

Getting to Zero: Survey Report



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EXECUTIVE SUMMARY

This report presents the findings from the survey project developed to explore what people from key groups think of the current services, what improvements they would suggest and any experiences of stigma they have faced.

Key findings include:

- People would like to have access to **multiple options for testing**, including both at home and in clinic settings but also through GPs.
- People are aware of wider or **more holistic service models**, focussed firmly on patient needs, elsewhere in the UK. This includes rapid and self-testing options as well as community-focussed one-stop-shop clinics. It is important that we design our services in Cardiff & Vale to be focused on maximising patient outcomes and are transparent and evidence based about choices that need to be made in light of limited resources. These are key tenets of values-based healthcare.
- **HIV stigma is still a problem** but is seen as largely due to misinformation rather than malice. Improving education and awareness will aid in reducing people's experiences of HIV stigma, including the use of role models. However, it is important that all forms of messaging show diverse representation of the communities affected by HIV in order to both improve awareness and reach of preventative programmes as well as decrease stigma.
- The findings directly **endorse two of FTC&V's targets** – diversification of and increased access to testing, and tackling stigma. The findings about diversification of targeting and messaging also rely on the third aim of improved data.

This report and its findings were produced by researchers at Cardiff University in collaboration with Fast Track Cardiff & Vale Steering Group.



INTRODUCTION

Background

In Cardiff, according to the latest and most reliable information (see Fast Track Cardiff & Vale's Data Paper, <https://fasttrackcardiff.files.wordpress.com/2020/07/ftc-report.pdf>), we appear to be doing very well on two of the initial FTC 90/90/90 targets – getting people into treatment (98% of those diagnosed) and getting them to undetectable (96% of those on treatment across the two clinics). This is a credit to our Welsh NHS, which provides good quality treatment, easily accessible to all those diagnosed and pre-exposure prophylaxis (PrEP) on demand to prevent the acquisition of HIV to all those eligible. However, on a preliminary analysis it is unclear whether we are reaching the first of the three targets; 90% of people with HIV diagnosed.

In order to get to zero new transmissions by 2030, Cardiff & Vale (and Wales in general) needs to focus on creating greater opportunities to test for HIV including targeting testing to those most at risk. We also need to remove both regulatory and social barriers to testing. Stigma is crucial as it sometimes prevents people from testing and deters some non-specialist NHS and social care staff from offering tests. It also allows false ideas about HIV to remain in circulation. To do this well, we also need to increase our access to accurate data on who has HIV; how they acquired it; and why those who test late do so.

In discussion with clinicians, councillors and community organisations a number of low to no cost initiatives have already been identified which could be effective locally in tackling late diagnoses and stigma. Public Health Wales is already seeking to increase access to quality data on HIV in Wales. Fast Track Cardiff & Vale (FTC&V) had also intended to consult locally about how services can best respond to the current challenges and reduce new diagnoses to zero. Lockdown measures introduced by the Covid-19 pandemic altered the approach and so a survey was developed to explore what people from key groups think of the current services, what improvements they would suggest and any experiences of stigma they have faced.

Procedure

An ad hoc online survey was created consisting of 21 questions split across five sections: demographics, local health services, testing for HIV, HIV stigma and (mis)information and HIV status (full survey in appendix). It contained both open and closed questions to allow for elaboration around certain topics. The survey was targeted at individuals who live or work in Cardiff & Vale (C&V) for whom HIV, access to testing for it or stigma about it are important issues. Respondents were recruited via social media platforms including Facebook (targeting relevant community groups) and Twitter, linking with key influencers. All responses were collected using Qualtrics® survey software and the survey was administered in collaboration with Cardiff Universities Centre for Trials Research. The survey went live on the morning of the 26/06/2020 and the last response was collected on the 29/08/2020.

FINDINGS

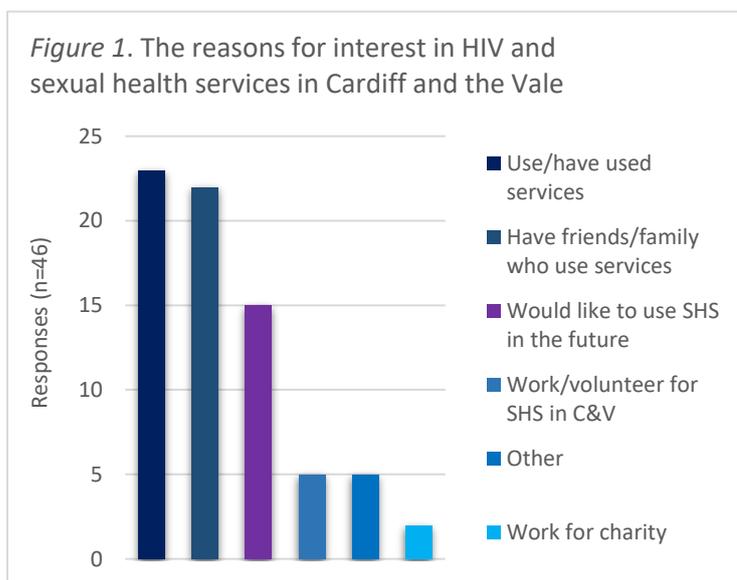
The survey had a total of 58 responses but only 36 people fully completed the survey. There were a further ten partly completed surveys which were included in the analysis. Twelve responses were not included in the analysis, these included eight which did not complete past the demographic questions, three that did not meet the criteria and one consent refusal. Findings are set out to match the sections of the survey with one difference of HIV status being part of the demographic data.

Demographics

Respondents were majority male (72%) with 1 non-binary person. Three people identified as trans. Ages ranged from 17 to 63 with an average age of 35 years. 85% of respondents were white British. The majority of individuals lived in Cardiff (37) with two residing in the Vale of Glamorgan; seven lived outside Cardiff but worked or used services in Cardiff. Of the 33 men, 70% had sex solely with other men in the last five years, two had sex only with women and six had sex with both men and women. Six of the 12 female respondents reported only having sex with men, three had sex with only other women and one had sex with both men and women. Five people reported not being sexually active within the last five years, three of whom were women. Over three quarters (78%) of the respondents knew their HIV status, with 10% of this group reporting being HIV positive. Six people did not know their status and two preferred not to say.

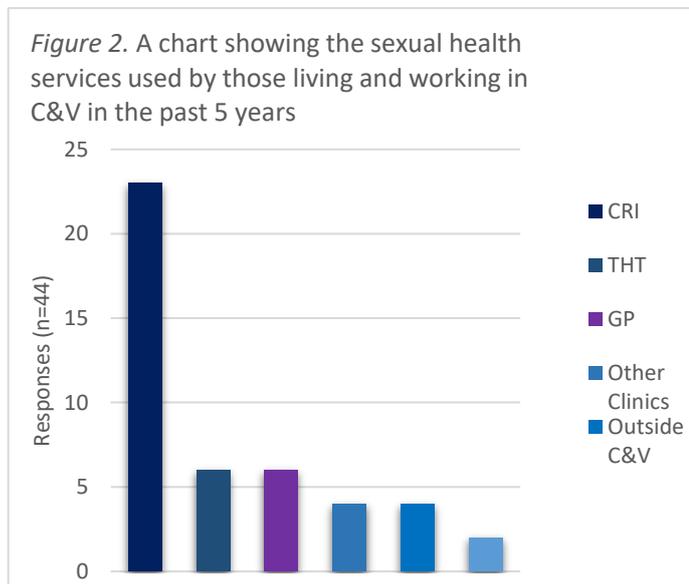
As *Figure 1* shows, half of the respondents' interest in HIV and sexual health services (SHS) was due to using or having used these SHS. The next most common reason was having friends and family who use the services in C&V, which just under half reported. Fifteen intended to use the services in the future. Five people's interest was solely working or volunteering for SHS, with five respondents giving other reasons including volunteering for an LGBT+ charity, wanting to remove the stigma around sexual health and improving the SHS in C&V. 15 of the respondents provided multiple reasons for their interest.

Figure 1. The reasons for interest in HIV and sexual health services in Cardiff and the Vale



Local Sexual Health Services

This section identified recent service use in Cardiff & Vale and explored the experiences of services used to understand what is working well and what can be improved. Data (Figure 2) showed that Cardiff Royal Infirmary (CRI) was the most commonly used service, with over half having used their services in the last five years. Six people had used Terrence Higgins Trust (THT) services with smaller numbers using GPs, the University Hospital of Wales and St. David’s clinics. Other sexual health services used included those online and services outside Cardiff & Vale.



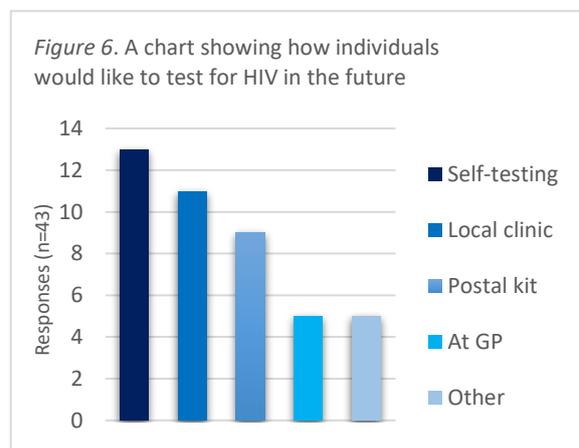
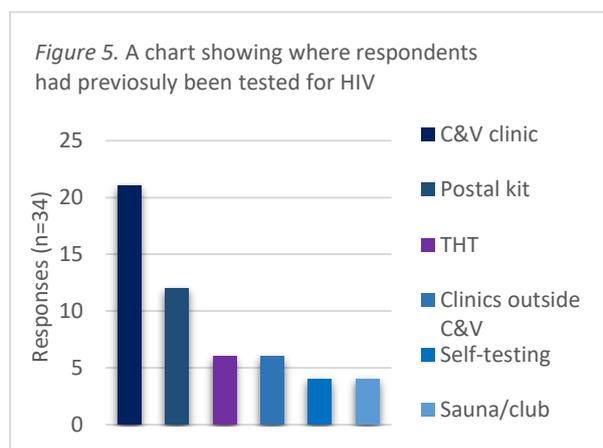
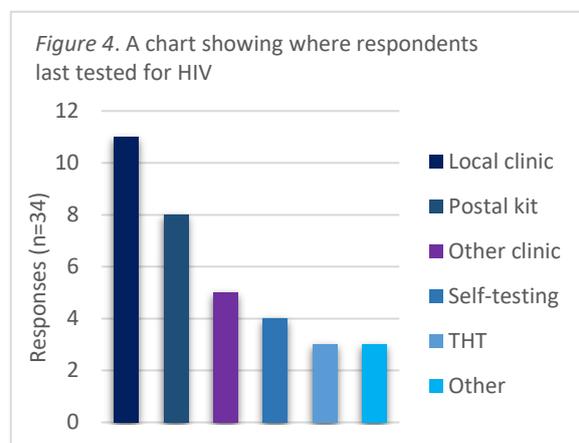
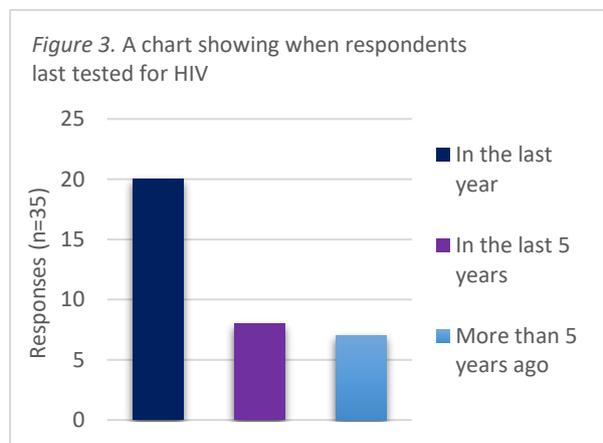
Ten respondents had never attended a sexual health service, with 30% having used multiple services in the previous five years. Ten people, seven of them women, reported never having used any of these services.

To understand how people felt about the services they had used, respondents were asked to provide comments on their experiences, with 17 individuals providing additional commentary. Positive comments focused on staff and services being helpful, non-judgmental and efficiently run, particularly the MSM and PrEP clinic whose *“service is fantastic”*. They gave not only personal experiences but those of others: *“My brother, my son and his girlfriend have used CRI, an excellent non-judgmental service”*. Praise was also given to THT for their support with HIV diagnoses. However, many people commented on long waiting times for STI testing, particularly in relation to CRI, with multiple mentions of a *“long wait for service”* and the need to book days off work to attend. One comment stated: *“A vast improvement over recent years at the CRI, but the provisions are still far too slow. We need a clinic like Dean Street that makes testing really easy and quick. Not good for those of us who work that there's not much after work provision.”* (56 Dean Street is a Soho, London “one stop shop” clinic focussed on the LGBTQI+ community including drop-in rapid testing, mental health support and evening hours). There were multiple references to the need for a Dean Street *“equivalent”*. Communication was highlighted as an issue: *“clinics very friendly and well organised, however outreach associations like Frisky Wales and Public Health Wales create problems due to poor communication”*. There was also reference to *“a huge reluctance at GPs ... to test for STIs”*, when clearly this is preferred by some. The lack of oral swab testing for HIV was raised, highlighting that rapid testing services are available in England but not Wales (Wales currently tests for HIV through blood samples analysed in labs).

HIV Testing

This section of the survey focused on services for HIV testing with interest on when and where people had previously tested for HIV and any issues they may have faced. As shown in *Figure 3* below, 57% (20/35) reported having had a HIV test in the last 12 months. Eight had received a HIV test in the previous five years and seven had not received one for over five years. Nine respondents had never been tested for HIV and of these, seven were women. *Figure 4* shows where people had last tested. Just under half had used an NHS clinic, with the majority using their local clinic. Sixteen had tested from home, the majority using a postal kit (8), with others self-testing (4) to get an instant result. Three tested at or through THT. Other places included GP surgeries and maternity screening. Of people testing any time in the past five years (*Figure 5*) the majority had tested in a C&V clinic, with one third having used a postal test kit as well as various other sources, shown below.

To identify the needs of people in C&V we asked how they would like to test for HIV in the future (*Figure 6*). While self-testing (where someone tests themselves and gets an immediate result) was most popular, it was closely followed by local clinics. Postal testing kits (whereby you send back the sample and wait to be told the result) were slightly less popular and this may suggest that if people have to wait for results anyway, some may prefer to attend a clinic. However, if we consider both self and postal testing as “at home” testing, this clearly takes the lead and the very strong uptake of the new postal testing scheme from Public Health Wales

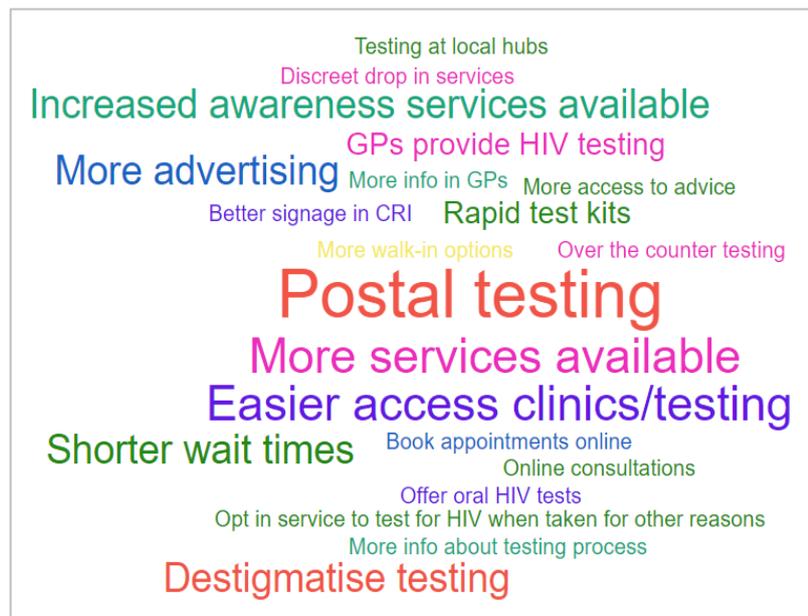


bears this out. Some showed interest in being tested at their GP, along with other locations such as a private clinic or bar/sauna.

To gauge how well services worked, respondents were asked if they had difficulty accessing a test for HIV in Cardiff & Vale. The vast majority (75%) had not experienced any difficulties. Of the 11 (n=43) who did have difficulty getting a test, four reported being unable to get an appointment at a clinic, two did not know where to get a test and two had to leave due to waiting too long at a clinic. One respondent reported not receiving a HIV test because: “*Was told by my GP I was not at risk because I was having 'straight sex' despite my partners being gay men*”.

This section of the survey ended with an open question that asked respondents to provide any suggestions of how to increase HIV testing. From the comments provided the data was grouped into themes. The data is presented visually in *Image 1* with larger words/phrases representing the most common suggestions. The most popular was to provide postal testing, with many focused on improving awareness of services with ‘more advertising’. As for services themselves, there was a clear desire for more services and easier access. An important point raised was also the need to destigmatise testing.

(Right) *Image 1*. A visual representation of themes from suggestions of how to increase HIV testing in C&V

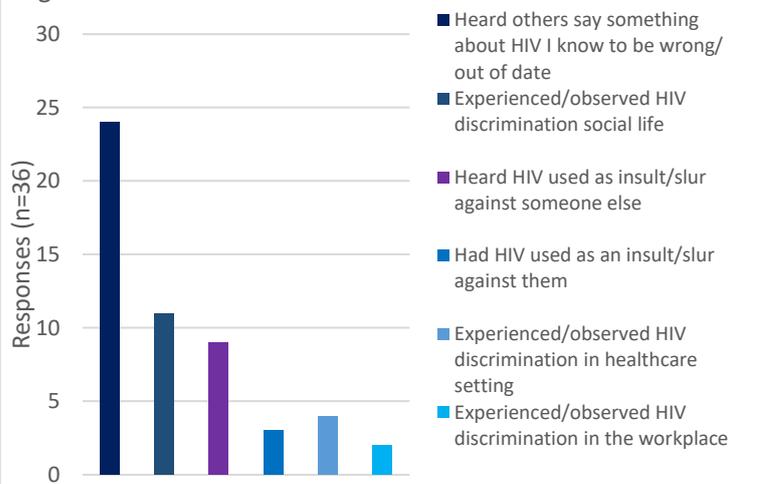


HIV stigma and (mis)information

Understanding experiences of HIV stigma is important to tackle and bring an end to it. Our survey explored individual experiences of stigma and misinformation. We also asked where they would get information how to live well with HIV and on whether public role models were helpful. Respondents were also asked to provide suggestions of how to tackle HIV stigma. *Figure 7* presents people’s experiences of HIV stigma and misinformation. Sadly only six respondents had no experience of any HIV stigma either towards themselves or others they knew. Over a third had experienced/observed HIV discrimination in their social life with nine having heard HIV used an insult or slur against someone else and three people having had HIV

used as an insult or slur against themselves. More people had seen or experienced HIV stigma or discrimination in a healthcare setting than in the workplace; this can be partially explained by people being more often required to disclose their HIV status in any healthcare setting than at work. A substantial majority of respondents had also heard someone say something about HIV that they knew to be wrong or out of date.

Figure 7. A chart showing the experiences of HIV stigma and misinformation



We provided an open text box to allow for descriptions of any stigma experienced. Ten people gave details with over half of them referencing the incorrect information or views others had about HIV, often relating to HIV being a gay disease or inaccuracy about how it is transmitted. Some provided detail of the experiences of stigma they had received in social groups as well as healthcare settings. Examples are provided below:

“HIV is only a gay issue and he was safe from it because he was straight”

“HIV can be gotten from dirty toilets and is a gay virus”

“I was speaking to a man online who insisted that oral sex and swallowing semen is completely safe and that HIV and all other STIs can only be spread by blood and saliva, not by semen, and that kissing is more dangerous than oral sex”

“go die like Freddie’... ‘You’re not African”

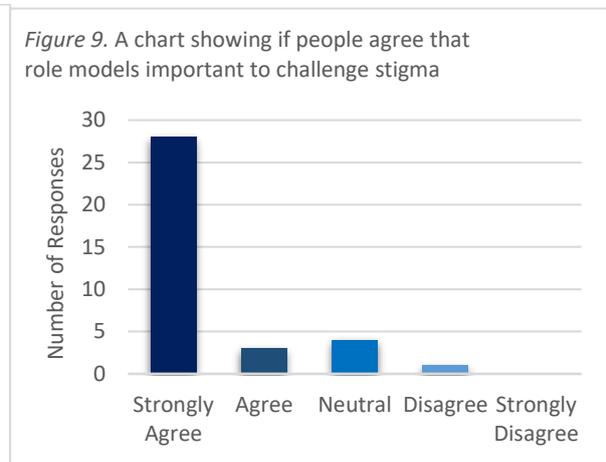
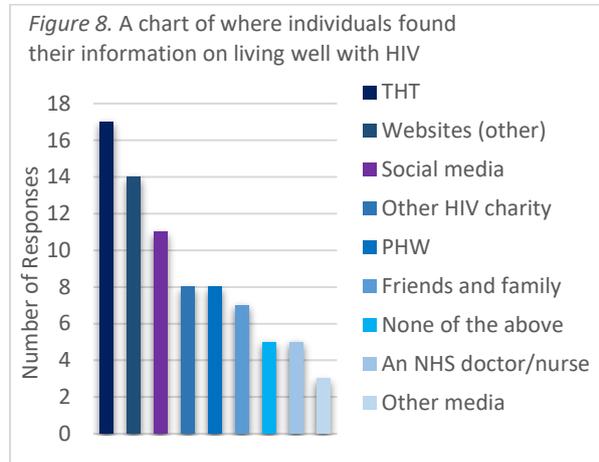
“Someone testing me for HIV in Cardiff implied being anything other than straight was to be promiscuous and also shouted at me for getting an STI. The whole system is archaic.”

One respondent’s views nicely summarise the overall theme: *“There is still a stigma around HIV, though I do believe people are becoming better educated. But more can be done to educate people about HIV”*.

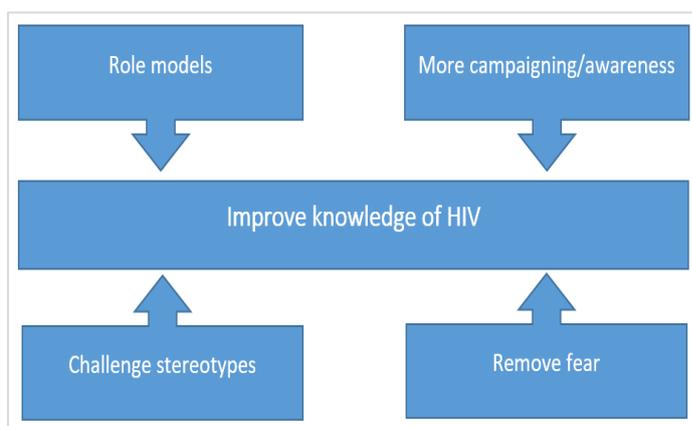
Figures 8 & 9 (next page) show the findings relating to where people found information and the importance of role models. The majority found information about living with HIV from THT, who have a website, helpline and a local office (17). The high responses for social media (11) and other websites (14) show that information is largely sought online compared to the handful that got information from a NHS nurse/doctor. Public Health Wales and other HIV charities (8) were relatively common sources of information with five people using none of the sources mentioned.

With Gareth Thomas’ recent campaign to end HIV stigma and publicly announcement of his HIV status we were curious if people thought role models were required to help end HIV

stigma. The findings show overwhelming support for this, with 31 out of 36 agreeing that role models are necessary to challenge HIV stigma. Four people were neutral while one disagreed with the need for role models.



Finally, respondents were asked to provide suggestions for how to tackle HIV stigma. This data was analysed by grouping themes from the data provided and is visually presented in a thematic map (*Image 2*). Appreciation for Gareth Thomas’ work as a role model was voiced along with the need for others. Particularly, more role models who are “other sexualities, genders and ethnicities” were requested and this links with challenging the stereotype mentioned multiple times of HIV being considered a gay disease or focused only on the LGBT+ community. The need was expressed to also remove fear of HIV among older and younger people to remove negative views. A particular need for more education in schools around this topic was noted. More campaigning being needed from bodies such as the NHS, Public Health Wales and local LGBT+ groups was mentioned along with awareness being promoted on dating apps for all sexualities and even TV shows relating to dating. The subthemes identified were grouped to fall within an overarching theme that to tackle HIV stigma we need to improve knowledge of HIV, as stigma is a by-product of ignorance.



(Left) *Image 2*. A thematic map from suggestions of how to tackle HIV stigma.

The findings from this section clearly show that people are still experiencing HIV stigma, with false or outdated beliefs playing a large part. Most people sought correct information online, most commonly through THT and many strongly agree that role models are important to challenge

stigma. Accurate information at all levels about the reality of modern HIV and who is impacted – clinical data, public messages, educational and in the media – is needed to challenge stigma.



CONCLUSIONS

While the numbers included in the survey are not huge, there are clear messages contained in the responses. The findings directly endorse two of FTC&V's targets – diversification of and increased access to testing, and tackling stigma. The findings about diversification of targeting and messaging also rely on the third aim of improved data.

It is clear that individuals would like to have access to multiple options for testing, including both at home and in clinic settings but also through GPs. It is also clear that people are aware of wider or more holistic service models, focussed firmly on patient needs, elsewhere in the UK. This includes rapid and self-testing options as well as community-focussed one-stop-shop clinics. It is important that we design our services in Cardiff & Vale to be focused on maximising patient outcomes and are transparent and evidence based about choices that need to be made in light of limited resources. These are key tenets of values-based healthcare.

The section on experiences of stigma highlight that HIV stigma is still a problem but is seen as largely due to misinformation rather than malice. Improving education and awareness will aid in reducing people's experiences of HIV stigma, including the use of role models. However, it is important that all forms of messaging show diverse representation of the communities affected by HIV in order to both improve awareness and reach of preventative programmes as well as decrease stigma.