

Report to: **Cabinet**  
Date: **26 June 2018**  
By: **Director of Adult Social Care and Health**  
Title of Report: **HIV Support Service**  
Purpose of Report: **To consider proposals for the HIV Support Service**

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## **RECOMMENDATIONS**

**Cabinet is recommended to:**

- 1. agree that the current service continues through 2018/19 and that self-care groups are established during this period to sustain support in future years;**
  - 2. agree to give notice to terminate the agreement with the HIV Support Service and withdraw funding; and**
  - 3. delegate to the Director of Adult Social Care and Health authority to take all necessary actions to give effect to the implementation of the above recommendations**
- 

### **1. Background**

1.1 An HIV Support Service has been commissioned by East Sussex County Council (ESCC) since 2009. During this time the service has been delivered by Terrence Higgins Trust (THT). The service was commissioned through the Commissioning Grants Prospectus and is now managed through a contract.

1.2 The service is commissioned to support adults with HIV and their carers to manage the impact of HIV, including maintaining independence and social inclusion, through individual and group support (Positive Self-Management groups) and information and advice.

### **2. Supporting Information**

2.1 The current gross budget for the HIV Support Service is £47,900 per annum. The current arrangements commenced in October 2014 and a contract is now in place for 2018/19. Over the contract period, the service initially reported support for 80 people per year, although this reduced to approximately 50 by 2017 and the number using the service has continued to fall.

2.2 The service works closely with East Sussex Healthcare Trust and Sussex Community Foundation Trust Genito-urinary Medicine (GUM) and HIV services.

### **3. Consultation Summary**

3.1 In the ten week consultation period from 19<sup>th</sup> April 2018 to 28<sup>th</sup> May 2018, clients who have used the service in the past two years, and approximately 200 HIV positive patients were contacted with a view to better understanding the impact the proposal could have on their lives. A consultation meeting with services users and the service provider was held on 22<sup>nd</sup> May.

3.2 A total of 42 comments or queries were received from people about the HIV Support Service prior to and during the consultation period. Comments have been received from members of the local community and are included in the consultation feedback.

3.3 Key messages from the consultation include:

- Organisations point out that the cutting the service would create inequality of support across Sussex.
- The service plays an important role in counteracting the stigma and lack of understanding from general services that people still experience.
- The majority of clients are from marginalised groups and need support to access traditional services.
- Specialist services are needed to ensure people get the support they need and don't reach crisis.
- People will become increasingly isolated and lose access to support groups they value.

3.4 Complimentary and positive comments were received about the good standard of support provided by the THT. All respondents noted the need to continue the service and they would feel increasingly socially isolated if direct HIV support was lost.

3.5 A consultation report is provided in Appendix 2 and copies of all responses received to the consultation are available in the Cabinet Room and the Members Room for Member's consideration.

#### **4. Alternative Service Provision**

4.1 The support needs of clients could be met through existing alternative provision in the county, including benefits advice, housing, employment, education, and immigration support, and support to manage to manage long term conditions.

4.2 Effective medication management is a local priority and a number of existing East Sussex Better Together and Connecting 4 You programmes, as well as community organisations, will continue to provide integrated support and technology-based solutions. HIV awareness-raising will be provided to services which may start to specifically support people with HIV, along with support to self-manage and develop network-based support.

4.3 HIV positive adults can access other community support via Health and Social Care Connect and East Sussex 1Space.

4.4 NHS England also commission HIV services and it is anticipated this provision will mitigate any impacts as a result of the THT contract not being renewed. This will ensure there is:

- Case management appropriate to the clinical and holistic needs of the patient
- Arranging access to support for meeting non HIV needs of patients and identify shared care help. These will include but are not confined to: primary care, sexual health, social services, family services, psychological support, community and third sector services, drugs & alcohol services and maternity services. Particular attention is paid to simplifying arrangements for vulnerable groups such as prisoners, migrants and those with learning disabilities.

#### **5. Impact of delivering the proposal**

5.1 In considering the proposals in this report, Cabinet Members are required to have 'due regard' to the duties set out in Section 149 of the Equality Act 2010 (the Public Sector Equality Duty). Equality Impact Assessments (EqIAs) are carried out to identify any adverse impacts that may arise as a result of the proposals for those with protected characteristics and to identify appropriate mitigations. A summary of the key impacts from the EqIA are attached at Appendix 3 and the full version of relevant completed EqIAs have been placed in the Members' and Cabinet Room and are available on the [Cabinet](#) pages of the County Council's website. They can be inspected upon request at County Hall. Members must read the full EqIAs and take their findings into consideration when determining these proposals.

5.2 The area of biggest impact is on adults with HIV and their carers. Most notably the population of people with HIV living in East Sussex is ageing and will potentially develop other long-term conditions alongside their HIV diagnosis. This is likely to increase demand on primary and acute health services, as well as demand for social care support. As the population of people with HIV ages, it will be important that local services understand the needs of older people with HIV and are able to support them.

5.3 If the proposal is agreed, the remaining contract period would be used to support people with HIV to access alternative services and to establish self-management networks to sustain their social connections.

## **6. Conclusion and Reason for Recommendations**

6.1 The impact of ceasing funding for this service to support people with HIV is likely to increase social isolation. However, the availability of alternative local services means that maintaining this provision is not considered good value nor sustainable given financial constraints.

### **KEITH HINKLEY**

#### **Director of Adult Social Care and Health**

Contact Officer: Angela Yphantides, Strategic Commissioning Manager

Lead Member: Councillor Maynard

Local Member: Countywide service

#### **BACKGROUND PAPERS:**

Appendix 1: HIV Support Service Summary

Appendix 2: Consultation Report

Appendix 3: Equality Impact Assessment Summary



## HIV Support Service Summary

2018/19 Budget		Capacity	Current Occupancy	Unit Cost	Tenure	Savings (FYE)
Gross	£47,900	80 places	50 in Quarter 3 (Oct-Dec 2017)	Q3 - £958 pa	Grant expires on 31 March 2019	£47,900
Income	£0		21 in Quarter 4 (Jan – March 2018)	Q4 - £2,281		
<b>Net Expenditure</b>	<b>£47,900</b>					



# ASC savings consultation 2018

## HIV Support Service

**Date:** June 2018

### Document summary

Results from the ASC savings consultation carried out between March and May 2018, focusing on the HIV Support Service

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## About this document:

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<p><b>Accessibility help</b> Zoom in or out by holding down the Control key and turning the mouse wheel. CTRL and click on the table of contents to navigate. Press CTRL and Home key to return to the top of the document Press Alt-left arrow to return to your previous location.</p>	

## Background

The Council agreed its budget for 2018/19 at its meeting on 6 February. It will see the Council make savings of £17 million. This includes a budget reduction for Adult Social Care and Health of nearly £10 million.

We used the consultation to ask for people's views on how we are proposing to make the savings. Shortly before the consultation launched, the Government announced some extra funding for social care provision. No decisions have been made yet on how the Council will spend the £1.6 million it will receive.

This report is about the savings proposal for the HIV Support Service. We are proposing to stop funding the service from March 2019.

The Council's Cabinet will consider recommendations, the consultation results and Equality Impact Assessments at its meeting on 26 June. All responses received in the consultation will be presented in Members Papers.

## Summary

This section provides a summary of the key themes and activity from the consultation. You can find the full results in the appendices.

We consulted on our savings proposals for the HIV Support Service between 19 March and 28 May 2018.

## Activity and events

Event type	Details	Attendees
Consultation meeting	22 May, Avenue House, Eastbourne	10

## Respondent numbers and response methods

The table below shows the different ways that respondents shared their views. Some people may have taken part more than once.

Method	Volume
Survey for all respondents (Paper and online)	25
Other feedback (Email, letter, call, video, feedback form)	Individual: 2 Org and group: 5
Event or meeting	10
<b>Total responses</b>	<b>42</b>

## Key messages

These key messages reflect the feedback received from organisations, groups and individuals across meetings, surveys and other feedback such as emails and letters.

- People and organisations disagree with, or are unhappy about, the proposal to stop funding the service.
- Both argue that there is still a need for this service and are concerned about the impact on people who need this support.
- Organisations point out that cutting the service would create inequality of support across Sussex.
- Both say that the service plays an important role in counteracting the stigma and lack of understanding from general services that people still experience.
- The majority of clients are from marginalised groups and need support to access general services.
- Specialist services are needed to ensure people get the support they need and don't reach crisis.
- People would become increasingly isolated and lose access to support groups they value.
- Reducing services that promote and support self-management could result in increased hospital admissions and increased costs to the local health economy.
- People said that the service should keep some of its funding and the long-term effects of cutting funding must be considered.
- Organisations suggested looking at joint resourcing for the service with other authorities and health services.

## Summary of themes by response method

### Survey for all respondents

#### Views on the proposal

- People disagree with, or are unhappy about, the proposal to stop funding the service and are concerned about how it would affect them and/or people who use the service.

#### The impact of the proposal

- People would become increasingly isolated and lose access to support groups they value.
- It would impact on people's physical health if they lose this support.

#### Suggestions

- Stop any wasting of money.
- Don't cut all of the funding for the service.
- Look at joint resourcing for this service with neighbouring authorities.

#### Other comments

- Consider the long-term effects of cutting funding.

### Other feedback via letter, email etc

#### Organisation and group feedback

##### Views on the proposal

- Organisations disagree with the cuts and say there is still a need for the service.
- Cutting the service would also create inequality of support across Sussex.
- The service plays a part in counteracting the stigma and lack of understanding that still exists around HIV.
- Previous cuts mean that any further reduction would hit core service delivery.
- The provider believes there isn't another organisation which could offer the same holistic range of services.
- People often feel unsafe disclosing their diagnosis when they access services and need support to do so.
- The majority of clients are from marginalised groups and need support to access traditional services.

##### The impact of the proposal

- Reducing services that promote and support self-management could result in increased hospital admissions and increased costs to the local health economy.
- The ongoing funding uncertainty and the impact it has on supporting hard-to-reach people and maintaining staffing levels.

##### Suggestion

- That the service is targeted more to an ageing demographic.
- That multi-sourced funding is explored across health and the local STP.

#### Individual feedback

##### Views on the proposal

- The service helps to fight stigma and it is an invaluable source of information.

## The impact of the proposal

- Cutting the service would impact on the HIV clinics and engagement with care, adherence to medication, public health and individual health.

## Events feedback

### Views on the proposal

- There is still stigma attached to HIV and the service plays a vital role in fighting that.
- There is still a lot to do to improve awareness and understanding of HIV and disclosure about it among professionals such as GPs and adult social care staff.
- The service helps to educate people and their families after diagnosis.
- It is important to have people to talk to and easy access to them.
- Services have already reduced in recent years and cutting the service suggests all the problems have been solved.

### The impact of the proposal

- This is a vital service and closing it would lead to preventable deaths.
- Specialist services are needed to ensure people get the support they need and don't reach crisis.

### Suggestions

- It would be better if the service was reduced rather than cut completely.

## Sample quotes

These comments are a small selection of the comments we received during the consultation. They have been chosen as they either reflect the key themes or offer a specific suggestion.

### Organisation comments

“We are gravely concerned by the potential inequity if East Sussex County Council goes ahead with a cut to THT’s budget: community voluntary sector support will be provided in West Sussex and in Brighton & Hove but not in East Sussex. We are similarly concerned for the public and for individual health.”

“People with HIV at our HIV services users’ forum have vociferously explained that HIV stigma prevents them from accessing generic services, e.g. social care, housing advice services, benefits agency, food bank, etc. for fear of negative reaction, lack of confidentiality, etc. THT acts as an advocate, facilitating our most vulnerable patients’ uptake of such services.”

“Specialist support services may be the only places where people living with HIV can be open about their status and there is a great danger that, without HIV specialist services, people living with HIV will drop out of the vital support that allows them to achieve optimal health and wellbeing.”

“The multi-sourced funding we are advocating requires making a reality of the expectations around joined-up and integrated commissioning, at local authority level via the JSNA and Health and Wellbeing Board process but also at the supra-local level of the STP [Sustainability and Transformation Partnership].”

### Individual comments including clients, carers, staff and the public

“People will receive support from non-specialist agencies, which still have to be paid for

but the outcomes are likely to be less satisfactory.”

“This would have a huge impact on me because I will be not encouraged to go out. This charity had many options for me to go out and meet friends to interact with.”

“I am speaking on behalf of a lot of the ethnic minorities - we get double isolated. Already society looks at you differently and then you have this as well. You need to work and provide a life for yourself again. I’m not sure whether that specialist service can be reproduced.”

“You are in a position when you are HIV+ that you have to educate people, you have to go through the process of explaining the whole thing and that is a burden.”

“Do not walk away yet, we still need the specialist services. We have the clinic service, it is wonderful, but the message is not out there, so outside the clinic we find a world that....”

“THT is like the mother that is not there, they are always watching.”

“It is a chronic illness – you are not going to die, but is like a chain with a ball to carry round and THT helps to lighten that load.”

“It is likely that it will be some of the most vulnerable members of our local community who will require services such as this and therefore, those least likely to be in a position to advocate for themselves. I think that the complete removal of such services will significantly increase the likelihood of poor health outcomes for those affected.”

“Unfortunately there is still a lack of understanding of issues involved in living with HIV by the GPs and others in the regular health care services. and there won't be an equivalent option left if the service is cut.”

## Appendix 1: Survey for all respondents

### Are you completing the survey as: (24 answered)

Please note that this was a multiple choice question.

Someone who has used the HIV Support Service	18
A family member or friend of someone who uses social care services	3
An employee of a health or social care organisation	1
A member of the public	5
A group or forum (providing an official response)	0
An organisation (providing an official response)	0
Other (please explain below)	0
Not Answered	1

### If you are providing an official organisation or group response, please tell us your:

None submitted.

### What do you think about our savings proposals? (22 answered)

**Top theme:** People disagree with or are unhappy about the proposal to stop funding the service and are concerned about how it would affect them and/or people who use the service.

The other key themes were:

- People would still have support needs, meaning it would be more expensive in the long term as they look to other services to fill the gaps.
- People value the specialist support offered by the service.

### How would people and organisations be affected by the proposals? (22 answered)

**Top theme:** People would become increasingly isolated and lose access to support groups they value.

The other key themes were:

- Cutting this service would impact on people's physical health.
- People would lose access to helpful advice which makes a difference to them.

### Do you have any suggestions for alternative ways of making the savings? (19 answered)

**Top theme:** People said that any wasting of money must be stopped and that the Council shouldn't cut all of the funding for the service.

The other key themes were:

- Look at joint resourcing for this service with neighbouring authorities.
- Lobby the government for more money.

### Do you have any other comments about the proposals?

12 people ticked 'No', while 8 ticked 'Yes'.

**Top theme:** Consider the long-term effects of cutting funding.

## About you questions

### Gender

	Respondents		Census
Male	15	60%	48%
Female	8	32%	52%
Prefer not to say	1	4%	N/A
Not answered	1	4%	N/A

### Transgender

No one identified as transgender, while 21 (84%) answered 'no' and 2 chose prefer not to say. The rest (2) did not answer the question.

### Age

	Respondents		Census
under 18	0	0%	19.8%
18-24	0	0%	7.3%
25-34	3	12%	9.6%
35-44	2	8%	12.5%
45-54	7	28%	14.2%
55-59	2	8%	6.3%
60-64	4	16%	7.5%
65-74	0	0%	11.2%
75+	3	12%	11.6%
Not answered	4	16%	N/A

## Location of respondents

The map shows the location of respondents who provided their post code. Of the 19 people who shared their views about these proposals and provided their post code, a total of 14 were mappable.

### HIV Support Service



30/05/2018

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Note: points may represent multiple addresses at the same postcode

## Ethnicity

	Respondents		Census
White British	16	64%	98%
White Irish	0	0%	
White Gypsy/Roma	0	0%	
White Irish Traveller	0	0%	
White other	0	0%	
Mixed White and Black Caribbean	0	0%	0.5%
Mixed White and Black African	0	0%	
Mixed White and Asian	0	0%	
Mixed other	0	0%	
Asian or Asian British Indian	0	0%	0.6%
Asian or Asian British Pakistani	0	0%	
Asian or Asian British Bangladeshi	0	0%	
Asian or Asian British other	0	0%	
Black or Black British Caribbean	0	0%	
Black or Black British African	5	20%	0.3%
Black or Black British other	0	0%	
Arab	0	0%	0.3%
Chinese	0	0%	
Other ethnic group	0	0%	
Prefer not to say	3	12%	N/A
Not Answered	1	4%	n/a

## Disability

16 (64%) respondents consider themselves to be disabled, while 7 don't and 1 chose prefer not to say. The rest (1) did not answer the question.

### Impairment type

Please note that this is a multiple choice question.

	Respondents	
Physical impairment	2	8%
Sensory impairment (hearing and sight)	1	4%
Long standing illness or health condition, such as cancer, HIV, heart disease, diabetes or epilepsy	14	56%
Mental health condition	6	24%
Learning disability	1	4%
Other	2	8%
Prefer not to say	1	4%

## Religion

8 (32%) respondents consider themselves to have a religion or belief, while 9 (36%) do not, and 7 chose prefer not to say. The rest (1) did not answer the question.

### Stated religion or belief

	Respondents		Census
Christian	8	32%	60%
Buddhist	1	4%	0.4%
Hindu	0	0%	0.3%
Jewish	0	0%	0.2%
Muslim	0	0%	0.8%
Sikh	0	0%	0%
Other	0	0%	0.7%
Not answered	16	64%	

## Sexuality

	Respondents	
Bi/Bisexual	2	8%
Heterosexual/Straight	6	24%
Gay woman/Lesbian	0	0%
Gay Man	11	44%
Other	1	4%
Prefer not to say	4	16%
Not answered	1	4%

## Marriage or civil partnership

6 respondents are married or in a civil partnership, while 12 (48%) are not and 6 chose prefer not to say. The rest (1) did not answer the question.

## **Appendix 2: Other feedback**

### **Organisation and group feedback**

The following organisations or groups mentioned the HIV Support Service in their consultation responses:

- 1) Hastings and District TUC
- 2) HIV Team
- 3) Terrence Higgins Trust
- 4) National AIDS Trust
- 5) Sussex HIV Network

### **Key themes**

The overall themes were:

- Organisations disagree with the proposal to cut funding for the service.
- There is a need for this service which enables people to stay well and to stay at home.
- If the cut went ahead it would create inequity of support across Sussex.
- It would remove a well-established safety net from already disadvantaged people.
- People living with HIV need holistic long-term condition management support to access appropriate healthcare and also to self-manage effectively.
- The stigma around HIV and the understanding of it remains poor. People often feel unsafe disclosing their diagnosis when they access services.
- The HIV support service plays a part in counteracting stigma and challenging discrimination.

The key concerns were:

- The service has already experienced cuts in funding, so further cuts would hit core service delivery.
- The majority of clients are from marginalised groups and need support to access traditional services.
- No other provider would be able to offer the holistic range of services currently on offer.

The key impacts were:

- Reducing services that promote and support self-management could result in increased hospital admissions and increased costs to the local health economy.
- The ongoing funding uncertainty and the impact it has on supporting hard-to-reach people and maintaining staffing levels.

Suggestions:

- That the service is targeted more to an ageing demographic.
- That multi-sourced funding is explored across health and the local STP.

## Responses

Please note that the summaries cover all topics that the organisations have provided feedback on and not just the ones directly relevant to this report.

Code: Org0024	April		Email	Hastings and District TUC
<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HIV support service	Carers support	DESSS	Intermediate care and day services (Milton and Firwood)	LD dps & residential
<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Overall	Older people's day centres	Supporting people (accommodation)	Supporting People (Community)	Stroke Recovery Service

### Summary

- They do not accept the rationale for cuts and are disappointed at the half-hearted Stand up for East Sussex campaign.
- They are concerned that staff in Adult Social Care are taking the brunt of the cuts, which would lead to inevitable delays in services for those members of the community who are least able to cope with them.
- The decimation of local services would remove well-established safety nets from already disadvantaged people (they name STEPS, Home Works, the Stroke Recovery Service, carers support, and the HIV Support Service).
- The lack of an Equality Impact Assessment in the consultation is telling.
- The staffing cuts would be false economy as people would have to wait much longer to access services and would inevitably end up on hospital wards.
- The abandonment of the preventative agenda would have the same effect.
- They urge councillors to consider using unallocated reserves to limit the impact and mitigate the proposals with the additional government funding.
- They are opposing the cuts and urge the Council to oppose national funding decisions.

Code: Org0039	May		Email	Terrence Higgins Trust
<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HIV support service	Carers support	DESSS	Intermediate care and day services (Milton and Firwood)	LD dps & residential
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Overall	Older people's day centres	Supporting people (accommodation)	Supporting People (Community)	Stroke Recovery Service

### Summary

- The organisation gives some background on itself and the typical treatment costs and challenges that those living with HIV face.
- It has been delivering services in the county for about 18 years, including the HIV support service.
- It welcomes the consultation on funding decisions that would potentially affect the organisation and delivery of care to those living with HIV.
- It says it has gained an excellent reputation for delivering high-quality support services for people living with HIV and their families and carers.
- The integrated approach it takes has been proven to build independence and wellbeing and to absorb pressure on public services.

- The organisation is sympathetic to the strains on the local budget and is working to be more agile and responsive. The cuts of previous years have made this task more difficult.
- There is no other provider that can offer the holistic range of services that it does.
- Despite the decline in new diagnoses, this group of people is ageing and often has complex health needs.
- The stigma around HIV and the understanding of it remains poor. This impacts greatly on people when accessing services such as social care, health and welfare.
- As people with HIV age, this is a particular issue in care home settings.
- At a recent forum, there were numerous comments about people feeling unsafe disclosing their HIV status and the importance THT plays in counteracting the stigma and challenging discrimination.
- The organisation provides social value through local fundraising.
- The ongoing uncertainty about funding presents challenges in supporting hard-to-reach people and maintaining staffing.
- The majority of clients are from marginalised groups and many of them do not access traditional services or find it hard to do so. Partnership working is therefore an important part of what they do.
- The HIV support service enables people to stay well and to stay at home through the support it provides.
- Having already experienced significant cuts, they believe that further cuts would be hugely detrimental to their core service delivery.
- There is a need for this service and more that can be for older people living with HIV.
- They would welcome discussions with ASC; for example, looking at targeting our services more to an older demographic.
- They can play a vital role in early intervention, providing support to enhance and maintain independence and wellbeing, and prevent physical and mental decline.

Code: Org0040	May	Email	National AIDS Trust
<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HIV support service	Carers support	DESSS	Intermediate care and day services (Milton and Firwood)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Overall	Older people's day centres	Supporting people (accommodation)	Supporting People (Community)
			Stroke Recovery Service

## Summary

- The HIV profile for East Sussex would be expected to generate varied and substantial demand for support in the county.
- Some people living with HIV have permanent impairments and complex support needs that are not always met by statutory social care packages.
- People living with HIV need holistic long-term condition management support to access appropriate healthcare and also to self-manage effectively.
- HIV support services, including counselling, can be low threshold, preventative and cost-saving interventions to avert acute ill-health and crisis.
- Stigma has not gone away. This affects the ability to come to terms with new

diagnosis and contribute to feelings of social isolation and to difficulties in coping.

- There is a danger that without specialist services, people living with HIV would drop out of the vital support that allows them to achieve optimal health and wellbeing.
- Comprehensive HIV support services are agreed to be an essential element in the HIV care pathway.
- The NHS Five Year Forward View places a strong emphasis on long-term condition management support.
- Local authorities have a legal obligation to undertake a needs assessment of local people living with HIV and Care Act duties around wellbeing, care and support and market-shaping duties.
- Funding HIV support services is a proven way of identifying and meeting all these obligations.
- HIV is a disability (under the Equality Act 2010) and people with HIV are disproportionately from gay and African communities.
- There is an equalities dimension to these services, linked to the Council's public sector equality duty, which needs to be taken into account before any decision on the future of these services is made.
- Support services have an important role in preventing the need for more expensive assessed health and care services.
- Under the Care Act the Council is still required to prevent, delay and reduce the development of further care and support needs, despite the Council saying it will move away from preventative services.
- They suggest that maybe Public Health funding could contribute towards the HIV Support Service or whether NHS funding could be explored.
- Discussions also need to take place with CCGs around shared funding for these services as part of their long-term condition management obligations.
- The multi-sourced funding they are advocating requires making a reality of the expectations around joined-up and integrated commissioning, at local authority level via the JSNA and Health and Wellbeing Board process but also at the supra-local level of the STP.
- Given the wealth of legal and policy expectations around the funding of HIV support services, simply to defund this service without vigorous exploration of other budgetary and commissioning options is not acceptable.
- What discussions have taken place at an STP level for economies of scale?
- The organisation also provided the full copy of their report 'Why we need HIV Support Services'.

Code: Org0042	May	Letter	Sussex HIV Network
<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HIV support service	Carers support	DESSS	Intermediate care and day services (Milton and Firwood)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Overall	Older people's day centres	Supporting people (accommodation)	Supporting People (Community)
			Stroke Recovery Service

## Summary

- They strongly disagree with the proposal to cut money from this service.

- While they understand the budgetary savings needed, cutting this particular service is likely to have only a short-term savings effect due to the number of people ageing with HIV.
- Reducing services that promote and support self-management could result in increased hospital admissions and increased costs to the local health economy.
- This service is a requirement of the HIV service specification and will need to be offered.
- There would be an impact across the HIV network because patients from East Sussex receive their HIV clinical care outside East Sussex – particularly but not exclusively in Brighton.
- If the cut went ahead it would create inequity of support across Sussex.
- The support of the service is essential in keeping people engaged in care and attending clinics.
- The service provides invaluable support including self-care and self-management to an already marginalised population.
- HIV remains a stigmatised and socially complex diagnosis that disproportionately affects already marginalised population groups.
- The service plays a vital role in supporting the newly diagnosed and enabling appropriate service use.
- When the East Sussex HIV service users’ forum recently met, HIV stigma was repeatedly cited as a barrier to effective communication in other services including housing, the Benefits Agency, the food bank, etc.
- People with HIV disengage from specialist HIV care for a variety of reasons, resulting from both patient- and service-related issues. With less support available, this is likely to be more prevalent.
- The service provides support that promotes effective liaison with GPs, helping to address issues of stigma and enabling appropriate sharing of information across health and social care.
- Some patients require the support of the service to self-manage and achieve the public health benefits of active antiretroviral therapy (ART) and limiting transmission.

Code: Org0043	May		Letter	HIV Team (East Sussex Healthcare NHS Trust)
<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HIV support service	Carers support	DESSS	Intermediate care and day services (Milton and Firwood)	LD dps & residential
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Overall	Older people’s day centres	Supporting people (accommodation)	Supporting People (Community)	Stroke Recovery Service

### Summary

- They are concerned about the proposal to cut funding for the service and about the impact that would have on people with HIV and the team’s ability to meet targets set for it.
- The county would be the only area within the local HIV Network with specialist provision.

- 
- HIV stigma often prevents people from accessing generic services for fear of negative reaction and lack of confidentiality.
  - The service acts as an advocate and increases uptake of generic services.
  - Closing the service would affect the most marginalised people with HIV and harm engagement in HIV care; adherence to medication; public health; individual health; mental health; and patient activation.
-

## Individual feedback

### About the feedback

<b>Number of respondents:</b>	2
<b>When it was received:</b>	May: 2
<b>How it was received:</b>	Email: 2
<b>Who it was from:</b>	Client: 1
	Councillor: 1

### Key themes

The overall themes were:

- East Sussex would be the only area within wider Sussex not to have this sort of support service.
- It has proved invaluable as an information source.
- The service helps to fight stigma.

The key impacts were:

- Cutting the service would impact on the HIV clinics and engagement with care, adherence to medication, public health and individual health.

## Appendix 3: Events feedback

### Key themes

The overall themes were:

- There is still stigma attached to HIV and the service plays a vital role in fighting that.
- There is still a lot to do to improve awareness and understanding of HIV among professionals such as GPs and adult social care staff.
- Practically people in general and voluntary services often have no idea of the confidentiality side around HIV and what disclosing means for someone.
- The service helps you to access general and voluntary services and challenge ignorance and misunderstandings.
- The service educates you and your family after diagnosis, meaning that your health and wellbeing is better than it would be otherwise.
- How important it is to have people to talk to and easy access to them.
- Even GPs make assumptions about HIV and whenever you seek treatment they assume your HIV is the cause or an issue.
- The support the service offers saves lives.

The key concerns were:

- Services have already reduced in recent years and other services are being cut, so this service is particularly important.
- Cutting the service suggests all the problems have been solved.
- People already experience issues with food bank vouchers and using the THT name with volunteers who lack training.

The key impacts were:

- This is a vital service and closing it would lead to preventable deaths.
- Specialist services are needed to ensure people get the support they need and don't reach crisis.

Suggestions:

- It would be better if the service was reduced rather than cut completely.

## Avenue House – 22 May

THT consultation event – 22 May 2018, Avenue House, Eastbourne

The meeting was opened. It was noted that the stigma associated with HIV may mean people do not wish to protest publicly and those present were thanked for attending the meeting.

A text from a service user was read out: “[A]s an adult with asthma, diabetes, HIV & autism I found it impossible to access "adult social services" support. I ended up in hospital very ill and, as M wrote, my death could reasonably have been expected within 18 months.

“Given ESCC absolute failure to engage/utter isolation, THT got me back into health care services and saved my life.

“So I have replied to the consultation but the one thing I would say tomorrow – if I could be there – is "cut off funding by all means but it is vital that you make sure your services are accessible in such a way as you have never achieved to date, otherwise people will die at your hands (or in the absence of your hands).

“I offer these words in the context of my disabilities but also as an articulate & educated man – still incapable of obtaining ESCC's help when my life depended on it.

“I ... still can't get help ... may God help anyone else. Please feel free to share in my absence.”

*Attendee comment: I have recently joined a peer mentoring group to work with social isolation. We rely on THT to provide back up if we run into problems.*

An outline of the THT support service and the speaker's role in HIV Services was given. She said that specialist knowledge about HIV is lacking, and knowledge is crucial to be able to access support. Work covers range of issues. THT provide practical support with changes to benefits and housing, supporting people to contact people with HIV and other services, learning to live with diagnosis, and thinking about disclosure.

An overview of the ASC spending cuts was given. The ASC funded services are covered in this contract. NHS funded services are separate and would need to be guided by their business case. Services are more vulnerable if solo funded.

It was suggested that the group could start by continuing previous discussions about stigma.

*Attendee comment: I was diagnosed HIV+ and had a heart attack. I was not working. I was issued food bank vouchers, and met by a middle class lady – you have to tick the form to say what your sexuality is, disabilities. It was intimidating. It also says who issued the vouchers and they asked what THT is. She said 'you would not want HIV or AIDs because you will die'. THT went down and spoke to the food bank afterwards. I had the same experience at the job centre. The worker spoke to me from behind glass because she had a cold. THT were able to go to educate others, so it does have a domino experience. I have been able to access ASC, they came out and did home assessments and installed handles. Now I have moved to Newhaven, which is in the middle of Eastbourne and Brighton. No one can help – I could not get food stamps, they were issued from Eastbourne – Brighton could not come out.*

*I have been able to access Lunch Positive in Newhaven to meet likeminded people. There is no welfare rights officer in Newhaven – one based in Brighton, which has a helpline but cannot provide 121 support. The alternative is to have to go to the CAB, who do not know. You do not have to disclose to dentist, for example. THT have helped to signpost to help.*

**Council:** So there's an impact from direct discrimination but sometimes it can be ignorance or lack of understanding.

*Attendee comment: I have often thought about two words – it's very difficult for others to understand – it is the lived experience. We are unique group – we face stigma all the time 100% of the time. It is difficult for administrators to understand.*

*I always said it would be easier if it was cancer, people would sympathise.*

*My feeling is that we are sitting here as 'patients' – we have undergone, witnessed and benefited from a medical miracle. Although we should enjoy that and should be empowered to enjoy it, we still face the problem that society does not understand. Disclosure –*

*administrators do not realise – at the foodbank, the kind lady did not understand what she was doing when she asked me to disclose. It is an enormous problem, you do need support to live in that kind of world and that is what THT provides. When we inevitably come across situations when a person does not realise what they have done, for example, someone had a PIP assessment, they decided to disclose, the assessor did not realise what a major step that was, to disclose to stranger. They said you've been telling me that your family help you with other problems, they said they had not told their family. It was wrong to suggest that he should do that, but they then upbraided him because they said that he was selfish. They do not understand the situation. THT is there to ensure that as many people do understand, when problems arise they are there and help to make the person feel more at ease with themselves. I understand the pressures of so many groups, but we do have unique need which is answered by THT.*

**Council:** You put that across very clearly and eloquently. It makes it easier for us to raise with councillors. Our purpose is to share the impact that cuts will have and also for us to think through what it does to health and social care budgets. There are only so many times you can be discriminated against and pick yourself up. We all have our own threshold, it impacts on mental health and the ability to look after yourself and to fight. Micro-aggressions build up. It is important to be able to go into a room with people who get it. The more we understand and can articulate that to decision makers – they make the ultimate decision, our job is to hear all of those things and weight up what impact it will have on the system. The Councillors read through everything, and the meeting is televised.

*Attendee comment: I was diagnosed about 4 years ago, to my shock. My understanding was to say I had AIDS because that was all I knew. The question was how long would I live. I had no knowledge except it was a death sentence. The next big hurdle was how to tell my family. Their reaction was as strong as mine – how long to live, and don't tell friends and family, that I should have treatment outside of Eastbourne as did not want people to find out. They would watch me and wash up the cup as soon as I put it down. It was very difficult for them and for me. What THT did was educate me first of all about how you catch it and to educate my family that they were not at risk of catching it. I don't think any other service could have done that. It is very specialised work. Without that I'm not sure where I would be – I would not be working, poor mental health wellbeing, probably would not be taking medication. It impacts on housing, not working, I know at the time I had money so I accessed counselling. That could not help me with the practical of how I caught it and not pass it on to my family. It was a very holistic approach that no other service could have given. At the time there used to be a group meeting once per month. People were telling me that they had children and were working, had survived 15 years. To see people thriving and having debate – how is that going to happen now? We have set up a peer group and are hoping to set up groups but without THT it would not work. We would be accessing other teams. The service was vital when I was diagnosed and still is vital. it was important for me to come today even though I was unwell, to say how important it has been, even if it is reduced hours but there so that we can access it.*

*Attendee comment: I would like to add, in mainstream society there is no problem but all of a sudden you get a diagnosis, which puts you in a different world. You have a cultural background which says that you are an outcast. You have to decide whether to tell your family. You find THT and all the stigma and self-righteous condemnation – you have people who can be a reference to rebuild your life. I don't know whether council can offer you 1-2-1, I can talk to everyone in the office, even if you just feel down and have a chat for 10 minutes. I am speaking on behalf of a lot of the ethnic minorities – we get double isolated. Already society looks at you differently and then you have this as well. You need to work and provide a life for yourself again. I'm not sure whether that specialist service can be reproduced.*

*Attendee comment: That's another aspect of stigma, there is a lot of internalising of the stigma which is also damaging to the self-image and impacts on mental health. It impacts on so many aspects.*

*Attendee comment: We used to have social groups and women's groups, if I was depressed I used to pick up the phone and they would just say come, give you a cup of tea. There was a time we did the mime dancing, funded by the council, at the community hall. We really enjoyed that and it showed that we are part of the community. Another time when I was having problems with the GP, they were asking what the other doctors or nurses said. THT sent me to see M, when I saw him, he said that when HIV is well controlled then my health is better than someone who does not have HIV. So if something is wrong then they need to look into it, not just refer me to the clinic. At times it is very difficult to say to the family, no family members know that I am HIV+. In African countries, they assume it is AIDS and they are going to die. I have kids at home, when I was diagnosed 2005–9 those family members would say to children that they have to behave because mum has AIDS and will die. If my children were not well, I did not know who I could talk to but could just pick up the phone. Then they would check whether I have any food, most of the time you do not have anyone to speak to. They would give food and coordinate all of the ladies and the group would help us a lot. Now I look at that building and ask where is THT now? I used to enjoy going to that building, where have they gone?*

*Comment: So that was quite a long time ago.*

*Attendee comment: There is a THT in Brighton, but it is very far. I did courses through THT and I still have those certificates and they helped me to do the care that I am doing now. It is building confidence and how to do your CV. There were a lot of courses and I really miss that. Over the years, the service has changed.*

*Attendee comment: I got diagnosed in January 2015, I was already suffering from anxiety and depression. M has been an amazing guide and been there and he drew me to THT. I could not tell my doctors and M sent them a letter. Without M and THT and no one to talk to I probably would have gone up to beachy head and jumped off. I am a fighter, I would not want anyone to go into that situation and not know who to talk to. Because I can go to THT and what people have said to me when I told them, I told a couple of friends and they just said 'when are you going to die?'. I did not know what to say to them. I froze. I told Ma and C at THT. I think that without THT's help, people who get it...*

*Attendee comment: I think [name removed] has touched on something else that I have noticed – you are in a position when you are HIV+ that you have to educate people, you have to go through the process of explaining the whole thing and that is a burden.*

*You thought that they were your friends and you find out who is and who isn't. You don't want to lose people.*

*Attendee comment: When you said that, I thought of every relationship, whether friendship or possible relationship that is added, which I've never had to think when to disclose or how. You cannot go to anyone else to have that discussion. You have to educate each person. It is not going to stop – a bit like mental health was 20 years ago.*

*You have to face that.*

*Attendee comment: Even going on holiday, through security, or going to a nightclub and you've got pills, you have to educate.*

*Attendee comment: Supposedly you can live a healthy life. But the medication does have side effects. Why would the service be cut when HIV is still there?*

*Attendee comment: I'm happy with the pills – I became undetectable. If it wasn't for the meds....*

*Attendee comment: That is a remarkable success story, but it isn't the only one. We have something to celebrate, we have lived through. Do not walk away yet, we still need the specialist services. We have the clinic service, it is wonderful, but the message is not out there, so outside the clinic we find a world that....*

*Attendee comment: We can access Sussex Beacon but their service is also being cut. If you have to go hospital....*

*Attendee comment: It was a very difficult time for me, knew about HIV but diagnosis was so difficult, had it not been for THT, I would not be here. In 2014, I took a diagnosis, I was not working, had no food...I was signposted to different organisations, had to accept that I had mental health problems that was related to HIV, lupus and fibromyalgia. Please do not close, there are so many other people being diagnosed, where will they go? With THT you can go there at any time on the phone, with doctors you do not get the chance to speak to them. THT is like the mother that is not there, they are always watching.*

*Attendee comment: Cutting THT implies that something that has been solved. I do not know if anyone knows the numbers, but I suspect that those figures are only reflecting the surface because people go to the doctor when they are sick, when they are not sick they do not know, what is happening in the interim, they do not know. THT does a fantastic job in educating people on the importance of accessing regular medical testing. This is going to be a cost anyway, if it is picked up early on and there is a definite programme of destigmatising. The tests are very simple but people are only doing it as a crisis, if this was introduced as a regular thing, like cholesterol or blood pressure, this would not be a problem. I think the problem is only going to get bigger. Eastbourne is starting to boom again, you need to be prepared for that. They are going to need this. The access point must not be a narrow point. THT has to be there as specialist service but you are going to firefighting.*

*Attendee comment: There are 7 service users here today, I think there are about 400 people in East Sussex – 350 odd use clinics and others go to other clinics. There are a lot of people out there who would not dream of entering this room.*

*Attendee comment: It is hard to come out and talk about losing any service. It is vital, people will die.*

*Attendee comment: It goes all the way – even something that for me, my HIV status is something that no one else knows about. If I die, they are not allowed to embalm you if you have HIV, so my family will find out. It is still quite archaic when it filters through. You cannot have normal travel insurance. It is a chronic illness – you are not going to die, but is like a chain with a ball to carry round and THT help to lighten that load.*

The Council summarised comments:

- People need access to other services, where you feel less stigmatised and less stressed and doesn't impact on mental health.
- There needs to be HIV awareness across ASC services, we could do a lot on that. The average person does not have to think. But when you are at work you need to be aware.
- Talked a lot about stigma and isolation and lack of specialist knowledge – it is tiring.
- Don't walk away yet – Think about what is coming in the future
- Like the mother that is not there – that kind of care will be lost.

*Attendee comment: To pick up on practical point – it is not their fault but the person you are talking to has no idea of the level of confidentiality that is required. They could not be expected to understand the level of confidentiality.*

Someone had a report of similar situation at foodbank in Eastbourne – the person had made a comment about why do you go to THT. There are 90 volunteers there – you could not train 90 volunteers. It is challenging as a lot of organisations are working with volunteers – there is throughput of staff and everyone does not attend the training because there is not time or money.

*Attendee comment: the Voucher for Tesco is better – I do not need to explain myself. Foodbank vouchers you have to put THT on them. It is a serious problem.*

*Attendee comment: I know when I go to the doctor, they don't have knowledge – the first thing they ask you about is your HIV, even if it is not related. It is under control, I'm undetected. There is stigma and lack of knowledge by professionals, because nothing has happened in the media since the 80s.*

Council: The group have been very articulate in communicating some of the day to day challenges.

*Attendee comment: In the NHS there is a terror of having to manage those things, if do not have THT standing beside us*

Someone asked whether information will be shared in the consultation. The Council explained about the consultation process and how to feed back.

## **Equality impact assessment – summary report for proposals to HIV Support Service**

The results of equality impact assessments must be published. Please complete this summary, which will be used to publish the results of your impact assessment on the County Council's website.

**Date of assessment update:** May 2018

**Manager(s) name:** Angela Yphantides **Role:** Strategic Commissioner

### **Impact assessment:**

The HIV Support Service is delivered by the Terrence Higgins Trust (THT) and currently supports 21 people.

The contract is due to expire in March 2019, and it is proposed that the service is not re-commissioned. The service runs in parallel with the HIV Prevention service (also delivered by THT), and commissioned by Public Health.

### **Summary of findings:**

**Data suggests that the proposals will have the highest negative impact on gender (men) and race and ethnicity (people from BAME backgrounds) who have a diagnosis, as they have a high prevalence.**

**As HIV is a chronic, long condition, there is also a marked negative impact for disability as a protected characteristic.**

- An aging population with a diagnosis will potentially develop other long-term conditions (also called co-morbidities) alongside their HIV diagnosis, which may increase access to primary and acute health services, as well as demand for social care.

However, support for clients to access wider local services means there is expected to be a neutral impact on across the protected characteristics. The support needs of clients are being met by existing alternative provision, across a range of services including immigration support, and health-based services support to manage long term conditions.

### **Summary of recommendations and key points of action plan:**

- Commissioners will continue to work with THT to support adults to transition to wider long term conditions services, benefits, advocacy, employment services.
- Effective medication management is a local priority and a number of existing ESBT/C4Y programmes, as well as community organisations, will continue to provide integrated support and technology-based solutions. HIV-awareness raising will be provided to services which may start to specifically support people with HIV.
- As the population of people with HIV ages, it will be important that local services understand the needs of older people with HIV and are able to support them.
- The new NHS England contract is anticipated to mitigate any impacts as a result of the THT contract not being renewed.

**Groups that this project or service will impact upon**

Please mark the appropriate boxes with an 'x'

	Positive	Negative	Neutral
Age			
Disability			
Ethnicity			
Gender/Transgender			
Marriage or Civil partnership			
Pregnancy and Maternity			
Religion/Belief			
Sexual Orientation			
Other (including carers/rurality etc)			
All			x