

# HIV support services – The state of the nations



## EXECUTIVE SUMMARY





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- 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 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

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- 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.



# RECOMMENDATIONS

- 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.



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## NORTHERN IRELAND

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- 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.

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# SHAPING ATTITUDES CHALLENGING INJUSTICE CHANGING LIVES



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**We provide fresh thinking, expertise and practical resources.**

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