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ACKNOWLEDGEMENTS

NAT warmly thanks our funders for this work: ViiV Healthcare, MSD and the Make a Difference Trust. We are enormously grateful to Matt Tanner, Rory MacFarlane and Samuel Dick, who volunteered their time to assist with data gathering and analysis. We would also like to thank all the commissioning bodies that responded to our request for data, and the many people living with HIV, HIV support services and clinicians who have shared their thoughts and experiences with us and given their time as we have undertaken our research and drafted this report.
EXECUTIVE SUMMARY

• HIV support services are those services that meet HIV-relevant physical, mental and emotional health needs that are apart from, but complementary to, clinical care. Without specialist support services, it is certain that some people will not receive the support they need to live well with HIV.

• In the context of very real concerns about the need to preserve vital state-funded support services for people living with HIV, NAT (National AIDS Trust) set out to establish the extent to which anecdotal reports of threats reflect an existing trend in decommissioning across the four nations of the UK. We sent Freedom of Information (FOI) Act requests to all public bodies which may have a potential role in commissioning HIV support services, in each of the four nations of the UK.

• There is significant variation in investment across the four nations, reflecting differences in overall population and population density, HIV prevalence, and health and care commissioning structures. Provision of HIV support services to small populations dispersed across a large geography raises particular issues for expenditure.

• Although national specificities limit the comparability of data across the UK, it is clear that disinvestment in HIV support services is a genuine trend in England and (to a lesser extent) Wales, while in Scotland and Northern Ireland expenditure remained steady over the years considered.

• Despite having different commissioning structures, all four nations exhibit some degree of uncertainty around commissioning responsibility and roles.

• In England, Scotland and Wales, different models of combined commissioning of prevention, support (and, in some cases, broader sexual health services) meant some commissioners were unable to state the specific level of investment in HIV support services. This could cause uncertainty in quantifying outcomes.

ENGLAND

• The total reported expenditure known to be exclusively for HIV support services reported by local authorities in England in 2016/17 is £4,416,043. There was a 28% decrease in expenditure between 2015/16 and 2016/17. This like-for-like yearly comparison only includes those local authorities which returned data for both years and are therefore likely to under-estimate decrease in expenditure (especially for London). The average per capita expenditure is £77.10 for every person accessing HIV care in London; and £69.83 for the rest of England. When joint contracts (including HIV prevention as well as support services) are considered, the total possible spend is £8,120,093.

• The total expenditure reported by Clinical Commissioning Groups (CCGs) in 2016/17 that was known to be dedicated to HIV support services was £312,668 in London and £275,780 in the rest of England. Expenditure was constant in London but saw a 2.1% cut from the previous year in the rest of England. Additional CCG expenditure on HIV support services that could not be separated from broader service provision was £1,181,530 in London in 2016/17 (a 1.9% cut from 2015/16 expenditure).

• Across England there was a marked decrease in reported expenditure on HIV support services in 2016/17, compared to the previous year. In London, there was a 20.9% decrease in like-for-like reported expenditure known to be on HIV support services from 2015/16 to 2016/17. In the rest of England the equivalent decrease was 31%.

• No local authorities shifted from not commissioning services in 2015/16 to providing them in 2016/17. Outside of London, 8.4% of English local authorities terminated all expenditure on support services in 2016/17. Although 25% of London boroughs commissioned at the same or higher value in
2016/17, another 43.8% of local authorities in the capital reduced their spending between 2015/16 and 2016/17. Over one-quarter of London boroughs and local authorities in the rest of England with known expenditure on support services experienced cuts in contract values of over 50%.

- NAT has been told about a number of proposed and confirmed in-year cuts to HIV support services that have come about since our FOI data was captured, which mean that the data presented here are a likely over-estimation of the current state of commissioning in England.

### SCOTLAND

- The total reported expenditure known to be exclusively on HIV support services in Scotland for 2016/17 was £307,325, which is a 6.6% increase on the previous year. The average per capita expenditure is £53.89 for every person accessing HIV care in Scotland. When joint contracts (including HIV prevention as well as support services) are considered, the total possible spend is £695,125.

- Despite the comparatively sparse geographical coverage for HIV support services in Scotland, coverage reflects prevalence and there is access to at least some HIV support services for a good percentage of the diagnosed population.

- Overall, the data indicate a slight increase in expenditure on HIV support service commissioning in Scotland in 2016/17, with a larger increase in expenditure known to be on HIV support services spending than for the expenditure including joint contracts. Although in real terms this increase is not especially large, it stands in marked contrast with the totals for England and Wales which showed a significant decrease in expenditure.

### WALES

- The total reported expenditure known to be exclusively on HIV support services in Wales for 2016/17 was £0. Total reported expenditure on HIV support services (including joint contracts) in Wales for 2016/17 was £135,352, which is a 34% reduction from 2015/16.

- The decrease in total expenditure including joint contracts between the two years is entirely attributable to complete termination of all expenditure known to be dedicated exclusively to HIV support services (as opposed to that commissioned jointly with prevention services).

### NORTHERN IRELAND

- The Public Health Agency (PHA) in Northern Ireland reported expenditure on HIV support services in 2016/17 of £123,358, which constitutes a 1.3% increase from 2015/16. We have not been able to identify local commissioning expenditure made by Health and Social Care Trusts.

- Expenditure levels in Northern Ireland have been preserved, meaning that there has not been decommissioning as there has been in Wales and England.
• It is crucial that there is a common understanding, within each nation, of where HIV support services fall within the care pathway, and that mechanisms are put in place to ensure their implementation.

• Clarity must be established around the responsibility for commissioning HIV support services across the UK. This will require national scale leadership in each nation.

• All authorities with potential commissioning responsibility (including local authorities, Clinical Commissioning Groups, Health Boards, Health and Social Care Partnerships, and Health, Social Care and Wellbeing Partnerships) should ensure that adequate HIV support services are provided in their areas, based on an assessment of local need.

• In areas where HIV support services are already provided, commissioning bodies should ensure that the types of provision currently available meet the needs of all the local population living with HIV.

• Where HIV support services are commissioned jointly with prevention services or other blood borne virus related services, commissioning bodies must ensure that sufficient resources are dedicated to support services to meet local need. This is likely to include an understanding of the split of investment dedicated to each activity.

• In areas where low HIV prevalence and/or low population density and geography make it difficult to justify the provision of traditional HIV support services, commissioning bodies should consider whether collaborative commissioning, online services, or other innovative practices could meet the support needs of people living with HIV in their areas.

• Given compelling evidence of need in NAT’s report ‘Why we need HIV support services: A review of the evidence’, complete decommissioning of all HIV support services in any area should cease.

ENGLAND

• Any decommissioning of existing services should only result from a change in need or when a suitable alternative is commissioned by the same body or a new commissioner. People living with HIV must be consulted to ensure that the new provision is adequate and procurement must be done in a way that maintains adequate provision and avoids costly loss of institutional memory.

• With a view to understanding their commissioning role, Clinical Commissioning Groups should familiarise themselves with the breadth of HIV support services that support condition self-management.

• Where HIV support services are provided as part of an integrated sexual health service (ISHS), those responsible for provision should be able to demonstrate how the ISHS meets local HIV support service needs. HIV support services should not be simple add-ons to wider sexual health services, and providers must have the appropriate expertise to meet local population needs.

SCOTLAND

• As Health and Social Care Partnerships develop in Scotland, local authorities and Health Boards should work together to further co-ordinate provision of HIV support services.

WALES

• Public Health Wales should publish HIV surveillance data at a Health Board level (analogous to that provided by Health Protection Scotland and Public Health England) to help facilitate local needs assessments.
Where HIV support services are provided as part of an integrated sexual health service (ISHS), those responsible for provision should be able to demonstrate how the ISHS meets local HIV support service needs. HIV support services should not be simple add-ons to wider sexual health services, and providers must have the appropriate expertise to meet local population needs.

**NORTHERN IRELAND**

- The Public Health Agency for Northern Ireland should publish HIV surveillance data at a Health and Social Care Board level (analogous to that provided by Health Protection Scotland and Public Health England) to help facilitate local needs assessments.

- Although it may be appropriate to retain centralised funding, Northern Ireland would benefit from strong co-operation across levels of government to establish local need for HIV support services. Where this is already in place, it should be made visible.
INTRODUCTION

Over the last few years, it has been apparent that funding for specialised HIV support services across the UK has been subject to the threat of cuts. Reports in England in particular, have suggested that changing commissioning arrangements, the termination of the AIDS Support Grant (ASG), and the advent of austerity measures have combined to result in a withdrawal of funds from well-established, effective HIV support services.

Within the general context of concern around HIV support service provision, this report from NAT’s FOI data provides a unique snapshot of how many local bodies are commissioning support services for their resident population living with HIV; what services are commissioned; and the general trend in expenditure on HIV support services. Our empirical evidence sheds light on the varied reactions from commissioning bodies to legislative and broader policy and financial developments, and draws attention to the consequences for HIV support service provision nationwide.

Although NAT has heard accounts of threats to services particularly from within England, we were concerned to identify commissioning patterns across the UK. Therefore, Freedom of Information (FOI) requests concerning expenditure on specialised HIV support services in 2015/16 and 2016/17 were sent to all potential local commissioning bodies in all four nations of the UK. Although our focus was on local bodies, reflecting the history of the main players in HIV support service funding, we have also noted where national commissioning plays a part. For example, in Northern Ireland some services are supported in part by the Public Health Agency and the Department of Health.

NAT’s contribution to the evidence in the debate over the future of support services does not stand alone. A recent report from the University of Sunderland focused on how well HIV support service providers are weathering the storm of austerity, identifying that many have considerable financial concerns over both the short and long term and some have been forced to close services. Meanwhile, recognising the extent of concerns around service provision and the implications of legislative changes, in 2016 the All Party Parliamentary Group on HIV & AIDS conducted an inquiry into the impact of the Health and Social Care Act 2012, and concluded that “the Government must... clarify commissioning responsibility for HIV support services and ensure they are not summarily cut across the country”.

Within the general context of concern around HIV support service provision, this report from NAT’s FOI data provides a unique snapshot of how many local bodies are commissioning support services for their resident population living with HIV; what services are commissioned; and the general trend in expenditure on HIV support services. Our empirical evidence sheds light on the varied reactions from commissioning bodies to legislative and broader policy and financial developments, and draws attention to the consequences for HIV support service provision nationwide.
WHAT ARE HIV SUPPORT SERVICES AND WHY ARE THEY NEEDED?

HIV support services are those services that meet HIV-relevant needs that are apart from, but complementary to, clinical care. They include a range of provisions that, for example, help people stay on medication, maintain adequate nutrition, broach emotional difficulties, disclose their status to their families, or get the right socio-economic support – all of which go to help people living with HIV achieve their optimal health and wellbeing, as well as having broader public health outcomes.

HIV support services are commonly provided by third sector organisations, and have a rich history of drawing from the wealth of experience and knowledge in the HIV community as well as from health and social care professionals.

In an earlier phase of our work on HIV support services, NAT asked support service providers what the essential services required by people living with HIV are, in their experience. The responses are shown in Figure 2.1. These results were endorsed through the results of a further survey conducted by NAT, in which HIV clinicians overwhelmingly supported this list as comprising essential HIV support services.\(^5\)

2.1 THE VALUE OF HIV SUPPORT SERVICES

The most recent count of the number of people seen for HIV care in the UK is 88,769.\(^6\) Not everyone who has an HIV diagnosis will need to draw on HIV support services and, among those who do, many will access them only at specific, often difficult moments in their lives. For example, the 2015 UK Stigma Survey found that 46% of people who had been diagnosed in the last year accessed local HIV support organisations.\(^7\)

### FIG. 2.1 – ESSENTIAL SUPPORT SERVICES FOR PEOPLE LIVING WITH HIV

<table>
<thead>
<tr>
<th>PEER SUPPORT</th>
<th>INFORMATION, ADVICE AND ADVOCACY, INCLUDING LEGAL ADVOCACY/REFERRALS</th>
<th>SELF-MANAGEMENT</th>
<th>SEX AND RELATIONSHIPS SUPPORT</th>
<th>PSYCHOSOCIAL SUPPORT</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-2-1 Support</td>
<td>Housing, Finances, Benefits, Employment, Social care support and care planning, Immigration</td>
<td>Treatment information, Adherence support, Long-term condition management, Healthcare engagement</td>
<td>Sexual health support, Disclosure support, Relationships support, Pregnancy and parenting support</td>
<td>Counselling, Mental health, General social support (which covers various emotional support services including befriending, and social activities that help with isolation and anxiety)</td>
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</tbody>
</table>
A Public Health England (PHE) survey found that over one-third of all people living with HIV had accessed HIV support services in the previous year.\(^8\) Alongside the knowledge that service use is episodic, this implies that a large percentage of the population diagnosed with HIV will access at least some services over the course of a few years.

Beyond showing how many people living with HIV draw on specialist HIV support services it is important to recognise what they provide that other services cannot. Firstly, HIV support services provide expert information based on an understanding of the complexity of HIV. Some services inherently require specialist provision. Peer support, by definition, must be provided by people living with HIV, but there are also many aspects of condition self-management and sex and relationships support that require detailed, specialist knowledge of both the physical and the sociological experience of living with HIV.

In theory, non-HIV specialist providers should be able to offer certain support services, such as benefits advice for example, to everyone in a local area. However people living with HIV have told NAT that too often generic service providers lack even a basic understanding of their HIV-related needs, and are therefore ill-equipped to provide the necessary support.\(^9\) Quite legitimately, service users have difficulty trusting those services that are unable to understand the complexities associated with their HIV status. Without specialist service provision, it is certain that some people will not receive the support they need to live well with HIV.

Secondly, HIV-related stigma remains a significant problem with attendant impact on the physical and emotional health of people living with HIV. Direct experience of stigma, and the fear of encountering it, prevents people from accessing the care and support that they need.\(^10\) Specialist HIV support can provide a stigma-free environment where people living with HIV can access the full range of services they need. It can also help people to build the confidence and resilience that can limit the damaging impact of HIV-related stigma in their lives more generally.\(^11\)

Thirdly, while people living with HIV who access treatment early can anticipate normal life expectancy, there are still others who have ongoing ill-health that means they require more support. Moreover, as the first cohort of people experience ageing with HIV, we can expect an increase in co-morbidities as well as the emergence of new sets of needs deriving from the intersection of HIV status with issues often experienced by older people, such as isolation and poverty. In other words, while certain people living with HIV may come to depend less on HIV support services, we can expect the level of overall need to remain high.

Some have suggested that with the advent of antiretroviral therapy (ART) and its fundamental transformation of the HIV epidemic, HIV support services are no longer required. As a direct counterargument, NAT has identified demonstrated continued need for HIV support services.\(^12\) Based on our work in this area, NAT is confident in making a key assumption underpinning this report, that HIV support services have been previously commissioned because they were needed, and any loss of expenditure reflects a decrease in the capacity to meet ongoing need. However, it is important to recognise that the converse is not true – the absence of existing provision does not demonstrate a lack of need.
There are two rationales behind our analysis of HIV support service provision. The first is that the historical provision of services indicates a need and, to be justified, reduction in service provision must be accompanied by a demonstrated change in need. The second is that the demand for HIV support services is proportional to diagnosed HIV prevalence.

In this context, to establish the state of the nations with regards to funding for HIV support services, NAT wanted to know how much commissioning bodies were spending on these services in 2016/17 and whether that expenditure reflected a change from 2015/16. We also wanted information on what types of support services were commissioned in these contracts.¹³

To obtain the required information we sent information requests made under the Freedom of Information Act 2000 to the commissioning bodies listed in Figure 3.1.

The purpose of the Freedom of Information (FOI) requests was to establish state funding for HIV support services. As an accepted part of the HIV care pathway that underpin clinical outcomes,¹⁴ support services for people living with HIV should be funded by the state. Other funding sources for HIV support services, including trusts, foundations and charitable giving, cannot provide a reliable alternative to state provision. Consequently, in this report any commentary on HIV support service provision refers to local government and NHS funded services, rather than the totality of available provision which includes voluntarily funded services.

An overview of the data analysis is given in the Appendix, and elements specific to each nation are discussed in the individual sections below. However, one crucial feature of the returned data that is common across the nations is the reporting of joint contracts for HIV prevention and support services, where commissioning bodies are unable to separate out expenditure specifically determined for HIV support services. The reported data therefore contains two sets of expenditures – the first gives total expenditure known to be exclusively on HIV support services, and the second gives expenditure including joint contracts.¹⁵ The two sets of figures demonstrate the range of support service expenditure in each of the nations – in practice, the actual figure spent on HIV support services will be somewhere between the two extremes.
There is some uncertainty over which bodies commission HIV support services in England. Until the implementation of the Health and Social Care Act 2012, Primary Care Trusts (PCTs) had been responsible for commissioning primary, secondary and community care and, in that capacity, had commissioned some HIV support services. Separately, the AIDS Support Grant (ASG), which was allocated to local authorities from central government since 1989, was used to fund a host of social care functions around the needs of people living with HIV, including HIV support services. The result was a patchwork of arrangements for HIV support service provision based on the specific histories of localised agreements.

There has remained a legacy of local authority commissioning of HIV support services despite the phasing out of ASG funding since 2010, but this source of funding has been particularly disrupted by austerity measures and cuts to local authority grants in the last few years.

From April 2013, the implementation of the Health and Social Care Act 2012 disbanded PCTs and divided HIV care and support functions between NHS England (treatment and clinical care), Clinical Commissioning Groups (long term condition management) and local authorities (public health and social care). PHE guidance on sexual health commissioning does not determine where commissioning responsibility for HIV support services now lies,¹⁶ but British HIV Association (BHIVA) guidance firmly establishes them as part of long term condition management.¹⁷

Given these commissioning arrangements, to establish the situation in England NAT sent FOI requests to both local authorities and CCGs. With some exceptions, we found that commissioning of HIV support services was carried out by local authorities rather than CCGs. The exceptions include, for example, CCGs in Sussex commissioning HIV support services, and Lambeth Council co-commissioning with Lewisham and Southwark CCGs (LSL). However, CCG and local authority commissioning tell different stories so we have reported on them separately.

Following the national overview, the sections below reflect first on local authority commissioning of HIV support services (including the co-commissioning arrangement in LSL) and then, separately, on CCG commissioning.

### 4.1 – National Overview for England

Total expenditure known to be exclusively for HIV support services reported by local authorities in England in 2016/17 is £4,416,043, a 42% decrease from the previous year. However, like-for-like data, which only includes those local authorities which returned data for both years, shows a decrease of 28%.

The total expenditure reported by CCGs in 2016/17 that was known to be dedicated to HIV support services was £312,668 in London and £275,780 in the rest of England. Expenditure was constant in London but saw a 2.1% cut from the previous year in the rest of England.

Figure 4.1 shows the total expenditure on HIV support services in England reported by local authorities for 2016/17, and the change from 2015/16 expenditure. Given the significant proportion of people living with HIV in London and the specificities of commissioning within the capital, expenditure has been presented for London, the rest of England, and an England total.
The data reflect that some local authorities in England reported expenditure on joint contracts, providing both HIV support services and HIV prevention, and were not able to extract an exact expenditure figure that was exclusively for support services. That is perhaps understandable because some of the intended outcomes for prevention services and support services coincide, or are at least closely allied. It means, however, that local authority expenditure on HIV support services must be reported within a range from the minimum level – that which is known to be spent exclusively on HIV support services – through to the maximum possible spend – which assumes that all the joint contract spending goes to HIV support services. In England, the range of local authority reported expenditure on HIV support services is from £4,416,043 to £8,120,093.

Comparing the reported expenditures given in Figure 4.1, it is apparent that joint contracts are particularly prevalent in the rest of England where known expenditure on HIV support services is less than half of the total possible expenditure including joint contracts. In London, expenditure known to be exclusively on support services makes up over 70% of the possible total expenditure. Therefore, the rest of England figure for total expenditure including joint contracts incorporates more prevention spending and is more likely to overestimate spending on HIV support services, in comparison with London.

### FIG. 4.1 – REPORTED EXPENDITURE BY LOCAL AUTHORITIES ON HIV SUPPORT SERVICES IN ENGLAND

<table>
<thead>
<tr>
<th></th>
<th>LONDON</th>
<th>REST OF ENGLAND</th>
<th>ALL ENGLAND</th>
</tr>
</thead>
<tbody>
<tr>
<td>REPORTED EXPENDITURE KNOWN TO BE EXCLUSIVELY FOR HIV SUPPORT SERVICES 2016/17 (2015/16)</td>
<td>£1,447,129 (£3,200,996)</td>
<td>£2,968,914 (£4,416,031)</td>
<td>£4,416,043 (£7,617,027)</td>
</tr>
<tr>
<td>% CHANGE IN TOTAL REPORTED EXPENDITURE KNOWN TO BE EXCLUSIVELY FOR HIV SUPPORT SERVICES SINCE 2015/16 (LIKE-FOR-LIKE DATA)</td>
<td>-54.8% (-20.9%)</td>
<td>-32.8% (-31%)</td>
<td>-42% (-28%)</td>
</tr>
<tr>
<td>REPORTED EXPENDITURE ON HIV SUPPORT SERVICES, INCLUDING JOINT CONTRACTS, 2016/17 (2015/16)</td>
<td>£2,056,943 (£3,800,810)</td>
<td>£6,063,150 (£7,792,163)</td>
<td>£8,120,093 (£11,592,973)</td>
</tr>
<tr>
<td>% CHANGE IN TOTAL REPORTED EXPENDITURE, INCLUDING JOINT CONTRACTS, SINCE 2015/16 (LIKE-FOR-LIKE DATA)</td>
<td>-45.9% (-15.3%)</td>
<td>-22.2% (-17.7%)</td>
<td>-30% (-17.1%)</td>
</tr>
</tbody>
</table>
Apart from uncertainty around the actual amount invested in HIV support services in the years of interest, the existence of joint contracts is not inherently problematic. However, it is worth noting the stronger tendency to award joint contracts outside London, which should be taken into account in any attempts to secure consistency of commissioning for HIV support services provision across England.

Not dissimilar to the questions raised by joint contracts, there is an emergent trend of awarding contracts for an ‘Integrated Sexual Health Service’ (ISHS) which includes the full gamut of genitourinary medicine (GUM) and Community Contraceptive and Sexual Health (CaSH) clinical sexual health services. The sums involved for ISHS contracts dwarf HIV support services spending and would render the data meaningless if included in the analysis. However, the chief rationale for excluding this expenditure from the figures for HIV support service expenditure in this analysis is that, unless the local authority could specify the value for the support services sub-contract, there is no evidence from the expenditure that support services are being commissioned within the ISHS.

The shift to ISHS contracts without specified sub-contract values makes funding for HIV support services vulnerable and simultaneously makes it harder to hold commissioning bodies to account. This problem affects the data for five local authorities in England for HIV support services expenditure, but is far more pronounced for HIV prevention spending.

Across England, but particularly in London, the data show a marked decrease in reported expenditure on HIV support services in 2016/17. This is especially true for expenditure known to be exclusively for support services which, in London, shows a greater than 50% decrease from 2015/16 figures.

However, the degree of change since 2015/16 is over-indicated in the reported data because some local authorities, particularly in London, were unable to provide detail of their expenditure on support services for the second year. In 2015/16, 31 of London’s 32 boroughs were able to provide expenditure data, but only 24 could provide equivalent data for 2016/17. As such, the reported data exaggerates the change in commissioning expenditure for London as a whole, simply because the figure for total reported expenditure in 2016/17 includes data from fewer local authorities.

To account for this problem, a second figure for change in expenditure was calculated using like-for-like data, which only included those local authorities that had known expenditure data for both 2015/16 and 2016/17. The bracketed data for ‘% change in total reported expenditure’ in Figure 4.1 gives the like-for-like calculation, which shows a 20.9% decrease for reported expenditure known to be on HIV support services in London from 2015/16 to 2016/17.

Only 13 of the 119 local authorities in the rest of England were unable to report data for both years, meaning that there is greater confidence in the value given for the decline in commissioning expenditure across England than there is for London. In the rest of England the decrease between 2015/16 and 2016/17 in like-for-like reported expenditure known to be on HIV support services was 31%, which is very close to the 32.8% decrease in the actual reported expenditure.

It is important to recognise that the like-for-like data most likely underestimates expenditure cuts, because by excluding the data where there was uncertainty due to consultation and review, we have excluded expected service cuts from the analysis. In fact, NAT knows the outcomes of some of the review processes and they have indeed resulted in lower expenditure in 2016/17.

Moreover, it has been reported to NAT that further cuts and wholesale decommissioning have happened since the FOI data was returned, so that reported expenditure has subsequently been reduced or threatened with reduction. Therefore, in England the situation for HIV support service funding is undoubtedly now worse than that shown by our data collected in mid-2016.
4.2 HOW MANY LOCAL AUTHORITIES IN ENGLAND COMMISSION HIV SUPPORT SERVICES?

There is considerable variation in diagnosed HIV prevalence across England, from 0 per 1,000 population in the Isles of Scilly to London, where all boroughs are in the high prevalence category (≥2 per 1000 people living with diagnosed HIV, as defined by Public Health England). Assuming that prevalence correlates roughly with demand for HIV support services, we might also expect to see some degree of correlation between prevalence and service provision.

Figure 4.2 establishes that over 70% of local authorities across England commissioned services in both 2015/16 and 2016/17, if we include those with unknown contract values.

As would be expected given prevalence, the percentage of London boroughs commissioning support services is higher than in the rest of England. However, two of 32 London boroughs did not provide any support for their residents living with HIV in 2016/17.

Across the rest of England, correlation of service provision with prevalence does not appear to be strong. Ten of the 26 local authorities with high prevalence did not provide support services in 2016/17, while services were provided by 62% of the local authorities with low prevalence.

Of course, these figures give no indication of whether expenditure is adequate, but they do suggest that even low prevalence areas recognise the importance of providing support services for their population living with HIV. This claim is, of course, qualified by the fact that 26.9% of local authorities across the rest of England did not commission HIV support services in either 2015/16 or 2016/17.

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**FIG. 4.2 – LOCAL AUTHORITY EXPENDITURE ACTIVITIES, INCLUDING JOINT CONTRACTS IN ENGLAND, 2016/17**

<table>
<thead>
<tr>
<th></th>
<th>London</th>
<th>Rest of England</th>
<th>All England</th>
</tr>
</thead>
<tbody>
<tr>
<td>No expenditure in 2015/16 or 2016/17</td>
<td>6.25</td>
<td>26.9</td>
<td>22.5</td>
</tr>
<tr>
<td>Decommissioned all services in 2016/17</td>
<td>25</td>
<td>8.4</td>
<td>6.6</td>
</tr>
<tr>
<td>Unknown contract value in 2016/17</td>
<td>43.75</td>
<td>12.6</td>
<td>15.2</td>
</tr>
<tr>
<td>Commissioned in 2016/17 - with less expenditure than 2015/16</td>
<td>18.75</td>
<td>18.5</td>
<td>23.8</td>
</tr>
<tr>
<td>Commissioned in 2016/17 - with same expenditure as 2015/16</td>
<td>6.25</td>
<td>29.4</td>
<td>27.2</td>
</tr>
<tr>
<td>Commissioned in 2016/17 - with more expenditure than 2015/16</td>
<td>4.2</td>
<td>4.6</td>
<td></td>
</tr>
</tbody>
</table>

% LOCAL AUTHORITIES
As already mentioned, NAT has been told about a number of proposed and confirmed in-year cuts to HIV support services that have come about since our FOI data was captured, which mean that the data presented here are a likely over-estimation of the current state of commissioning.

4.3 HOW HAVE HIV SUPPORT SERVICE CONTRACT VALUES CHANGED IN ENGLAND SINCE 2015/16?

Another way of throwing light on the change in support services expenditure is to examine the change in contract values, rather than overall expenditure. These figures provide more nuance than absolute expenditure because they indicate the relative change in service provision in a locality and therefore provide a better indication of the impact on service users in that area. For example, both Halton and Cambridgeshire reported a cut of £10,000 for 2016/17. In Halton, no local authorities shifted from not commissioning services in 2015/16 to providing them in 2016/17. In fact, the data show a trend to decommissioning of support services outside London where 8.4% of local authorities reported that they had terminated all expenditure on support services for 2016/17. On a more positive note, one-third of local authorities in the rest of England commissioned either at the same or higher value in 2016/17.

Although 25% of London boroughs also commissioned at the same or higher value in 2016/17, the threat of service cuts is also evident in London where contracts were of a lower value in 43.75% of local authorities. Moreover, the decision to commission support services for 2016/17 had not been made by five of the boroughs (15.6%) when their FOI response was produced. Bearing in mind that NAT’s information request was sent in April, after the start of the financial year, it is a matter for concern that some local authorities were unable to specify whether they would commission support services for 2016/17. While this uncertainty does not necessarily reflect wholesale decommissioning it does show that cuts were proposed and contracts were under threat.
where the contract value in 2015/16 was £20,000, that change reflects a 50% cut in services; whereas in Cambridgeshire with expenditure in 2015/16 of £40,000, it reflects a 25% cut.

Similarly to the figures for total expenditure, the trends in contract values can only be calculated where figures have been given for both 2015/16 and 2016/17. We have also excluded those local authorities that did not commission support services in either year, which would appear as a 0% change and thus would skew the average change in contract value.

The average change in contract values gives an indication of how far services have been cut for the region as a whole. In London, the average change in contract value in 2016/17 where there is a known figure for support services was a 23.1% cut. For the rest of England the average change was a 26.2% cut.

The range of change in contract values indicates the variation in trends in service provision across the region. In London the range of changes in contract value was from a 33.3% increase to a 77.8% cut. In the rest of England the range was from a 20.9% increase to a 100% cut (i.e. wholesale decommissioning).

Over one-quarter of both the London boroughs (5/19) and the local authorities in the rest of England (14/53) with known expenditure on support services experienced cuts in contract values of over 50%.

Therefore the change in local authority expenditure on HIV support services shows considerable variation across London and the rest of England, with a worrying number of local authorities showing drastic cuts in service provision.

### 4.4 HOW MUCH IS SPENT ON HIV SUPPORT SERVICES IN ENGLAND PER PERSON LIVING WITH HIV?

The bulk of the data analysis so far has focused on change in expenditure, on the assumption that HIV support services have been previously commissioned because they were needed, and any reduction in expenditure reflects a decrease in the capacity to meet need.

However, there is an alternative rationale for justifying HIV support service expenditure based on HIV prevalence in an area, which is premised on the assumption that the need for HIV support services is directly proportional to HIV prevalence. Using a per capita expenditure figure (based on number of people...
living with HIV who are accessing treatment and care services) enables a description of variation in spending between areas, while also taking into account variation in HIV prevalence.

We calculated an average per capita spend for both London and the rest of England on a like-for-like basis, only including those local authorities where data is held for both 2015/16 and 2016/17, and using PHE data on the number of people receiving HIV care.\textsuperscript{20}

The results, given in Figure 4.4, indicate that London has a slightly higher per capita expenditure known to be exclusively on support services in 2016/17 than the rest of England. However, given economies of scale that can accrue to high prevalence areas, it is likely that there is a higher level of support service provision available across London for similar per capita expenditure.

The rest of England has a far higher per capita expenditure in 2016/17 than London when joint contracts are included. However, given the high proportion of joint contracts outside of London it is not possible to establish how much of this funding goes to HIV support services rather than on prevention work,
What type of HIV support services are commissioned in England for people living with HIV?

Although the key question for NAT’s work on HIV support services was to establish the trends in expenditure, we also used our FOI request to find out which HIV support services are commissioned. We wanted to know which HIV support services are provided by local authorities in 2016/17, and whether there was a change since 2015/16 in the services commissioned.

Of course, without an indication of expenditure for each type of HIV support service it is not possible to ascertain the breadth and depth of available services. The results given in Figure 4.6 add some further nuance to the more blunt instrument of absolute expenditure, although there are no particular standouts of HIV support services that are either favoured or ignored across the board by the commissioning process.

Sex and relationships support is the service least commissioned in London, but psychosocial support is that which is least commissioned in the rest of England. The types of HIV support services commissioned might suggest different sets of need, but it also might reflect different cultures of understanding among commissioners and different assumptions about generic provision.

The data for London show no consistent commissioning pattern, with a slight decrease in peer support, sex and relationships support and psychosocial support in 2016/17, but a slight increase in self-management support for the same period.

The figures for the rest of England show a small but consistent decrease between 2015/16 and 2016/17 for each service type, most likely reflecting the general trend in decommissioning.
4.6 WHAT HIV SUPPORT SERVICES DO CLINICAL COMMISSIONING GROUPS (CCGS) COMMISSION?

At the time of our FOI request there were 211 CCGs in England, although subsequently there has been one merger and one proposed merger. There are 32 CCGs in London which share boundaries with local authorities, but outside London CCG and local authority boundaries are not contiguous.

CCGs are responsible for the commissioning of primary, secondary, and community care and, particularly in relation to HIV support services, this includes all aspects of long term condition management. Health
Lambeth Council commissioned HIV support services on behalf of Lambeth, Southwark and Lewisham CCGs (as ‘LSL’), and we have included the CCG data in with the local authority data already discussed. Though this model demonstrates how collaborative commissioning can be effective, it has not protected local people living with HIV from experiencing substantial cuts to their services. Services in LSL have been subject to in-year cuts, despite it being the area of highest prevalence in the country.

All of the 12 remaining CCGs report commissioning services via Mildmay Hospital and respite care. Mildmay is a dedicated HIV hospital in East London that supports people (both in-patient and day services) with neurocognitive impairment or complex physical needs, including day services. While this is clearly a vital support service for some people living with HIV, the rehabilitation and end-of-life care it engages in is generally associated with clinical services rather than open access support services. From the data NAT has collected it is impossible to disentangle the funding streams that are dedicated to HIV support services, therefore we have recorded this expenditure separately.

For 2016/17, expenditure was £1,181,530, reflecting a 1.9% cut on the previous year. However, three CCGs were unable to provide expenditure data so this figure underestimates actual expenditure.

Three CCGs report commissioning HIV support services in addition to Mildmay or respite care in 2015/16 and 2016/17. These include £50,000 spent on a voluntary sector provider for a range of HIV support services, and three clinical nurse specialist (CNS) services. The reported value for the CNS services is £312,668 in total, although one of the three CCGs did not report an expenditure figure so this figure underestimates expenditure. Moreover, NAT expects that there may have been a general under-reporting of CNS provision by CCGs. The total reported expenditure of £312,668 remained constant from 2015/16 to 2016/17.
HIV support services commissioned by CCGs in the rest of England

Nine of 186 CCGs in the rest of England responded that they commission HIV support services. On closer analysis, it became apparent that of these nine CCGs, only six (3.2%) provide what could be described as HIV support services of the sort detailed in our list of essential services.

One Sussex CCG responded that they commissioned step down services in 2015/16 although funding for 2016/17 was unknown at the time of the response. These are very specific services, dissimilar from most open access support and, as with the funding for Mildmay Hospital, it is not possible to separate out what expenditure goes exclusively to HIV support services as we have defined them. Reported expenditure for HIV support services that could not be separated from broader service provision was £25,239 in 2015/16, but expenditure for 2016/17 was unknown.

Between them, the remaining five CCGs reported expenditure known to be dedicated to HIV support services in the rest of England in 2016/17 was £275,780, which is a 2.1% cut from the previous year.

One Cheshire CCG funded a service to provide HIV support services in all of the categories established as essential services. Expenditure was £36,000 in both 2015/16 and 2016/17.

Two CCGs in Sussex between them contributed £239,780 in 2015/16 to a Community HIV Specialist Service provided by Sussex Community NHS Foundation Trust that covers the full range of support services. While not formalised for 2016/17 the intention was to commission at the same amount plus uplift for 2016/17. This result confirms a response from one of the Sussex local authorities that services are commissioned by the CCG.

Two other CCGs in the South of England commissioned small amounts in 2015/16 – expenditure for one was £6,000 and the second described “a small additional element of core grant funding for work with people living with HIV”. The low levels of funding mean that there would probably be only minor impact on service provision and further, one of these decommissioned services entirely in 2016/17 and the other was unable to indicate if funding would continue.

Of the remaining three CCGs that reported providing HIV support services, one CCG in the South reported that it was developing a service model. Anecdotally NAT knows that this CCG took over funding the local HIV support service for a brief period when the associated local authority cut funding, but that CCG funding has also now been terminated. Two further CCGs reported funding for Termination of Pregnancy services which are important provisions but do not constitute HIV support services.

Over and above the lack of obligation to provide HIV support services understood by the overwhelming majority of CCGs, in different ways these five responses – indicating either decommissioning or a misunderstanding of what constitutes HIV support services – give some troubling indication of how CCGs understand their role in commissioning the necessary support for people living with HIV.

Although it was not part of the FOI request, well over half of the responses from CCGs in the rest of England included assertions that HIV support services should be commissioned by other institutions. The other commissioning bodies mentioned were NHS England (82 responses), Public Health England (nine responses), and local authorities (49 responses). These results suggest that the lack of clear commissioning mandate has left CCGs, in particular, in considerable doubt concerning which bodies are responsible for commissioning HIV support services.

One CCG responded that “All services commissioned by [this] CCG should be accessible to those with HIV/AIDS. Commissioners have moved away from conceptualising and contracting services according to health condition and moved towards inclusivity and equality of access.” The idea of ensuring ‘equality of access’ sounds positive but deflects attention from the need for specialist knowledge and competence.
in service provision. Further, we do not have enough information to know whether the impact of HIV-related stigma on accessing support services is taken into account when determining how to achieve equal access to services.

While NAT believes that CCGs are the ideal commissioning home for HIV support services given their role in long term condition management, this model of equal access to services unqualified by concerns about specialist knowledge and stigma-free environments does not appear to meet the requirements of those people living with HIV and in need of support to live well with HIV. This signals that if CCGs are to take on the role of commissioning services, care must be taken to ensure how that provision is undertaken.23

Ultimately, while there are pockets of HIV support services provided by CCGs across England, these are few and far between. Moreover, there is a strong tendency, especially in London, for services to be linked to clinical care. While these are necessarily important services, HIV support comprises a much wider set of provisions. If CCGs are to take on providing HIV support services which both support the provision of clinical services and limit the need for them, it is crucial that the breadth of provision is directly linked to local need that is well understood within local authorities.
The total reported expenditure known to be exclusively on HIV support services in Scotland for 2016/17 was £307,325, which is a 6.6% increase on the previous year.
Overall, the data indicate a slight increase in expenditure on HIV support service commissioning in Scotland in 2016/17, with a larger increase in expenditure known to be on HIV support services spending than for the expenditure including joint contracts. Although in real terms this increase is not especially large, it stands in marked contrast with the totals for England and Wales which showed a significant decrease in expenditure.

One caveat is that decommissioning may have already happened in the years prior to NAT’s data collection. Of course, that characteristic is true for all four nations, but anecdotal reports suggest that some decommissioning may have happened earlier in Scotland than it did in the rest of the UK.

5.2 HOW MANY HEALTH BOARD AREAS IN SCOTLAND COMMISSION HIV SUPPORT SERVICES?

No Health Board areas decommissioned services entirely in 2016/17 in Scotland. As shown in Figure 5.2, of the seven areas that commissioned HIV support services...

As in England, the Scottish data show that contracts are awarded jointly for HIV support services and prevention. As we do not know what proportion of these joint contracts was spent on HIV support services, the value of these contracts should be understood as the absolute maximum in the range of possible expenditure. In Scotland, the range of reported expenditure on HIV support services is from £307,325 to £695,125.

Joint contracts account for 55.8% of the total expenditure reported in Scotland (compared to 45.7% of reported expenditure in England). The consequence is that the figure for total expenditure including joint contracts incorporates more prevention spending and is, therefore, more likely to overestimate per capita spend on HIV support services in Scotland, in comparison with England.

Apart from creating uncertainty about the precise level of investment in support services in Scotland, the existence of joint contracts is not inherently problematic. Joint contracts for HIV prevention and support services may well be logical given that some of the intended outcomes coincide, or are at least closely allied. However, it is worth noting the stronger tendency to award joint contracts in Scotland, as that should be taken into account in any attempts to secure consistency of commissioning for HIV support services provision.

<table>
<thead>
<tr>
<th></th>
<th>2015/16</th>
<th>2016/17</th>
<th>% CHANGE</th>
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<tbody>
<tr>
<td>REPORTED EXPENDITURE KNOWN TO BE EXCLUSIVELY ON HIV SUPPORT SERVICES</td>
<td>£288,399</td>
<td>£307,325</td>
<td>+6.6%</td>
</tr>
<tr>
<td>REPORTED EXPENDITURE ON HIV SUPPORT SERVICES, INCLUDING JOINT CONTRACTS</td>
<td>£686,199</td>
<td>£695,125</td>
<td>+1.3%</td>
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</tbody>
</table>
services in 2016/17, two reduced expenditure between 2015/16 and 2016/17 but the other five commissioned with the same or greater expenditure.

It is instructive to note the impact on the data of the small number of Health Board areas in Scotland (especially in comparison with local authorities in England), such that one decommissioning decision can appear artificially as a significant shift in activity. In fact, the 16.7% of areas described here as commissioning with less expenditure only actually represents a £16,675 or 2.4% decrease in the total reported expenditure.

Given the high percentage of Health Board areas with no expenditure in either year, we examined the relationship between the number of people attending for HIV clinical services and the availability of support services.

Firstly, the two Health Board areas with highest prevalence (≥1 HIV diagnoses per 1,000 population, Lothian and Greater Glasgow and Clyde) both commission HIV support services. Furthermore, only one area with a prevalence greater than 0.5 per 1,000 does not commission services and, since the FOI requests were returned, NAT has been informed that the relevant NHS Board is conducting a needs assessment for HIV support services in that area.

Secondly, 86.5% of the population attending for HIV monitoring in Scotland live within a Health Board area that provides HIV support services. Moreover, if the Health Board area that is conducting the needs assessment for HIV support service provision decided to commission services, that figure would rise to 94.2%.

These data effectively show that despite the comparatively sparse geographical coverage for HIV support services in Scotland, there is access to at least some HIV support services for a good percentage of the diagnosed population. Of course, as with the other nations, living in an area where some HIV support services are provided does not automatically mean that the provision would be sufficient, or suitable to meet the specific support needs of everyone living with HIV.

Moreover, in Scotland there is a small percentage of people living with HIV in areas where no support services are available which are also characterised by low population density.
5.3 HOW HAVE HIV SUPPORT SERVICE CONTRACT VALUES CHANGED IN SCOTLAND SINCE 2015/16?

Reporting on the change in contract values at the Health Board level can indicate the variation in expenditure across the nation.

As shown in Figure 5.3, the average change in contract values between 2015/16 and 2016/17 where there is known expenditure for HIV support services is +3%, and for total expenditure including joint contracts the change is +0.5%.28

While the average changes in contract values are both very minimal, the range of changes in contract values shows greater variation. For known expenditure on HIV support services the change in contract values ranges from a 6.4% decrease to an 18.5% increase, and for total expenditure including joint contracts the range is from an 8.9% decrease to an 18.5% increase.

In practice, however, only three Health Board areas had a change in contract value – one increase of 18.5% and two decreases, both of less than 10%.

In combination, the average change and the range of changes in contract show that HIV support service provision has remained reasonably consistent over the last two years in Scotland.

5.4 HOW MUCH IS SPENT ON HIV SUPPORT SERVICES IN SCOTLAND PER PERSON LIVING WITH HIV?

Expenditure per person living with HIV provides an alternative measure of HIV support service provision.

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**FIG. 5.3 – CHANGE IN HIV SUPPORT SERVICE CONTRACT VALUES IN SCOTLAND, 2015/16 – 2016/17**

- Range of change in contract value for expenditure known to be on HIV support services
- Average change in contract value for expenditure known to be on HIV support services
- Range of change in contract value for expenditure including joint contracts
- Average change in contract value for expenditure including joint contracts

<table>
<thead>
<tr>
<th>% CHANGE IN CONTRACT VALUE</th>
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<tbody>
<tr>
<td>-100 -90 -80 -70 -60 -50 -40 -30 -20 -10 0 10 20 30 40 50 60 70 80 90 100</td>
</tr>
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</table>

- Range of change in contract value for expenditure known to be on HIV support services: -6.4% to 18.5%
- Average change in contract value for expenditure known to be on HIV support services: 3%
- Range of change in contract value for expenditure including joint contracts: -8.9% to 18.5%
- Average change in contract value for expenditure including joint contracts: 0.5%
which gives some idea of the extent to which service needs are being met in different Health Board areas, on the assumption that expenditure should be roughly proportional to HIV prevalence.

Figure 5.4 shows the average per capita expenditure calculated across all Health Board areas in Scotland.29 One notable feature is that the expenditure including joint contracts is disproportionately high. This is because it has been affected by a particularly high per capita expenditure figure for one Health Board area.

The anomalously high per capita spend occurred in NHS Highland, the Health Board area with the highest expenditure in Scotland but one of the lower prevalence rates. It is possible that the comparatively high expenditure could be explained by the additional difficulties and cost of providing a service to a low number of people spread across a large rural area, particularly as the figure is for expenditure including joint contracts and therefore might go to services such as prevention outreach rather than support provision.

The range of average per capita expenditure known to be on HIV support services in 2016/17 across Health Boards areas (excluding those with zero expenditure) is from £42.25 to £289.66. (If the notable NHS Highlands expenditure is excluded the range for expenditure including joint contracts is from £42.25 to £356.52.)

The variation in Health Board expenditure can be seen clearly in Figure 5.5 which plots reported expenditure against the number of people attending for monitoring, for each Health Board area. Assuming HIV support service spending is proportional to HIV prevalence, we would expect to see expenditure increase as the number of people attending for monitoring increases.

The data is characterised by the anomalous particularly high level of expenditure in Highland, but also by a number of Health Board areas with zero expenditure.

The correlation between HIV incidence and spend is moderate for known support services expenditure, but reasonably strong between diagnosed HIV prevalence and total expenditure including joint contracts.30 The correlation is affected by the number of Health Board areas with zero expenditure, such that it is reasonable to assume that when HIV support services are commissioned in Scotland expenditure is reasonably proportional to the number of people who might need services.

It is important to remember that these data do not comment on adequacy of service provision, rather that levels of provision are moderately consistent across Health Board areas.

**FIG. 5.4 – EXPENDITURE ON HIV SUPPORT SERVICES PER PERSON SEEN FOR HIV CARE IN SCOTLAND, 2016-17**

<table>
<thead>
<tr>
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<th>SCOTLAND</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>AVERAGE PER CAPITA EXPENDITURE KNOWN TO BE EXCLUSIVELY ON HIV SUPPORT SERVICES, 2016/17 (2015/16)</strong></td>
<td>£53.89 (£53.96)</td>
</tr>
<tr>
<td><strong>AVERAGE PER CAPITA EXPENDITURE ON HIV SUPPORT SERVICES, INCLUDING JOINT CONTRACTS, 2016/17 (2015/16)</strong></td>
<td>£192.76 (£195.25)</td>
</tr>
</tbody>
</table>
One of the limitations associated with only asking Health Boards whether they commission particular categories of services is that a positive response does not indicate breadth of services, nor whether they are targeted at specific sub-groups of people living with HIV in a way that meets the needs of the local population. For example, a peer support group targeted at MSM provides no support for anyone outside that sub-group of people living with HIV.

Nevertheless, it does appear that Health Boards in Scotland generally recognise the need for the range of HIV support services, and commission accordingly.

5.5 WHAT TYPE OF HIV SUPPORT SERVICES ARE COMMISSIONED IN SCOTLAND FOR PEOPLE LIVING WITH HIV?

Of the seven Health Board areas commissioning services, four provide services within all the categories (see Figure 1.2), and three provide all categories except psychosocial support.
Wales has a lower HIV prevalence than England and Scotland and also, given the population size, has a comparatively small absolute number of people living with HIV (1,877 at December 2015). Access is a significant issue for service delivery in general in the rural and valley areas of Wales. Nevertheless, the need for HIV support services remains present, as specified in the HIV care pathway for Wales and the Sexual Health and Wellbeing for Wales Action Plan.\(^{31}\)

Sexual health and wellbeing is the joint responsibility of local authorities and seven Health Boards which, via Health, Social Care and Wellbeing (HSCWB) Partnerships, “must demonstrate that the sexual health and wellbeing needs of their local population are met in their delivery plans”.\(^ {32}\) Therefore, in Wales, NAT sent Freedom of Information requests to both Health Boards and local authorities.

Several of the FOI responses from local authorities indicated that Health Boards are responsible for commissioning HIV support services in Wales, although others did respond with details of local authority expenditure. While some Health Boards reported expenditure, still others indicated that this was not a part of their remit. There does seem to be some uncertainty around commissioning responsibility at the local level that does not marry with the responsibilities laid down in the Sexual Health and Wellbeing for Wales Action Plan.

NAT used Health Board areas for analysis in Wales. However, data for diagnosed HIV prevalence is available only at the national scale rather than at the Health Board area level. Moreover, only a few areas in Wales reported expenditure making disaggregated analysis relatively meaningless. Therefore, the expenditure data given below is analysed at the national scale and does not show the variability across Wales that a disaggregated analysis would provide.

We have shown variability in provision across Wales by describing the commissioning activity and the types of support services provided within each Health Board area.

### 6.1 National Overview for Wales

The total reported expenditure known to be exclusively on HIV support services in Wales for

<table>
<thead>
<tr>
<th></th>
<th>2015/16</th>
<th>2016/17</th>
<th>% change</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Reported expenditure known to be exclusively on HIV support services</strong></td>
<td>£70,096</td>
<td>£0</td>
<td>-100%</td>
</tr>
<tr>
<td><strong>Reported expenditure on HIV support services, including joint contracts</strong></td>
<td>£205,448</td>
<td>£135,352</td>
<td>-34.1%</td>
</tr>
</tbody>
</table>

**FIG. 6.1 – REPORTED EXPENDITURE ON HIV SUPPORT SERVICES IN WALES**
2016/17 was £0. Total reported expenditure on HIV support services (including joint contracts) in Wales for 2016/17 was £135,352, which is a 34% reduction from 2015/16.

The services which make up this total expenditure include one joint contract for HIV prevention and support services, and a second contract to provide support for people living with HIV, hepatitis A or hepatitis B.

In 2016/17 there was no reported expenditure known to be exclusively for HIV support services. However, this figure does not reflect all expenditure on HIV support services; rather it indicates the minimum expenditure in a possible range. The possible range of reported expenditure for HIV support services in Wales in 2016/17 was between £0 and £135,352.

The 34% decrease in total expenditure including joint contracts in 2016/17 is entirely the consequence of the complete termination of expenditure that is known to be dedicated exclusively to HIV support services (as opposed to joint contracts).

Apart from uncertainty around the exact expenditure on HIV support services in Wales, the presence of joint contracts is not inherently problematic as some HIV support and prevention services can have allied objectives. However, the fact that there has been a complete shift to joint contracts indicates a possible de-prioritisation of HIV support services that is cause for concern.

As there is no breakdown of HIV prevalence data by Health Board area, we have been unable to calculate the average per capita Health Board spend on support services, as we have for England and Scotland. An alternative and less precise calculation is to compare overall spend in Wales with the overall HIV positive population, which results in a per capita figure of £72.11 – but we would caution against comparison with other nations where a more precise calculation has been possible.

### 6.2 HOW MANY HEALTH BOARD AREAS IN WALES COMMISSION HIV SUPPORT SERVICES?

As shown in Figure 6.2, of the seven Health Board areas in Wales, four reported no expenditure on HIV support services in both 2015/16 and 2016/17, while one

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**FIG. 6.2 – COMMISSIONING BODIES EXPENDITURE ACTIVITIES, INCLUDING JOINT CONTRACTS IN WALES, 2016/17**

<table>
<thead>
<tr>
<th>% HEALTH BOARD AREAS</th>
</tr>
</thead>
<tbody>
<tr>
<td>No expenditure in 2015/16 or 2016/17</td>
</tr>
<tr>
<td>Commissioned in 2016/17 - with less expenditure than 2015/16</td>
</tr>
<tr>
<td>Decommissioned all services in 2016/17</td>
</tr>
<tr>
<td>Commissioned in 2016/17 - with same expenditure as 2015/16</td>
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area that commissioned services in 2015/16 cut that expenditure completely in 2016/17. Of the remaining two Health Board areas, one reported commissioning at the same amount, while the second still commissioned services in 2016/17 but at a lower amount.

Given that Wales is disaggregated into such a small number of areas, single decisions appear as a very significant shift. In fact, the 14.3% of areas decommissioning services in Wales reflects one Health Board terminating a £65,000 contract. By way of contrast, 10 local authorities decommissioned services in England in 2016/17 which comprised 6.6% of commissioning activity.

Another factor that must be taken into consideration is that Cardiff and Vale University Health Board (UHB), one of the Health Board areas that reported no commissioning expenditure for HIV support services, provides all sexual health services through an Integrated Sexual Health Service (ISHS) that is not externally commissioned.

The presence of an ISHS is not unique to Wales; there is also an emergent trend of awarding ISHS contracts in England. However it is likely that the impact of underreporting services would be particularly disproportionate in the case of Cardiff. Not surprisingly, Public Health Wales data indicate that the Cardiff region has the highest number of HIV diagnoses in Wales, so it is reasonable to assume that HIV prevalence is comparatively high here as well. Therefore, if there is investment in HIV support services within the Cardiff and Vale region a significantly higher number of people living with HIV might have access to services than our data indicate.

In England, the presence of ISHS contracts tends to mean that commissioners are unable to identify the expenditure that goes to HIV support services. This suggests that they, and potentially service providers, cannot quantify their level of service provision. These concerns may be moot in Cardiff which is somewhat unique within the UK given that services are not externally commissioned. However, if that is not the case, adding HIV support services on to much bigger GUM and CaSH contracts risks provision being inadequate.

### 6.3 WHAT TYPE OF HIV SUPPORT SERVICES ARE COMMISSIONED BY HEALTH BOARD AREAS IN WALES?

There is no consistency in the type of services provided across the three Health Board areas that reported expenditure. One area commissioned within all the named HIV support service categories except psychosocial support in both 2015/16 and 2016/17. A second area provided only information, advice and advocacy in 2015/16 but that was decommissioned for 2016/17. The third Health Board area commissioned across all the HIV support service categories in 2015/16, but decommissioned peer support, sex and relationships support and psychosocial support in 2016/17.

NAT’s data does not extend to indicating the amount of expenditure on each support service type. It is important not to overstate the level of provision. For example, in the case of the third Health Board area described above, the combined value for peer support, sex and relationships support and psychosocial support in 2015/16 was £5,096.

It is also important not to assume that the presence of HIV support services necessarily means that what is provided is necessarily suitable for everyone living with HIV. For example, some services are particularly targeted at pregnant women or MSM so are only suitable for that sub-group.

The specifics of the HIV epidemic and of population density in Wales mean that HIV support service provision may be more complex than in other areas of the UK. Regional collaborative commissioning has been proven to be successful in the past, and may be part of the solution for meeting HIV support service needs in Wales.
Northern Ireland has the lowest incidence of HIV among the UK nations; 934 people were seen for HIV care in 2015. Therefore there is a similar problem to Wales in terms of a small, possibly dispersed population needing access to HIV support services. As for Wales, there is no publicly available data that breaks down HIV incidence into sub-national areas.

The Sexual Health Promotion Strategy and Action Plan for Northern Ireland mentions information and advice services among those necessary for maintaining good sexual health and specifies a process for implementing adequate support services as part of GUM services. However there is no service specification for Northern Ireland that establishes support services as part of the HIV care pathway.

In terms of HIV support service expenditure, all Health and Social Care Trusts responded to our FOI requests stating either that they did not commission services, or that they did not hold the data we had requested. Anecdotal reports suggest that some services are locally commissioned in Northern Ireland but, despite further efforts, we have not been able to identify local commissioning expenditure made by Health and Social Care Trusts.

Notably, three Trusts referred us to the Public Health Agency (PHA) in their responses to our FOI. We subsequently identified PHA expenditure on HIV support services in 2016/17 of £123,358, which constitutes a 1.3% increase from 2015/16. The services provided include peer support; information, advice and advocacy; sex and relationships support; and psychosocial support.

As the expenditure is provided on a national basis, it equates to a per capita expenditure known to be exclusively for HIV support services of £132.07 per person seen for HIV care in Northern Ireland.

Given that data both for HIV prevalence and HIV support service expenditure is available only at the national scale, we cannot establish the variation
in HIV support service provision across Northern Ireland. Therefore, for this report, a question remains outstanding in terms of how many people being seen for HIV care in Northern Ireland have reasonable access to HIV support services.

Simply because of the inflated costs involved in distributing support to a small, dispersed population (as shown in Highland, in Scotland, for example), it is worth considering whether the relatively high per capita figure Northern Ireland facilitates access to HIV support services. Without disaggregated data, NAT is unable to draw further conclusions on provision in Northern Ireland. However, it is worth noting that expenditure levels have been preserved, meaning that the expenditure that is available has not been subject to decommissioning as it has in Wales and England.
Northern Ireland it became apparent that it was also necessary to obtain information from national bodies to get an accurate picture of state funding for HIV support services.

THE FOI REQUEST

NAT’s Freedom of Information request for HIV support service expenditure was part of a larger request that also included questions on HIV prevention and testing expenditure. The text of the request that pertains to HIV support services is given on the following page.

ASSESSING THE RESPONSES

We had an excellent response rate; the data is missing for only one local authority in each of Scotland and Wales and a handful of CCGs in England. NAT would like to thank all commissioning bodies who responded to the FOI request.

Some commissioning bodies reported that they did not hold, or were unable to provide the requested information. We interpreted this to mean that there was no expenditure on HIV support services on the grounds that state bodies necessarily hold data for the services they commission. We have no reason to doubt the veracity of the data, except in Northern Ireland where one response does not seem to reflect the situation on the ground. The matter is discussed further in the relevant section.

The FOI requests provide two years’ worth of data but describe only recent history, and inevitably capture
**FOI REQUEST**

**Re. spending in 2015/16 and plans for 2016/17**

NAT (National AIDS Trust) is asking for specific information on services commissioned for Primary HIV prevention; HIV testing services (outside of GU services) and support services for people living with HIV. It would be appreciated if your authority could provide us with the information set out in the questions below. For more information about this request and where to return it to, please contact us on the details at the bottom of this document.

**SUPPORT FOR PEOPLE LIVING WITH HIV**

1. Did you provide any funding through contracts or grants for services specifically supporting people living with HIV?

2. Is support for people living with HIV explicitly mentioned within the contractual documentation for any generic services you funded?

3. If the answer to either of the above, please fill in the following in relation to these services:

(You may have more than one service. Please copy and paste a new table for each service)

<table>
<thead>
<tr>
<th>Service/contract description</th>
<th>Expenditure in 2015/16</th>
<th>Is this contract commissioned for 2016/17 and if so what is the value of the contract</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support type</td>
<td></td>
<td>Does the contract include this service, yes/no (please also add any further information you wish to include)</td>
</tr>
<tr>
<td>Peer support for people living with HIV (e.g. group or 1-2-1 peer support)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information, advice and advocacy for people living with HIV (e.g. housing or benefits advice)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-management (e.g. treatment and adherence information and healthcare engagement)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex and relationships support (e.g. sexual health support and disclosure support)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychosocial support (e.g. counselling and mental health services)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other (please specify)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
In Scotland and Wales. In addition, Health Board areas are coterminous with groups of local authorities, meaning that a total figure could be derived for the area that includes both Health Board and associated local authority spending. In Northern Ireland, the locality was pre-defined as the Health and Social Care Boards areas, as these were the only bodies that received the FOI requests.

In England, the situation is somewhat different. London is unique in terms of both the concentration of HIV prevalence and HIV support service expenditure. Therefore, data was disaggregated first into London and rest of England, and then by local authority within these two ‘regions’. Where relevant the data are combined for an ‘All England’ figure. CCG spending could not be as easily amalgamated with local government areas as was possible for the NHS spending in other nations. In any case, it tells its own story so the analysis of CCG spending has been kept separate.

The specifics of disaggregation are explained further in the individual data descriptions for each nation.

**ANALYSING THE DATA**

The FOI request asked commissioning bodies whether they have any contracts specifically for HIV support services in 2015/16 and 2016/17, and if they have any other contracts with key performance indicators which specifically mention people living with HIV. The intention was to capture all spending that was targeted at people living with HIV, without erroneously including expenditure that simply ‘would not exclude’ people living with HIV. For example, one local authority reported expenditure on a contract where a Citizen’s Advice Bureau (CAB) officer works in an HIV clinic, with the capacity and knowledge required to tailor standard CAB services to people living with HIV. Generic CAB services, however, would not be classified as HIV support services.

Our data analysis identified total and per capita spend on HIV support services, and the trends in expenditure between 2015/16 and 2016/17 for each nation. However, given that HIV support services are generally commissioned locally, much of our analysis involved using data disaggregated into local areas. This enabled measurement of the variation in total and per capita expenditures and provision between local areas, which are then averaged across each nation.

In Scotland and Wales the data is disaggregated by Health Board area. In practice, Health Boards account for most of the expenditure on HIV support services in Scotland and Wales. In addition, Health Board areas are coterminous with groups of local authorities, meaning that a total figure could be derived for the area that includes both Health Board and associated local authority spending. In Northern Ireland, the locality was pre-defined as the Health and Social Care Boards areas, as these were the only bodies that received the FOI requests.

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The specifics of disaggregation are explained further in the individual data descriptions for each nation.

Per capita expenditure was calculated using data for the number of people seen for HIV care. This decision was made on the grounds that while some HIV services, such as prevention and testing, are relevant to both the general and the undiagnosed population, demand for HIV support services only comes from those who have an HIV diagnosis.

In England, the only publicly available data for the population with an HIV diagnosis, disaggregated by local authority, are PHE’s data on the number of people aged 15-59 “accessing HIV related care”, valid at December 2015. Although this figure excludes those lost to care and those not yet attending, it is the most consistent publicly available data.

PHE provides the same data for all four UK nations at the national scale. In both Wales and Northern Ireland, where absolute numbers of people living with HIV are low (1877 and 934 respectively, at December 2015), there is no publically available disaggregated data for the diagnosed population, which limits the amount of
analysis that can be done at Health Board or Health and Social Care Board level.

Health Protection Scotland (HPS) provides data, disaggregated to Health Board level, for both the number of people with an HIV diagnosis and the number "attending for monitoring". As with the other nations we have used the data for those attending for monitoring, however the dataset is different from PHE’s both in the age range (HPS reports for all ages) and the date (September 2016). Figures for the number of people seen for care in Scotland are lower in PHE data (4,191) than in HPS data (4,501), presumably accounted for by the number of people with an HIV diagnosis outside PHE’s age range and new diagnoses between December 2015 and September 2016. The discrepancy means that the calculated per capita spend is possibly underestimated for Scotland in relation to the other three nations. However, to allow for disaggregated analysis while maintaining consistency with national level data, we have used HPS data across the analysis for Scotland.

Interestingly, the HPS data show that most of the difference between the numbers diagnosed and attending for care are due to those lost to monitoring, rather than new diagnoses not yet receiving care. It is useful to know that using numbers attending for care generally does not exclude newly diagnosed people, who are known to have need of HIV support services.
ENDNOTES

1 For results from earlier phases of our investigation into HIV support services see NAT. Why we need HIV support services: A review of the evidence, 2017.

2 APPG on HIV & AIDS, The HIV Puzzle: Piecing together HIV care since the Health and Social Care Act, 2016. p.6

3 While this report examines the extent of HIV support service provision in some depth, the data collected cannot give an indication of whether that provision is sufficient for the needs of people living with HIV that it is designed to serve.

4 For more details of these survey results see NAT. Why we need HIV support services: A review of the evidence, 2017.

5 Public Health England estimate that there are 101,200 people living with HIV in the UK. In this report we use the figures for the number of people attending for HIV care (monitoring and access to treatment) as a proxy for the number of people diagnosed with HIV who, by definition, are the group of people who might need HIV support services. For a more detailed explanation, see the ‘Analysing the data’ section in the Appendix.


7 Maeghan Kall on behalf of the study group for Positive Voices National Survey of People Living with HIV, Public Health England, Personal Communication.

8 Based on the outcome of focus groups conducted by NAT in 2015 in order to understand how people living with HIV use HIV support services and the value they place on them.

9 The People Living With HIV Stigma Survey UK, National findings, 2015.


11 For a more detailed and specific version of the arguments given here about demonstrated ongoing need and the consequences of it not being met, see NAT. Why we need HIV support services: A review of the evidence, 2017.

12 This section of the report briefly describes our methodology and the key features of the returned data which determined our analytical and reporting choices. See the Appendix for a much fuller explanation of our methodology, the fundamentals of our analysis, and the full text of the Freedom of Information instrument sent to commissioning bodies.


14 In a very few cases joint contracts were for services other than prevention and support, for example for support around blood borne viruses.


16 The change in total reported expenditure is over-estimated because some local authorities were unable to provide expenditure data for 2015/16. The bracketed figure gives a better approximation of actual change because it only includes local authorities where data is available for both years. This is explained in more detail in the text.


18 While contracts may not align with the financial year, we would expect the budgets of local authorities and the services they commission to be established by the start of the financial year.

19 For the purposes of this report, NAT has described per capita expenditure in England as the number of people ‘seen for care’ (as described by Public Health England) on the grounds that these are the group of people who may have need of HIV support services. See the ‘Analysing the data’ section of the Appendix for an explanation of the data used to calculate per capita expenditure.

21 Pearson’s coefficient is less than 0.5 for both sets of expenditure data (total expenditure, including joint contracts, and expenditure known to be exclusively on support services).

22 Step down services, often but not always including short-term accommodation, support people to transfer from hospitals and other secure settings back into their own homes and communities.

32 NHS


34 For the purposes of this report, NAT has described per capita expenditure in Northern Ireland as the number of people ‘seen for care’ (as described by Public Health England), on the grounds that these are the group of people who may have need of HIV support services. See the ‘Analysing the data’ section of the Appendix for an explanation of the data used to calculate per capita expenditure.
SHAPING ATTITUDES
CHALLENGING INJUSTICE
CHANGING LIVES

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to transforming society’s response to HIV.

We provide fresh thinking, expertise
and practical resources.

We champion the rights of people living with
HIV and campaign for change.

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