



TARGETED PREVENTION SERVICES FOR SEXUAL HEALTH - REPORT ON THE CONSULTATION TO INFORM FUTURE COMMISSIONING INTENTIONS JANUARY 2019

1. INTRODUCTION

1.1 Somerset County Council is responsible for commissioning sexual health prevention services to reduce the transmission of HIV and sexually transmitted infections and reduce unplanned pregnancies. Since April 2013 Public Health has commissioned a collaborative model of sexual health services incorporating the mandated provision of free and open access to contraception, HIV testing and the testing and treatment of sexually transmitted infections in conjunction with targeted prevention. This service is known as the Somerset-wide Integrated Sexual Health service (SWISH), with the core clinical services provided by Somerset Partnership NHS Foundation Trust and the prevention services provided by The Eddystone Trust, under two separate contracts both with individual outcomes and collaborative outcomes. There are three specific sexual health indicators in the Public Health Outcomes Framework:

- Under 18 conceptions
- Chlamydia diagnoses (15-24 year olds)
- People presenting with HIV at a late stage of infection

1.2 The targeted prevention service (TPS) has three elements:

- Targeted HIV prevention
- Targeted sexual health promotion
- Support to people living with HIV

1.3 Targeted services include community outreach to those at highest risk of poor sexual health through e.g. point of care testing for HIV, targeted chlamydia testing for 15 to 24 year olds, targeted condom and behaviour change interventions and Public Sex Environments (PSE) interventions. The Eddystone Trust sub-contracts support to improve the sexual health and wellbeing of LGBT young people through the 2BU LGBT youth support service. In addition to targeted services The Eddystone Trust is also responsible for delivering the Somerset C-card condom distribution scheme for 13-19 year olds which is a universal service. As well as the targeted services provided by The Eddystone Trust, Somerset Partnership delivers a targeted vulnerable young people's sexual health nurse outreach service and is responsible for the overall chlamydia screening programme for 15 to 24 year olds.

1.4 The contract for the core clinical provision with Somerset Partnership is for the five year period 1st April 2016 to 31st March 2021 in recognition of the clinical nature of the service, the contract value and the significant service transformation to integrated services required under the new specification. The contract for the TPS with The Eddystone Trust was for the three-year period 1st April 2016 to 31st March 2019 with the option to extend. The shorter contract length was in recognition that this was a new model of prevention services and it would be necessary to better understand need and effectiveness and how it was reducing demand on sexual health treatment services. SCC made the decision to not extend the contract beyond the three-year contractual period whilst it reviewed the three elements of the service and the effectiveness of the new collaborative model of provision.

1.5 As part of the review of TPS a consultation was set up to provide a mechanism for service users and non-service users to give feedback on what they valued about the services and their thoughts on what type of services could be delivered in future.

2. CONSULTATION ON THE TARGETED PREVENTION SERVICE

2.1 The consultation on the TPS involved:

- A focus group with HIV positive service users and in some cases their supporters
- A dedicated confidential email address to provide feedback to sexual health commissioners at SCC
- An online questionnaire through Somerset Consults

The consultation was promoted through:

- the Somerset Sexual Health Network
- a local media release from SCC communications
- promotion through the SCC social media account
- an SCC elected members briefing
- information provided through the SWISH clinics
- direct contact with HIV service users by The Starling Clinic (Taunton and Somerset NHS Foundation Trust's HIV treatment service) and The Eddystone Trust

3. FOCUS GROUP WITH HIV POSITIVE SERVICE USERS

3.1 Sexual health commissioners at SCC arranged with The Starling Clinic to hold an evening focus group meeting with HIV positive service users on Tuesday 18th December 2018. The focus group consultation was a closed group accessed by invite only to ensure the confidentiality of attendees. The meeting was attended by three sexual health commissioners from SCC, the HIV specialist nurse from The Starling Clinic and 16 service

users. Of the service users 14 were HIV positive service users and two were carers; 14 of the group were male and two were female.

3.2 SCC had requested that The Eddystone Trust did not attend the meeting to enable service users to speak freely with commissioners about the services they receive and what they would like for the future. However, three members of The Eddystone Trust attended the meeting citing that they had not seen the communication regarding not attending. The group of service users agreed that Eddystone could stay for the discussion as service users would have the opportunity at the end of the session to speak with commissioners on a one to one basis. However, it transpired after the meeting that some of the group had not wanted The Eddystone Trust in the meeting.

3.3 The focus group started with an introduction and presentation by one of the sexual health commissioners (appendix 1) including:

- An overview of Public Health and sexual health commissioning
- The national and local context regarding funding and service demand
- The new Somerset Health and Wellbeing Boards 'Improving Lives Strategy'
- Information regarding HIV in Somerset on HIV diagnosis, prevalence and late diagnosis and new initiatives such as Pre Exposure Prophylaxis (PrEP)
- The Targeted Prevention Service provision
- Questions for the group on what helps them to live well with HIV, barriers to accessing health and social care services and ideas on how people with HIV can be supported
- Next steps in relation to the review and options going forward

3.4 The group was informed that notes would be taken by one of the sexual health commissioners to capture feedback from the group discussion. Group members were advised that they would be able to talk on a one to one basis with commissioners at the end of the session. There was also a display board with information on the 'Improving Lives Strategy', HIV in Somerset and questions for service users with flip charts available for additional written comments.

3.5 Feedback from HIV positive service users

There were a number of service users who articulated their thoughts and concerns, with a few members of the group who did not actively take part in the wider group discussion. Some of the group members did not find the presentation useful whilst others did want to hear the information being provided, particularly in relation to HIV in Somerset. The Eddystone Trust representatives did not participate in the discussion as agreed. A summary of the feedback from service users can be found below:

- People recognise what self-care is (from Improving Lives Strategy) and felt that this was enabled through what The Eddystone Trust provided; people know when they need help. An important element of the service is the support provided at time of diagnosis and knowing where to go for support. An HIV diagnosis still leads to a fear of death for many and support services enable people to work through this.
- There is still considerable stigma associated with HIV and misunderstanding amongst both the public and service providers. There can be triggers that lead to people needing support, such as attending for a flu jab or getting a tattoo. Support workers are needed to step in at times of crisis; it's not always possible to manage own condition so need a known worker who is a trusted source of information and support.
- There are some people who will have been diagnosed out of area and will need to know how to access support locally.
- There were some questions over the HIV data presented regarding numbers being seen for care in Somerset and how robust this information was. Commissioners and the HIV specialist nurse were able to clarify the reporting mechanisms for HIV which informs this data and enables local commissioners to know how many people diagnosed with HIV there are living in Somerset.
- The feedback given in the group clearly demonstrated the value placed on the support services they received, and The Trust was described as doing an 'incredibly good job'.
- Some of the comments related to the clinical services provided through SWISH with concerns that this service would not be able to meet their needs. The new integrated sexual health service was unpopular with some members of the group particularly as it has led to the GUM service being removed from the hospital site where it was previously co-delivered with the HIV treatment service. One service user cited that he did not have confidence in the service as when he attended he saw a nurse who could not answer his questions as contraception was her area of expertise.
- Users wanted to know if the existing peer support groups would be continued; these were very valued. It was felt important that newly diagnosed people have support from those already diagnosed positive. However, as HIV is such a unique condition that is still stigmatised, support groups need to be for more than those just newly diagnosed. They enable people to see other people living their lives and to discuss common challenges such as medications and side effects. The groups helped people deal with other issues such as negative social media and hate crime and often speakers are organised to attend to give information.
- It was important for the group that HIV support services were tried and tested and delivered by a service that understands the needs of HIV positive people. This was felt to be best delivered face to face rather than through digital access such as online or telephone. An example was given of how occupational health support did not work through the telephone service for someone who was HIV positive.

The support provided alongside the HIV Clinic was important as it enabled access straight away. One individual would not have contacted the service if there had not been a support worker based alongside the HIV clinic whom they were able to immediately contact.

- Many service users said that they had come into contact with support services by chance.
- The face to face support was really valued, particularly it's accessibility and being able to meet the worker anywhere. There is a gap after first diagnosis and many people rely on Eddystone for continued support even when not in crisis, such as housing.
- A number of service users (12) had been trained as part of the national mentor project (Project 100) to become mentors to newly diagnosed HIV positive peers. They completed the qualification a year ago but had not yet commenced delivery and did not want to lose the opportunity if The Eddystone Trust were no longer a local provider. There was loyalty to The Eddystone Trust who had supported them through the programme.
- There was some feedback regarding the importance of continuing prevention services. This included the need for condoms at Public Sex Environments (PSE), community outreach such as in homeless shelters and talks in Further Education colleges.
- There were anxieties about the future of support services and continuity of services if no longer delivered by The Eddystone Trust, especially as there are less than four months to the end of the contract and individual staff may start to leave. Assurance was sought that services would continue in April. Questions were asked why the integrated sexual health service was not undergoing a review at the same time; commissioners clarified that the longer contract is due to service scale, the transformation from separate contraception and genitourinary medicine services (GUM) into an integrated sexual health service and funding value. A number were concerned that THT would be delivering the service in future and said this would be unpopular with both male and female service users.

As the meeting was ending the focus shifted to priorities to enable people to live well and specific comments to this were:

- There needed to be a safety net, a continuous group with peer support as part of this but there is also need for professional support. The service would need to provide a mixed model and be resilient. Peer support does not suit everyone, some people need one to one support. Services have to 'be now' when needed and be delivered by committed people. The service would need to provide tailored support as all have different treatments.
- Some of the service users stated they would not be here now without the service; Eddystone 'fix problems'. Home visiting was important as people are often isolated and / or living in rural areas. There can be barriers such as the cost and time of travelling.

- Need to continue with a worker alongside the HIV clinic.
- Continued prevention work is important, with a need to have a worker going to PSE sites, and that it would be good to have more home testing available.
- People were happy with the service that they currently receive, they didn't want this put at risk by looking to ensure the service supports all people who are HIV positive in Somerset .
- Commissioners were asked to rethink their decision because it impacts people who are not yet positive.
- People value the skill of the worker who provides help with benefits and employment e.g. after 26 years of being out of work, getting back into work. But it is noted you don't have to have HIV to require this type of support.
- Investment is needed in people who are positive to educate to reduce diagnosis.

3.6 The commissioners advised that there was an online consultation until 24th December 2018 and a confidential email address for further feedback. The consultation would be analysed after Christmas and the group wanted another meeting with the commissioners with more detail about the plans; it was agreed to schedule something for late January / early February 2019.

3.7 A number of service users gave feedback to commissioners at the end of the session in small groups. Individual feedback demonstrated an understanding of what commissioners were trying to do and whilst The Eddystone Trust was valued, the feedback primarily focused on one individual worker that service users did not want to lose and not necessarily the whole organisation.

3.8 There was a comment that maybe this pot of money could be used differently and consider using to fund additional PrEP places.

3.9 Three written testimonies from HIV positive service users were given to the sexual health commissioners. One was read out at the focus group by a service user, one was provided by a service user who was unable to attend the focus group, and the HIV specialist nurse shared a testimony from a service user through the TPS confidential email account. This was the only communication that went to this account.

3.10 The key themes from the testimonies were:

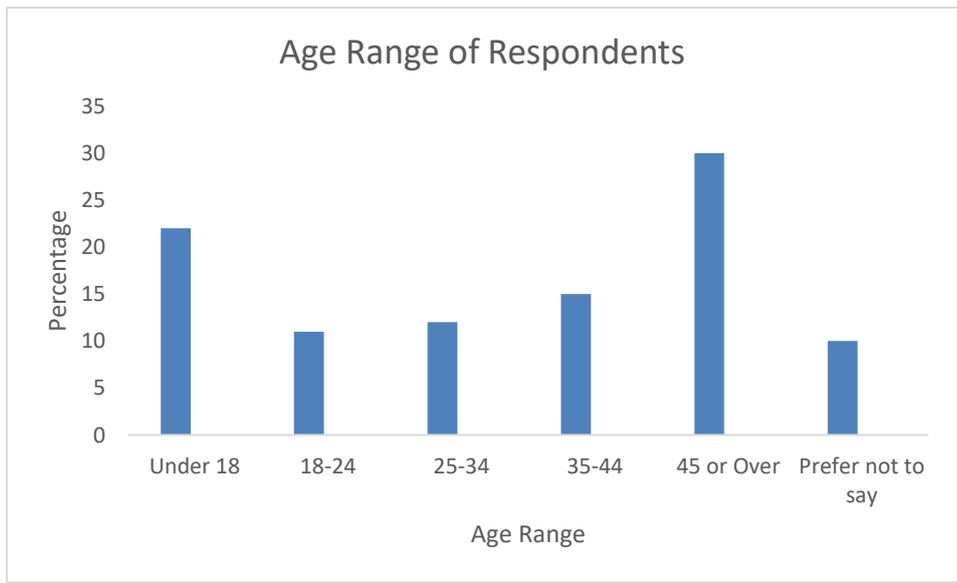
- Initial HIV diagnosis distressing and life changing
- Concerns re disclosure and relationships with family and friends and job.
- Mental health concerns including anxiety, depression, suicidal thoughts.
- Stigma including from hospital staff not within HIV services (overheard).

- Eddystone Trust worker providing lifeline – safe space, non-judgemental, treated as normal person, a “familiar face”.
- Support services enabled acceptance, management of medication, mental health support, finding work, claiming benefits and assessment support.
- Support groups important, but not all have courage to use especially at first diagnosis and need face to face (would not use telephone support) plus concerns re confidentiality.
- SWISH clinic does not understand need of this client group.
- All these testimonies stated the individuals would not be here now without the support given.

4. DEMOGRAPHIC CHARACTERISTICS & RESPONSES OF INDIVIDUALS RESPONDING TO THE ONLINE CONSULTATION:

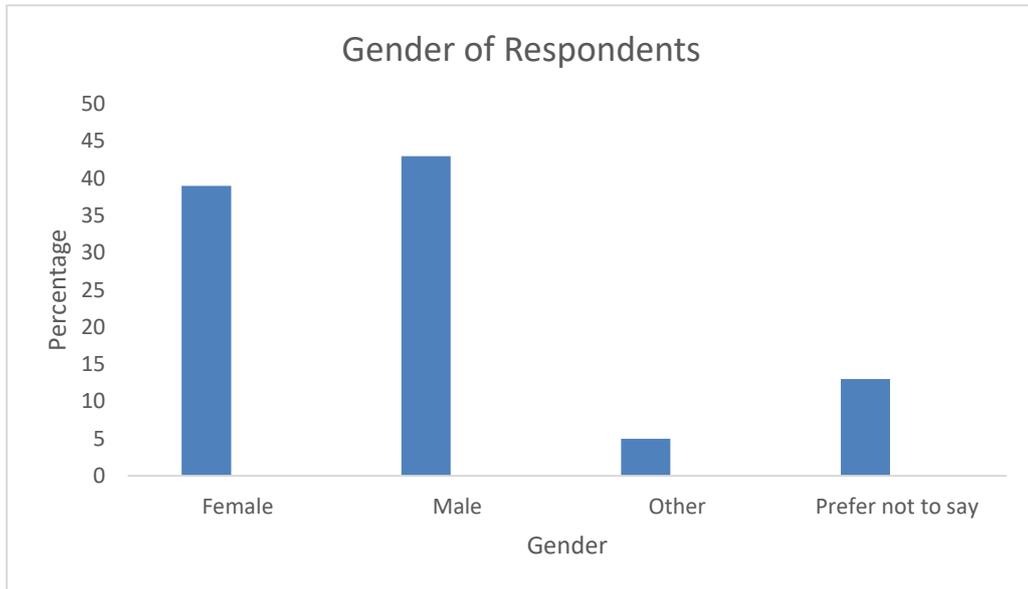
4.1 There were 100 responses to the online questionnaire and the demographics of the responses are detailed below. Whilst the survey was aimed at service users and potential service users approximately 8% of the responses were from professionals who had engaged with The Eddystone Trust to provide support to their client groups.

4.2 There was a good distribution across the age ranges with the largest numbers of responses for the ‘under 18s’ and the ‘45 and over’ age brackets. This reflects the responses of the younger age group accessing support mostly through the LGBT support group 2BU, which was also true of the responses from 18-24 year olds. The older age group mainly represented those living with HIV.

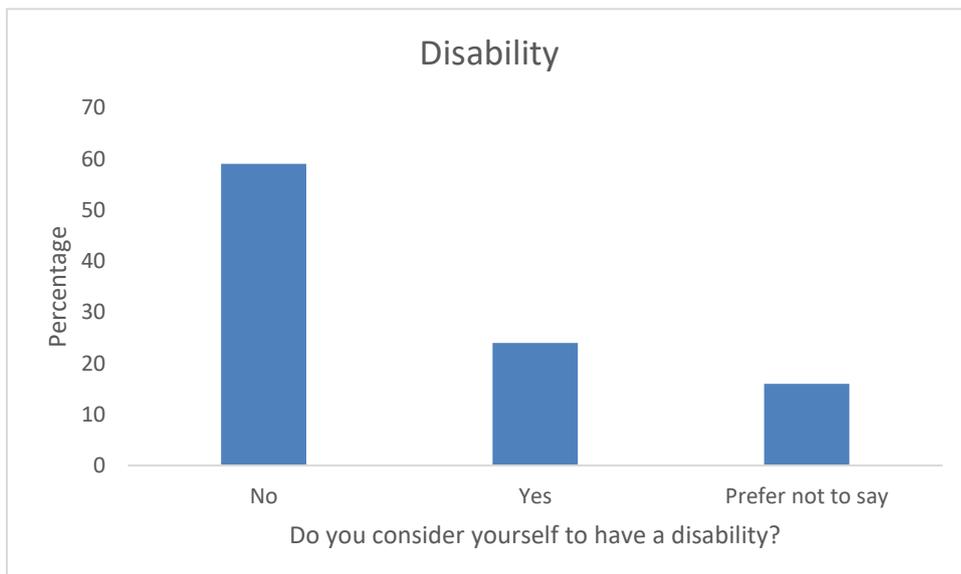


4.3 72% of respondents stated their gender was the same as that assigned to them at birth with 14% saying their gender did not match completely the sex they were registered at birth demonstrating a good response from

transgender men and women. The clear majority of those whose gender did not match the sex they were registered with at birth were young people with most being under 18.

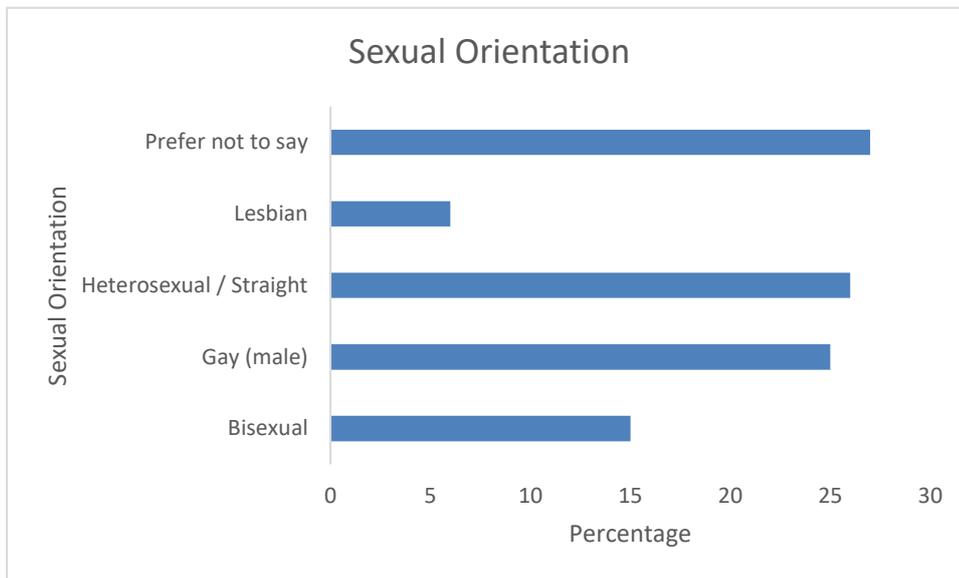


4.4 24% of respondents stated they considered themselves to have a disability. This would be higher than might have been anticipated however the majority of those stating they had a disability were those using the HIV support services.

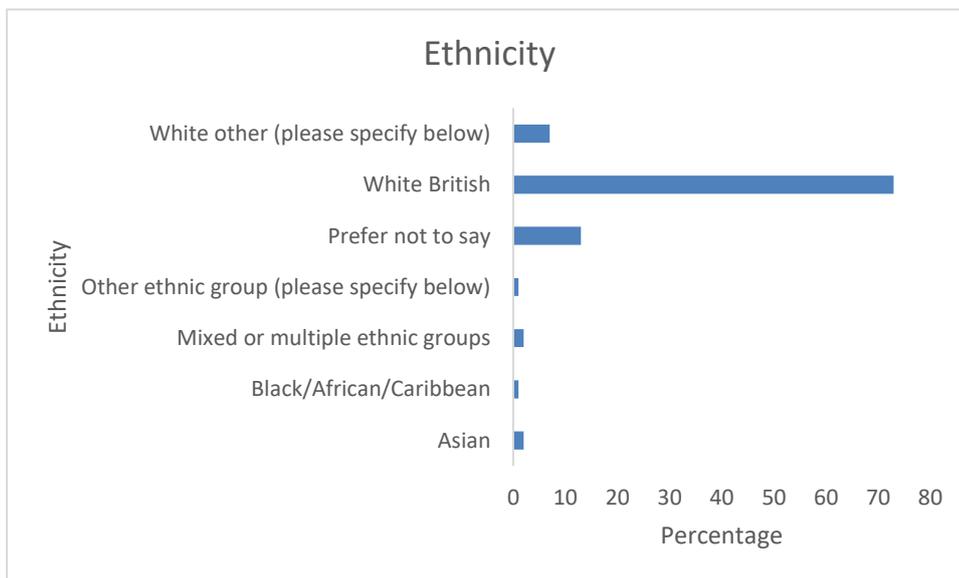


4.5 There was good representation across the different sexual orientations although 27% did not state their sexual orientation. The largest representation was from gay men at 25% of respondents and

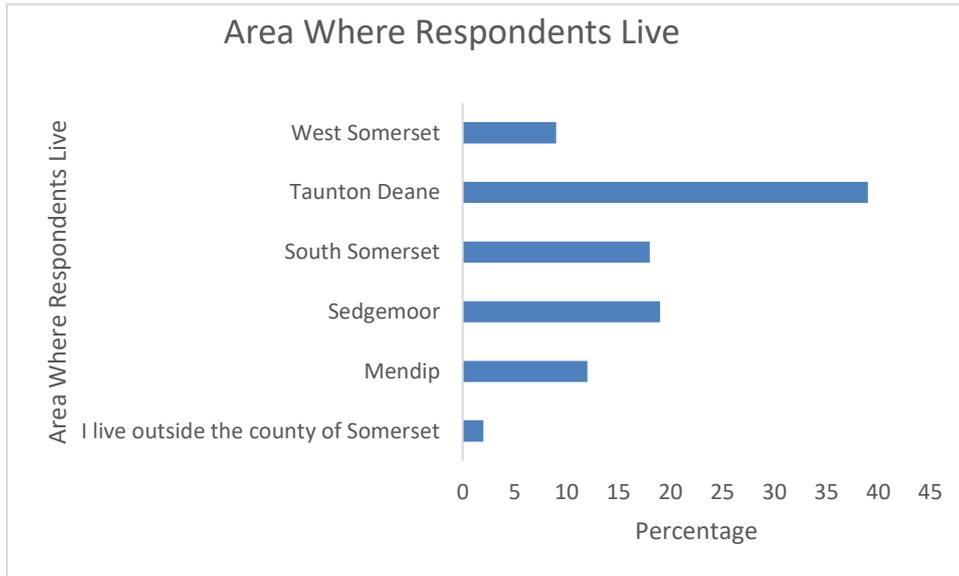
heterosexuals at 26% (however nearly a quarter of heterosexual responses were from professionals).



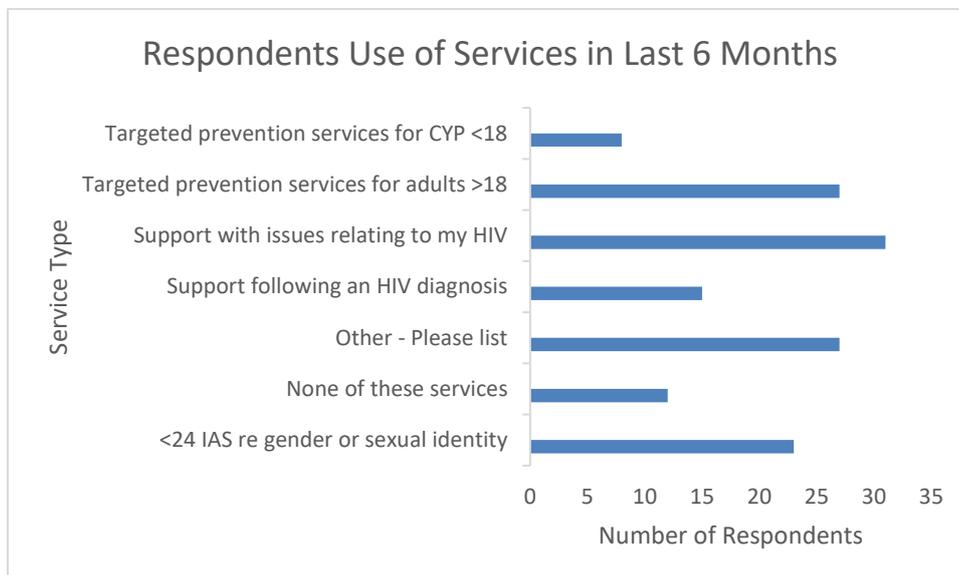
4.6 Most respondents stated that they were White British (73%) or White Other (7%) with 13% preferring not to state their ethnicity.



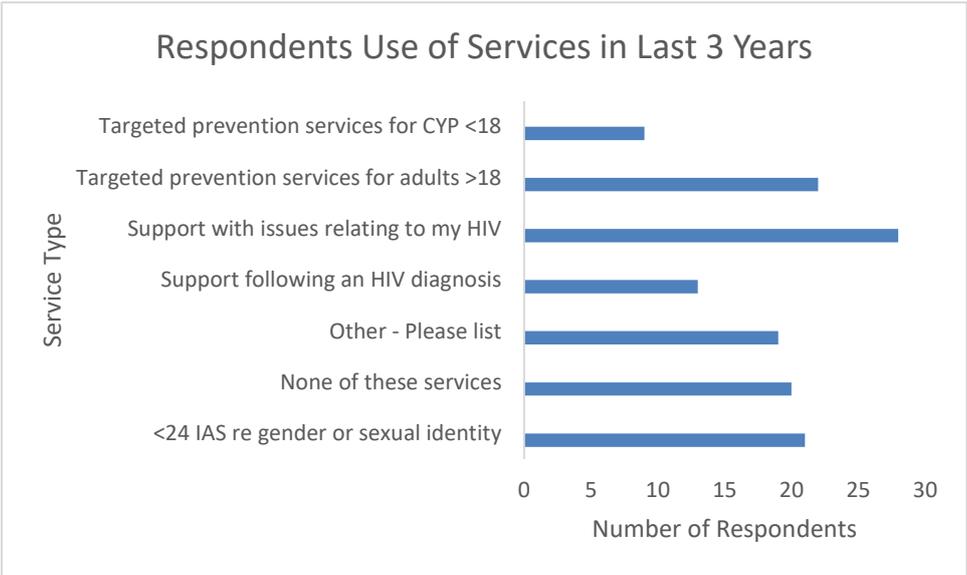
4.7 There was representation from all 5 districts of Somerset with the majority living in the Taunton Deane area at 39%.



4.8 A number of respondents had used services within the last 6 months with some using more than one service. The younger age ranges typically used the support services for gender and sexual identity and LGBT support through the youth support group 2BU. Those using HIV support services were also likely to also be using the adult targeted preventions services.



4.9 Of those using services within the last three years, the majority were those using HIV support services many of whom also used adult targeted prevention services. The majority of young people using services were using the support services for gender and sexual identity and LGBT issues.

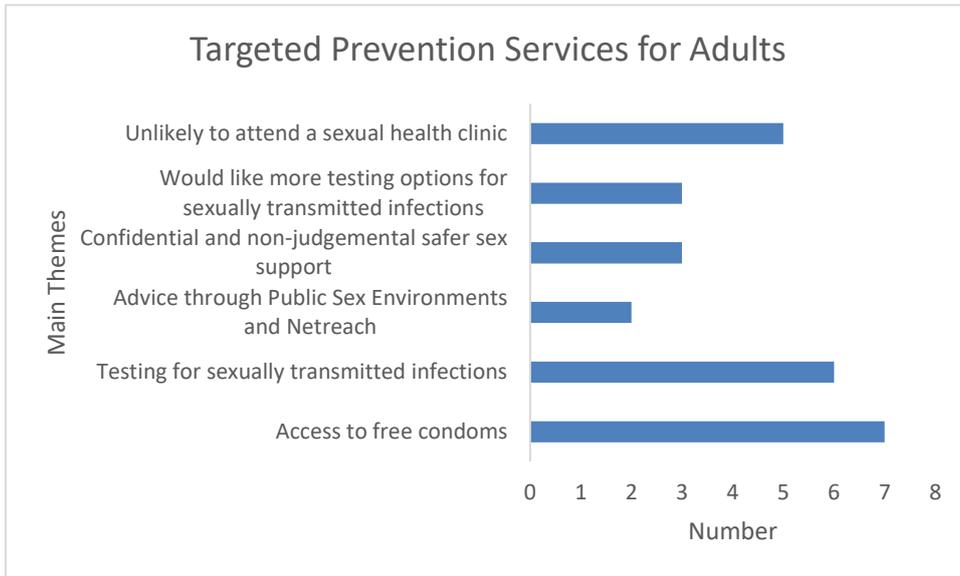


4.10 The majority of the young people who responded to the survey did so in relation to support they received for gender and sexual identity from 2BU, the LGBT youth support service. The main themes were that this service provided a safe and supportive environment for young people to meet peers, safely explore their identity and receive information and support on a range of issues including emotional health and wellbeing and sexual health. The main theme in relation to improving services related to the need for more support and promotion in schools and colleges.

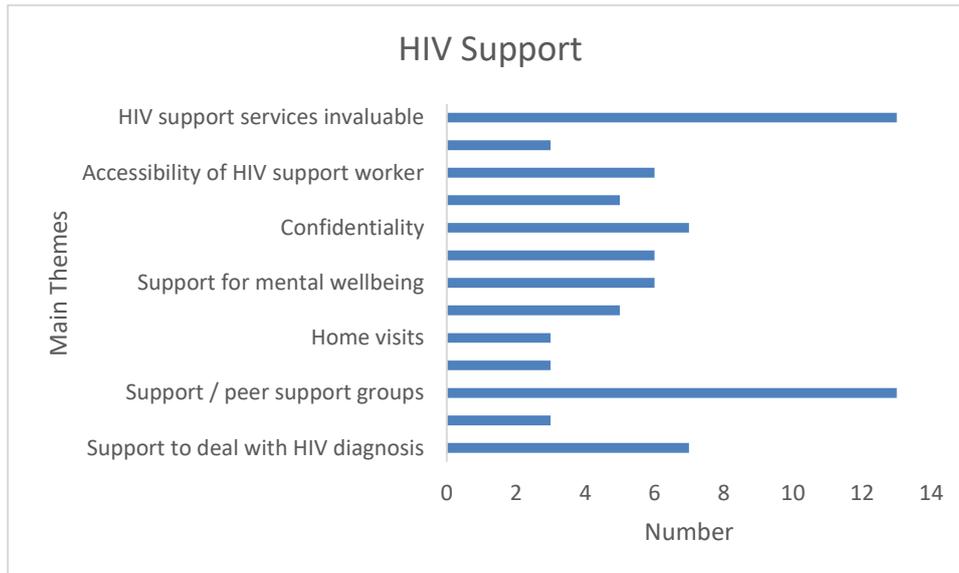


4.11 The responses in relation to targeted prevention services for adults valued the access to free condoms and testing for sexually transmitted infections (STIs). A number said they would not use a sexual health clinic with some

citing concerns about being judged and liked the non-judgemental and confidential support that the targeted prevention service offered. A small number said they accessed services through public sex environment and Netreach interventions. In relation to improving or developing new services the overriding theme was a request for more testing options for STIs including home testing.



4.12 For those who responded saying they had used services for support when first diagnosed with HIV or for ongoing needs relating to their HIV diagnosis, a number of strong themes emerged. These reflected the themes from the HIV service user focus group including the value placed on the specialist and confidential nature of the service and its accessibility, the support provided for mental wellbeing, dealing with HIV diagnosis and disclosure and the value of the HIV support groups to enable people to live well. The majority of respondents highly valued the services they had received and did not want to see this change. Other suggestions for improved services included the opportunity for more community support for blood testing and CD4 count, access to complementary therapies and a specific women’s support group.



5. CONCLUSION

5.1 The consultation on Targeted Prevention Services received a good response and has provided commissioners with a number of key themes to inform future commissioning arrangements:

- There was a general level of support and value attached to the services and support provided under the current contract, but also understanding of where support could be improved.
- Support services for people living with HIV need to be accessible, community based and delivered by workers who are informed and a trusted source of information and support. The services need to be opportunistic with support at first diagnosis but also responsive for when a need arises. The HIV support worker enables access to other services providing a navigator and advocate role. It is recognised that the HIV support service can't meet all need but does enable access to wider support without always having to disclose HIV status. There is ongoing stigma associated with HIV and a need for awareness raising and training in health and social care services. Support groups are important to enable people to live well and manage their condition in a safe and supportive environment. There are some concerns that the integrated sexual health service does not fully understand the needs of HIV service users and a number of service users remain disappointed that GUM services have moved out of the hospital to a community setting.
- Targeted services for young people who identify as LGBT and support around gender and sexual identity are important for mental wellbeing and services need to enable a safe space providing both peer support and expert advice and information. There is a need for more training and support to schools and colleges on LGBT issues and support to LGBT young people in these settings.

- There was less response in relation to adult targeted prevention services due to the nature of these services. What was valued about these services was non-judgemental advice regarding safer sex and access to condoms and testing for sexually transmitted infections. In regard to improving services the main theme was more access to online and home testing for sexually transmitted infections.

APPENDIX 1

Living Well With HIV - Support Services in Somerset



Living_Well_With_H
IV_Dec_2018.pptx