

**NHS GGC Staff HIV Stigma and Discrimination Survey,  
2013**

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# Contents

1. Executive summary	3
2. Introduction	5
3. Methodology	13
4. Findings	16
4.1. The sample	16
4.2. Basic HIV knowledge	18
4.3. Attitudes towards people living with HIV	20
4.4. Awareness of HIV discrimination	22
4.5. Staff training needs	23
5. Discussion and conclusions	32
6. Recommendations	36
Appendix A	38

## 1. Executive Summary

- Following a series of concerns raised by people living with HIV who reported experiencing stigma and discrimination within NHS GGC, it was agreed that a survey should be conducted to better understand NHS GGC staff's HIV knowledge, attitudes towards those living with HIV, awareness of HIV discrimination within the health service and to assess staff training needs.
- 3971 staff, representing almost 10% of the NHS GGC staff population, took the time to participate in the survey.
- Staff reported reasonably good knowledge of the routes of HIV transmission, with the majority correctly identifying blood and sexual fluids as transmitting the virus. However there was very low awareness that HIV can be transmitted in breast milk from mother to child.
- Staff also had a good understanding of the changes in HIV related morbidity and mortality with treatment advances. Although few were aware that HIV treatment greatly reduced how infectious someone was by suppressing the amount of the virus circulating in different bodily fluids.
- Attitudes expressed by staff towards people living with HIV were mixed. In particular there were worrying attitudes expressed about HIV positive women's rights to pregnancy and perceptions that HIV positive migrants may come to the UK to take advantage of our free healthcare (so called 'health tourism'). It is likely these attitudes are due to poor understanding of the advances in support for pregnant women diagnosed with HIV and also misguided stories from the press on 'health tourism'.
- There was poor awareness that HIV was included within the Equality Act 2010 as a protected characteristic and therefore discrimination of anyone living with HIV was unlawful.
- Staff who participated overwhelmingly agreed that there was a need for further training on HIV and took the time to provide feedback on the design, delivery and content of this training.

- HIV positive patients attending the Brownlee Centre were given an opportunity to comment on the findings of the survey and to shape the recommendations.
- A number of recommendations relate to reviewing existing and developing a new flexible portfolio of training for staff. In particular there is a need to raise awareness of the protection afforded people living with HIV by the Equality Act 2010 and how this applies to the NHS.
- HIV positive patients are keen to support the design of future staff-facing training and awareness raising campaigns. Patients also support the development of a patient toolkit to help empower patients to challenge HIV stigma and discrimination.

## **2. Introduction**

### **2.1. HIV Epidemiology**

When HIV infection first emerged in the UK in the early 1980s two groups were predominantly affected: intravenous drug users and gay men. Other groups affected included those in receipt of blood products and transfusions. At this time little was known about HIV infection and for most individuals it signalled the beginning of a rapid decline in their health and subsequent death. A stigmatising rhetoric soon emerged, with the groups who were already marginalized, gay men and drug users, classed as 'deserving' victims, and other victims, such as haemophiliacs, classed as 'innocent'. The ignorance and fear surrounding HIV alongside the fact that it was associated with these marginalized groups fuelled early stigma and discrimination, which persists to the present day.

The epidemiology of HIV in the UK and NHS Greater Glasgow and Clyde (GGC) has changed significantly over the last 30 years, in part due to improvements in our knowledge of and ability to prevent transmission. The introduction of needle exchange programmes and other harm reduction approaches with drug users has almost eradicated transmission via this route. Advances in reducing vertical transmission, from mother to child, have also almost eradicated transmissions via this route within the UK.

Gay, bisexual and other men who have sex with men remain the largest group involved in HIV transmission which occurs within the UK and within Scotland. Over the last fifteen years the UK has witnessed an increase in heterosexual transmission, predominantly where HIV has been acquired abroad amongst people with Black African ethnicity who have subsequently come to the UK and been diagnosed here. In NHS GGC this change in epidemiology coincided with the refugee and asylum seeker dispersal contract awarded to Glasgow City Council in 2001, which resulted in an influx of migrants from Sub-Saharan African countries with high HIV prevalence.

Presently NHS GGC diagnoses approximately 100 new cases of HIV annually and by the end of 2012 had diagnosed a cumulative total of 2101 individuals. As of March 2013 the health board is responsible for the care of almost 1400 people living with diagnosed HIV.

## **2.2. HIV Treatment and Care**

As mentioned in the early years of the HIV epidemic there was poor understanding of the virus, the impact it had on the body and how to treat infection. Those diagnosed in the 1980s received palliative care to prepare for death. By the late 1980s and early 1990s prognosis improved slightly with the introduction of the first anti-retroviral treatments, however these resulted in disabling side effects and merely prolonged life expectancy marginally. It wasn't until the late 1990s that more successful treatments emerged which provided much better quality of life. Treatment has continued to improve in the intervening years, and it is believed that if someone is diagnosed early and receives and adheres to treatment they can live a comparatively healthy and normal life.

As treatment and prognosis have evolved over the last thirty years, so too has the treatment and care service provided by NHS GGC. As expected HIV services have had to evolve from palliative care models towards the management of long term conditions. Currently the Brownlee Centre provides care for HIV positive patients in NHS GGC. The centre has a multi-disciplinary team of health care and support services, which includes: consultants in both infectious disease and genitourinary medicine; nursing staff; a psychiatrist; sexual health advisors; counsellors; pharmacists; dieticians and other health care specialists; and a peer support and patient engagement manager.

## **2.3. HIV Stigma and Discrimination**

Since the early days of the epidemic those infected with HIV have faced stigma and discrimination. This was fuelled by the early associations between HIV and groups within society who were already stigmatised and discriminated, drug

users and gay men, and also the fear and ignorance surrounding the then fatal disease. HIV stigma and discrimination persists today across the world.

Stigma can be described as “an attribute that is deeply discrediting,” and that reduces the bearer “from a whole and usual person to a tainted, discounted one”.<sup>1</sup> Discrimination is when someone is treated differently than another person in a way that is unfair. It can be based on a person gender, faith, race, age, disability, or sexual identity. HIV is regarded as a disability by the Equality Act 2010, and therefore discrimination of an individual on the basis of their HIV diagnosis is unlawful in the UK.

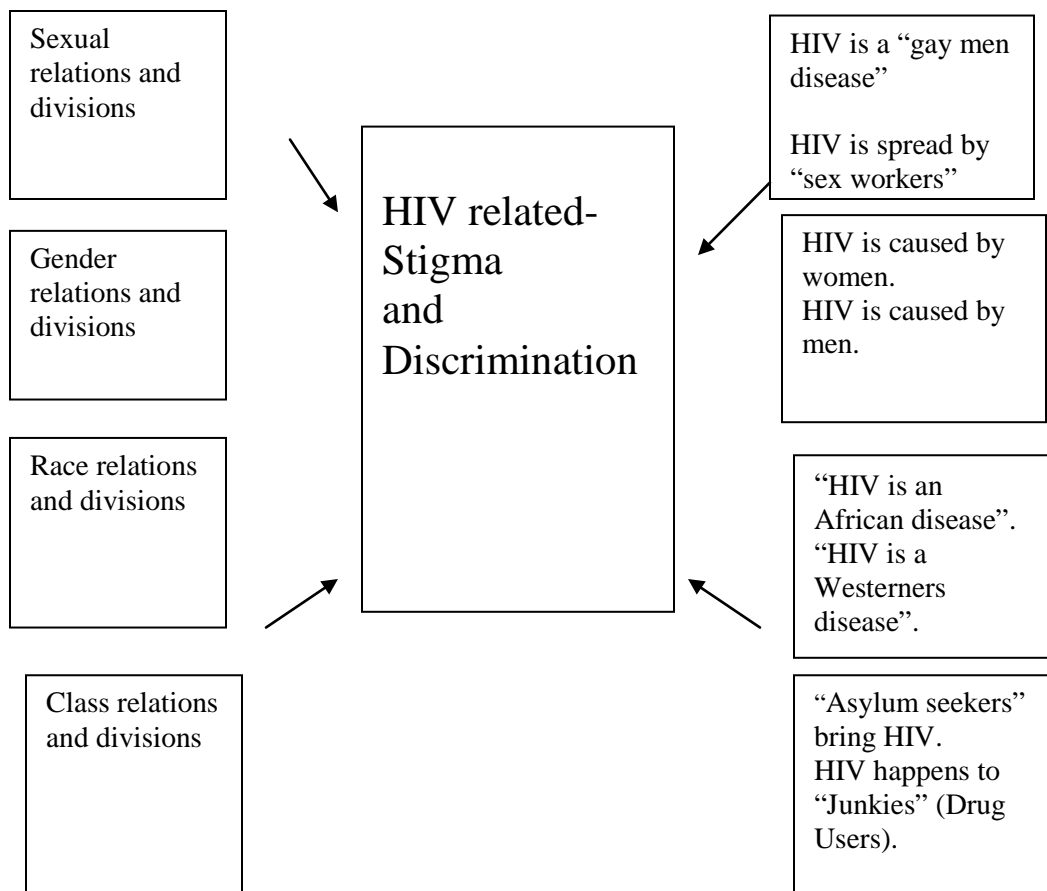


Figure 1: Adapted for Glasgow context from Parker & Aggleton: The link between HIV and pre-existing sources of stigma and discrimination.<sup>2</sup>

<sup>1</sup> Erving Goffman. “Stigma and Social Identity.” Stigma: Notes on the Management of Spoiled Identity.

<sup>2</sup> Parker R. and Aggleton P. HIV/AIDS-related stigma and discrimination: a conceptual framework and an agenda for action. Population Council: Horizons Program. 2002

It has been suggested that inequalities in social, political, and economic power become the foundations on which stigma is propagated. In the case of HIV stigma, structural violence and pre-existing stigmas based on sexuality, gender, race and socioeconomic class/status strengthen the power of stigmatizers and intensify the stigma and discrimination experienced by the victim (Fig 1 above).<sup>3</sup> As a result HIV stigmatisation is also a process of devaluation which results in social inequality.

HIV related stigma and discrimination can take different forms and are manifested at different levels- societal, community and individual- and in different contexts. The following summarises the current evidence of HIV stigma and discrimination from a UK and Scottish context.

At an individual level, evidence suggests that stigma is manifested internally in contexts where HIV as a status is highly stigmatised or where there is lack of openness to discuss issues related to sexuality or gender. This may lead to self-isolation or internalisation of negative attitudes which in turn devalues a person's self worth, resulting in low self esteem, depression and disengagement from treatment and care. A recent Scottish study with people living with HIV found that 59% experienced low self-esteem, 25% felt suicidal and over a third self-isolated. This study also demonstrated how the people living with HIV often also experience stigma related to their sexual orientation, asylum or migration status or their behaviours, which further compound HIV stigma.<sup>4</sup>

Stigma can also manifest at a community level depending on the type of cultural systems prevailing in a community and how they influence the response to an individual diagnosed with HIV. For example, evidence suggests that in the UK a

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<sup>3</sup> Mahajan, A et al. Stigma in the HIV/AIDS epidemic: A review of the literature and recommendations for the way forward. 2008

<sup>4</sup> Scottish Public Health Network (ScotPHN). Treatment and Care Needs Assessment: People Living with HIV.2009



Black African living with HIV might not only face stigmatization from the broader British society due to pre-existing xenophobia or racism, but also suffer rejection from his/her own community due to pre-existing HIV stigma which would associate their diagnosis with homosexuality or promiscuity. This stigma results in a community turning against rather than supporting an individual diagnosed with HIV.<sup>5</sup>

Gay men diagnosed with HIV often have a similar experience. A Scottish study found that not only are they stigmatised and discriminated by the wider society for their sexual identity, but within gay communities they are stigmatised and discriminated due to their HIV status.<sup>6</sup> This community level stigma and discrimination often leads to fear of disclosure of HIV status for people living with HIV both to family, friends and partners, but also within their wider communities.

The final level of stigma and discrimination which individuals can experience is at the structural or institutional level. This is when the processes, structures or procedures of an organisation lead to the stigmatisation or unfair treatment of someone living with HIV. There have been several studies of this within the NHS in the UK, which suggests that HIV stigma and discrimination still exist in these settings.<sup>7</sup> In a London based survey conducted in 2008, around half of respondents who reported discrimination experienced this in health care

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<sup>5</sup> Doods, C et al. Outsiders Status: stigma and discrimination experienced by gay men and African people with HIV. Sigma Research. 2004

<sup>6</sup> Flowers, P et al. Community, responsibility and culpability: HIV risk management amongst Scottish gay men. Journal of Community and Applied Social Psychology. 2000; Smit, P et al. HIV-related stigma within communities of gay men: A literature review. AIDS Care. 2012.

<sup>7</sup> Power, L et al. A national study of people over 50 living with HIV. Joseph Rowntree Foundation. 2010; Levett, T et al. Access to dental care for HIV patients: does it matter and does discrimination exist? Intl J STD AIDS. 2009; Scottish Public Health Network (ScotPHN). Treatment and Care Needs Assessment: People Living with HIV.2009; Palattiyil G and Sidhva D. A Report on HIV Human Rights and Asylum Seekers in Scotland. They call me you are AIDS. Edinburgh.2011; Palattiyil G and Sidhva D. A Report on HIV Human Rights and Asylum Seekers in Scotland. They call me you are AIDS. Edinburgh.2011

settings.<sup>8</sup> A 2009 Scottish survey found a fifth (21%) of respondents experienced disclosure of their HIV status without prior consent by a health care worker.<sup>9</sup>

Experience of stigma and discrimination within the health service is not only unlawful but also results in poorer engagement with these services leading to adverse outcomes for the health and wellbeing of individuals. Further HIV stigma can create barriers to accessing HIV testing which contributes to late diagnosis of HIV and poorer treatment outcomes for individuals.

## **2.4. Rationale for the survey**

As described above the Brownlee centre consists of a multi-disciplinary health care team, which seeks to meet the treatment care and wider support needs of people living with HIV in NHS GGC. One component of this team is the HIV Peer Support Project, which facilitates peer support for people living with HIV. The manager of this service also has a role in wider patient engagement. Through this work patients had begun to report experiences of HIV stigma and discrimination within the health service.

Initial investigation found that patients often only wished to discuss incidents with specialist staff when attending routine care and they rarely reported them at source or in retrospect via the existing complaints procedures. To explore this further a patient seminar was held in March 2013 and when asked why there was reluctance to complain, patients stated and agreed that this was due to:

- being singled out and drawing more attention
- fear of further discrimination
- labeled as a 'moaner' or 'troublemaker'
- scared of the process and the system is not easy

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<sup>8</sup> Elford, J et al. HIV-related discrimination reported by people living with HIV in London, UK. *AIDS and Behavior*. 2008

<sup>9</sup> Scottish Public Health Network (ScotPHN). *Treatment and Care Needs Assessment: People Living with HIV*. 2009

- not deserving of better treatment (self stigma)

To address this and create a way of meaningfully evidencing the nature and extent of HIV-related stigma and discrimination patients, specialist staff and partner organisations were engaged to develop novel reporting processes to capture incidents. This process was not intended to supersede the Board's complaints procedure, but with some patients being unwilling to formally complain it has been created as a complimentary means to capture data without breaching confidentiality. The intention is to explore how to report these incidents to the organisation so that appropriate action can be taken.

To date from March 2013 over a 9 month period there have been 14 incidents reported affecting a diverse cross section of the cohort. This demonstrates that HIV stigma and discrimination is not tied to a particular demographic such as age, sexuality or ethnicity. Staff groups involved range from consultants, doctors, nurses and infection control staff. The incidents fell under the following broad themes:

- inappropriate questioning e.g. asking how patient got HIV
- inappropriate and non-standard treatment e.g. double gloving
- confidentiality e.g. overtly discussing the 'HIV patient' in open ward environment
- attitudinal e.g. appearing 'nervous' of patient when learning of diagnosis
- denial of treatment e.g. would not put theatre staff at risk by carrying out procedure

In response to the growing number of reports and concerns expressed by patients it was agreed that a staff survey should be designed to better understand healthcare workers' existing knowledge of HIV, their values and attitudes towards people living with HIV, their awareness of existing stigma or

discrimination of people living with HIV within the health service, and finally to assess the staff training and support needs.

### **3. Methodology:**

#### **3.1. The questionnaire**

A self-report anonymised questionnaire was used (See appendix 1). The questionnaire was designed to gather information on employment demographics; basic HIV knowledge levels; attitudes towards people living with HIV; awareness of current HIV discrimination within the health service; and finally assessing current training needs regarding HIV. The intention was to keep the questionnaire short and it was limited to 24 multiple choice questions and included one free text question, in total taking less than 5 minutes to complete. The questionnaire was piloted before it was launched with a small group of staff to ensure accessibility. An online version of the questionnaire was hosted by Survey Monkey and linked back to further information on HIV and current training opportunities within NHS GGC when participants had completed the survey. Hard copies were also made available.

Staff were assured that participation was voluntary and were given contact details for the Senior Health Improvement Officer-Sexual Health, who was leading on the project, if they wished further information on the project.

#### **3.2. Recruitment**

The aim was to sample a cross section of the NHS GGC staff population, and therefore a multi-method approach to recruitment was utilized between **[INSERT DATES]**. The URL for the online version of the questionnaire was disseminated as follows:

- An 'All NHS GGC Staff' email from the Director of Public Health
- An email to Clinical Directors in Acute settings asking them to disseminate to their staff
- An email sent via Acute Healthy Working lives mailing list
- Inclusion in the Acute Brief
- Reminder on Staffnet (NHS GGC staff intranet)

- Reminder messages on payslips

Paper copies were also made available at:

- NHS GGC Patient information service at Victoria Hospital
- NHS GGC Patient information service at Stobhill Hospital
- Weigh in at work scheme

The online survey remained open for XDAYS and paper copies were collected for XDAYS.

### **3.3. Data analysis**

The small number of paper copies of the survey were entered manually into the online version of the survey when data collection had closed. Survey Monkey exported the data as Microsoft Excel spreadsheets. Data was analysed using both Microsoft Excel and SPSS version 20. Univariate and bivariate analyses were conducted. Pearson chi squared test was used to detect statistical significance (with  $p$  value  $< 0.05$ ). Given the small numbers in some categories, the validity of statistically significant results was also checked and caution was used when interpreting such results.

A simple knowledge index was constructed to assess participants overall HIV knowledge. Participants were given a point for each correct knowledge question they answered (across questions 9-12), which gave a score between 0 and 4. A score of 0 was labelled as not at all knowledgeable and a score of 4 was completely knowledgeable.

Thematic analysis was used to explore the qualitative information collected via the free text question which asked participants to consider their further training needs.

### **3.4. Limitations**

Although all attempts were made to maximize the reach of the study we can not guarantee that all staff groups across different sites and specialties were reached. Staff who participated may have been those more likely to engage with such projects, or may have prior knowledge, awareness or experience of people living with HIV, and therefore introduce a degree of bias.

The questionnaire design did not capture information on age, gender, sexuality, ethnicity or years in service with the NHS, all of which may contribute to differences in knowledge, attitude, confidence and previous access to HIV training. Data on the sample's attitudes to sexual and ethnic minorities and intravenous drug use was not collected which may also have impacted on attitudes towards people living with HIV given the over-representation of men who have sex with men, Black Africans and people who have injected drugs amongst the NHS GGC HIV cohort.

Although the response rate to the questionnaire was high at 10.5% and the sample appears relatively diverse, caution should be exercised in generalizing these findings to a different geographical location since this study was carried out in NHSGGC.<sup>10</sup>

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<sup>10</sup> NHS Greater Glasgow and Clyde currently employs approximately 38,000 staff.

## 4. The findings

### 4.1. The Sample

In total 3971 individuals participated. They were drawn from across the Health Board sectors, predominantly from the Acute sector and Partnerships, which included the 6 community health (and care) partnerships (CH(C)Ps).

Table 1

Health Board Sector	Individuals	Proportion (%)
Acute sector	2259	56.9%
Partnerships	1096	27.6%
Other services	348	8.8%
Corporate services	244	6.1%
Staff Bank	24	0.6%
	N=3971	

There was a reasonable spread of staff drawn from across the different Acute Sector divisions, with a fifth (22%) from the surgery & anaesthetics and other common divisions including rehabilitation & assessment (16%); Emergency Medical Services (15.0%) and Diagnostics (13.7%).

Unsurprisingly Glasgow City CHP staff were the predominant group within the Partnerships Sector accounting for three fifths (58.9%), followed by 15.3% from Renfrewshire CHCP and smaller numbers across the remaining three partnerships.

When participant's current base was considered over half (51%) were drawn from hospitals/acute settings and the remainder from a range of settings. Nursing and Midwifery staff emerged as a large group when the sample was split by staff group accounting for two fifths (38.7%). Administrative and Clerical staff accounted for a fifth (19.2%) and Allied Health Professionals made up 13.1% of the sample.<sup>11</sup>

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<sup>11</sup> Administration and Clerical included records staff, clerical services, information, finance, human resources, and other central administrative functions.



Three quarters (74.2%) of the sample reported they had direct contact with patients, and these individuals were mainly drawn from medical/dental, nursing and midwifery and allied health professional staff groups, and based within Partnerships or Acute Health Board sectors.

## 4.2. Basic HIV Knowledge

The questionnaire included four questions designed to assess basic HIV knowledge (questions 9-12, appendix 1). Staff were asked to identify routes of HIV transmission, and then asked whether the following statements were true or false:

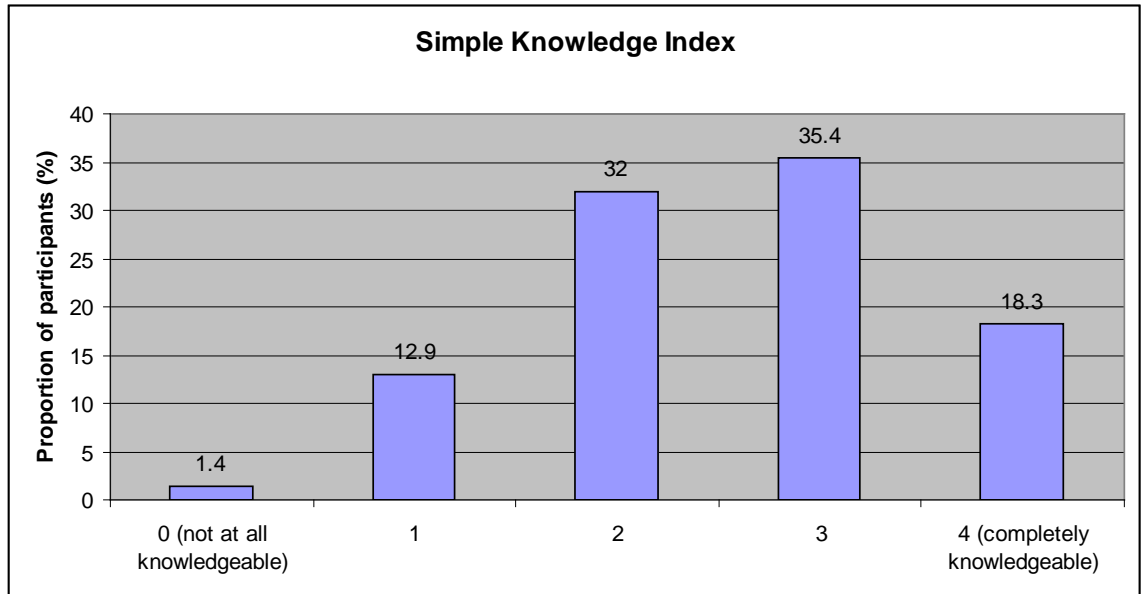
- HIV can be transmitted via infected bodily fluid if it comes into contact with healthy unbroken skin.
- People living with HIV are now able to live longer and healthier lives.
- Someone living with HIV but successfully on treatment is far less likely to pass the virus on.

Staff appeared to have good knowledge about the improvements in HIV treatment with the majority (96.9%) correctly stating that HIV positive patients are able to live longer and healthier lives. However knowledge of the impact HIV treatment has on infectivity was less encouraging with only a third (36.6%) of respondent correctly agreeing that someone with HIV on successful treatment was less likely to pass the virus on. Although the majority of participants could correctly identify blood (99.2%); semen (84.1%) and vaginal fluid (81.9%) as routes of HIV transmission, there was poor knowledge of transmission via breast milk, with only two fifths correctly identifying this (59.7%). Two fifths (59%) of participants correctly identified all four bodily fluids. There was also a poorer understanding of the risks associated with infected bodily fluid coming into contact with healthy unbroken skin, with over a quarter of participants incorrectly stating that this presented a transmission risk.

Using the four knowledge questions a simple knowledge index was constructed to rate respondent's basic HIV knowledge levels on a five point scale from not at

all knowledgeable to completely knowledgeable.<sup>12</sup> As Fig 2 below illustrates, over half (55%) of the sample got at least 3 out of the 4 questions correct.

Fig. 2.



Acute and partnerships sectors reported better basic HIV knowledge (rated as fairly to completely knowledgeable), with bank staff rated as having poorest knowledge. Across staff groups medical/dental and pharmacy staff had best knowledge levels while administrative and clerical staff, health improvement, executive and senior management and personal and social care services all reported the lowest knowledge levels.

Within the acute sector specifically, just over a half (55%) had fairly to complete knowledge. Amongst them, the women/children services and surgery & anaesthetics followed by emergency/medical services divisions reported the highest levels. Overall staff reporting direct contact with patients tended to have better HIV knowledge.

<sup>12</sup> As described in the methodology questions individuals were given a point for each of the four HIV knowledge questions (questions 9-12) they answered correctly to give a score for their overall HIV knowledge between 0 (not at all knowledgeable) and 5 (completely knowledgeable).

### 4.3. Attitudes towards People Living with HIV

The questionnaire included five questions designed to assess staff attitudes towards people living with HIV (questions 16-19 and 22, appendix 1). Staff were asked how often they could identify someone infected with HIV by looking at them and also to rate how strongly they agreed/disagreed with the following:

- An HIV positive woman has as much right to get pregnant as a woman who does not have HIV.
- Most people living with HIV were infected because of irresponsible behaviour.
- Lots of people come to the UK to get free HIV treatment.
- Caring for/treating a patient who is HIV positive increases health care staff's chances of becoming infected with HIV.

The majority (87.0%) of participants stated that they could never identify someone living with HIV just by looking at them. Three quarters (71.8%) also stated disagreement with the statement suggesting that most people acquire HIV due to irresponsible behaviour.<sup>13</sup> However fewer staff expressed positive attitudes for the other statements. Only a third (29%) of participants disagreed with the statement relating to HIV treatment tourism.<sup>14</sup> Just half (53.3%<sup>15</sup>) of participants agreed with the statement relating to a HIV positive woman's right to pregnancy and only two thirds (65.4%) disagreed that health care staff would be at risk of transmission when caring for an HIV positive patient.<sup>16</sup>

Across the five attitude questions partnerships and acute sector staff expressed the most positive attitudes towards people living with HIV when compared to the other sectors. Staff from the bank sector expressed the least positive attitudes.

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<sup>13</sup> Including individuals who disagreed or strongly disagreed with the statement 'Most people living with HIV were infected because of irresponsible behaviour'.

<sup>14</sup> Including individuals who stated they disagreed or strongly disagreed with the statement 'Lots of people come to the UK to get free HIV treatment.'

<sup>15</sup> Including individuals who agreed or strongly agreed with the statement 'An HIV positive woman has as much right to get pregnant as a woman who does not have HIV'.

<sup>16</sup> Including individuals who disagreed or strongly disagreed with the statement 'Caring for/treating a patient who is HIV positive increases health care staff's chances of becoming infected with HIV.'

Amongst staff groups the medical/dental group expressed the most positive attitudes, followed by Nursing/Midwifery and AHP/Therapeutic groups.

As would be expected there was a positive association between HIV knowledge levels and expressing favourable attitudes towards people living with HIV. As knowledge levels increased attitudes towards people living with HIV became more favourable.<sup>17</sup> In turn those who expressed more positive attitudes were also more likely to express a higher degree of confidence in caring for an HIV positive patient.<sup>18</sup>

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<sup>17</sup> The knowledge index described on page 14 rated an individual's knowledge using the four knowledge questions. An attitudes index was similarly constructed using the five knowledge questions. When these were correlated a positive association was found. The strength of this association (Gamma) was 25% which implied that knowledge levels were a surely a good predictor of respondent's favourability in attitudes and that knowing a respondent's knowledge level allowed prediction of their respective attitude up to 25% more accurately.

<sup>18</sup> Again using an attitude index, constructed using the five attitude questions, suggested that respondent's attitudes were a good predictor (28% predictive potential) of their degree of confidence a respondent and this was a positive association.

#### **4.4. Awareness of HIV Discrimination**

The questionnaire included three questions which assessed participants' awareness of HIV discrimination (questions 13-15, appendix 1). Two thirds (66.5%) of respondents claimed to be unaware or to have never witnessed discrimination of a patient living with HIV within the health service, however this left a third (33.5%) of participants who believed discrimination did occur. Staff from the Partnerships and Acute sector reported a higher degree of awareness than other sectors. Amongst staff groups awareness was highest among medical/dental and nursing/midwifery and also amongst staff with direct patient contact. There was also a positive association between basic HIV knowledge levels and awareness of HIV discrimination, as knowledge increased so did the chance of an individual reporting awareness of HIV discrimination with the health service.<sup>19</sup>

Only 3.1% of participants stated that they were aware of HIV positive patients having been denied treatment, although two fifths (42.0%) claimed they were unsure if this ever happened.

It was worrying that only a third (32.7%) agreed that HIV is a protected characteristic under the Equality Act, and a fifth (17.9%) claimed this was false whilst half of the participants just did not know (49.4%).

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<sup>19</sup> This relationship had a predictive potential of 16% and was positive meaning as any increase in the knowledge level led to an increase awareness of the occurrence of discrimination of patients due to their HIV status within NHSGGC.

#### **4.5. Staff Training Needs**

The final section of the questionnaire focused on the training needs of staff (questions 20, 21, 23-25, appendix 1). Staff were asked to assess their current level of knowledge and confidence in caring for an HIV positive patient; to reflect on their perceived need for future BBV (Blood Borne Viruses) training; and whether they had attended any recent BBV training. Finally participants had the option of using a free text questions to voice any further thoughts on their training needs.

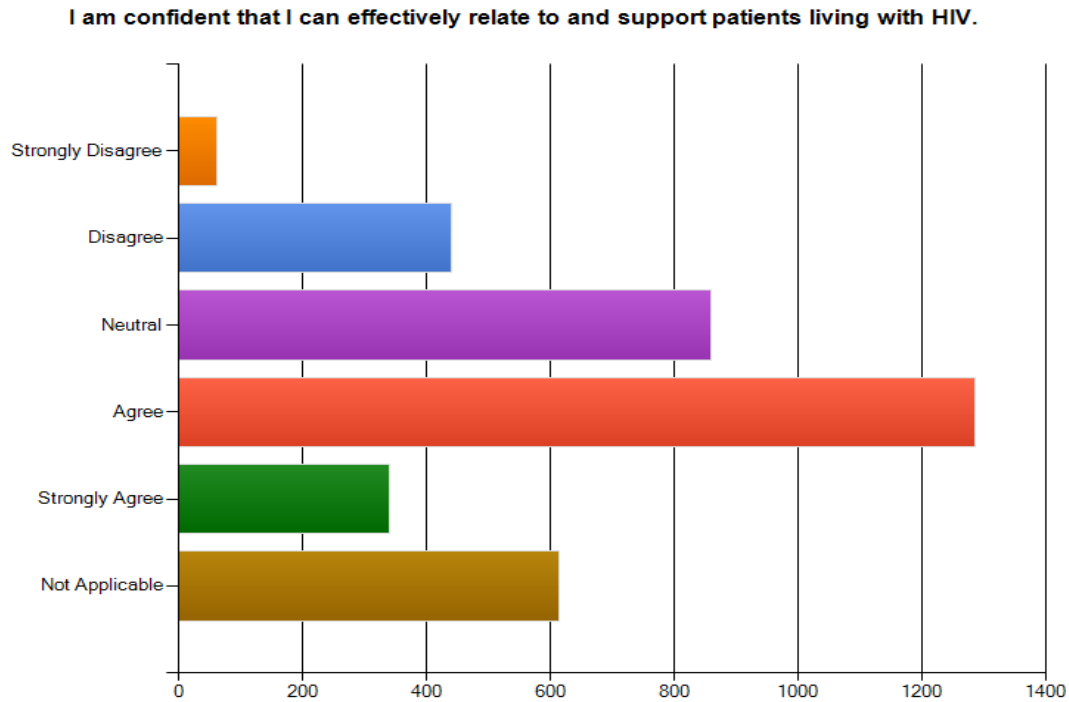
Only half (47.2%) of respondents felt they had adequate knowledge to ensure they treated HIV positive patients fairly and less than half (45.2%) felt a degree of confidence in caring for someone living with HIV (Fig. 3). Staff from the acute and partnerships sectors, reported the highest levels of confidence. Across staff groups, the medical/dental and nursing/midwifery groups reported highest confidence, with Pharmacy and AHP/Therapeutic group being the least confident.

There was a positive relationship found between basic HIV knowledge level and confidence in caring for an HIV positive patient. As knowledge levels increased there was a corresponding increase in confidence.<sup>20</sup>

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<sup>20</sup> In fact, findings suggested that knowledge levels were a good predictor (22% predictive potential) of the degree of confidence a respondent had and as knowledge increased so did the confidence of dealing with an HIV patient.

Fig. 3.



Given that only 8.3% of respondents had attended any BBV training the previous 12 months, it was encouraging that almost two thirds (63.5%) felt they needed BBV training as they were likely to encounter HIV positive patients.<sup>21</sup> The participants who had attended BBV training recently were more likely to work within the acute or partnerships sectors and across staff groups to be from nursing/midwifery and medical/dental groups. Staff from Partnerships, Acute and Other services sectors were more likely to express a need for BBV training, whereas Corporate and Bank sector staff were least likely. Across staff groups nursing/midwifery, AHP/therapeutic and medical/dental staff groups were more likely to express BBV training needs, with administrative, health improvement and senior management least likely. Staff with direct patient contact were more likely to recognise a need for BBV training and to have recently attended such training.

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<sup>21</sup> Respondents were classified as expressing a need for training if they disagreed or strongly disagreed with the statement 'I do not feel the need to be trained in BBV since it is unlikely that I will encounter HIV positive patients'.



As mentioned participants were also given the opportunity to describe their future training needs with the inclusion of a free text question and almost a fifth (698 individuals) made use of this opportunity. Thematic analysis of these comments has provided rich intelligence on respondents thoughts on the benefits of, facilitators and barriers to attending BBV training, and also on training content, which are outlined below and in the tag cloud (Fig. 4).

Fig. 4: Tag cloud summarises themes which emerged free text responses relating to BBV training.

Awareness Basic Training BBV Training Blood Borne  
Virus Date Info Facts Further Training High Risk Area Illness Infection  
Knowledge Learn Pro Line Mental Health Not been Offered Patients  
People with HIV Psychological Regular Updates Relevant Side Effects  
Staff Study Treatment Understanding Update on HIV

#### 4.5.1. Perceived benefits of HIV training

Staff identified a number of benefits to attending HIV training including increasing their knowledge, dispelling myths and misconceptions, increasing their skills and confidence in treating HIV positive patients. They also recognised that training would also in turn benefit patients living with HIV, illustrated by the following quotes:

*“I feel all NHS staff should be trained in BBV so that they can recognise the signs and symptoms and be knowledgeable about how to treat and care for people with HIV”*

*“A greater awareness for all staff would be beneficial and an awareness of how we respond would make the patient journey more comfortable”*

*“Standard BBV training for all staff would be highly useful to dispel many of the myths and untruths surrounding HIV and other BBV's”*

Even staff who felt they rarely come into contact with HIV positive patients identified benefits to BBV training:

*“It probably is highly unlikely that I will, knowingly, come into contact with HIV Positive individuals but I still believe BBV Training would be advantageous for all NHS staff”*

#### **4.5.2. Barriers and facilitators for attendance of BBV training**

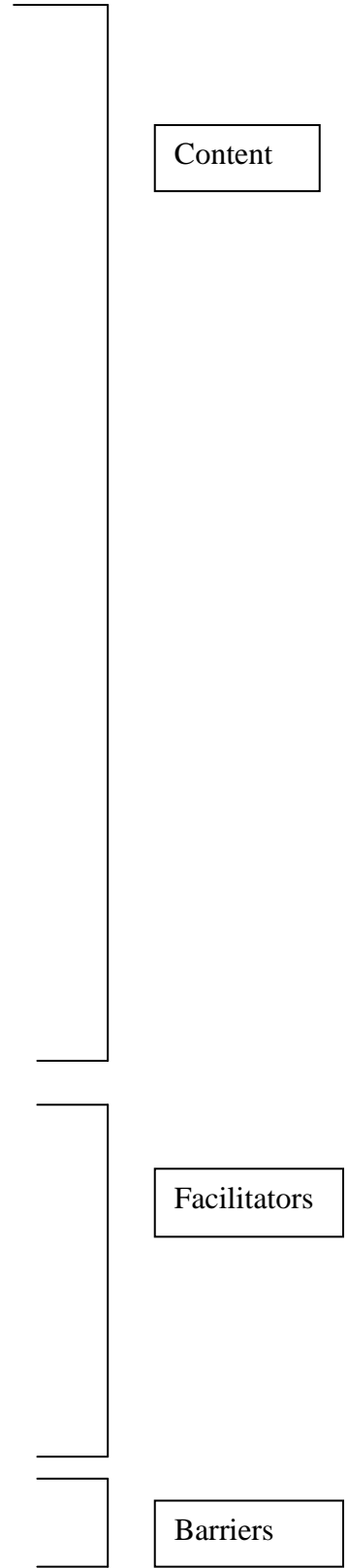
The mind map below (Fig. 5) gives an overview of the barriers and facilitators to training identified by participants. Barriers to BBV training included reduced time available for attending training, that BBV training competes against other mandatory training and that it is less likely to be viewed as a priority by staff and managers.

*“It must be remembered that there is increasing pressure from many different areas of hospital working where they feel their training is important. In truth all is important but realistically there is not enough time to take on board all extra training issues”*

Despite these barriers staff were able to identify possible facilitators which could be considered for BBV training, again summarised in the mind map below (Fig X). Providing a flexible package of training opportunities was viewed as a facilitator, which may include formal lectures, seminars or workshops; use of online learning opportunities, such as Learn Pro, and offering regular updates such as using a newsletter to disseminate knowledge. Staff also felt that having training based within their departments/wards or providing flexibility in times of trainings, such as evening sessions, might overcome the barrier of reduced time available for off-site training.

Others also suggested that agreeing protected training time for staff generally would facilitate training uptake, or including BBV training within the mandatory training programme for clinical staff.

Fig.5 : Mind map



#### **4.5.3. HIV training Content**

Respondents provided lots of feedback on the areas that they felt HIV training should cover. Some respondents identified several population groups affected by HIV they wanted to know more about, including older people, pregnant women, children, and health care workers. Respondents wanted to better understand the care needs of these groups and in particular how their HIV may impact on these:

*“I work with older adult patients in psychiatry, whilst not an issue currently, I do wonder about the implications of HIV positive patients care as they start to be above the 65 year cut-off and how we can prepare for this, specifically in terms of managing HIV dementia”*

*“Increased knowledge of effects, risks and treatment of children born to HIV positive mothers in the longer term. Also knowledge of the side effects in the longer term of HIV drug treatments both in utero and thereafter”.*

Many respondents recognized that an HIV diagnosis may have a negative impact on an individual's mental health and wellbeing, and wished to understand how to appropriately support people living with HIV:

*“As a psychologist working with children, young people, and their families, I feel I would benefit from a more in depth understanding of the experiences of those individuals and families affected by HIV - in terms of psychological adjustment, stigma, and daily life stressors related to the condition”*

*“As a critical care nurse I feel it would benefit me immensely to have BBV training and possibly some counselling skills as I occasionally have to deal with patients receiving news of their HIV status”*

Respondents recognized there was a need to cover HIV stigma and discrimination in BBV training, with some suggesting that having the skills to

challenge stigma would be useful for the benefit of HIV positive patients and colleagues:

*“I think we all need training around HIV. I don't deal directly with patients, however, what if a work colleague is infected with HIV. We surely should all be trained to deal appropriately with situations which could arise and also it would help destroy some of the myths surrounding HIV and help avoid discrimination not only for patients but for all NHS staff as well. I don't know a lot about HIV but would be happy to go to training to learn more”.*

*“I have heard about staff going overboard with PPE when they are aware of a patients HIV status, and making the patient extremely uncomfortable about it. Staff should be aware of the standard precautions and their effectiveness in protecting staff.”*

It was clear that staff required both basic information on HIV transmission, detection, the impact the virus has on someone's health and the support available for people diagnosed with HIV in NHS GGC. Staff from clinical settings also wished more specialised information on current HIV treatment:

*“General awareness of HIV including how it can be passed on, treatments and outcomes and the rights of patients with HIV. For information purposes as do not have patient contact but would be good to have a source for this information”.*

*“Signs symptoms how it affects the person infected? The current treatment and how effective it is? What support is available to staff/patients in dealing with HIV? How as a practitioner I can support someone if they come to me and are looking for support/info”.*

*“I personally would like to have more knowledge about the treatment plans and medication that is prescribed for treatment of HIV as it is appropriate to my work place (pre op)”*

*” Guidance on prescribing and likely interactions of antiretrovirals and other medication that I recommend to the GP”.*

It was also apparent that many staff had a poor understanding of the routes of HIV transmission, including occupational exposure, and the effectiveness of standard precautions in infection control.

*“How it can be accidentally contracted and what steps can be taken to avoid this danger. What to do in the event that you suspect you may have been exposed to it, e.g. a client at reception who has a cut on his / her hand touches your hand and the person's blood ends up on your hand”*

*“How to deal with bleeding nose, incontinence”.*

*“I struggle with when someone has a diagnosis of HIV which other health professionals should be made aware when passing over details. ... Some thought it was up to me to read her past medical history and find out independently as the likelihood of passing on the disease would be down to me not taking enough care if there was an open wound etc... It would not have made me discriminate against this lady in any way but I would have taken more care to dress wounds etc.”*

Participants also expressed a need for guidance on the rights of HIV positive patients, and how the law may impact on the treatment and care of these patients, such as what should be reported, disclosed and recorded in case notes:

*“Confidentiality, how to document in case notes, who needs to know about condition*

*“Specific to what if any restrictions there are and the indications for these restrictions regarding treatment of HIV patients. What the legal implications are and what contact numbers we have to acquire information at the time of treatment to help clarify issues surrounding this type of patient”*

## 5. Discussion and Conclusions

Given the high response rate and the broad range of staff who participated in the questionnaire, it is clear that the methodology employed was very successful. In particular the questionnaire had good reach amongst acute sector staff and more generally with staff with direct patient contact, and therefore staff which future HIV training would likely be targeted at. It may be worth utilizing similar methods for reaching staff with campaigns, information or training opportunities relating to HIV in the future.

Basic HIV knowledge was varied. Overall respondents had a high knowledge relating to improvements in HIV prognosis with treatment advancements, and of HIV transmission via blood and sexual fluids. However there was poor awareness of transmission via breast milk from mother to child. There was also poor awareness of the reduced infectivity associated with successful treatment or that healthy skin is a natural barrier to the virus if exposed to infected bodily fluids. Knowledge varied across health care settings and staff groups, with acute sector staff and the medical/dental and pharmacy staff groups displaying the highest levels. There is clearly a need to educate staff on the basics of HIV transmission and treatment, and the findings could be used to target staff groups with the appropriate levels of information and training.

When participants attitudes towards people living with HIV were considered some findings of concern emerged. A majority believed that HIV positive people come to the UK for access to free treatment, half expressed some reservations about the rights of HIV positive women to get pregnant, and a third believed that HIV positive patients posed a transmission risk to health care staff. These attitudes varied across health board sector and by staff group, with acute and partnerships sectors expressing the most positive attitudes, amongst whom the medical and dental staff groups rating most positive. Bank staff expressed the least positive attitudes across groups.



It would seem that many of the negative attitudes expressed may be explained by poor HIV knowledge. In fact a positive correlation was found between knowledge and attitudes, with increases in HIV knowledge linked to expression of increasingly positive attitudes. This suggests that investment in HIV training would result in an overall increase in positive attitudes towards HIV positive patients.

Overall there was low awareness of the protection afforded people living with HIV by the Equality Act 2010 amongst participants. A third of participants believed that HIV related stigma and discrimination occurs within the health service, although only a very small number reported HIV positive patients have been denied treatment. These findings are concerning given the legal protection afforded by the Equality Act 2010. It suggests that NHS Greater Glasgow and Clyde staff could potentially be in breach of the Act as a result of low awareness of the rights of people living with HIV and therefore highlights the need for staff training in this area.

Only a small proportion of respondents reported attending BBV training in the previous 12 months, so it was unsurprising that only half of the sample reported adequate knowledge levels (47.2%) and confidence (45.2%) in their ability to adequately and effectively care for HIV positive patients. Confidence was highest in the acute sector and amongst the medical/dental and nursing/midwifery staff groups. It was also unsurprising that as knowledge levels increased there was a corresponding increase in participants confidence in caring effectively for HIV positive patients, again highlighting the benefits of investment in further training for staff. This was echoed by participants with two thirds (63.5%) expressing a need for BBV training.

It was encouraging that so many participants took the time to reflect and feedback their thoughts on the benefits of, facilitators and barriers to attending BBV training, as well as giving thought to the content of such training, via the free

text question at the end of the survey. Respondents appreciated that investment in staff training was not only beneficial to staff skills and confidence but in turn would also improve the care and experience of HIV positive patients, and HIV positive health care staff.

Although staff acknowledged that there were increasing barriers for staff to attend any training, they helpfully indicated many options which could help to prioritise BBV training and make it more accessible for staff, including agreeing protected training time, inclusion in mandatory training, and a flexible programme of training ranging from annual updates, evening sessions, department based sessions to elearning.

When reflecting on the content of HIV training staff expressed a need to know more about specific population groups affected by HIV and their unique health and care needs; the impact of stigma and discrimination and the wider mental health needs of people living with HIV and how best to support them; advances in HIV treatment; and the impact of the law on HIV positive patients rights and the role of health care staff. It was also evident that basic training on HIV, in particular how to reduce risk of occupational exposure was needed as staff expressed confusion in this area.

### **Brownlee Centre HIV Patient Forum Feedback**

It was strongly felt that patients be engaged early to discuss the findings of the report and to feedback on the conclusions and recommendations. A recent development has been the creation of a Brownlee Centre HIV Patient Forum and the preliminary findings of the survey were presented to them on 02/10/2013 which generated the following feedback and comment on the work:

- The forum expressed concerns that newly diagnosed individuals might think being treated with poor attitudes or discrimination is common with a diagnosis.

- The forum questioned the perception that HIV positive patients were a 'risk' to staff. The argued that given advances in treatment that those living with HIV and responding to treatment were actually less infectious than someone who is living with undiagnosed HIV. Given the large proportion of individuals who are undiagnosed health service staff should treat everyone equally.
- The patients emphasized the importance of trust and security which has been established with the Brownlee Centre. Poor experiences in other health care settings and a lack of trust in these services means that many patients view the Brownlee as their default point of engagement for all health issues, rather than just those directly related to their diagnosis.
- The question "Who is 'scared' of who?" was asked. Patients reflected that healthcare workers are scared of HIV but that this equally resulted in fear of the healthcare staff felt by the patient, as they worry how their fear of HIV will impact on their both their ability to treat patients safely and effectively and also on patient experience.
- Lack of trust in health care staff out side of their HIV clinic leads to worry about the treatment patients will receive.
- The forum was keen that patients have a role in staff education. They discuss empowering and training patients to challenge stigma and discrimination.
- The use of patient stories to highlight the impact of different experiences, both good and bad, was suggested.
- Some patients argued that HIV training should be compulsory/mandatory, and also that there should be a varied approach to training delivery and that this should incorporate novel methods for raising awareness, both of the issue bit also of the training and resources available.

## 6. Recommendations

Current BBV training should be reviewed in light of the findings of this questionnaire to better understand how it can be enhanced or re-designed to better meet the training needs of staff. In particular the following should be considered:

- Thought should be given to the level, depth and content of training required by different staff groups and a series of appropriate training options designed for each.
- For staff with a degree of knowledge and skills opportunities should be created for updates or refreshers which put a particular emphasis on changes in HIV treatment and care.
- Training packages should be flexible and seek to overcome barriers staff experience in attending training. This could involve delivering training across a number of platforms/settings (online, on-site and off-site, email newsletters), varying the length of trainings appropriate to their content and have increased flexibility in the times available for staff to attend training.
- Consideration should be given to the inclusion of BBV training within mandatory training programmes for some staff groups.
- The mechanisms used to engage staff for the questionnaire provided good reach and should be replicated for the promotion of future training opportunities and dissemination of information on HIV.

The questionnaire also provided an indication of the content of future HIV/BBV training, which should include:

- Basic information on HIV transmission, epidemiology within NHS GGC/Scotland, treatment and care.
- HIV and pregnancy

- HIV stigma and discrimination, in particular the emotional impact on people living with HIV and the implications for health service staff of the Equality Act 2010.

#### Patient Forum Recommendations

- Patients should be involved in the design of training resources and campaigns to ensure that content reflects and validates their experiences
- A toolkit should be created to train and empower patients to challenge HIV Stigma and Discrimination at source.

## Appendix 1: Questionnaire

1. Which part of the Board are you employed in?
  - a. Acute
  - b. Partnerships
  - c. Other services
  - d. Corporate
  - e. Bank
2. If you selected Acute, which type of service are you employed in?
  - a. Diagnostics
  - b. Emergency care/Medical services
  - c. Facilities
  - d. Regional services
  - e. Rehabilitation & assessment
  - f. Surgery & anaesthetics
  - g. Women & Children's
  - h. Acute HQ
  - i. Other
3. If you selected Partnerships, which one are you employed in?
  - a. East Dunbartonshire
  - b. West Dunbartonshire
  - c. East Renfrewshire
  - d. Renfrewshire
  - e. Inverclyde
  - f. Glasgow City
4. If you selected Other Services, which service are you employed in?
  - a. Specialist children's services
  - b. Oral health
  - c. Sexual health
  - d. Mental health
  - e. Child Protection Unit
  - f. Pharmacy
  - g. Homelessness
  - h. Other
5. If you select Corporate, which service are you employed in?
  - a. Board
  - b. Health information & technology

- c. Finance
  - d. Human resources
  - e. Public health
  - f. Other
6. On which site are you mainly based?
- a. Beatson
  - b. Brownlee
  - c. Caledonia House
  - d. Drumchapel
  - e. Dykebar
  - f. Gartnavel General
  - g. Gartnavel Royal
  - h. Glasgow Dental Hospital
  - i. Glasgow Royal
  - j. Health Centre/clinic
  - k. Homeopathic Hospital
  - l. Inverclyde Royal
  - m. JB Russell
  - n. Leverndale
  - o. Lightburn
  - p. Mansionhouse
  - q. Parkhead Hospital
  - r. Ravenscraig
  - s. Royal Alexandra
  - t. Royal Hospital for Sick Children
  - u. Southern General
  - v. Sandyford
  - w. Stobhill
  - x. ACH Stobhill
  - y. Vale of Leven
  - z. Victoria Infirmary
  - aa. ACH Victoria Infirmary
  - bb. Other
7. To which staff group do you belong? (Select one answer only, the one that best describes your main role)
- a. Executive Grades/Senior Managers
  - b. Medical/Dental

- c. Doctors in training
  - d. Medical/Dental support group (incl. dental nursing, hygienist etc.)
  - e. Salaried General Practitioner
  - f. Salaried General Dental Practitioner
  - g. Pharmacy (incl. pharmacy technicians)
  - h. Other therapeutic staff (psychology, counselling, optometry, etc.)
  - i. Administration and Clerical (e.g. records staff, clerical services, information, finance, HR, other corporate services and central functions, etc.)
  - j. Health Improvement
  - k. Ambulance
  - l. Nursing and midwifery
  - m. Support services
  - n. Personal and social care
  - o. Healthcare science/ scientific and technical (incl. BMS, clinical sciences, physiology, etc.)
  - p. Allied Health Profession (physiotherapy, occupational therapy, radiography, dietetics, speech and language therapy, clinical etc.)
  - q. Other
8. Do you have direct contact with patients?
- a. Yes
  - b. No
9. HIV is a blood borne virus found in: (tick all that apply)
- a. Blood
  - b. Semen
  - c. Vaginal fluid
  - d. Breast milk
  - e. None of the above
10. HIV can be transmitted via infected bodily fluid if it comes into contact with healthy unbroken skin
- a. True
  - b. False
  - c. Not sure
11. People living with HIV are now able to live longer and healthier lives
- a. True
  - b. False
  - c. Not sure



12. Someone living with HIV but successfully on treatment is far less likely to pass on the virus
- True
  - False
  - Not sure
13. Discrimination of patients due to their HIV status occurs within NHS GGC
- Never
  - Rarely
  - Sometimes
  - Always
  - Don't know
14. In NHSGGC sometimes people living with HIV are denied medical treatment
- True
  - False
  - Don't know
15. HIV is a protected characteristic that protects an individual from discrimination from the point of diagnosis.
- True
  - False
  - Not sure
16. An HIV positive woman has as much right to get pregnant as a woman who does not have HIV
- Strongly disagree
  - Disagree
  - Neutral
  - Agree
  - Strongly agree
17. Most people living with HIV were infected because of irresponsible behaviour
- Strongly disagree
  - Disagree
  - Neutral
  - Agree
  - Strongly agree
18. Lots of people come to the UK to get free HIV treatment
- Strongly disagree
  - Disagree
  - Neutral

- d. Agree
  - e. Strongly agree
19. I can tell by looking at someone if he/she is infected with HIV
- a. Always
  - b. Very often
  - c. Sometimes
  - d. Rarely
  - e. Never
20. I have an adequate amount of knowledge about HIV to ensure patients/clients are treated fairly
- a. Yes
  - b. No
  - c. Not sure
  - d. Not applicable
21. I am confident that I can effectively relate to and support patients living with HIV
- a. Strongly disagree
  - b. Disagree
  - c. Neutral
  - d. Agree
  - e. Strongly agree
  - f. Not applicable
22. Caring for/treating a patient who is HIV positive increases health care staff's chances of becoming infected with HIV
- a. Strongly disagree
  - b. Disagree
  - c. Neutral
  - d. Agree
  - e. Strongly agree
  - f. Don't know
23. In the past 12 months, did you attend any BBV (Blood Borne Virus) training?
- a. Yes
  - b. No
24. I do not feel the need to be trained in BBV (Blood Borne Viruses) since it is unlikely that I will encounter HIV positive patients.
- a. Strongly disagree
  - b. Disagree
  - c. Neutral

- d. Agree
- e. Strongly agree
- f. Not applicable

25. Please use this space to tell us about any additional training, knowledge or skills you think you need around HIV.