and HIV support services.

Where numbers with HIV are relatively low within a particular CCG boundary, there should be proactive discussion with other local CCGs for joint commissioning of HIV support services at an appropriate scale.

CCGs should be using STPs (sustainability and transformation plans) and place-based commissioning to secure collaboration across CCGs, local authorities and NHS England in the commissioning of HIV support services.

NHS England should both advocate for HIV support services to be in place locally and revisit its own commissioning practice and HIV service specification to identify how it can commission an appropriate element of such services.

Local authorities continue to have significant commissioning responsibilities for HIV support services, even if CCGs have a lead commissioning role. In particular, they have a public health interest in people with HIV being supported in safer sex, healthcare engagement and adherence to medication in order to minimise the onward transmission of HIV in their area. Their social care duty, and especially its preventive focus, also means local authorities should consider a commissioning contribution to local HIV support services and their promotion of wellbeing. There should be formal discussions between CCGs and local authorities about how they can work together to support people with HIV in their area.

Any transfer of commissioning responsibility for HIV support services from local authorities to CCGs must be properly agreed and managed to ensure no break or gap in service provision.

ENDNOTES

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- 2 'Cutting the Ribbon? : the Current Health of UK based HIV/AIDS Organisations and the Effects of Austerity (2016)' p.5 see <http://www.stophivcuts.org/press-resources>
- 3 Such quotations are followed by the first name of the individual and '#StopHIVCuts' to show they have been taken from the campaign website
- 4 HIV support services have in the past sometimes been described as 'HIV social care', reflecting the fact that many were commissioned in England using the AIDS Support Grant, before that grant was ended. In fact these support services meet a spectrum of needs going beyond what is now usually included within social care provision, so we prefer to use the term 'HIV support services'.
- 5 Respondents could add further service elements if not included in the menu
- 6 Drawn from responses to NAT survey of HIV support service providers 2016
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SHAPING ATTITUDES CHALLENGING INJUSTICE CHANGING LIVES



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