HIV-related Stigma in Healthcare Settings in Ireland:

Findings from a Collaborative Joint Stakeholder Study

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CONTENTS

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LIST OF ACRONYMS

DOH =   **Department of Health**

FTC =   **Fast Track Cities**

GUM =   **Genitourinary medicine**

HCW =   **Healthcare worker**

HEI =   **Higher Education Institution**

HIQA =   **Health Information and Quality Authority**

HSE =   **Health Service Executive**

ICGP =   **Irish College of General Practitioners**

IDA =   **Irish Dental Association**

IDHA =   **Irish Dental Hygienist's Association**

IDS =   **Infectious Disease Society**

IMO =   **Irish Medical Council**

IMNO =   **Irish Nurses and Midwives Organisation**

MSM =   **Men who have sex with men**

PEP =   **Post-exposure prophylaxis**

PLHIV =   **People living with HIV**

PrEP =   **Pre-exposure prophylaxis**

SHCPP =   **Sexual Health and Crisis Pregnancy Programme**

Executive Summary

Background and context

It has long been acknowledged that HIV-related stigma creates barriers across all levels of the care continuum including accessing testing, treatment and engagement in care. Stigma in healthcare settings in particular can impact negatively on the well-being of people living with HIV, and is implicated in a range of health-avoidance behaviours that can lead to adverse health outcomes.

In 2019, with support from the government of Ireland, the cities of Galway, Cork, Limerick and Dublin signed up to the Fast-Track Cities Initiative. By signing the Paris Declaration, cities commit to accelerating and scaling up the local HIV responses to attain the UNAIDS 95-95-95 targets for 2025: 95% of People living with HIV (PLHIV) know their status, 95% of people who know their status are on treatment and 95% of people on treatment have an undetectable viral load. The Paris Declaration also explicitly underscores the importance of addressing stigma as part of this effort, asserting that 'we will develop and promote services that are innovative, safe, accessible, equitable and free from stigma and discrimination' (UNAIDS, 2014, p. 3).

Although 27% of PLHIV in Ireland have reported experiencing stigma in healthcare settings (HIV Ireland, 2017), stigma in healthcare settings has not been measured previously. This research aimed to address this gap in the evidence base so that potential areas for intervention could be identified.

Aims and objectives

The objectives of the research were:
1) To measure HIV-related stigma in healthcare settings among i) healthcare workers and ii) people living with HIV;
2) To gather rich qualitative data on HIV-related stigma from people living with HIV and other stakeholders;
3) To work collaboratively with people living with HIV and other stakeholders, including healthcare workers, to make policy and practice recommendations to address stigma in healthcare settings.

Methods

The research adopted a collaborative joint-stakeholder approach, with people living with HIV and healthcare workers embedded within the research process. Two national surveys aimed at healthcare workers and people living with HIV were conducted. Questionnaire items were adapted for the Irish context with input from a stakeholder advisory panel. Interviews were subsequently carried out with people living with HIV, health workers, HIV support service providers, and a policy-maker. Preliminary findings were presented at a stakeholder roundtable in order to collaboratively generate recommendations.

Key findings

Two-hundred and ninety-eight' (n=298) healthcare workers and eighty-nine (n=89) people living with HIV participated in the surveys. Sixteen people participated in the interviews and a further fifteen participated in the roundtable.

Key findings from the surveys include:
- **40% of healthcare workers say they would worry at least a little about drawing blood from a person living with HIV**
- **25% of healthcare workers say they have observed a colleague talking badly about a person living with HIV at least once in the past 12 months**
- **21% of healthcare workers report using special measures that they would not use with other patients**

- **80% of health care workers have not received training in stigma and discrimination**
- **44% of people living with HIV report being asked how they got HIV by a healthcare worker**
- **24% of people living with HIV report having been told to come back later, made to wait or put last in a queue**
- **20% report having been denied service in the past 12 months**
- **54% report having avoided healthcare for worry about how they will be treated by healthcare workers.**

Key findings from the interviews suggest that fear of occupational HIV-transmission may be compounded by a lack of training, knowledge gaps about advances in HIV treatment, and confusion about post-exposure prophylaxis. Improving knowledge of 'U=U' was highlighted as a key priority. Barriers identified to uptake of training included existing biases, and a perceived lack of support from management and senior staff. Participants identified a need for policy and practice guidelines to provide greater clarity for healthcare workers.

Recommendations to respond to the issues identified were generated via consultation with stakeholders. Seventeen actions were recommended across the domains of: Training and education; Policy/practice guideline development; Public awareness; and Research.[1]

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[1] A full list of recommendations is located on pages 40-42.

KEY **FINDINGS**

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21% of healthcare workers report using special measures that they would not use with other patients

80% of healthcare workers have not received training in stigma and discrimination

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25% of healthcare workers say they have observed a colleague talking badly about a person living with HIV at least once in the past 12 months

44% of people living with HIV report being asked how they got HIV by a healthcare worker

54% of people living with HIV report having avoided healthcare for worry about how they will be treated by healthcare workers

24% of people living with HIV report having been told to come back later, made to wait or put last in a queue

20% of people living with HIV report having been denied service in the past 12 months

Section 1: Introduction

It is widely acknowledged that stigma in healthcare settings adversely impacts on the health and well-being of people living with HIV (Feyissa et al., 2019). Such adverse impacts include reduced adherence to antiretroviral (ARV) medication, which can affect viral load and physical health outcomes (Katz et al., 2013; Martinez et al., 2012). People who experience stigma may also delay care or avoid attending certain facilities (Kinsler et al., 2007). In addition to leading to worse health outcomes on an individual level, stigma creates barriers to accessing testing, treatment and care and thus has implications for prevention of HIV more broadly (Gesesew et al., 2017). For this reason, HIV-related stigma is recognised as a social and structural determinant of health, as well as a human rights and public health issue of global concern (Greenwood et al., 2022; Nyblade et al., 2021).

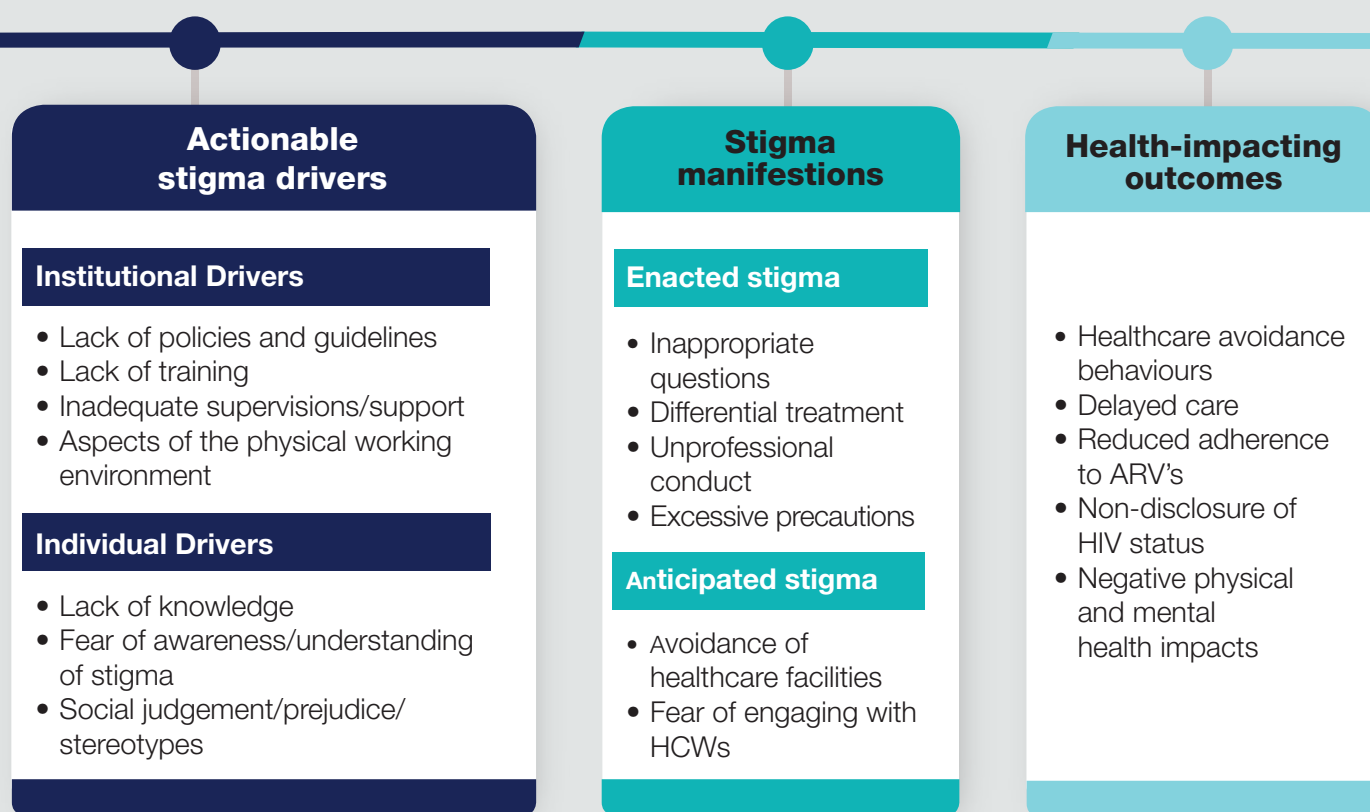## How is stigma in healthcare settings conceptualised?

Stigma may be defined as a social process that leads to the differentiation and devaluation of an individual or group of individuals that can lead to negative outcomes or diminished life chances. HIV-related stigma is understood to encompass a variety of interactions and experiences at the individual and interpersonal, or *micro-level*; the organisational, environmental or *meso-level*; and the broader structural or *macro-level* (Stangl et al., 2019a). This multi-level perspective is called a socio-ecological approach and it emphasises the multiple, intersecting and over-lapping influences on an individual's life, health and well-being.

Different factors that contribute to stigma in healthcare settings may be identified. These are termed 'drivers' and have been defined as 'factors considered to produce or cause stigma' (Nyblade, 2019, p.2). In healthcare settings these can include 'negative attitudes, fear, beliefs, lack of awareness about both the condition itself and stigma, inability to clinically manage the condition, and institutionalized procedures or practices' (p. 2). Other structural factors implicated in the stigma process in healthcare settings include policies (or lack thereof), laws, and social or cultural norms.

The term 'stigma manifestations' is used also to describe types of stigma that an individual might experience – anticipated stigma, enacted stigma, internalised stigma and structural stigma (Stangl et al., 2013). HIV-related stigma can also often overlap with other stigmas (Friedland et al., 2020; Relf et al., 2019a; Stangl et al., 2019b; Stangl et al., 2013). This is sometimes called intersectional (Relf et al., 2021), or compound stigma (Sengupta et al., 2011), and it describes the additional stigma that can be experienced by individuals belonging to marginalised populations (including, but not limited to, sex workers, LGBT+, racial and ethnic minorities and injecting drug users) by merit of their membership of that population.

Drawing on the socio-ecological approach, Jain and colleagues (2012) provide a useful framework for addressing and measuring stigma and discrimination in healthcare facilities, drawing on their review of the evidence (see figure 1 below). The framework identifies actionable drivers of stigma at both the individual and institutional levels and their relationship with stigma outcomes and health impacts. The drivers at the individual level include: lack of knowledge, awareness and understanding of stigma; social judgement, prejudice and stereotypes; and fear of infection. At the institutional level, drivers include: lack of policies and guidelines; inadequate trainings; characteristics of the physical working environment; and inadequate supervision and support.

Actionable stigma drivers

Institutional Drivers

- Lack of policies and guidelines
- Lack of training
- Inadequate supervisions/support
- Aspects of the physical working environment

Individual Drivers

- Lack of knowledge
- Fear of awareness/understanding of stigma
- Social judgement/prejudice/ stereotypes

Stigma manifestions

Enacted stigma

- Inappropriate questions
- Differential treatment
- Unprofessional conduct
- Excessive precautions

Anticipated stigma

- Avoidance of healthcare facilities
- Fear of engaging with HCWs

Health-impacting outcomes

- Healthcare avoidance behaviours
- Delayed care
- Reduced adherence to ARV's
- Non-disclosure of HIV status
- Negative physical and mental health impacts

Figure 1: Framework for understanding HIV-related stigma in healthcare settings (adapted from Jain et al., 2012)

Experiences of HIV-related stigma in healthcare settings may range from outright denial of care, reduced quality of service or altered conditions of service, use of stigmatising language or inappropriate questions, and stigmatising behaviours, such as the use of excessive infection prevention measures. Although 27% of PLHIV in Ireland have reported experiencing stigma in healthcare settings (HIV Ireland, 2017), and some of the challenges faced have been qualitatively documented (Vaughan et al., 2020), HIV-related stigma in Irish healthcare settings has not been measured previously. This study sought to address this gap by capturing the perspectives and experiences of i) healthcare workers and ii) people living with HIV in order to identify potential areas for intervention.

Aims and objectives

The overall aim of the research was to identify the needs and priorities of people living with HIV and health and social care practitioners in addressing HIV-related stigma in healthcare settings in Ireland. The objectives of the research were:

1) To measure HIV-related stigma in healthcare settings among i) healthcare workers and ii) people living with HIV;
2) To gather rich qualitative data on HIV-related stigma from people living with HIV and other stakeholders;
3) To work collaboratively with people living with HIV and other stakeholders, including healthcare workers, to make policy and practice recommendations to address stigma in healthcare settings.

This research report sets the findings of the study. Section 2 below outlines the methods used in this study. Sections 3, 4 and 5 give an overview of the survey and interview findings. Section 6 provides a brief summary discussion of findings and outlines recommendations.

Section 2: Methods

Introduction
This section of the report gives details of the methods used in carrying out this research. The overall project structure and approach is described first, outlining in particular the role of the stakeholder panel. Described next is the development of the questionnaires as well as recruitment and data collection and data analysis methods. Following this there is a brief description of the sampling, recruitment, and data collection procedures for the qualitative part of the study.

Project approach and structure

The project ran from January to November 2022 and was structured in several phases as outlined in figure 2 below. These involved 1) a review of the evidence on measuring HIV-related stigma in healthcare settings; 2) data collection using quantitative and qualitative methods; 3) stakeholder consultation and feedback. Ethical approval for all aspects of the project was obtained from the University of Galway Research Ethics Committee prior to commencing recruitment of participants, including the stakeholder panel.

The research adopted a collaborative approach, with people living with HIV and healthcare workers embedded within the research process. A stakeholder panel consisting of five people living with HIV and four health and social care workers was recruited to advise and provide input on questions included in the surveys and qualitative interview topic schedules, to give feedback on findings, and to advise on how to present findings. Over the course of the project three meetings were held with the stakeholder panel online via Zoom; panellists were invited to give their input in group discussions and using Padlet, an online collaborative tool used for sharing ideas in real-time.
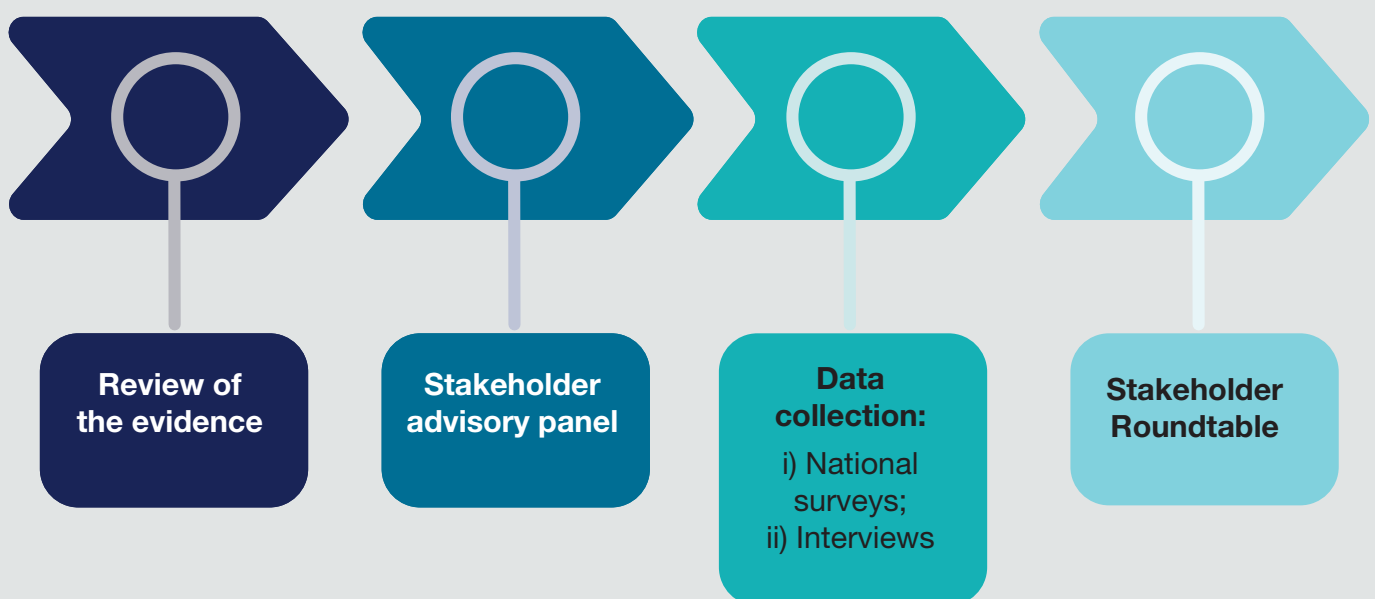

| Review of the evidence | Stakeholder advisory panel | Data collection: i) National surveys; ii) Interviews | Stakeholder Roundtable |

Figure 2: Stages of project

A stakeholder roundtable, involving 15 people including people living with HIV, researchers or academics, medical students and health professionals, and staff from HIV service providers/civil society organisations was held towards the end of the project to provide further feedback on the findings and to work collaboratively to generate recommendations from the research undertaken.

Development of questionnaires to measure HIV-related stigma in healthcare settings

Guidance from UNAIDS on monitoring and assessing country HIV and AIDS responses recommends including indicators and measures that capture stigma and discrimination experienced by people living with HIV and by key populations (i.e. sex workers, gay men, transgender people and people who use drugs) in healthcare settings. The Global AIDS Monitoring (GAM) recommendations draw on indicators developed, trialled and validated in three countries by the People Living with HIV Stigma Index (Friedland et al., 2020), among other sources (Jain & Nyblade, 2012; Nyblade et al., 2013; Nyblade et al., 2009; Stangl et al., 2013; UNAIDS, 2017). Key measures of HIV-related stigma and discrimination experiences in healthcare settings include denial of care; advice not to have sex; being the subject of gossip or negative talk; verbal abuse; physical abuse; avoidance of physical contact; and sharing of HIV status without consent. There are strong recommendations to assess the extent of avoidance of healthcare facilities and/or engaging in care due to anticipation of stigma. Measuring avoidance of healthcare by people living with HIV who have not yet started or have discontinued treatment is encouraged in order to capture HIV-related health outcomes and behaviours and identify priority areas for intervention. It is also recommended that experiences of stigma in disparate healthcare settings are identified, with separate measures capturing experiences of stigma in HIV-specific clinics and general healthcare services (UNAIDS, 2022; see also: Srithanaviboonchai et al., 2017).

The Health Facilities Questionnaire was identified as the only standardised tool for measuring HIV-related stigma among healthcare workers (Nyblade et al., 2013). This survey instrument was developed following a multi-stage process, which included a review of the evidence and a collaborative content development workshop involving multiple stakeholders, including people living with HIV. The tool contains 18 core questions that capture manifestations of stigma and specific and actionable drivers of HIV-related stigma in healthcare settings, including: fear of contracting HIV in the workplace, attitudes towards PLHIV and key populations, awareness of or observed stigma and discrimination, and aspects of the health facility environment, including policy. The questionnaire also captures demographic data on profession, gender, age, length of service in healthcare and experience of working in HIV specialist care. The tool was trialled and validated in six countries initially and has since been adapted, and employed in both higher prevalence (Ikeda et al., 2019; Pudpong et al., 2014; Srithanaviboonchai, et al., 2017) and lower prevalence (Stringer et al., 2016) contexts. It should be noted that the indicators contained in the tool have been endorsed and recommended by the UNAIDS indicator registry to track the HIV epidemic, and responses to it, as part of standardised global AIDS monitoring measures.[2]

Two separate questionnaires were thus drawn up using the Health Facilities Questionnaire for the healthcare worker survey and drawing on the Global AIDS monitoring recommendations and the UNAIDS indicator registry for the people living with HIV survey. All questionnaire items were presented to the stakeholder panel for advice on appropriate language, inclusion and exclusion of items and overall acceptability. On the advice of the panel, several adaptations were made to make them more appropriate for the Irish context. For example, changes were made to the way in which

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gender and sex was asked in the HCW survey. The panel also advised on the addition of a question to the HCW survey regarding knowledge of U=U[3] and a question to the PLHIV survey on whether the respondent had been asked by a healthcare worker how they acquired HIV.

National surveys: Recruitment, data collection and data analysis

Once finalised, the surveys were administered via Qualtrics, an online questionnaire platform. Findings were analysed using SPSS27™. Data collection ran for 9 weeks from the end of May through to the end of July. The healthcare worker survey was open to anyone working in any capacity in a healthcare environment, while the second survey was open to any person living in Ireland with HIV. A variety of methods were used to promote the study and recruit a convenience sample of participants, including:

- Advertisements through hospital staff apps, newsletters, ezines and other hospital staff fora
- Email invitations and advertising via professional organisations, trade unions (e.g. Irish Nurses and Midwifes Organisation (INMO), Irish Dental Hygienists Association, Infectious Disease Society)
- Phone invitations to General Practitioners/primary care staff
- Social media campaign (Twitter, LinkedIn, Instagram)
- Promotion via national media (RTE news; RTE Brainstorm) and sector-specific publications (i.e. Hospital Professionals News)
- WhatsApp messages through professional networks
- Using extant researcher networks within university schools of medicine
- Dissemination through HIV support organisations, including HIV Ireland; Sexual Health West; Cork Sexual Health Centre; Gender, Orientation, Sexual Health, HIV (GOSHH); and AIDS care education and training (ACET).
- Dissemination via support groups (e.g. Positive Now).

Qualitative interviews: Sampling, recruitment, data collection

For the qualitative data collection phase, a sampling matrix was generated to help ensure a plurality of perspectives were collected, and included people living with HIV, healthcare workers, service providers and a policy-maker. A combination of purposive, convenience and snowball sampling was carried out, with recruitment occurring via email invitations, and public advertisements on social media channels. Women and migrants living with HIV were especially encouraged to participate, as these groups are frequently overlooked in HIV research. Efforts were also made to include both HIV specialists and non-specialists in the healthcare workers cohort.

Distinct interview schedules were developed for each group of participants. Development of interview schedules was a collaborative process, with input from the stakeholder panel as outlined above. Questions centred on experiences/perceptions/observation of stigma in healthcare settings; knowledge/training/policy gaps or needs; and barriers to implementing stigma reduction measures.

Interviews of between 30 and 60 minutes were carried out with 16 participants via Microsoft Teams or Zoom and recorded and transcribed. Transcripts were uploaded to NVivo™ software for qualitative content analysis.

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[3] U=U stands for undetectable equals untransmittable and refers to the fact, underpinned by a robust evidence base, that people living with HIV who are on effective antiretroviral treatment cannot pass the virus on.

Section 3: Findings from survey of healthcare workers

Introduction

Two-hundred and ninety-eight (298) complete and valid responses were recorded and analysed from the healthcare worker survey. Participants were predominantly female (79%). At 33%, nurses and midwives were the main health professional represented, followed by doctors (24%), dental professionals (11%), and management/administration/professional services and other non-clinical (9%). Just over half the sample were over the age of 40 and just over half had more than ten years working in their profession. The majority (71%) of the sample reported no experience working in HIV-specific care.

Table 1: Demographic characteristics of participants in healthcare worker survey

Demographic Characteristic	Response	N	%
Age	<20 years old	2	1
	21-30 years old	67	23
	31-40 years old	68	23
	41-50 years old	91	30
	51-60 years old	53	18
	>60 years old	17	6
Sex/Gender	Female	234	79
	Male	63	21
Professional role	Nurse	98	33
	Doctor	70	24
	Dental professionals	32	11
	Allied health professionals	26	8
	Pharmacists and pharmacy technicians	12	4
	Psychology and mental health professionals	3	1
	Social workers and social care workers	19	7
	Management, administration, professionals services, and other non-clinical	30	9
	Medical scientist/Surveillance scientist	8	3
Length of time in medical service	<5 years	51	17
	5-10 years	65	22
	10-20 years	71	24
	20-30 years	74	25
	>30 years	36	12
Ever worked in a clinic/department that specialised in HIV care	**Yes**	87	29
	No	210	71

In the sub-sections that follow, the overall findings of the healthcare worker survey are organised into institutional and individual drivers of stigma. It should be noted that respondents were permitted to not answer questions if they so wished, thus the overall number of respondents varies from indicator to indicator. Raw numbers have been provided alongside the percentages for transparency.

Institutional stigma drivers

This section presents the findings in respect of institutional stigma drivers. Specific actionable drivers of stigma that were measured included training received, knowledge of institutional practices and policies and observed stigma.

Training

Three-quarters of respondents had received training in infection control and universal precautions, which broadly aligns with the number of respondents working in front-facing clinical roles. A similar proportion of respondents reported receiving training in patients' informed consent and, privacy and confidentiality. Fewer reported that they had received training in stigma and discrimination towards specific populations (29%), while a fifth received training in HIV stigma and discrimination.

Table 2: Responses to questions on training received by HCWs		
Received training in the following:	**N**	**%**
HIV stigma and discrimination	60	20
Infection control and universal precautions	224	75
Patients informed consent, privacy and confidentiality	217	73
Stigma and discrimination towards specific populations	87	29

Policies, practices, and environment

Respondents were asked questions about policies and practices in their healthcare facilities. These questions were designed to capture actionable institutional drivers of stigma including unethical practices (i.e. testing without informed consent), workplace discrimination policies, and knowledge of policies, practices and protocols to prevent work-place transmission of HIV. Notable gaps in knowledge or awareness of institutional policies were apparent. A quarter of respondents were unaware if it was acceptable to test for HIV without consent; almost a fifth were unaware if they would get into trouble for discriminating against a patient living with HIV; over half were unaware if their facility had written guidelines to protect people living with HIV from discrimination; and just under a fifth were unaware if their facility had protocols and procedures to protect them from workplace transmission of HIV.

Table 3: Responses to questions on institutional policies and practices			
Policy/Practice	**Response**	**N**	**%**
In my facility it is not acceptable to test a patient for HIV without their consent	Yes	191	65
	No	29	10
	Don't know	75	25
I will get into trouble at work if I discriminate against patients living with HIV	Yes	228	77
	No	11	4
	Don't know	57	19
I have access to adequate supplies in my health facility to reduce my risk of becoming infected with HIV	Yes	232	78
	No	5	2
	Don't know	24	8
	Not applicable	297	12
My health facility has written guidelines to protect patients living with HIV from discrimination	Yes	60	20
	No	69	23
	Don't know	168	57
There are standardised procedures/protocols in my health facility to reduce my risk of becoming infected with HIV	Yes	218	73
	No	12	4
	Don't know	52	18
	Not applicable	16	5
There are procedures/protocols in my health facility for needlestick injuries and/or other exposure incidents	Yes	276	93
	No	5	2
	Don't know	7	2
	Not applicable	10	3

Observed stigma

Respondents were asked questions to capture observed stigma. These indicators are designed to give insight into the institutional environment, and the culture and acceptability of stigma. It should be noted that this question was asked only of the respondents who have seen patients living with HIV in their health facility in the previous 12 months and thus was answered by a smaller proportion of the overall sample (n=177-179). The majority of respondents reported never having seen a colleague unwilling to care for or providing poorer quality of care to people living with or thought to be living with HIV (87% and 84% respectively), however a quarter of respondents reported having observed a colleague talking badly about people living with or thought to be living with HIV on at least one occasion.

Table 4: Responses to questions on observed stigma

Observed stigma			
In the past 12 months how often have you observed the following:	**Response**	**N**	**%**
Healthcare workers unwilling to care for a patient living with or thought to be living with HIV	Never	155	87
	Once or twice	20	11
	Several times	3	2
	Most of the time	0	0
Healthcare workers providing poorer quality of care to patient living with or thought to be living with HIV, relative to another patient	Never	150	84
	Once or twice	25	14
	Several times	4	2
	Most of the time	0	0
Healthcare workers talking badly about people living with HIV or thought to be living with HIV	Never	133	75
	Once or twice	36	20
	Several times	7	4
	Most of the time	1	1

OBSERVED STIGMA:
% of HCWs who experienced the following at least once

30
25
20
15
10
5
0

13%

16%

25%

Healthcare workers unwilling to care for a patient living with or thought to be living with HIV

Healthcare workers providing poorer quality of care to patient living with or thought to be living with HIV, relative to another patient

Healthcare workers talking badly about people living with HIV or thought to be living with HIV
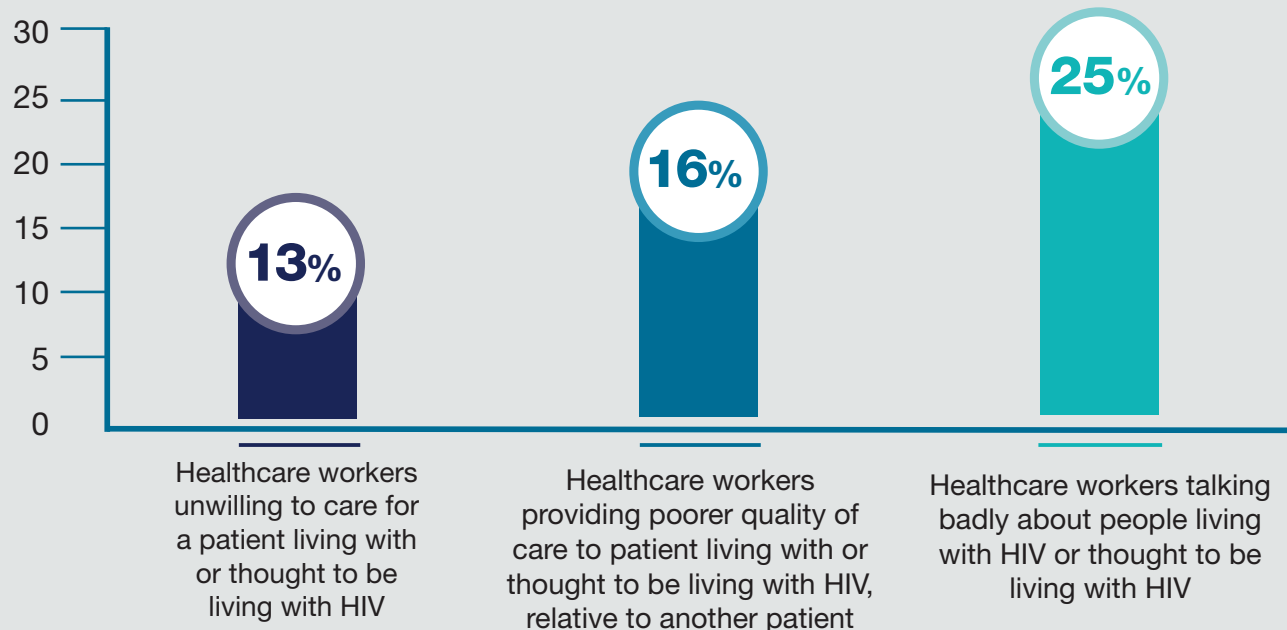
Figure 3: Observed stigma

Individual stigma drivers

Actionable individual drivers of stigma include knowledge of HIV transmission, fear of HIV transmission, lack of awareness or understanding of stigma, and social judgement, prejudice, or stereotypes about people living with and/or affected by HIV. This section outlines the findings in respect of the indicators in the survey aimed at capturing these domains.

Fear of HIV transmission

Respondents were asked questions regarding their level of worry performing certain activities/actions when caring for patients with HIV, with Likert-style response options ranging from 'Not worried' to 'Very worried' and a not-applicable option for those not in front-facing clinical roles. The majority of respondents indicated they would not be worried carrying out casual contact activities such as touching an item of clothing belonging to a person living with HIV (87%) or taking the temperature of a person living with HIV (80%). However 29% indicated they would be at least a little worried about dressing the wounds of a patient with HIV, and 40% would be at least a little worried about drawing blood from a person living with HIV.

Table 5: Responses to questions on worry about acquiring HIV through occupational activities

How worried would you be about getting HIV if you did the following?			
Practice	**Response**	**N**	**%**
Touched the clothing of a patient with HIV	Not worried	260	87
	A little worried	14	5
	Worried	2	0.7
	Very worried	1	0.3
	Not applicable	21	7
Dressed the wounds of a patient living with HIV	Not worried	149	50
	A little worried	62	21
	Worried	13	4
	Very worried	11	4
	Not applicable	63	21
Drew blood from a patient living with HIV	Not worried	110	37
	A little worried	82	28
	Worried	20	7
	Very worried	15	5
	Not applicable	70	23
Took the temperature of a patient living with HIV	Not worried	239	80
	A little worried	5	2
	Worried	1	0.5
	Very worried	1	0.5
	Not applicable	52	17

FEAR OF INFECTION:
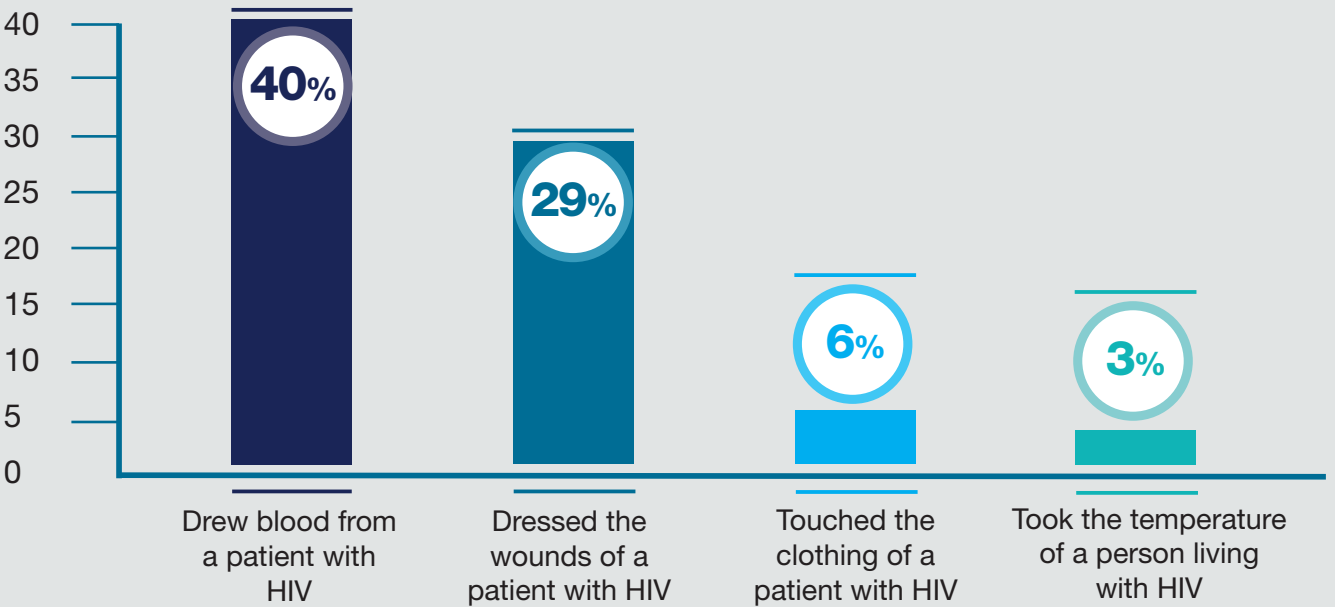**% of HCWs who would worry at least a little about the following activities**

Figure 4: Fear of infection

Knowledge of U=U and vertical (mother-to-child) transmission

Questions were posed to assess beliefs about HIV-positive women having children and their knowledge or understanding of U=U. U=U stands for 'undetectable equals untransmittable'. This means that people living with HIV who have an undetectable viral load cannot transmit the virus to others. This includes vertical transmission; thus women living with HIV who are on treatment cannot transmit the virus to their children. The majority of respondents agreed with both statements, however a gap in knowledge of U=U was apparent, with 17% indicating they did not know if people with an undetectable viral load could transmit the virus. A small proportion (10%) of respondents indicated they did not know if women with HIV should be allowed to have babies.

Table 6: Responses to questions on knowledge of U=U and beliefs about HIV positive women having children

Understanding of vertical transmission and U=U			
	Response	**N**	**%**
Women living with HIV should be allowed have babies if they wish	Agree	261	88
	Disagree	6	2
	Don't know	31	10
People living with HIV who are on effective treatment and have an undetectable viral load cannot transmit the virus	Agree	228	77
	Disagree	19	6
	Don't know	51	17

Stigma practices: Measures taken by HCW when caring for people living with HIV

Respondents were asked questions about the types of measures they take when providing care to patients living with HIV. These questions are aimed at capturing HCW knowledge/fear of transmission and excessive infection prevention practices that may enact stigma. The vast majority of respondents indicated they did not avoid physical contact (81%) or wear double gloves (73%). Thirty-one percent said they wear gloves during all aspects of the patient's care, while just over a fifth said they use special measures that they do not use with other patients. Respondents who indicated they use special measures they do not use with others were asked to provide examples in free-text responses. Some of these are provided in table 8 overleaf.

Table 7: Responses to questions on measures taken when providing care or services to patients living with HIV

Do you typically use any of the following measures when providing care or services for a patient living with HIV?	Response	N	%
Avoid physical contact	Yes	10	3
	No	240	81
	Not applicable	46	16
Wear double gloves	Yes	38	13
	No	215	73
	Not applicable	42	14
Wear gloves during all aspects of the patient's care	Yes	92	31
	No	152	51
	Not applicable	52	18
Special measures you do not use with other patients	Yes	61	21
	No	192	65
	Not applicable	43	14

Table 8: Free-text responses on extra measures used by HCWs with patients living with HIV

Extra measures used by HCWs with patients living with HIV	Professional role
"Double glove taking bloods"	Nurse or Midwife
"End of day appointment"	Dental Professional
"Eye wear for blood draw"	Nurse or Midwife
"Needle resistant gloves"	Doctor
"Double wipe down"	Dental Professional
"Would have used gloves when giving the flu vaccine when that would not have been standard"	Pharmacy Professional
"They use mouthwash at beginning and end of treatment if not taking PrEP [sic]"	Dental professional
"Avoid placing nasal bridles if the situation arose"	Allied health professional
"Would schedule patient with HIV at the end of the working day to ensure optimum clean down after treatment"	Dental Professional

Secondary and perceived stigma

Respondents were asked questions to capture their experiences of secondary and perceived stigma. These indicators can give insight into respondents' perceptions and worries about working with, and being associated with, people who live with HIV. The majority of respondents indicated they were not worried about secondary stigma from family, friends and colleagues as a result of working with patients who are HIV positive. Just over a quarter however believed that colleagues in their facility would be at least somewhat hesitant to work with a co-worker living with HIV, regardless of their duties.

Table 9: Responses to questions on secondary and perceived stigma

Secondary and perceived stigma			
	Response	**N**	**%**
How hesitant would healthcare workers in your facility be to work with a co-worker living with HIV, regardless of their duties?	Not hesitant	156	52
	Somewhat hesitant	70	24
	Very hesitant	7	2
	Don't know	65	22
How worried are you about colleagues avoiding you because of your work caring for patients living with HIV?	Not worried	283	98
	A little worried	3	1
	Worried	2	0.7
	Very worried	1	0.3
How worried are you about friends and family avoiding you because you care for patients living with HIV?	Not worried	281	97
	A little worried	6	2
	Worried	2	0.7
	Very worried	2	0.7
How worried are you about people talking badly about you because you care for patients living with HIV?	Not worried	272	94
	A little worried	8	3
	Worried	5	1.7
	Very worried	3	1

Attitudes and opinions about people living with HIV

Respondents were asked questions about their attitudes, opinions and beliefs about people living with HIV. These questions were aimed at capturing information about the actionable stigma drivers of social judgement, prejudice and stereotypes.

The overwhelming majority of respondents indicated they disagreed that: PLHIV do not care if they infect others (97%); PLHIV should feel ashamed of themselves (98%); PLHIV have had many sexual partners (94%); PLHIV become HIV-positive as a result of irresponsible behaviours (89%); and that HIV is a punishment for bad behaviour (99%).

Table 10: Responses to questions on opinions of PLHIV

Opinions about PLHIV: Do you agree or disagree with the following statements:			
	Response	**N**	**%**
Most people with HIV do not care if they infect other people	Agree	10	3
	Disagree	285	97
People living with HIV should feel ashamed of themselves	Agree	5	2
	Disagree	293	98
Most people living with HIV have had many sexual partners	Agree	19	6
	Disagree	276	94
People get infected with HIV because they engage in irresponsible behaviours	Agree	34	11
	Disagree	264	89
HIV is a punishment for bad behaviour	Agree	4	1
	Disagree	292	99

Attitudes towards key population groups

Respondents were asked questions to assess their willingness to treat four key affected population groups (people who inject drugs, men who have sex with men, sex workers and migrants) in order to capture their views of and attitudes towards these population sub-groups. The overwhelming majority of respondents disagreed with statements that if they had a choice they would choose not to provide services to MSM, sex workers and migrants. However, thirteen-percent of respondents indicated they would not provide services to people who inject drugs if they had a choice. Respondents who replied in the affirmative to this statement were asked why, and invited to reply in a free-text box. The majority of those who responded cited 'difficult' behaviour as the reason they would prefer not to provide services to this sub-group.

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Table 11: Responses to questions on willingness to care for key populations

Please tell us if you agree or disagree with the following statements:	Response	N	%
If I had a choice I would prefer not to provide services to people who inject drugs	Agree	38	13
	Disagree	260	87
If I had a choice I would prefer not to provide services to men who have sex with men	Agree	5	2
	Disagree	290	98
If I had a choice I would prefer not to provide services to sex workers	Agree	5	2
	Disagree	293	98
If I had a choice I would prefer not to provide services to migrants	Agree	4	1
	Disagree	293	99

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Section 4: Findings from the survey of people living with HIV

Introduction
Eighty-nine (89) complete and valid responses were recorded and analysed from people living with HIV. Of these, the majority were male (77%); over the age of 40 (70%); and identified as MSM (68%). More than half were in full-time employment (55%) and the overwhelming majority reported being on treatment (98%) and having an undetectable viral load (95%).

The findings reported here are for the overall sample, and are presented with the proviso that, given the small sample size, they may not be representative of the entire population. As with the other survey, respondents could choose to skip questions if they wished, therefore total numbers may vary slightly. Percentages given are valid for the number of respondents that answered the questions only, thus actual numbers are provided also for clarification.

Table 12: Demographic characteristics of participants in PLHIV survey			
Demographic Characteristic	**Response**	**N**	**%**
Age	<20	1	1
	21-30	6	7
	31-40	20	22
	41-50	32	36
	51-60	21	24
	>60	9	10
Sex/Gender	Female	15	17
	Male	68	77
	Non-binary	1	1
	Prefer not to say	4	5
Sexuality	Bisexual	11	12
	Gay or lesbian	56	64
	Straight	19	22
	Other	1	1
	Prefer not to say	1	1
Employment status	Full-time employed	54	61
	Part-time employed	12	13
	Unemployed	4	5
	Disability support	4	5
	Other	14	16
Member of key population	MSM	61	68
	Migrant	3	3
	Ethnic Minority	2	2
	People who take drugs	5	6
Taking antiretrovirals (ARVs)	Yes	84	98
Undetectable viral load	Yes	83	95

Experiences of stigma in HIV care

Respondents were asked questions about their experiences in the past year of stigma in HIV-specific healthcare settings (i.e. HIV, ID or GUM clinics). Overall the proportion of respondents reporting experiencing stigma in these settings was very low. Nevertheless, twelve percent reported that other people had been told about their HIV status without their consent and seventeen percent reported that they had been told not to have sex because of their HIV status.

Table 13: Responses to questions on stigma in HIV-specific healthcare settings in the past 12 months

In the past 12 months when seeking *HIV-specific healthcare*, have you experienced any of the following from any health facility staff[4] because of your HIV status:	Response	N	%
Denial of health services	Yes	5	6
	No	73	87
	Don't know	6	7
Verbal or physical abuse	Yes	4	5
	No	78	93
	Don't know	2	2
Telling other people about your status without your consent	Yes	10	12
	No	65	76
	Don't know	10	12
Been told not to have sex because of your status	Yes	14	17
	No	70	82
	Don't know	1	1
Been pressured or forced to start antiretroviral treatment	Yes	4	5
	No	81	94
	Don't know	1	1
Been pressured or forced to change your ARV treatment	Yes	4	5
	No	79	93
	Don't know	2	2

[4] The question specified that this could include non-clinical staff such as, for example, receptionists or administrators.

Experiences of stigma in other healthcare settings

Respondents were asked about their experiences of stigma during the past year in healthcare settings outside of their HIV clinics. In comparison with the findings from HIV-specific clinics, a higher proportion of respondents reported negative experiences including: 44% being asked by a HCW how they got HIV; over a quarter reporting a HCW using infection control measures beyond the usual; just under a quarter reporting being told to come back later, put last in a queue or being made to wait until the end of the day; seventeen percent reporting denial of dental services; and a fifth reporting denial of services.

Table 14: Responses to questions on experiences of stigma in other healthcare settings in the last 12 months

In the last 12 months, when seeking healthcare outside of where you receive your regular HIV care, have you ever experienced any of the following treatment by health facility staff because of your HIV status:

	Response	N	%
Been asked by the healthcare worker how you got HIV	Yes	37	44
	No	46	55
	I don't know	1	1
Healthcare worker used infection control in excess of the usual	Yes	22	26
	No	56	67
	I don't know	6	7
Been told to come back later, put last in a queue or made to wait longer than other patients	Yes	20	24
	No	61	74
	I don't know	2	2
Denial of dental services	Yes	14	17
	No	66	82
	I don't know	1	1
Denied services	Yes	17	20
	No	65	78
	I don't know	2	2

Stigma-related health avoidance behaviours

In order to capture the impacts of stigma on health behaviours, respondents were asked a series of questions on health avoidance behaviours as a result of stigma. Of those that responded to these questions: Two-fifths reported avoiding care as a result of concern that the HCW would disclose their status to others; over half avoided care because of worry about how they would be treated by HCWs; over half avoided care because of worry that someone they know might see them attending a HIV service; 57% reported that shame about their status put them off attending a service; and approximately a half avoided seeking care because they felt anxious or depressed about their status.

Table 15: Responses to questions on healthcare avoidance

Have you ever avoided seeking healthcare for any of the following reasons:	Response	N	%
Worrying that the healthcare worker will disclose my status to other people	Yes	34	40
	No	50	59
	Don't know	1	1
Worrying about how I will be treated by healthcare workers	Yes	45	54
	No	38	46
	Don't know	-	-
Worrying that someone I know will see me attending the HIV service	Yes	45	53
	No	38	45
	Don't know	2	2
Feeling ashamed about my status	Yes	59	57
	No	35	41
	Don't know	2	2
Feeling depressed or anxious about my status	Yes	40	49.4
	No	40	49.4
	I don't know	1	1.2

Free text responses

Respondents were asked at the end of the survey if they had any further comments. Below is a selection of comments that were provided. Some have been edited to protect identities and confidentiality.

"The stigma that occurs in these settings is very subtle. The questions asked here are certainly fundamental, but I think there is a great deal that is conveyed in glances between healthcare workers, in certain comments ("are you having a lot of sex") and so on."

"Admin [in ID clinic] is remote and haughty, even fearful of patients, I observe."

"Stigma around working and medicals for joining a new company have been the most difficult part of my diagnosis."

"My GP has consistently been unaware and lacking in any in-depth knowledge around HIV and any information or help I have ever received has come from attending the HIV clinic I go to."

"I really hope this survey can enlighten people to the stigma that surrounds HIV, I have health workers almost afraid to touch me or stand close to me once they know of my status."

"Women living with HIV being denied to do IVF (in-vitro fertilisation) in Ireland. Even though they are U=U. This is unfair."

"The staff at my local clinic are superb. Despite my shame they have always treated me with utmost respect."

"Nurses should not be judgemental and opinionated at STI Check clinics, more access to STI clinics and every healthcare staff should be told difference between HIV and AIDS. Also general public should be made aware of U=U."

Section 5: Qualitative interview findings

Introduction

Interviews were conducted with sixteen people between August and September 2022, including six people living with HIV; five health workers, including an infectious disease doctor, a clinical nurse specialist (CNS), two nurses and an emergency medical technician (EMT); four HIV support service providers; and one policy-maker. The interviews had two key aims: i) to gather rich data on participants' knowledge, experiences and perceptions of stigma and its drivers; and ii) to explore participants' views on measures to address the problem of HIV-related stigma in healthcare settings.

In this section, the findings from these interviews are presented, focusing on experiences of stigma in healthcare settings, drivers of stigma, and measures to address stigma. Impacts of stigma on people living with HIV are noted, and participants views on potential barriers to training are also explored. Beyond gender and cohort, demographic details of participants are withheld to protect anonymity. Similarly, quotes have been edited for length, but also to omit any potentially identifying information.

Experiences of stigma in healthcare settings

Experiences of stigma in healthcare settings reported by participants varied. A service provider, who provides support, advice and advocacy services to people who have experienced stigma in healthcare settings described the types of cases they see in their service:

> The majority of situations would be somebody who had been refused a service. And the next most common thing would be somebody who had been treated differently within a service … left at the end of a queue for the day for example, going in for a colonoscopy, surgery or something ... The third would be around issues … people feel about being asked how they acquired HIV – that would come up a lot. *(Female, Service Provider)*

One man described an encounter with a physiotherapist in a hospital in 2019 where she claimed she would be unable to attend to him. The man was able to self-advocate, complained and the situation was resolved, however the encounter may be emblematic of the types of knowledge gaps that lead to healthcare workers denying service:

> The physiotherapist said, 'I can't have you in the gym in the hospital because then it will have to be cleaned … so it would be a whole afternoon of no one else being able to use it because you've been in.' *(Male, living with HIV)*

Other experiences described by participants included negative reactions once the patient's status had been disclosed:

> I said 'I'm HIV positive' and she just basically jumped out of her seat.
> *(Female, living with HIV)*

So, you'll hear people describe, you know, the junior doctor stood back quickly. The nurse got up to double glove. There were furtive glances between the two staff members.
(Female, Service Provider)

Several participants alluded to having experienced, engaged in, or observed staff members double-gloving:

The discrimination that I would have felt in other healthcare environments as an inpatient in different hospitals actually; double gloving when there was no need. I challenged her on this and the nurse said that was her own opinion, she was entitled to do that.
(Male, living with HIV)

You do get people that will say 'Oh that patient has HIV, like make sure to wear two pairs of gloves.' I've heard that being said.
(Male, Doctor)

Accounts of staff using other excessive or unnecessary infection control measures were also relayed. One man living with HIV described an experience around 2018/2019 as a patient in hospital for a procedure that would not typically require healthcare workers to be in full protective equipment. He was placed in an isolation unit, despite this procedure usually being carried out in a unit with other patients:

They came in in what I keep referring to as full body armour – they were in full gowns and masks and hair-nets and everything. And I said, 'Why are you dressed like that? 'Well, because you know your condition.' … Oh so because I'm HIV positive, you think you need to be in all of this?' 'Yes.'
(Male, living with HIV)

Participants who were living with HIV described the different ways such stigma experiences impacted them. The man quoted above who had to push back against staff wearing full PPE to treat him said the whole experience made him feel 'dirty'; the woman whose nurse jumped from her seat when she disclosed her status said she felt 'embarrassed' and 'annoyed.' Another man living with HIV said he no longer disclosed his status to dentists as it didn't feel 'safe.' One of the service providers summed up her perception of the impact of stigma experiences in healthcare settings as triggering, traumatic and causing doubt and confusion for clients:

We've seen people who we would have known for years, right, very, very reconciled with their HIV status. Just getting on with life. You know, we don't see them in counselling. We don't see them needing advocacy services. But something will happen and they will say, 'You know, it brought me back to when I was first diagnosed' … It makes people doubt other information that they're getting and causes a lot of confusion because they look to the healthcare people as being the experts. *(Female, Service Provider)*

Participants living with HIV were not without agency and several described how they had challenged stigmatising behaviours by healthcare workers, for example explaining that double gloving wasn't necessary, demanding an explanation for certain behaviours/actions, and making complaints to management. It was recognised, however, that patients are vulnerable and disclosure of one's status can be difficult, thus pushing back and self-advocating can be extremely difficult for some people:

> There is kind of mixed emotions really because you feel helpless. You're there and you need help. You can't—you're not in a place to say' I'm going home.' You're in the bed because you need help. *(Female, living with HIV)*

Stigma drivers

In general, there was a perception that attitudes had improved towards people living with HIV. However, several healthcare workers speculated that social and cultural attitudes to sex may play a role in the stigma generally surrounding HIV, and that healthcare workers were not immune to such biases:

> And maybe this goes back around to our Catholic upbringing and sex, which we don't talk about. S. E. X. [spells out the word sex]. I think that might be part of it as well. *(Female, Clinical Nurse Specialist)*

Participants offered other reasons for what they thought underpinned stigma in healthcare settings. Fear of infection was identified as one major driver of stigmatising behaviours among healthcare staff:

> I don't think that there's maybe the same level of blame, but I think that there's still the 'I'd rather stay away from them just in case.' There's still a fear aspect of getting it. *(Female, Nurse)*

Fear of infection seemed to stem from a lack of knowledge about transmission risks and a lack of contact with or experience of working with patients with HIV. In this quote, a nurse describes the reaction of her colleagues when a patient living with HIV arrived at their facility:

> This was the first time, it seemed, that there had ever been an HIV patient needing a biopsy in this facility. And everyone was like 'What do we need to do? How do we do this? What precautions do we need to take? Should we gown up? Do we double glove for the procedure? How do we send the samples down to the lab? Do we need to let the lab know?' *(Female, Nurse)*

This was compounded by a lack of knowledge around the advances in medical treatments. A nurse described how she had not heard of U=U until she was asked about it during the research interview, admitting that she didn't 'have a great grasp on how the modern treatments and stuff are working.' While she surmised that this lack of knowledge may be accounted for by a twenty year gap between her training and her current practice, even those who had qualified more recently had knowledge gaps. According to one doctor:

I've had kind of a teaching role at different points as well with medical students and often, when you mentioned topics such as U=U, people are amazed and they might have gone through four, five years of medicine and never heard of it. *(Doctor, Male)*

Pointing to potential challenges in translating knowledge about HIV undetectability to healthcare workers, the same doctor said he had observed scepticism among healthcare workers, even infectious disease colleagues, some years ago when the U=U message started to be promoted. When asked about what might be driving this, he acknowledged the difficulties in assimilating new information and changing practices:

I think it's difficult for there to be a kind of a paradigm shift in anything; there'll often be resistance met. *(Male, Doctor)*

Such challenges may be especially acute where healthcare worker anxieties about occupational transmission may be mediating stigmatising behaviours. Such anxieties should not be dismissed as irrational; however perceptions of risk, particularly around needlestick injuries, may be exaggerated, especially in the context of viral undetectability. For example, a nurse working in a vaccination centre described how staff administering vaccines generally do not wear gloves except for with patients that disclose HIV status. When informed about U=U she was asked if this knowledge would change her practice at all:

Personally, I would still wear gloves, and I would encourage the staff to as well.
(Female, Nurse)

Potentially compounding healthcare worker anxieties about occupational transmission further, there was an apparent lack of knowledge and confusion around post-exposure prophylaxis (PEP). PEP is available to healthcare workers where there has been known exposure to HIV and where there may be a risk of occupational transmission, however there appeared to be misunderstandings around the implications of taking PEP:

You fill up the needlestick form … and get the bloods done, and out of work for 6 months. Because you're on PEP, you're not able to work for quite some time … You can't share the bathroom. You're six months separated from spouses. You can't engage in sexual activity.
(Male, Emergency Medical Technician)

A clinical nurse specialist, with specific expertise in PEP was clear that there was absolutely no requirement or rationale for a six month hiatus from work if a course of PEP was required. She also clarified that confirmatory tests are usually performed within four months. In her view, there was a lot of confusion about PEP, it was stressful for staff and that the pathways and protocols could be unclear, even among consultant doctors and managerial staff. Ultimately, this appeared to stem from a lack of awareness and education about PEP more broadly, and a lack of clear communication about PEP pathways and protocols specifically:

I think there's a gap of knowledge around awareness that PEP is available … If in doubt, you start your path and you're going to be fine. *(Female, Clinical Nurse Specialist)*

There's a lot of anxiety there that probably doesn't need to be there. I don't think there's really much formal awareness of it [PEP]. *(Male, Doctor)*

With regard to policies on HIV-stigma and discrimination specifically, none of the healthcare workers interviewed were aware that any existed in their work-places, although some mentioned broader policies around patient dignity and respect. There was a sense from service providers with extensive experience of supporting and advocating for clients who had experienced stigma in healthcare settings that the lack of a clear policies and mechanisms for addressing stigma was contributing to on-going problems with stigma in healthcare facilities:

Even within a hospital, the left hand doesn't know what the right hand is doing. So, you might have a department that works very differently from another department. A case came up in January. Then they got the complaint, and they said 'Oh no, this was just like a once-off kind of thing.' It happened again in March. Another person came in, said the exact same thing had happened. Two completely unrelated and provable incidences of this, and yet they had 'taken care' of it. *(Female, Service Provider)*

Views on measures to address stigma

All participants interviewed spoke of the need for an update to, or development of, training for healthcare workers to bridge apparent knowledge gaps and other issues. It was pointed out by one nurse that at least some education on HIV would be needed by most, if not all, healthcare workers given that people living with HIV are aging normally and in need of services beyond that of the HIV clinics and general practice:

[Healthcare staff] are going to come across HIV. It's there. People live with it now. *(Female, Clinical Nurse Specialist)*

One approach suggested by several participants living with HIV was the need to emphasise to healthcare workers the importance of professional conduct, and engaging patients with dignity, respect and empathy:

Even if it's basic level of making sure people are aware that it is a person sitting in front of you, not just a statistic … show a little bit of empathy and respect. *(Male, living with HIV)*

Improving knowledge of 'U=U' was highlighted as a key priority by many participants, who acknowledged the potential of the message to reduce stigma for people living with HIV and to reduce anxieties around occupational transmission for healthcare workers:

I've explained it myself to healthcare workers. So even that I find still a shock, that undetectability is still something that healthcare workers need to be made aware of, when it's such a powerful thing to tell somebody. *(Male, living with HIV)*

While the need for and importance of improving knowledge and practice was noted, participants identified various barriers to training uptake, including existing biases, and a perceived lack of support from management and senior staff:

I wonder if it would be that the people who don't see that there's a problem are the very ones that need to do the training. *(Female, Nurse)*

If I say [to consultant] … 'Oh hi I want to go to a HIV stigma online workshop,' I feel I'd be laughed at. *(Male, Doctor)*

Conversely, embedding training and education on HIV issues and stigma in existing programmes, having on-site, in-person workshops and having protected time were seen as facilitators to training uptake:

If it was actually in person … during an intern teaching session or … grand rounds … you have to go to anyway. Or have a morning off to go to it, or you know attend in person in a hospital, I think there would actually be good uptake there. *(Male, Doctor)*

Unless it's mandatory, unless you get your time back, then I don't know what the uptake would be. *(Female, Nurse)*

In addition to training, participants acknowledged the need for practice guidelines which would provide some welcome clarity. It was pointed out that this would need to be underpinned by supportive healthcare facility structures, with management and senior staff showing leadership:

Well, I'd love to have guidelines to go by … having something structured that we could refer to. *(Female, Nurse)*

You need to see management doing it. So it needs to come from the top down, not from the bottom up. *(Male, Emergency Medical Technician)*

The need for greater clarity and guidelines was echoed by the policy-maker who was interviewed. They pointed to potential areas for policy-level interventions in order to address stigmatising practices in the care of people living with HIV:

> There's such a gap in national standards and guidance around these things … you find that U=U message, but it's not in a clinical document that is used as part of people's training or as part of their practice guidance or SOPs[5]. So it is about continuing to develop these pieces of work, whether its information leaflets or guidance. Or like for tasks, it's a position statement. *(Female, Policy-maker)*

Finally, participants pointed to the need both in hospitals and more broadly in Irish society to raise awareness of the current realities of living with HIV, in particular to underscore messages about treatment and viral undetectability, but also the need to address anachronistic and out-dated views of the condition:

> So, I feel like the awareness campaign, the posters and everything, the materials, the resources, they should be distributed to the whole hospital. *(Female, Service Provider)*

> Let's normalise it you know … It's a medical condition, but it's really easy to control. And the majority of people do really well with this. Trying to change the perception of what HIV is. You know, it's from the eighties and nineties where people had this terrible prognosis to something that is now totally livable. *(Female, Clinical Nurse Specialist)*

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[5] SOPs = standard operating procedures.

Section 6: Summary conclusion

This study sought to address the gap in the evidence base on HIV-related stigma in health settings in Ireland by carrying out two national surveys and a series of qualitative interviews. The findings indicate that stigma in healthcare settings in Ireland remains a problem.

The findings from the survey conducted with people living with HIV indicated that 44% of respondents reported being asked by a HCW how they got HIV; 26% reported a HCW using infection control measures beyond the usual; 24% reported being told to come back later, put last in a queue or being made to wait until the end of the day; and 20% reported denial of services. The findings in respect of health avoidance behaviours are indicative of the impact of stigma experiences on individuals and lay bare how it can negatively affect health outcomes. Of particular concern is that two-fifths of respondents reported avoiding care as a result of concern that the HCW would disclose their status to others, and over half avoided care because of their worry about how they would be treated by HCWs. Although the sample size for this survey was low, the findings are also reflected in the results of the healthcare worker survey and the qualitative interviews.

Findings from the healthcare worker survey suggest that fear and anxiety about occupational transmission are major drivers of stigma in healthcare settings, with 40% reporting they would worry at least a little about drawing blood, and 29% about dressing a wound of a person living with HIV. Approximately a third said they would wear gloves during all aspects of the patient's care, however this may need to be interpreted in the context of COVID-19, where increased protective measures have become usual practice. While casual contact was not a source of worry for healthcare workers, approximately a fifth of HCWs reported using special measures that they do not use with other patients. This suggests that anxieties around occupational transmission can and do result in stigmatising practices. This aligns with the findings from the survey of people living with HIV, with over a quarter reporting a HCW using infection control measures beyond the usual, and with accounts of similar behaviours and practices observed or experienced by interviewees.

The relative prevalence of such practices, and the worries underpinning them, may seem discordant with the finding that a significant majority of respondents (77%) agreed that people living with HIV who had an undetectable viral load could not transmit the virus. As observed by one of the interviewees however, this may point to difficulties with paradigm change. Fear is a learned behaviour that can become deeply embedded in social and work practices and simply introducing new information to counter it may not be enough to change those practices. This suggests that passive awareness-raising about U=U alone may not be sufficient to create behaviour change. Thus greater efforts may be needed to legitimise the U=U message and to translate knowledge into practice.

The findings around attitudes towards people living with HIV suggest that stigma in healthcare settings is not driven by social judgement and prejudice, with the overwhelming majority disagreeing with statements that PLHIV do not care if they infect others (97%); should feel ashamed of themselves (98%); have had many sexual partners (94%); become HIV-positive as a result of irresponsible behaviours (89%); and that HIV is a punishment for bad behaviour (99%). Similarly, attitudes to key population sub-groups were largely positive. A slight outlier in the findings here was in respect of people who use drugs, with 13% of respondents indicating they would prefer not to provide services to this population compared to 2% who responded similarly in respect of MSM and sex workers, and 1% in respect of migrants. In keeping with the concept of compound stigma, this suggests that people who use drugs may experience greater levels of stigma than other people living with HIV.

It is clear that fear of HIV and lack of knowledge around transmission risks is being compounded by several institutional-level factors. The findings on observed stigma point to institutional cultures or environments where stigma may be tacitly accepted, with just over a quarter reporting that colleagues in their facility would be at least somewhat hesitant to work with a co-worker living with HIV, regardless of their duties; and a quarter reporting having observed a colleague talking badly on at least one occasion about people living with, or thought to be living with, HIV. This would appear to be corroborated by accounts from interviewees who reported observing various stigmatising behaviours from colleagues.

Likely exacerbating the issue further is a lack of institutional policies that explicitly address stigma, with only 20% of health and social care worker respondents indicating that their workplace had such guidelines. Another institutional-level gap of relevance was knowledge of protocols to reduce risk of occupational transmission of HIV, with 18% reporting they were unsure if such protocols existed. Findings from the interviews suggest that there is lack of awareness of and a considerable amount of confusion about PEP. Given that PEP is highly effective, measures to address this gap could help to reduce healthcare worker anxieties and fears about occupational transmission, which may in in turn help reduce the stigma towards people living with HIV.

Training and education may also help to address knowledge gaps and reduce healthcare worker fears about HIV. Findings from the interviews suggest that training should be incentivised, as time, management structures, and existing biases were identified as potential barriers. Given existing workloads and resourcing/capacity deficits in the healthcare system currently, it would seem unlikely that mandatory HIV or stigma training would be feasible or welcome. This suggests that in addition to training and education initiatives, explicit policies and guidelines around the non-stigmatising care of people living with HIV might have a broader reach and a potentially greater impact.

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Recommendations

A note on the development of recommendations:
The recommendations outlined here were developed in consultation and collaboration with a group of fifteen stakeholders including people living with HIV, healthcare workers, medical students, academic researchers and service providers. This consultation occurred in September 2022, as part of a stakeholder roundtable workshop, during which preliminary findings from the study were presented to the stakeholders and their views were elicited on measures to address the issues identified by the study.

Participants in the roundtable were asked to note down thoughts and suggestions and a group discussion was facilitated. Participants in this process were also facilitated to provide further feedback in writing after the event. Notes from that event were written up and synthesised, and subsequently analysed alongside the findings in order to generate recommendations.

Four domains for action were identified and recommended by participants in the roundtable. These include: Training and education; Policy/practice guideline development; Public awareness; and Research. These recommendations are presented in table 16 overleaf, along with suggestions for who could lead or be involved in these actions. In addition to recommendations, participants in the roundtable identified key issues which should be highlighted and general principles to guide development of intervention measures:

General principles

- People living with HIV should be included at all stages of the development of policies, training and research. A panel of stakeholders living with HIV should be recruited to participate in expert advisory group to the next national sexual health strategy (GIPA principle)
- Opportunities for cross-sectoral collaboration and co-ordination of efforts at national and local/regional level should be identified (e.g. Fast Track Cities; SHCPP; HSE; civil society; PLHIV; HEI researchers)
- A collaborative and multi-disciplinary approach should be adopted with initiatives, and stakeholders from allied health, occupational health, pharmacy, dentistry, general practice and private healthcare providers should be included
- Buy-in is needed from national representative organisations (e.g. IMO, INMO, ICGP, IDA, IDHA)
- Incentives will be needed to encourage uptake of training among HCWs (e.g. protected time)
- To ensure patient dignity and respect a rights-based approach should be adopted to align with existing HIQA guidance on best practice
- Key issues that need high-lighting include knowledge and awareness of U=U, and addressing the ageing profile and on-going care needs of people living with HIV.

Table 16: Study recommendations by domain

Key action area	Stakeholders
Training and education	
Development of module on sexual health and HIV for national delivery on health professional programmes across Irish HEIs as part of National Standard Curriculum (examples of similar projects include the National Standard Curriculum on MECC and Chronic Disease Prevention and Management)	Sláintecare/HSE/HEIs/SHCPP/PLHIV
Review and update of existing healthcare worker training and education programmes to integrate or 'mainstream' HIV issues	HEIs/HSE
Development of online CPD module for health and social care professionals, including managers and administrators on HSEland	HSE/HEIs/SHCPP
Funding for provision of in-person workshops and training to be provided at the local level to complement to online programmes	SHCPP/HSE/DoH/FTC
Policy and practice guidelines	
Position statement(s) needed on U=U[6]	HSE/SHCPP/IDS/Professional organisations
Development and communication of guidance on occupational PEP protocols	HSE/SHCPP/HIQA
Development of guidance on non-stigmatising care for people living with HIV	SHCPP/HIQA/PLHIV
Inclusion of measures/guidance to reduce stigma in model of care for sexual health services in next sexual health strategy; develop mechanisms for monitoring and evaluation of stigma reduction efforts	DoH/SHCPP/Sláintecare/PLHIV
Resources (e.g., factsheets, posters, leaflets) explaining and promoting 'U=U' to be developed and provided to all healthcare providers, including dentists and GPs, and other private providers	SHCPP/HSE/FTC/PLHIV/Civil Society Organisations

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[6] See for example position statement from Canadian Association of Nurses in HIV/AIDS Care: https://canac.org/wp-content/uploads/2020/06/CANAC-Position-Statement-on-UU.pdf

Key action area	Stakeholders
Public awareness	
• Public awareness campaign of U=U	HSE/SHCPP/DoH/PLHIV/ Civil society organisations
• 'Myth-busting' campaign to counter HIV anachronisms	HSE/SHCPP/DoH/PLHIV/ Civil society organisations
• Promotion of existing guidelines for media reporting on HIV	HSE/SHCPP/DoH/PLHIV
Research	
• People living with HIV to be included in development, planning and implementation of research projects	Researchers/PLHIV
• Develop, pilot and evaluate complex stigma intervention programme for healthcare facilities	SHCPP/DoH/Researchers
• Inclusion of HIV and stigma indicators on national sexual health survey for national monitoring	SHCPP/Researchers
• Qualitative research is needed to better understand healthcare workers experiences, views and beliefs on occupational blood borne virus (BBV) risks	Researchers/HSE

Strengths and limitations

This research has some limitations which should be noted. First, despite best efforts, recruitment for the surveys was challenging; thus the sample size for the healthcare worker survey is relatively modest, while the sample size for the survey of people living with HIV is small. Owing to concerns around privacy and survey length, data were not collected on certain demographic variables, for example on geographic location, religion or ethnicity. This limits the scope for performing analysis on, for example, differences between rural and urban settings or the mediating impact of religious or cultural beliefs. A strength of the study however is its use of multiple methods and various data sources, which allows for triangulation. This, to a certain, extent mitigates the negative impact of the modest sample sizes, increases validity and reliability, and allows for a fuller, more nuanced picture to be arrived at. Input from stakeholders was also a considerable strength of the study, increasing pertinence and acceptability of the study to participants and relevance to knowledge users; thus the study has significant knowledge translation potential.

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