

The Healthcare Experiences of People Living with HIV in Scotland

Research Report | **November 2014**

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1. Introduction

This report presents the findings of research conducted amongst people living with HIV in Scotland. The research explored their experiences of the behaviour of healthcare staff towards them and whether they believed this was affected by their HIV status.

The research was conducted during July and August 2014. It took the form of a questionnaire which participants could complete either online or on paper and then submit to Waverley Care.

The findings of the research are being used to help in the targeting and content of resources for healthcare professionals in Scotland. These resources will aim to inform, challenge and inspire healthcare professionals in their treatment of, and professional interaction with, people living with HIV.

2. Acknowledgements

Thank you to all the individuals living with HIV who took part in the survey and shared their experiences. We appreciate people's openness and know that some of the experiences shared will have been very painful and so we are grateful for people's courage in making them known.

Thank you to the Scottish Government for funding this work as part of their Sexual Health and Blood Borne Virus Framework 2011-15.

Thanks also for the support of NHS boards across Scotland in promoting the survey to people attending specialist HIV services. Thank you to Dona Milne from NHS Lothian and Nicky Coia and John Barber from NHS Greater Glasgow & Clyde in consulting on the production of the questionnaire alongside Waverley Care colleagues, volunteers and service users and Story UK.

Finally, thank you to Professor Vivienne Cree and The University of Edinburgh for their support and guidance in the construction of the research questionnaire and production of this report. Also, I am grateful to them for my appointment as a University of Edinburgh Knowledge Exchange Fellow for the duration of this project.

3. Executive Summary

Stigma and discrimination have been closely associated with HIV since the discovery of the virus in the early 1980s. Over the past few years, when discussing stigma in Scottish society, people living with HIV have highlighted that some staff working in healthcare settings have displayed stigmatising and discriminatory behaviour towards them.

Recent research reports amongst people living with HIV in the UK supported this claim by citing significant percentages of people stating that they had been treated differently or badly by healthcare workers because of their HIV status.

To quantify the problem, Waverley Care carried out research amongst people living with HIV in Scotland. The research investigated the experiences of people living with HIV as to the behaviour of healthcare staff in relation to their HIV status. It also gathered examples of both stigmatising and excellent behaviour and explored whether stigma is more prevalent in certain healthcare settings.

The research focused on staff who do not work in HIV specific settings in order to provide insight into the behaviour of healthcare staff who are less likely to have specialist knowledge of the condition. Questions were structured to gather experiences that occurred within the last two years to ensure that the results were not influenced by historical experiences of stigma by the survey respondents.

A questionnaire was drafted and made available both online and on paper. It was promoted by NHS boards across the country and by Waverley Care and other agencies.

Responses represented the views of 2.8% of people estimated to be diagnosed and living with HIV in Scotland in 2014. The sample was found to be a reasonably accurate representation of the age, gender and sexuality of people living with HIV in Scotland with a slight under-representation of individuals from black and ethnic minority individuals (BME) groups.

81% of respondents reported having had, in the last 2 years, an excellent experience of someone who works within a health service behaving positively towards their HIV status. Most of these experiences occurred in general practice and were from doctors. The key themes that emerged here included being treated with respect, care and compassion and no different to HIV negative patients. People also highlighted as excellent, health professionals who sought to improve their knowledge of HIV and did not bring up an HIV diagnosis unnecessarily.

32% of respondents reported experiencing, within the last two years, poor treatment, service or stigma from someone who works within a health service, which they believed related to their HIV status. Again, most of these experiences occurred within the setting of general practice and with doctors. The majority of descriptions for this poor behaviour were attributed to staff displaying fearful or negative body language or facial expressions, having very poor knowledge of HIV or unnecessarily disclosing a patient's HIV status to other people. Some respondents reported being refused treatment because they were living with HIV.

The survey results also highlighted that the fear of stigma is more prominent than stigma itself as 29% of people had experienced stigma within the last year but 39% feared it and so did not disclose their status to a healthcare professional.

The research results demonstrate that there is a lack of consistency in NHS and healthcare settings in Scotland. Excellent treatment, behaviour and care are evidenced but so are negative experiences that clearly demonstrate HIV stigma and discrimination.

The importance that respondents gave to GP settings has directed Waverley Care to focus our work on challenging HIV stigma within GP practices in Scotland.

A number of recommendations were also identified from the results of the research:

For healthcare professionals

- Improved knowledge of how HIV is transmitted
- Reminders about patient confidentiality rules
- Reminders of standard universal precautions relating to infection control
- Improved knowledge about the risk of patients infected with HIV but undiagnosed
- Improved knowledge about how an individual being diagnosed as HIV positive and on successful treatment can lead to an undetectable viral load and a greatly reduced risk of passing HIV onto others
- Improved knowledge about, and practice of, person-centred working practices
- Improved knowledge of the Equality Act (2010) and that HIV is a protected characteristic
- Improved knowledge of the damage stigmatising behaviour can have on an individual and society.

For people living with HIV

- Work and resources designed to reduce and challenge self stigma amongst people living with HIV should be developed. Particular focus should be given to raising their expectations of how they should be treated by healthcare professionals and empowering them to challenge or make complaints about stigmatising behaviour.

General

- Consider ways of encouraging more individuals from black and ethnic minority communities to participate in future research projects.

4. The Research

4.1. Background

Since the first discovery of HIV in the 1980s, people living with the virus have experienced stigma and discrimination. This has been evidenced in extensive research studies conducted across the world. Stigma is about 'differentness' and people stigmatising those they deem different to themselves.¹ For people living with HIV, stigmatising behaviour can appear in many forms but can include verbal and physical abuse, rejection and exclusion from activities.² This can lead to devastating feelings of isolation, depression and fear in those on the receiving end.³

Many factors influence these stigmatising attitudes and behaviour but the main causes are often reported as:

- a lack of understanding and myths about how HIV is passed between people
- judgements about sexual behaviour and social groups that are most affected by HIV e.g. gay men, black Africans, intravenous drug users.⁴

Since 2012, with funding from the Scottish Government, Waverley Care has been delivering a focused campaign designed to raise awareness of HIV in Scotland and challenge HIV related stigma. This work contributes to Outcomes 3 and 5 of the Scottish Government's Sexual Health and Blood Borne Virus Framework 2011 – 2015.

Outcome 3 – People affected by blood borne viruses lead longer healthier lives

Outcome 5 – A society where the attitudes of individuals, the public, professionals and the media in Scotland towards sexual health and blood borne viruses are positive non-stigmatising and supportive.

The campaign is called Always Hear (www.HIVAlwaysHear.org) and has produced targeted resources for Scottish secondary schools and churches and promoted anti-stigma messages to the Scottish general public through press and social media.

'Stigmatising behaviour can appear in many forms'

During the promotion of the campaign it became apparent that stigmatising behaviour from people working in health settings was a major concern for people living with HIV. These reports are supported by the findings of a number of studies of the experiences of people living with HIV in England and the UK in recent years.^{2,3,5} These surveys all cited significant percentages of people living with HIV stating that they had been treated differently or badly by a healthcare worker because of their HIV status. Additionally, critical reports from patients in NHS Greater Glasgow and Clyde services had prompted the health board to conduct a wide-scale survey of its employees. This survey investigated staff knowledge and attitudes relating to HIV and

1 Goffman, E (1963) *Stigma: Notes on the Management of Spoiled Identity*

2 The People Living with HIV Stigma Index in the UK (2009) Initial Findings '*Give Stigma the Index Finger*'.

3 Weatherburn, Keogh, Reid, Dodds, Bourne, Owuor, Hammond and Jessup. (2009) '*What do you need? 2007-8* Findings from a national survey of people with diagnosed HIV. Sigma Research

4 Nyblade, L. Pande, R. Mathur S, Macquarrie, K. Kidd, R. Banteyerga, H. Kidanu, A. Kilonzo, G. Mdwambo, J. Bond, V. *Disentangling HIV and AIDS stigma in Ethiopia, Tanzania and Zambia*. ICRW: Washington, D.C; 2003

5 The National AIDS Trust (2014) '*HIV Patient Information and NHS Confidentiality in England*' www.NAT.org.uk

the results prompted the NHS board to draw up plans for activity to address stigma amongst staff⁶.

The adverse effects of stigmatising behaviour by health professionals can be significantly detrimental to both individuals and the wider society. The negative effects may include:

- Poor experience of health professionals' behaviour may lead to **poor engagement with health services**⁷. This is likely to result in adverse health and wellbeing outcomes, and poor mental and physical health^{8,9}
- Stigma may contribute to **non-adherence to HIV medication**¹⁰
- Stigma has been found to create a **barrier to HIV testing**^{11,12}
 - people undiagnosed are more likely to pass on HIV¹³
 - reluctance to test delays diagnosis which may result in poorer health and increased long-term health costs¹⁴
- **Increasing negative healthcare experiences for people living with HIV** – as the number of people over 50 who are living with HIV increases, their additional health issues associated with age also increase.¹⁵ This may lead people to need to access a wider range of specialties outside of the HIV clinics and so face a greater a risk of stigmatising behaviour from those who have had little contact with HIV patients.

‘Stigma has been found to create a barrier to HIV testing’

Another reason stigmatising behaviour needs to be addressed is that healthcare staff are putting themselves and their employers at risk of prosecution as they are breaking the law. HIV is a protected characteristic under the Equality Act (2010) so it is illegal to treat someone living with HIV differently because of their HIV status.

To combat these negative experiences and effects, Waverley Care is turning the attention of the Always Hear campaign to healthcare professionals and we are looking to produce resources which will inform, challenge and inspire them. It was determined

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- 6 NHS Greater Glasgow & Clyde (2013) *'NHS Greater Glasgow and Clyde Staff HIV Stigma and Discrimination Survey 2013'*
- 7 Monger, M. (2011). *'Stigma: Barrier to quality of life and health care'* *HIV Clinician* Volume 23, No.2
- 8 Bogart, L. M., Wagner, G. J., Galvan, F. H., Landrine, H., Klein, D. J., & Sticklor, A. (2011). *'Perceived discrimination and mental health symptoms among black men with HIV: Cultural Diversity and Ethnic Minority Psychology'*
- 9 Leserman, J. (2008). *'Role of depression, stress, and trauma in HIV disease progression.'* *Psychosomatic Medicine*, June 2008, Volume 70, Issue 5
- 10 Gonzalez, J. Batchelder, A. Psaros, C. Safren, S. (2011) *'Depression and HIV/AIDS Treatment'*
- 11 Flowers, P. Knussen, C. Li, J. and McDaid, L. (2012) *'Has testing been normalized? An analysis of changes in barriers to HIV testing among men who have sex with men between 2000 and 2010 in Scotland.'* *HIV Medicine*
- 12 Turan, J. M., Bukusi, E. A., Onono, M., Holzemer, W. L., Miller, S., & Cohen, C. R. (2011). *'HIV/AIDS stigma and refusal of HIV testing among pregnant women in rural Kenya: Results from the MAMAS study'* *AIDS and Behavior*
- 13 Attia, S. Egger, M. Zwahlen, M. Low, N. (2009) *'Sexual transmission of HIV according to viral load and antiretroviral therapy: systematic review and meta-analysis'* *AIDS*, London, England.
- 14 Krentz, H. B. Gill, M. J. (2011) *'The Direct Medical Costs of Late Presentation (<350/mm) of HIV Infection over a 15-Year Period'* *AIDS Research and Treatment* 2012
- 15 Caley, M. Sidhu, K. (2010) *'Estimating the future healthcare costs of an aging population in the UK: expansion of morbidity and the need for preventative care.'* *Journal of Public Health*, Oxford, England

that we should conduct research amongst people living with HIV in Scotland who are using NHS services in order to:

- accurately target the resources at one section of the population of Healthcare workers in Scotland to effect maximum change, and
- provide content for the resources and base them on recent and accurate experiences of patients.

4.2. Ethical Considerations

To ensure that the study was conducted ethically, when constructing the research questionnaire and methodology, attention was given to relevant questioning, inclusivity, confidentiality, anonymity, handling of data and any potential psychological harm to participants. Consent to taking part in the research was taken as assumed from the voluntary completion and submission of the questionnaires. All responses were anonymous unless the respondent was interested in speaking further about their experiences and therefore chose to provide their contact details for future contact from Waverley Care.

The research questionnaire and methodology were assessed and approved by The University of Edinburgh's School of Social & Political Studies Research Ethics Committee. This approval also provided reassurance to partners who were asked to promote the study to their contacts and patients. Additional assessment of the survey was also carried out by individual NHS boards and approval to promote the survey within clinical settings was granted by:

- NHS Ayrshire & Arran
- NHS Borders
- NHS Fife
- NHS Forth Valley
- NHS Grampian
- NHS Greater Glasgow & Clyde
- NHS Highland, Argyll & Bute
- NHS Lanarkshire
- NHS Lothian
- NHS Tayside

NHS Orkney, Shetland and Western Isles do not provide HIV clinical services. Patients are referred to mainland NHS boards.

4.3. Aims

The research was conducted with people living with HIV. It aimed to investigate their experiences of the behaviour of healthcare staff in relation to their HIV infection.

More specifically the research aimed to

- Quantify the problem of HIV stigma amongst healthcare workers in Scotland through gathering statistics
- Gather examples of both stigmatising and excellent behaviour by healthcare workers towards people living with HIV
- Explore whether stigma is more prevalent in specific healthcare settings.

The research focused on staff who do not work in HIV specific settings in order to provide insight into the behaviour of healthcare staff who are less likely to have

specialist knowledge of the condition. Anecdotal evidence collected by Waverley Care in advance of this study, supported by research studies³ indicates that poor behaviour of healthcare professionals towards people living with HIV is likely to be highest amongst those working outside of HIV specialist settings.

4.4. Methodology

A targeted review of research literature in relation to HIV and stigma was conducted as part of this study using The University of Edinburgh's 'Searcher' resource discovery tool. 'Searcher' allows access to the library's catalogue, e-journals and a large number of licensed collections.

A self-administered questionnaire was then used to gather the views and experiences of people living with HIV in Scotland (see "Appendix 1" on page 22). The questionnaire was available both online and in paper format. The online version was securely hosted by www.surveymonkey.com.

'The research focused on staff who do not work in HIV specific settings'

The questionnaire was designed to be short to encourage maximum participation from survey respondents. It consisted of 17 questions which were primarily multiple choice with some free text options to capture more details of experiences.

All responses were anonymous unless the respondent was interested in speaking further about their experiences and therefore chose to provide their contact details for future contact from Waverley Care.

The information we chose to gather from the questionnaire included:

- Demographics – geographical region, age, gender, sexuality, ethnicity
- About participants' experiences in the last two years
 - whether they had experienced poor treatment or stigma from a health professional, or whether they had experienced excellent treatment and positive behaviour from a health professional
 - which area of healthcare these experiences occurred in (dentistry, general practice, hospital etc)
 - which member of staff was involved (Receptionist, Doctor, Nurse, Pharmacist etc)
- About participants experiences in the last 12 months
 - whether they had experienced stigma in a health setting
 - whether fear of stigma stopped them disclosing their HIV status to a health professional.

The survey was piloted with four people in Edinburgh who are living with HIV and a small number of adjustments were made in response to their feedback.

Participants for the survey were recruited by working in partnership with HIV clinicians from NHS boards across the country. Postcards promoting the online survey and paper copies of the questionnaire were handed out to patients who were living with HIV and attending specialist HIV services. Posters were also distributed to promote the research and NHS Greater Glasgow & Clyde encouraged people to complete the survey by emailing a patient mailing list.

Promotion of the survey was also conducted by Waverley Care staff to people who use the charity's services and also via www.waverleycare.org. Additionally social media was used as a promotional tool with posts advertising the survey on Facebook and Twitter.

It should be highlighted that the survey questions were structured to only ask respondents for experiences within the last two years or, for two questions, the last 12 months, so that the results provide a more accurate picture of the current behaviour of health professionals. It was important for this research that the results were not influenced by historical reports of stigma from the 1990s or early 2000s that may have been experienced by people who have been living with HIV for many years. The timeframe for the last two questions was restricted to just 12 months to provide an annual baseline of stigma amongst health professionals in Scotland.

5. The Research Findings

5.1. Responses

130 responses were received in total. 63 returned the survey via the online research tool www.surveymonkey.com and 67 responses were submitted on paper. While most participants answered all the questions on the questionnaire, a small number, 14, opted to respond to some questions only.

The total number of responses, captured over a six week period, represents the views of 2.8% of the 4705 people estimated to be diagnosed and living with HIV in Scotland.¹⁶ Responses were received from across the country representing all NHS boards that promoted the survey. The majority of responses were received from people resident in the NHS Lothian (30% of responses) and NHS Greater Glasgow & Clyde regions (29% of responses), which correlates with the geographical spread of people living with HIV in Scotland. (32% NHS Lothian and 30% NHS Greater Glasgow & Clyde).¹⁶

5.2. Demographics

Age

The majority of respondents were aged between 31 and 50 (58%) and 51-64 (25%). Fewer responses were received from those 18-30 (10%) and 65 or over (5%).

National data is held on the current age group of people living with HIV who are attending clinics for monitoring/treatment. When compared to this data, the sample is fairly typical of the age range of the population of people being seen by HIV clinicians in Scotland.¹⁷

Gender

72% of respondents were male and 27% were female. One respondent identified as being transgender.

This is again representative of the population of people living with HIV in Scotland as Health Protection Scotland statistics show that of those diagnosed with HIV infection up to June 2014, 72% were male. In 2013 78% of those newly diagnosed were men and in 2012 this figure was 76%. This trend has been fairly consistent since the collection of HIV data began in Scotland. However it should be noted that no data was available for a comparison to be made with the gender breakdown of people currently diagnosed and living with HIV in Scotland.

Sexuality

The majority of survey respondents (52%) identified as gay/lesbian and all were male. 32% of respondents identified as heterosexual of which 66% (27) were women and

16 Health Protection Scotland (2014) *'HIV Infection and AIDS: Quarterly report to 30 June 2014'* www.hps.scot.nhs.uk

17 Health Protection Scotland (2014) – individual reports *'HIV reports Scotland, by Year of Report and Age at Diagnosis to 30 June 2014'* and *'Current Age Group of HIV infected persons attending for monitoring/treatment (or recently reported) as at 30 June 2014'* received on request from Health Promotion Scotland via correspondence 8th October 2014.

34% (14) men. 3% identified as bisexual and 14% of people chose not to specify their sexuality.

No data is held on a national level as to the sexuality of those living with HIV in Scotland. However we can assume the survey sample to be fairly typical of the population of people living with HIV in Scotland from data supplied around routes of transmission. In 2013, for new diagnoses where the probable route of transmission was determined, 48% of new diagnoses were among men who have sex with men.

'The majority of survey respondents identified as gay'

Ethnicity

From national data held on the ethnicity of people living with HIV in Scotland who are attending clinics for monitoring and treatment, 75% describe themselves as a category of 'White' and 20% as a category of 'Black'.¹⁸

The survey had a slightly higher percentage of respondents who identified as a category of 'White' in comparison to the national data of people living with HIV. 82% identified as 'White' and 16% as 'Black' with 2% of people of respondents answering 'Other' or 'Prefer not to say'.

5.3. Positive Experiences

81% of respondents reported having had, in the last two years, an excellent experience of someone who works within a health service where that person's behaviour towards the respondent's HIV status was very positive.

The top four areas of healthcare where these experiences occurred were:

- General Practice (41 examples)
- Hospital Out-Patient (35 examples)
- Sexual and Reproductive Health Services (29 examples)
- Dentistry (26 examples)

[See Appendix 2 for full results]

The top four roles held by staff cited as being involved in this positive treatment were:

- Doctor (71 examples)
- Nurse (45 examples)
- Administrator / Receptionist (32 examples)
- Allied Health Professional (31 examples)

[See Appendix 2 for full results]

18 Health Protection Scotland (2014) – individual report '*Ethnicity of HIV infected persons attending for monitoring/treatment (or recently reported) as at 30 June 2014*' received on request from Health Promotion Scotland via correspondence 8TH October 2014.

82 responses were provided for what was excellent about the treatment/ service. The key themes of these responses were that people felt they had received excellent service if:

- they were treated with
 - respect
 - no different manner than before they were diagnosed or to other HIV negative patients
 - care and compassion
 - no judgement
 - professionalism
 - equality
- their HIV status was not brought up unnecessarily
- their HIV status was not treated as a big deal
- the health professional sought to improve their knowledge about HIV
- the health professional sought to put the patient at ease
- the health professional listened
- confidentiality was reassured and maintained.

The following are quotes from the responses that highlight the key themes.

"I was treated with respect as a 'normal' person no different to anyone else"

"Care, concern and compassion were displayed"

"Being non-judgemental towards me"

"To me this means that HIV is never brought up unnecessarily"

"I was treated as an individual person and not for my HIV status"

"They took the time to seek knowledge of HIV"

"I haven't disclosed my status to many people & it was a big thing having to let them know but it wasn't an issue ...I always felt comfortable and was shown respect"

"Treated in a friendly non-condescending manner"

"He put me at ease"

"Highly professional on all counts"

"Calm, realistic and providing positive support and reassurance"

“Professional knowledge and working practice of HIV”

“They...reassured me that it would be confidential and not discussed within the workplace by staff.”

Additionally the findings were interrogated to observe whether certain groups of people had differing experiences from the general population. Compared to the 81% of all respondents, a marginally lower 78% of gay and bisexual people reported positive experiences and a significantly higher 95% of all black/other ethnic group respondents agreed.

5.4. Negative Experiences

32% of respondents reported experiencing, within the last 2 years, poor treatment, service or stigma from someone who works within a health service which they believe to be because they are HIV positive.

The top 4 areas of healthcare where this stigma was experienced were:

- General Practice (15 examples)
- Hospital Out-Patient (11 examples)
- Hospital In-Patient (10 examples)
- Hospital A&E / Sexual & Reproductive Health Services (both 7 examples each)

(See “Appendix 3: Negative Experiences” on page 28 for full results)

The top 4 roles held by staff who provided poor treatment, service or stigma were:

- Doctor (24 examples)
- Nurse (14 examples)
- Administration / Receptionist (8 examples)
- Allied Health Professional / Pharmacist (both 6 examples each)

(See “Appendix 3: Negative Experiences” on page 28 for full results)

The descriptions chosen by respondents for their poor treatment / service / stigma were:

- They displayed fearful / negative body language or facial expressions (18 examples)
- They had very poor knowledge of HIV (14 examples)
- They unnecessarily disclosed my HIV status to other people (11 examples)
- They wore gloves unnecessarily / wore double gloves (9 examples)
- I was only offered appointments at the end of the day (8 examples)
- I was refused treatment (6 examples)
- I was referred to as the HIV patient (6 examples)
- They asked me how I contracted HIV (5 examples)
- Respondents also provided additional comments to highlight other examples of poor treatment, service or stigma. These included illustrations of poor knowledge of HIV and inappropriate / unprofessional comments
 - a ‘no-entry’ sign being put up on a patient’s door because, a healthcare worker informed them, they were ‘contagious’

- a doctor referred to a patient's HIV status as AIDS
- on discovering that the patient's relationship status was single, a healthcare worker commented that it will be very difficult for them to find a partner
- a patient being asked if they were gay and after responding 'yes' told 'That's how you got it then.'

Again the findings were interrogated to examine whether certain groups of people had differing experiences from the general population. Compared to 32% of all respondents, a lower 24% of gay and bisexual people reported negative experiences. However, a significantly higher 50% of all black and other ethnic group respondents reported negative experiences.

5.5. Stigma

Survey participants were asked 'How many times in the last 12 months have you experienced HIV stigma or discrimination from someone who works within a health services?' The responses were:

- 0 times – 71%
- Once – 12%
- Twice – 5%
- Three times – 7%
- Four times – 2%
- Five or more times – 3%

39% of respondents also reported that, in the last 12 months, fear of HIV stigma or discrimination has stopped them from telling someone who works within a health service that they are living with HIV.

Of this 39%, less than half (42%) reported having experienced stigma within the last year.

Of the 61% that did not report fear of stigma hindering their disclosure to a health professional, 21% had reported experiencing stigma within the last year.

5.6. Expectations of Health Professionals

To gather the views of people taking the survey on their expectations of health professionals in relation to HIV, respondents were asked if they would like to add or change anything about the following statement:

- We believe that every health professional in Scotland should
 - Know the key, up-to-date basic facts about HIV
 - Challenge HIV stigma displayed by any patient, colleague or other individual
 - Treat every patient with a long term medical condition equally, no matter what that health condition is (e.g. HIV, diabetes, high blood pressure)

28 respondents suggested amendments which included:

"Be aware of confidentiality and principles of disclosure"

Black female aged 31-50

“Be aware of local / national services that can help the patient” (e.g. voluntary sector organisations)

White gay male aged 31-50

“that care should be taken to ensure that non-HIV medication is compatible with the patient’s HIV treatment”

White female aged 65+

“Know about the effect of stigma upon people living with HIV”

White gay male aged 31-50

“Up to date training on the BIG difference between Aids & HIV”

White gay male aged 18-30

“Appreciate the historical impact of discrimination on people living with HIV and how appalling the treatment was in the past/ early days for long-term survivors”

White female aged 51-64

“Challenge is an aggressive word that, in certain circumstances, could make the HIV+ person even more uncomfortable. Perhaps the word ‘address’ would be better, and add the word ‘timely’ too?”

White gay male aged 31-50

Undertake “attitudinal training ... [which] includes not only HIV but also sexuality, age, ethnicity, belief, problem drug/alcohol use. If there is a concern re. stigma, then it might need more than informal challenge, i.e. referral re. complaints’ procedure.”

White gay male aged 51-64

6. Commentary, Conclusion and Recommendations

6.1. Commentary and Conclusion

The survey results demonstrate that the research successfully achieved its aims of:

- Quantifying the problem of HIV stigma amongst healthcare workers in Scotland through gathering statistics
- Gathering examples of both stigmatising and excellent behaviour by healthcare workers towards people living with HIV
- Exploring whether stigma is more prevalent in specific healthcare settings.

The methodology employed was largely successful in achieving a representative sample of people living with HIV geographically, and by age, gender, sexuality and ethnicity. Respondents identifying as black or from an ethnic minority were marginally under-represented when compared to the national data of people living with HIV, therefore similar future studies should consider ways of encouraging black and ethnic minority participants.

Positive Experiences

It is encouraging that so many respondents reported excellent experiences of health professionals' behaviour in relation to their HIV positive status. This is clear evidence that the behaviour of the majority of health professionals is considered by people living with HIV, to be appropriate, professional and reassuring.

It could be argued however that some of the experiences reported are not 'excellent' but rather the behaviour that every patient, regardless of their medical condition, should expect from a health professional. Studies suggest that due to HIV stigma in society and/or previous poor experiences, the expectations of how people living with HIV anticipate being treated, are low.⁷ In this case, 'normal' treatment may be viewed as excellent.

These low expectations could be attributed to what is described as 'self-stigma' – where people incorporate society's ideas about perfection and discredit themselves.¹ In the 2009 People Living with HIV Stigma Index in the UK study, respondents reported that, as a result of their HIV status, they felt ashamed (44%), blamed themselves (48%) and had low self esteem (63%). This should not take away from the positivity of 81% of people reporting good experiences.

Negative Experiences

32% of people reporting poor treatment, service or stigma is not unexpected when considered in light of the results of other UK research into healthcare stigma amongst people living with HIV.

- The 2004/5 East London project survey of people living with HIV cited that 14% of respondents had experienced discrimination from healthcare staff
- In the 'What do you need?' 2007/8 Sigma Research study, 19% of respondents reported discrimination from healthcare staff in the previous 12 months

- The People Living with HIV Stigma Index reported that 17% of respondents reported having been denied health services at least once in the previous 12 months because of their HIV status
- Most recently as part of the National AIDS Trust (NAT) Patient Information and Confidentiality Study 2013, 40% of respondents reported that they had been treated differently or badly by a healthcare worker because of their HIV status

The NAT survey did not limit its question to reports within the previous 12 months, however, similar to the question in this current study, it asked respondents to report a wider range of negative treatment by asking about behaviour or treatment that is 'different' or 'poor'. This behaviour by healthcare workers is still unacceptable but may not have been deemed by some as extreme as 'discriminatory' which may explain the difference in the results across the surveys.

It is reassuring that there was no evidence of direct homophobic behaviour by health professionals; in reality negative experiences amongst gay and bisexual respondents were below that of the general sample. However it is concerning that black or ethnic minority respondents were more likely than white respondents to report negative experiences, although it should be remembered that there were only 22 responses from black and minority ethnic people.

When interpreting the results of the survey, it could be argued that some negative interactions with healthcare staff may have been misinterpreted by survey respondents as being directly linked to their HIV status. In practice, a healthcare professional may provide a poor standard of treatment and care to all patients irrespective of HIV status. This may again be attributed to 'self-stigma' experienced by some people living with HIV, as discussed earlier in this report. This assertion could be particularly applied to the 15 negative experiences described as '[the health professional] displayed fearful / negative body language or facial expressions'. This is because a degree of interpretation is required with this response. However, even if we set aside this description of negative experiences, not all responses can be called into question. 59 other experiences were recorded and examples of poor behaviours such as 'they unnecessarily disclosed my HIV status to other people', or 'I was refused treatment' are not so open to interpretation and is clear evidence of unacceptable behaviour and practice.

If the causes of this poor treatment, service or stigma are considered, a number of issues are identified amongst healthcare staff that need to be addressed. These are:

- Poor knowledge of how HIV is transmitted
- Failure to adhere to patient confidentiality codes of practice
- Poor adherence to standard universal precautions relating to infection control
- Poor understanding about the risk of patients infected with HIV but undiagnosed^{19,20}

19 www.aidsmap.com/Primary-infection-and-sexual-transmission/page/1322881/

20 Phillips, A, Cambiano, V, Nakagawa, F, Brown, A, Lampe, F, Rodger, A, Miners, A, Elfords, J, Hart, G, Johnson, A, Lundgren, J, Delpech, V. (2013) *'Increased HIV Incidence in Men Who Have Sex with Men Despite High Levels of ART-Induced Viral Suppression: Analysis of an Extensively Documented Epidemic.'*

- Poor understanding about how an individual diagnosed as HIV positive and on successful treatment can lead to an undetectable viral load and a greatly reduced risk of passing HIV onto others^{21,22}
- Not using person-centred working practices (as promoted in the Scottish Government's '*Healthcare Quality Strategy for NHS Scotland*' (May 2010)²³)
- Low awareness that HIV is a protected characteristic under the Equality Act (2010). The Act makes it illegal to treat people living with HIV less favourably than other people or behave in a way that violates the dignity of someone living with HIV or creates an offensive environment for them.²⁴

Stigma

The results in this section highlight that the fear of stigma is more prominent than the stigma itself with 29% of people experiencing stigma in the last year but 39% fearing it to the point of not disclosing their status to a healthcare professional. This statement is further supported by 58% of people fearing stigma but not actually experiencing it in the last year.

Further research could be conducted to investigate the source of this stigma. Possibilities to explore would include

- negative experiences that occurred within health settings prior to the last year
- experiences of stigma outside of health settings that make people fearful of disclosure across all areas of their life
- self-stigma (discussed earlier in sections 5.3 and 5.4 of this report.)

These findings are important for evidencing the need for action to encourage people, and allow them to safely, disclose their HIV status. Disclosure is considered essential for the care, treatment and support of people living with HIV, for example being able to appropriately support psychological needs and ensure prescribed medications do not negatively interact with each other. Two African studies support this view and assert that disclosure improves physical well-being by facilitating people's ability to obtain services and manage their HIV.^{25,26}

Overview

The research results demonstrate that not all practice within the NHS and healthcare settings is the same. The service delivered is affected by an individual's personal manner, levels of knowledge related to HIV and confidentiality, and the implementation of knowledge and NHS standards of practice.

21 www.aidsmap.com/Viral-load-and-sexual-transmission-risk/page/1322782/

22 Attia, S. Egger, M. Muller, M. Zwahlen, M. Low, N. (2009) '*Sexual transmission of HIV according to viral load and antiretroviral therapy: systematic review and meta-analysis*'. AIDS

23 The Scottish Government '*The Healthcare Quality Strategy for NHS Scotland*' May 2010 www.scotland.gov.uk/Resource/Doc/311667/0098354.pdf

24 www.gov.uk/discrimination-your-rights

25 Mlambo, M., & Peltzer, K. (2011). '*HIV sero-status disclosure and sexual behavior among HIV positive patients who are ART in Mpumalanga, South Africa*'. *Journal of Human Ecology*, 35

26 Deribe, K., Wodemichael, K., Wondafrash, M., Haile, A., & Amberbir, A. (2008). '*Disclosure experience and associated factors among HIV positive men and women clinical services users in southwest Ethiopia*'. *BMC Public Health*, 8

The findings highlight that not all healthcare staff are yet adhering to the person-centred, clinically effective and safe working practices that form the Scottish Government's '*Healthcare Quality Strategy for NHS Scotland*'.

The strategy, which is a development from the 2007 '*Better Health, Better Care Action Plan*',²⁷ recognises that excellence in the delivery of healthcare services through a person-centred approach will support '*everyone in Scotland to live longer healthier lives and participate more productively both economically and socially.*'

The results of this survey suggest that person-centred working is not integrated in the practice of all healthcare staff and calls in to question the effectiveness of assessment and training and subsequent monitoring of practice. Good person-centred working should be able to support patients to feel confident and safe and work through any self-stigma.

That GP practices were identified as the healthcare environment where both the most negative and the most positive experiences occurred is interesting. It makes sense that the majority of experiences worth reporting occur in what is probably the most regularly used healthcare service for people living with HIV outside of specialist HIV care. Across Scotland for the general population, 24.2 million practice nurses and GP consultations occurred in the year 1 April 2012 – 31 March 2013 compared to 4.6 million outpatient attendances and 1.6million inpatient / day case discharges for the same period.^{28,29}

This information has prompted Waverley Care to focus the development of the resources challenging stigma amongst healthcare professionals on GP practices.

Excellent insights, statistics and quotes have also been provided by this research for Waverley Care to use in the production of resources to challenge and inspire healthcare professionals to provide excellent care.

6.2. Recommendations

For healthcare professionals

- Improved knowledge of how HIV is transmitted
- Reminders about patient confidentiality rules
- Reminders of standard universal precautions relating to infection control
- Improved knowledge about the risk of patients infected with HIV but undiagnosed
- Improved knowledge about how an individual being diagnosed as HIV positive and on successful treatment can lead to an undetectable viral load and a greatly reduced risk of passing HIV onto others
- Improved knowledge about, and practice of, person-centred working practices
- Improved knowledge of the Equality Act (2010) and that HIV is a protected characteristic

27 The Scottish Government '*Better Health, Better Care Action Plan*' www.scotland.gov.uk/publications/2007/12/11103453/0

28 ISD Scotland GP Consultations / Practice Team Information Statistics www.isdscotland.org/Health-Topics/General-Practice/GP-Consultations/

29 ISD Scotland GP Consultations Annual in-patient, day case and outpatient activity – Summary for Scotland and NHS Boards of treatment; financial years 2004/05 to 2013/14 www.isdscotland.org/Health-Topics/Hospital-Care/Outpatient-Activity/

- Improved knowledge of the damage stigmatising behaviour can have on an individual and society.

For people living with HIV

- Work and resources designed to reduce and challenge self-stigma amongst people living with HIV should be developed with particular focus on empowering people living with HIV for interactions with health professionals and raising their expectations.

General

- Consider ways of encouraging more individuals from black and ethnic minority communities to participate in future research projects.

Appendix 1

Survey of people living with HIV

Improving the healthcare experiences of people living with HIV in Scotland

We know that people living with HIV in Scotland have different experiences of healthcare staff in relation to their HIV status.

We want to work towards a Scotland where all interactions in health settings for people living with HIV are good ones. In order to help this to happen we are gathering details of your experiences with healthcare staff that don't work in HIV specific settings.

We will use the information you give us in this survey to produce resources which will **inform, challenge and inspire health professionals**. You can choose if you want to give us your name or to remain anonymous. All information will be treated confidentially and it is not expected that you name any specific individuals or locations.

We want to create a healthcare environment where you don't need to worry about disclosing that you are HIV positive, and when you do disclose, that you are always treated with respect.

Survey closes Friday 15th August 2014.

You can complete this survey online at www.waverleycare.org/survey.

This is work funded by the Scottish Government and ethically approved by The University of Edinburgh.

Section A – About You

1. Which NHS board area do you live in?

- | | | | |
|--|--|--|--|
| <input type="checkbox"/> NHS Ayrshire & Arran | <input type="checkbox"/> NHS Forth Valley | <input type="checkbox"/> NHS Lanarkshire | <input type="checkbox"/> NHS Tayside |
| <input type="checkbox"/> NHS Borders | <input type="checkbox"/> NHS Grampian | <input type="checkbox"/> NHS Lothian | <input type="checkbox"/> NHS Western Isles |
| <input type="checkbox"/> NHS Dumfries & Galloway | <input type="checkbox"/> NHS Greater Glasgow & Clyde | <input type="checkbox"/> NHS Orkney | <input type="checkbox"/> Prefer not to say |
| <input type="checkbox"/> NHS Fife | <input type="checkbox"/> NHS Highland | <input type="checkbox"/> NHS Shetland | |

2. How old are you?*

- | | | |
|--------------------------------|-------------------------------------|--|
| <input type="checkbox"/> 18–30 | <input type="checkbox"/> 51–64 | <input type="checkbox"/> Prefer not to say |
| <input type="checkbox"/> 31–50 | <input type="checkbox"/> 65 or over | |

*You must be 18 or over to complete this survey

3. What is your gender?

- | | |
|--------------------------------------|--|
| <input type="checkbox"/> Female | <input type="checkbox"/> Other |
| <input type="checkbox"/> Male | <input type="checkbox"/> Prefer not to say |
| <input type="checkbox"/> Transgender | |

4. What is your sexuality?

- | | |
|---------------------------------------|--|
| <input type="checkbox"/> Bisexual | <input type="checkbox"/> Other |
| <input type="checkbox"/> Gay/Lesbian | <input type="checkbox"/> Prefer not to say |
| <input type="checkbox"/> Heterosexual | |

5. How would you describe your ethnicity?

A White

- Scottish
- English
- Welsh
- Northern Irish
- British
- Irish
- Gypsy/Traveller
- Polish
- Other White Group

B Asian, Asian Scottish or Asian British

- Pakistani, Pakistani Scottish or Pakistani British
- Indian, Indian Scottish or Indian British
- Bangladeshi, Bangladeshi Scottish or Bangladeshi British
- Chinese, Chinese Scottish or Chinese British

C Black, Black Scottish or Black British

- African, African Scottish or African British
- Caribbean, Caribbean Scottish or Caribbean British
- Black, Black Scottish or Black British

D Other Ethnic Group

- Arab
- Other

E Mixed

- Any Mixed / Multi-Ethnic Group

F

- Prefer not to say

Section B – About Your Experiences

PLEASE ANSWER THESE QUESTIONS ONLY ABOUT SERVICES AND STAFF THAT ARE **NOT** HIV SPECIFIC.**

6. In the last 2 years, have you experienced poor treatment, service or stigma from someone who works within a health service, that you believe was because you are HIV Positive?

- Yes
- No (If 'No' go to question 10)

7. If yes, in which of the following areas of healthcare did you have the poor experience?

(you can select more than one)

- Addiction Services
 - Dentist
 - General Practice
 - Hospital: Out-Patient
 - Hospital: In-Patient
 - Hospital: A&E
 - Maternity Services
 - Mental Health Services
 - Pharmacy
 - Sexual & Reproductive Health Services
 - Other Healthcare Setting
Please specify:
-

8. And from which members of staff? (you can select more than one)

- Administration / Receptionist
 - Allied Health Professional
(e.g. physiotherapist, dietician, podiatrist, counsellor etc.)
Please specify:
 - Dentist / Dental Assistant
 - Doctor
 - Emergency Services Staff
(e.g. paramedic, ambulance technician etc.)
 - Nurse
 - Pharmacist
 - Support Services
(e.g. porter, cleaner, security etc.)
 - Other
Please specify:
-

PLEASE ANSWER THESE QUESTIONS ONLY ABOUT SERVICES AND STAFF THAT ARE **NOT** HIV SPECIFIC.**

9. How would you describe the poor treatment / service / stigma?

(you can select more than one)

- | | |
|--|---|
| <input type="checkbox"/> They asked me how I contracted HIV | <input type="checkbox"/> They unnecessarily disclosed my HIV status to other people |
| <input type="checkbox"/> They wore gloves unnecessarily / wore double gloves | <input type="checkbox"/> They had very poor knowledge of HIV |
| <input type="checkbox"/> I was refused treatment | <input type="checkbox"/> I was only offered appointments at the end of the day |
| <input type="checkbox"/> They displayed fearful / negative body language or facial expressions | <input type="checkbox"/> I was referred to as 'The HIV patient' |

Other
Please describe:

Please feel free to provide more detail of this experience:

.....

.....

.....

.....

.....

Need more space? Go to page 6.

10. We believe that every health professional in Scotland should:

- Know the key, up-to-date basic facts about HIV
- Challenge HIV stigma displayed by any patient, colleague or other individual
- Treat every patient with a long term medical condition equally, no matter what that health condition is (e.g. HIV, diabetes, high blood pressure)

Is there anything you would like to add or change about these statements?

- No**
- Yes**

Please provide details:

.....

.....

.....

.....

.....

Need more space? Go to page 6.

PLEASE ANSWER THESE QUESTIONS ONLY ABOUT SERVICES AND STAFF THAT ARE **NOT** HIV SPECIFIC.**

11. In the last 2 years, have you had an excellent experience of someone who works within a health service where their behaviour towards your HIV status was very positive?

- Yes** **No** (If 'No' go to question 15)

12. In which of the following areas of healthcare did this positive experience occur?

(you can select more than one)

- | | | |
|---|--|---|
| <input type="checkbox"/> Addiction Services | <input type="checkbox"/> Hospital: A&E | <input type="checkbox"/> Sexual & Reproductive Health Services |
| <input type="checkbox"/> Dentist | <input type="checkbox"/> Maternity Services | <input type="checkbox"/> Other Healthcare Setting |
| <input type="checkbox"/> General Practice | <input type="checkbox"/> Mental Health Services | Please specify: |
| <input type="checkbox"/> Hospital: Out-Patient | <input type="checkbox"/> Pharmacy | <input type="text"/> |
| <input type="checkbox"/> Hospital: In-Patient | | |

13. And involving which members of staff? (you can select more than one)

- | | | |
|---|--|---|
| <input type="checkbox"/> Administration / Receptionist | <input type="checkbox"/> Dentist / Dental Assistant | <input type="checkbox"/> Pharmacist |
| <input type="checkbox"/> Allied Health Professional
(e.g. physiotherapist, dietician, podiatrist, counsellor etc.)
Please specify:
<input type="text"/> | <input type="checkbox"/> Doctor | <input type="checkbox"/> Support Services
(e.g. porter, cleaner, security etc.) |
| | <input type="checkbox"/> Emergency Services Staff
(e.g. paramedic / ambulance technician etc.) | <input type="checkbox"/> Other
Please specify:
<input type="text"/> |
| | <input type="checkbox"/> Nurse | |

14. What was excellent about the treatment/service?

Please provide details:

.....

.....

.....

.....

Need more space? Go to page 6.

15. In the last 12 months how many times, if ever, have you experienced HIV stigma or discrimination from someone who works anywhere within a health service?

- | | | |
|-----------------------------------|-----------------------------------|---|
| <input type="checkbox"/> 0 | <input type="checkbox"/> 2 | <input type="checkbox"/> 4 |
| <input type="checkbox"/> 1 | <input type="checkbox"/> 3 | <input type="checkbox"/> 5 or more |

16. In the last 12 months has the fear of HIV stigma or discrimination stopped you from telling someone who works within a health service that you are living with HIV?

- Yes** **No**

17. If you have any other comments you would like to make about the issues raised in this survey – please provide them here:

.....

.....

.....

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.....

.....

Thank you for taking part in our survey

****Please note that by excluding experiences from HIV specific services we are not suggesting that excellent or poor behaviour doesn't exist within these areas. Instead we have chosen to focus this work on non-HIV specific staff to be targeted in our efforts to improve behaviour.**

Appendix 2: Positive Experiences

Area of Healthcare	Number of positive examples	Percentage of positive examples
General Practice	41	21%
Hospital Out-Patient	35	18%
Sexual & Reproductive Health Services	29	15%
Dentistry	26	13%
Pharmacy	16	8%
Hospital – A&E	15	8%
Hospital – In-Patient*	14	7%
Other Healthcare Setting	9	5%
Mental Health Services	7	4%
Maternity Services	3	2%
Addiction Services	3	2%

*Other Healthcare Setting Examples:

HIV specialist clinic – 3 responses
 3rd sector agency – 1 response
 Opticians – 1 response
 Counselling – 1 response
 Community treatment centre – 1 response
 Occupational health – 1 response
 Not specified – 1 response

Member of Staff	Number of positive examples	Percentage of positive examples
Doctor	71	29%
Nurse	45	19%
Administration / Receptionist	32	13%
Allied Health Professional (e.g. physiotherapist, dietician, podiatrist, counsellor etc.)	31	13%
Dental / Dental Assistant	29	12%
Pharmacist	16	7%
Other*	4	2%
Emergency Services Staff (e.g. paramedic, ambulance technician etc)	10	4%
Support Services (e.g. porter, cleaner security etc.)	3	1%

*Other Examples:

Not specified – 2 responses
 Addiction Worker – 1 response
 Support Worker – 1 response

Appendix 3: Negative Experiences

Area of Healthcare	Number of negative examples	Percentage of negative examples
General Practice	15	24%
Hospital Out-Patient	11	18%
Hospital – In-Patient	10	16%
Hospital A&E	7	11%
Sexual & Reproductive Health Services	7	11%
Dentist	4	6%
Pharmacy	3	5%
Other Healthcare Setting*	2	3%
Mental Health Services	2	3%
Maternity Services	1	2%
Addiction Services	0	0%

*Other Healthcare Setting Examples

Podiatrists – 1 response

Optician – 1 response

Member of Staff	Number of negative examples	Percentage of negative examples
Doctor	24	39%
Nurse	14	26%
Administration / Receptionist	8	13%
Allied Health Professional (e.g. physiotherapist, dietician, podiatrist, counsellor etc.)	6	10%
Pharmacist	6	10%
Other*	2	3%
Support Services (e.g. porter, cleaner, security etc.)	1	2%
Emergency Services Staff (e.g. paramedic, ambulance technician etc)	0	0%

*Other Examples:

Midwife – 1 response

Health advisor – 1 response