A Scoping Study of Available HIV Data, Services and Support in the Four Fast-Track Cities of Ireland

Dublin – Cork – Galway – Limerick

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FAST-TRACK CITIES

A scoping study of available HIV data, services and supports in the four Fast-Track Cities of Ireland

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List of abbreviations

ART	Antiretroviral Therapy
CEO	Chief Executive Officer
CHO	Community Healthcare Organisation
CI	Confidence Interval
CIDR	Computerised Infectious Diseases Reporting
CNS	Clinical Nurse Specialist
ECDC	European Centre for Disease Prevention and Control
EPR	Electronic Patient Record
ESF	Enhanced Surveillance Form
FTC	Fast-Track Cities
GAM	Global AIDS Monitoring
gbMSM	Gay, bisexual and men who have sex with men
GMHS	Gay Men's Health Service
GP	General Practitioner
HCP	Healthcare Professional
HIV	Human Immunodeficiency Virus
HPSC	Health Protection Surveillance Centre
HSE	Health Service Executive
IAPAC	International Association of Providers of AIDS Care
ID	Infectious Diseases
IT	Information Technology
LCDC	Local Community Development Committee
LGBTQI	Lesbian, Gay, Bisexual, Transgender, Queer, Intersex
MSW	Medical Social Worker
N/A	Not Applicable
NGO	Non-Governmental Organisation
NI	Northern Ireland
NVRL	National Virus Reference Laboratory
PrEP	Pre-Exposure Prophylaxis
SAG	Study Advisory Group
SHP	Sexual Health Programme
SDG	Sustainable Development Goals
SJH	St James's Hospital
STI(s)	Sexually Transmitted Infection(s)
UNAIDS	Joint United Nations Programme on HIV/AIDS
WHO	World Health Organization
WP	Work Package
WTE	Whole Time Equivalent

Glossary

Chemsex	Chemsex is a specific form of drug use and involves using one or more drugs, to facilitate or to enhance sex, usually among gay, bisexual and other men who have sex with men. The three common drugs associated with chemsex are methamphetamine, mephedrone and GHB/GBL.
HIV indicator condition(s)	HIV indicator conditions are conditions or symptoms that are more common in people with underlying HIV infections than in people without a HIV infection. It is recommended, in national guidelines and by the World Health Organization, to test for HIV when HIV indicator conditions are present.
Key, vulnerable and marginalised population groups	For the purpose of this report, these populations include: gay, bisexual and other men who have sex with men, people who inject drugs, people from migrant populations, people engaged in sex work, people in prison and other closed settings, trans and gender diverse people, and homeless people.
Non-governmental organisation (NGO)	A non-profit organisation that operates independently of the government, typically one whose purpose is to address a social or political issues. NGOs are also sometimes called third sector or civil society organisations.
Treatment as prevention (TasP)	Treatment as prevention (TasP) refers to taking HIV medication to prevent the onward transmission of HIV.
U=U	Undetectable = Untransmittable, relates to the fact that people living with HIV who are antiretroviral therapy (ART) and have a supressed viral load have a zero risk of transmitting the virus to their sexual partners.

Foreword

Sexual health and wellbeing is a key priority for this Government, under the National Sexual Health Strategy (2015-2020). Key sexual health initiatives delivered and funded since 2015 include the National Condom Distribution Service (2015), the pre-exposure prophylaxis (PrEP) programme, joining the HIV Fast-Track Cities Initiative (2019), the Free Contraception Scheme, currently open to women aged 17-35 (2022), the national free home STI testing service (2022) and a wide range of sexual health related research, educational supports, information and public information campaigns.

These services are core elements of our National Sexual Health Strategy's key aims; to improve sexual health and wellbeing across the life-course, inclusive of gender, sexual orientation, culture, ethnicity, religious background and other forms of diversity, and to reduce negative outcomes, such as HIV and sexually transmitted infections or unplanned pregnancies.

The United Nations' Sustainable Development Goal (SDG) 3.3 aims to end the HIV epidemic by 2030, with SDG targets, globally, of 95-95-95 by 2030 (95% of all people living with HIV knowing their status, 95% of people who know their status on treatment, and 95% of those on treatment being virally suppressed).

In recent years we have seen the launch of major initiatives in the action against HIV in Ireland. The first of these saw Ireland joining the global Fast Track Cities Initiative, aimed at boosting HIV prevention and treatment, and reducing stigma, in 2019. The second was the launch of the HIV pre-exposure prophylaxis (PrEP) programme. This is an important programme and a critical addition to our efforts to prevent new HIV infections. In 2024, we have invested an additional €600,000 in our PrEP programme (total annual funding; €5.9m) and €720,000 in additional funding for the free home STI testing service, which includes HIV (total annual funding, €4.27m).

We are also progressing further development of the HIV Fast-Track Cities Initiative in Dublin, Cork, Limerick and Galway, in supporting people living with HIV and countering the stigma they may experience.

I would like to thank all of those involved in preparing this report, which aims to provide a baseline description of existing services, to document the current challenges and gaps, and make recommendations to inform future development of our four Fast-Track Cities. This report provides insights into the current and future needs of people living with HIV. It is helping to inform service development in the four Fast-Track Cities and their surrounding areas. The report, and Fast-Track Cities implementation, will also support Ireland meeting its international obligations with regard to the SDGs, UNAIDS and our other international commitments, by 2030.

Foreword by Minister Colm Burke TD,
Minister of State for Public Health, Wellbeing and the National Drugs Strategy

Introduction

I am delighted to introduce this report, which was undertaken and completed by the HSE Sexual Health Programme (SHP), HSE Health and Wellbeing, Access and Integration, in collaboration with IQVIA. This purpose of this study was to provide a baseline description of HIV prevention, care and support services available and identify the challenges and gaps in service provision, and to inform the development of city-level implementation plans for each of the Fast-Track Cities in Ireland.

This report contributes to the evidence-based approach to strategy implementation set out in the National Sexual Health Strategy 2015–2020, which identifies a need for robust and high-quality sexual health information to underpin policy, practice, service planning and strategic monitoring.

Within the HSE, evidence-based practice to improve population health and wellbeing is a priority and it is imperative that decisions about health care services and supports are based on current, valid and relevant research and evidence.

I would like to thank the members of the Study Advisory Group for their time and expertise; Caroline Hurley, Project Manager SHP, Rachael Metrustry, Project Officer SHP, Dr Éadaoin Butler, former Acting Research Manager SHP, Dr Nicola O'Connell, Research Manager SHP, Professor Jack Lambert, Infectious Diseases Consultant Mater Misericordiae Hospital, Stephen O'Hare, Executive Director HIV Ireland, and Dr Martin Davoren, Executive Director Sexual Health Centre Cork.

Finally, I wish to extend a sincere thank you to those who participated in the study, providing the evidence for this report. Their valuable contributions and insights have informed the recommendations arising from this work. These recommendations will be used by Ireland's four Fast-Track Cities as they develop their city implementation plans and support future service provision.

Professor Fiona Lyons
Clinical Lead/Medical Director for Sexual Health
HSE Sexual Health Programme

About the HSE Sexual Health Programme

The Health Service Executive (HSE) Sexual Health Programme (SHP) is a national policy priority programme situated within Health and Wellbeing, Access and Integration. The SHP is responsible for implementing the National Sexual Health Strategy 2015–2020[1]. The aims of the strategy are to improve sexual health and wellbeing and to reduce negative sexual health outcomes among the Irish population. The Strategy's vision is for "everyone in Ireland to experience positive sexual health and wellbeing and have access to high quality sexual health information, education, and services throughout life".

To read the Strategy, click here.

About IQVIA

IQVIA is a global healthcare data science company providing supports to health systems, healthcare providers and life sciences companies, ranging from the delivery of clinical trials through to patient support programmes and healthcare consulting projects including primary market research.

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1. The timeframe of the current strategy was extended and a new strategy is underdevelopment within the Department of Health. https://www.gov.ie/en/policy-information/8feae9-national-sexual-health-strategy/

About the authors

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Rachael holds a BSc in Biomedical Science from Technological University Dublin and an MSc in Public Health from the London School of Hygiene and Tropical Medicine. During her Master's degree, she specialised in sexual and reproductive health and completed a dissertation with MSI Reproductive Choices. She is a Project Officer in the HSE Sexual Health Programme, and predominantly works on the clinical actions of the National Sexual Health Strategy (2015-2020).

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Acknowledgements

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The authors would like to acknowledge and appreciate the expert guidance of the Study Advisory Group, and the Fast-Track City Steering Groups who provided invaluable support throughout the duration of the project.

The authors would also like to thank everyone who participated in the study.

Executive Summary

Introduction

In 2019, the four cities Dublin, Cork, Galway and Limerick, signed up to the HIV Fast-Track Cities Initiative, committing to scale up local HIV responses to help end the HIV epidemic by 2030.

In Ireland, HIV clinical care is provided in public hospital settings, and a variety of non-governmental organisations (NGOs) and community-based organisations provide dedicated support services for people living with HIV, and/or HIV prevention interventions for key populations. There are also a number of member organisations and networks for people living with HIV that advocate and provide additional supports for people living with HIV in Ireland.

As people living with HIV are living longer, the total number of people living with HIV in Ireland, who require HIV care and support services, continues to increase. In addition, there are continued new infections each year, though this number has decreased in recent years. There is also an increase in the number of individuals living with HIV coming to Ireland to study and work, or seeking international protection. This has increased the workload within HIV clinical services and increased the demand for community support services.

Until now, no assessment had been made on the availability of HIV prevention, care, and support services in Ireland, or the unmet need. This is the first HIV scoping study conducted in Ireland, to provide a baseline description of existing services, to document the current challenges and gaps, and make recommendations to inform the implementation of the Fast-Track Cities Initiative in Ireland.

The aims of this study are to describe the existing HIV prevention, care and support services available in each of the Fast-Track Cities, and through engagement with stakeholders, identify the challenges and gaps, and invite suggestions for improvement. The findings of this study will provide the evidence base for the development of local implementation plans to scale up local responses and meet the needs of people living with HIV.

Methods

This study included three work packages (WPs). WP1 consisted of qualitative interviews with Public Health personnel to gather information on the availability of local HIV surveillance data. WP2 involved five online consultation surveys with HIV stakeholders, to gather stakeholder input on the available HIV prevention, care and support services. This consultation collected both quantitative and qualitative findings from over 180 stakeholders across Ireland. WP3 involved analysing, collating and synthesising the findings from WP1 and WP2 to describe the available HIV prevention, care and support services in Ireland, the challenges, gaps and suggestions for improvement. A Study Advisory Group (SAG) provided oversight and support for the successful completion of the study and drafted a set of recommendations to inform decisions on the implementation of the Fast-Track Cities Initiative in Ireland.

Study Findings

Public Health stakeholders (n=10) representing the regional Public Health Departments and the National Health Protection Surveillance Centre (HPSC) took part in the interviews. These comprised of Public Health Specialists and Surveillance Scientists, who described the regional and national HIV surveillance processes and available data. Interviewees explained that HIV notification data is available at the county level to support HIV surveillance and monitoring for Fast-Track Cities but a number of challenges to data completeness were reported, including limited staff resources for participation in regional HIV surveillance and inefficiencies in the data collection process due to lack of electronic systems for reporting enhanced HIV data. Challenges described to the development of local HIV epidemiological profiles include lack of a database of people living with HIV in Ireland and limited staff and modelling capacity within HPSC.

HIV stakeholders (n=183) representing a wide range of service providers and service users took part in the online consultation. Service providers included HIV clinical services, community (and member) organisations and public sector authorities and departments. Seventy people living with HIV provided the perspective of service users through the online consultation. Regarding HIV clinical care, HIV patients echoed the challenges that were reported by clinical survey respondents. These challenges include insufficient staff resources and time to discuss individual care needs and support patients to better self-manage their HIV care. In addition, the need for dedicated resources within clinics and referral pathways for the management of complex HIV care and comorbidities, in particular psychology care and supports and addressing the needs of patients as they become older, were also identified as challenges.

Support services for people living with HIV are provided through NGOs/community organisations and HIV member organisations, and the challenges reported by these providers were reiterated by service users. These include limited and inequitable availability of community support services for those living with HIV, in particular peer-support programmes, counselling and mental health supports. The greatest barrier to the provision of community support services reported by NGOs and member organisations was the lack of funding.

Additional findings reported by stakeholders included challenges relating to HIV-related stigma which impact on access to HIV prevention, care and community support services. There is limited representation of people living with HIV in the development of services and on relevant working groups and this needs to be improved. All stakeholders commented on the importance of having information on the available HIV and other community support services to improve collaboration between service providers and improve referral pathways for people living with HIV.

Recommendations

Based on the findings from the study, the Study Advisory Group (SAG) developed and agreed a set of specific recommendations for the FTC Steering Groups and a set of recommendations for all relevant HIV stakeholders.

Recommendations for the FTC steering groups

It is proposed that the cities of Dublin, Cork, Galway and Limerick, take ownership of their local FTC initiatives. Each of the four cities has a FTC Steering Group which comprises representation from relevant local HIV and city stakeholders. The SHP will continue to support the initiative by remaining on the city steering groups and supporting collaboration between cities and with the Department of Health. The capacity of the FTC Steering Groups to deliver on the initiative will be dependent on the successful sourcing of funding for the management of the initiative and for the improvement of local HIV services and supports.

The following recommendations were developed to support each FTC Steering Group make evidence-based decisions on the management of the HIV FTC initiative in Ireland, and to support the development of local FTC implementation plans.

The FTC Steering Groups should:

- Develop local FTC implementation plans, in consultation with local stakeholders, for the next three years based on the findings of the study and include budget considerations within these plans.
- Ensure that people living with HIV are appropriately represented on the steering groups in the development of the FTC implementation plans and their delivery. Implementation plans should give careful consideration to barriers such as HIV-related stigma that may prevent people living with HIV from participating and that may impact on service delivery.
- Seek funding opportunities through national and regional HSE processes and through other/external funding mechanisms, as appropriate.
- Align the initiative to national strategies and collaborate to identify areas where they can work together across the cities, to leverage efficiency and avoid duplication.
- Use county geographical boundaries to define the HIV Fast-Track City boundaries, as these are the most feasible geographical boundary at present. HIV data is available at the county level and the county boundaries are more relevant to the existing public sector structures as well as the delivery of HIV prevention, care and support services.
- Determine the local governance and management structures for the implementation of the initiative in each city, in consultation with local authorities and HIV stakeholders.
- Explore the feasibility, capacity and resources required to develop city-level epidemiological profiles with the regional and national departments of Public Health.

Recommendations for HIV stakeholders

In addition to the above recommendations for the FTC Steering Groups, the following set of recommendations was agreed by the SAG to inform the FTC Steering Groups in the development of their city-level implementation plans. These recommendations should also be taken into consideration by all relevant stakeholders in their work to improve the provision of HIV care and support services, and the availability of HIV prevention interventions in Ireland.

The city steering groups will be required to review the recommendations listed below, and in collaboration with local stakeholders, agree their relevance within the local context, and prioritise them within their local FTC implementation plans.

The current epidemiological HIV context also requires consideration in the development of implementation plans and service planning, where the number of individuals living with HIV seeking care and support in Ireland has increased significantly in recent years, in part due to individuals coming to Ireland seeking international protection, to study and work, and new infections occurring in Ireland. This has increased the workload within HIV clinical services and increased the demand for community support services.

Representation of people living with HIV

- Representation of people living with HIV in relevant national and local fora needs improvement and it is likely that achieving this will require capacity building programmes or interventions to improve the capacity and confidence of people living with HIV to meaningfully participate and be able to more broadly represent the diverse community of people living with HIV.

- People living with HIV should be more involved in service design and delivery. This is heavily reliant on volunteers and consideration needs to be given to how volunteers can be better supported to improve their participation.

HIV-related stigma

- More work is required at both national and local levels to combat all aspects of HIV-related stigma among the general population and among service/healthcare providers. This includes work to remove stigma as a barrier to HIV testing or accessing services. All stakeholders should consider HIV-related stigma in all aspects of service planning and delivery, which will require collaboration between national and local stakeholders and researchers.

HIV-related funding

- Funding was identified as an issue that needs to be addressed across the HIV continuum. Funding is required for staff resources and IT infrastructure within HIV clinics and Public Health Departments, and to expand community HIV prevention interventions and support services for people living with HIV.
- The reported funding challenges and gaps for NGOs/community organisations who provide community prevention and support services should be considered. The reported challenges and gaps related to issues such as core (administration) funding costs, the funding needs of HIV member organisations, sustainability of funding for support services, and the additional costs associated with meeting the needs of diverse or marginalised communities.
- More transparent local funding mechanisms are required, both for (sexual) health and social inclusion funding, to improve access to appropriate and efficient local funding, and to enable community organisations to meet the needs of their communities.

HIV surveillance data

- Public HIV clinics, Local Departments of Public Health and HPSC require sufficient resourcing to meet national HIV surveillance requirements. This includes having appropriate IT infrastructure and sufficient staff resources to gather and analyse the regional and national HIV surveillance data.
- Locally available information, on the numbers and population groups attending HIV clinical services and on the new HIV notifications, would be useful to inform local support needs and service planning.

HIV clinical care

- There is a need to improve the provision of person-centred HIV care within clinical services, such as improving the time available to patients to discuss and manage their individual care needs and to support patients to better self-manage their HIV and overall health and wellbeing. This requires having sufficient and dedicated staff resources within HIV clinics, such as counsellors, medical social workers (MSW) and clinical nurse specialists (CNS).
- The areas of complex HIV care and the management of comorbidities require further consideration, such as the need for dedicated resources during clinics or for joint/coordinated care. This includes psychology care and supports, and addressing the needs of patients as they become older. Improved referral pathways are required within clinical services and to community supports, such as counselling and peer-support groups.
- HIV clinic infrastructure and flexibility in access to care could be improved, including consideration of the use of technology, for example the establishment of a patient portal to better access/monitor their results.

Support services for people living with HIV

- Individuals and/or marginalised groups may require additional supports to improve retention in care and maintain viral suppression. This includes community supports (more key workers and outreach services), more time/resources within HIV clinics (dedicated HIV nurses/nurse specialists, psychosocial supports, social workers) and co-administration of HIV care within community settings (addiction/prison settings).
- The availability of HIV support services through NGOs/community organisations and HIV member organisations should be improved, in particular peer-support programmes, counselling and mental health supports. This should take into consideration the local needs of marginalised or rural communities, the provision of local services and outreach and making safe spaces available for peers to meet.

Collaboration between services and stakeholders

- Improved bi-directional communication and collaboration is required between all local HIV services (HIV clinical services, NGOs, member organisations and peer-support groups) in order to enhance information and pathways on services available to people living with HIV. This includes information on social events for people living with HIV. As the FTC initiative supports multi-stakeholder engagement, it may be an ideal mechanism for information exchange and coordination between local stakeholders.
- Signposting and referral pathways should be improved, between local HIV services and existing health promotion programmes, self-management and social welfare supports, primary care and chronic disease services.

HIV testing

- Late HIV diagnoses remains a challenge and could be reduced through the expansion of HIV testing strategies. For HCPs, this includes education on HIV transmission and testing, such as indicator condition testing, to improve the offer of HIV testing in clinical settings. For individuals (and specific population groups), this includes education on HIV transmission, U=U, HIV-related stigma and the expansion of HIV testing strategies, including community HIV testing, to improve HIV testing uptake.

HIV prevention interventions

- Expansion of HIV prevention interventions should take into consideration bespoke/targeted interventions to reach specific population groups.
- Access to local HIV clinical, surveillance and ethnicity data could be improved and utilised to inform the development of targeted interventions.
- Challenges in relation to accessing specific HIV prevention interventions were highlighted throughout the report, such as improving access to PrEP services as a priority, and improving access to PEP, in particular out of hours and in locations other than emergency departments.

Communications and campaigns

- Delivery of HIV awareness and prevention campaigns should continue, including U=U messaging, to improve knowledge among the general public, HCPs and specific population groups (including in different languages). Care needs to be taken in the development of HIV messaging to not inadvertently increase HIV-related stigma. This highlights the importance of including people living with HIV in service planning and delivery.

Education and training

- Gaps in knowledge and understanding of HIV transmission were reported to impact on individuals accessing HIV prevention interventions or testing for HIV. It is important that education resources for young people include up-to-date information on HIV/STI prevention.
- Improved HIV education resources are required, as well as increased availability of training for service providers and healthcare workers. Regular HIV knowledge updates for professionals would be useful, to support the consistency of messaging to service users.

Chapter 1 Introduction

In 2021, the Sexual Health Programme (SHP), HSE Health and Wellbeing, commissioned a scoping study to provide a baseline description of existing HIV prevention, care and support services, and review the gaps in HIV service provision in each of the four Fast-Track Cities in Ireland; Dublin, Cork, Galway and Limerick. The contract was awarded to IQVIA following a tender procurement process and the study was undertaken in collaboration with SHP.

This scoping study will contribute to the evidence base for the implementation of the Fast-Track Cities Initiative in Ireland, and will inform the development of city-level implementation plans.

1.1 Fast-Track Cities Initiative

In all regions of the world, the prevalence of HIV is higher in cities and urban areas. Cities are home to large numbers of people belonging to key populations who may be more vulnerable to HIV, which include gay, bisexual and other men who have sex with men (gbMSM), people from migrant populations, people who inject drugs, trans people and people engaged in sex work. Ending the epidemic requires ensuring that resources, services, and support for preventing and treating HIV, reach the populations and places most in need.

The Fast-Track Cities Initiative is a global partnership between cities and municipalities around the world and four core partners; the International Association of Providers of AIDS Care (IAPAC), the Joint United Nations Programme on HIV/AIDS (UNAIDS), the United Nations Human Settlements Programme (UN-Habitat), and the City of Paris. The initiative's aim is to build upon, strengthen, and leverage existing HIV programmes and resources to accelerate locally coordinated, city-wide responses to help end the HIV epidemic by 2030[2].

Since the initiative was launched on World AIDS Day 2014 in Paris, over 500 cities and municipalities globally have signed the Paris Declaration on Fast-Track Cities, committing to accelerate and scale up their local HIV responses to attain the 2025 UNAIDS targets[3]:

- 95% of people living with HIV knowing their HIV status
- 95% of people who know their HIV-positive status on HIV treatment
- 95% of people living with HIV on HIV treatment with suppressed viral loads
- Zero stigma and discrimination

In 2019, at a meeting with the Department of Health and HIV Stakeholders, it was agreed for the four largest cities to join the HIV Fast-Track Cities initiative. The SHP was tasked by the Department of Health to establish the initiative in collaboration with community partners[4].

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2. United Nations Sustainable Development Goals (SDGs) https://sdgs.un.org/goals/goal3
3. UNAIDS Global AIDS Strategy 2021-2026. https://www.unaids.org/en/Global-AIDS-Strategy-2021-2026
4. https://www.gov.ie/en/press-release/f5b6ea-fast-track-cities-taoiseach-and-ministers-for-health-announce-450k-f/

On 13 June 2019, the *Paris Declaration* was signed by the Mayors of the cities Dublin, Cork, Galway and Limerick and NGO partner organisations; HIV Ireland, Sexual Health Centre Cork, Sexual Health West and GOSHH, with support from the Department of Health.

Steering groups have been established for each of the Fast-Track Cities, and comprise of representatives from NGO partner organisations, people living with HIV, adult public HIV clinical services, HSE Departments of Public Health, HSE SHP, HSE Community Healthcare Organisations (CHO) and HSE Health and Wellbeing, HSE Social Inclusion, local authorities in each of the four cities, and the Department of Health. This scoping study will inform the work of the steering groups in the development of city-level Fast-Track Cities implementation plans.

1.2 HIV epidemiology in Ireland

HIV is a notifiable disease under the Infectious Disease Regulations since 2011[5]. Since 2012, all cases of HIV are reported to HSE Public Health via the Computerised Infectious Diseases Reporting (CIDR) system. HIV surveillance forms[6] are completed by the practice or clinic where HIV is diagnosed (or the referral HIV clinic) and provided to the regional Departments of Public Health (see Appendix 3) who enter the data onto CIDR. National data is analysed and reported by the Health Protection Surveillance Centre (HPSC)[7].

To ensure meaningful analysis of the HIV epidemiology in Ireland, the HPSC present data on (a) first-time diagnoses – people diagnosed in Ireland who were not previously aware they had HIV and (b) total diagnoses – all diagnoses in Ireland including those who were already aware of their diagnosis and those whose status was unknown[8].

First-time HIV diagnoses

The rate of first-time HIV diagnoses (3.4 per 100,000 population) decreased by 16% in 2022 compared to pre-pandemic year 2019[8].

The key population group affected by HIV in Ireland remain gay, bisexual and other men who have sex with men (gbMSM), accounting for 58% of first-time diagnoses in 2022. The rate of first-time diagnoses among gbMSM in 2022 was 11% lower than the rate in 2019 and 36% lower than the peak in 2015. Eighty percent of first-time diagnoses in gbMSM in 2022 occurred in those born in either Ireland (41%) or Latin America and Caribbean (39%).

Heterosexuals accounted for 34% of first-time diagnoses in 2022 and the number of first-time diagnoses among heterosexuals is 33% lower than the peak in 2018. Over two thirds of diagnoses among heterosexual females (69%) are in those born in sub-Saharan Africa while the largest proportion of diagnoses among heterosexual males were born in Ireland (50%).

The number of first-time diagnoses among people who inject drugs remains low and accounts for <5% of new diagnoses.

Among people with a first-time HIV diagnosis, 45% were diagnosed late (CD4 count <350 cells/µl) which is similar to the proportion diagnosed late in recent years. This is of concern as it has been shown that late HIV diagnosis is associated with poorer outcomes and an increased likelihood of ongoing HIV transmission. Groups with a higher proportion presenting late in 2022 were: females; those aged 50 years and over; those born in sub-Saharan Africa; living outside HSE East; people who inject drugs; and heterosexual males.

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5. https://www.hpsc.ie/notifiablediseases/listofnotifiablediseases/
6. https://www.hpsc.ie/a-z/hivandaids/surveillancedocuments/
7. https://www.hpsc.ie/a-z/hivandaids/hivdataandreports/
8. https://www.hpsc.ie/news/newsarchive/2023newsarchive/title-23563-en.html

Total HIV diagnoses

In 2022, there was a large increase (68%) in the overall number of diagnoses, compared to pre-pandemic year 2019. This is largely attributable to an increase in diagnoses among people with a previous diagnosis outside Ireland. Among this group, 84% reported their region of birth to be Latin America and Caribbean (32%), sub-Saharan Africa (27%) or Eastern Europe (25%). While these people are unlikely to have benefited from HIV prevention programmes in Ireland, it is of vital importance that they are promptly linked to HIV care on arrival in Ireland for their own individual benefit and to prevent onward transmission. In 2022, of the 548 people who were previously diagnosed with HIV abroad, 92% were reported to have transferred their care from another country to Ireland and 88% had a supressed viral load (where viral load was known)[8].

The increase in total HIV diagnoses is largely influenced by increased migration to Ireland in 2022, compared with previous years. Travel restrictions, which were in place during the COVID-19 pandemic were lifted in 2022. In addition, in February 2022, the Russian invasion of Ukraine resulted in 67,448 Ukrainian refugees to Ireland (from February 2022 to 11 December 2022)[9]. Conflict in Ukraine has also increased movement of people from surrounding countries and 2022 saw the highest annual number of applications for International Protection in Ireland[10].

1.3 Current HIV context

As people living with HIV are living longer, the total number of people living with HIV in Ireland, who require HIV care and support services, continues to increase. In addition, there are continued new infections each year, though this number has decreased in recent years. There is also an increase in the number of individuals living with HIV coming to Ireland to study and work, or seeking international protection. This has increased the workload within HIV clinical services and increased the demand for community support services.

At the time of the study (April–July 2022), HIV clinical care was provided in nine public hospital settings, seven adult public HIV clinics which are located in Dublin, Cork, Galway and Limerick, and there is a joint paediatric HIV clinic in two hospitals in Dublin (see Appendix 1). Since then, a new HIV clinical service has commenced in Waterford.

There are a number of NGOs and community-based organisations that provide dedicated support services for people living with HIV, or HIV prevention interventions for key populations. Some of these organisations provide both HIV prevention and support services for people living with HIV. In addition, there are a number of member organisations and networks for people living with HIV that advocate and provide additional supports for people living with HIV. See Appendix 1 for further details.

People living with HIV are at the heart of the Fast-Track Cities Initiative and representation is sought for each of the city steering groups. The study endeavoured to engage and consult with as many people living with HIV as possible, to ensure their opinions and views were represented.

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[9] https://www.cso.ie/en/releasesandpublications/fp/p-aui/arrivalsfromukraineinirelandseries8/

[10] International Protection Office Statistics 2022, December statistics, http://www.ipo.gov.ie/en/ipo/pages/statistics

1.4 Study aims and objectives

Aims

- Identify the quality and completeness of HIV data available at the city and county level for each of the Fast-Track Cities to inform the city boundaries and the development of city-level HIV epidemiological profiles.
- Provide a baseline description of HIV prevention, care and support services available in each of the Fast-Track Cities.
- Identify the gaps in HIV prevention, care and support services in each of the Fast-Track Cities to inform the development of city-level implementation plans.

Objectives

1. Review the available HIV surveillance and treatment data and resources required to develop local HIV epidemiological profiles.
2. Review the provision of HIV clinical care and the availability of support services for people living with HIV.
3. Review the available community HIV prevention and support services and the existing funding structures.
4. Document the opinions of people living with HIV on the available services and supports.
5. Document the challenges and gaps with all stakeholder groups.
6. Consider HIV-related stigma and discrimination in discussion with stakeholders.
7. Describe the existing HSE and city authority structures for each of the Fast-Track Cities.

This report presents the findings from multi-stakeholder consultations of available HIV data, services and support in the four Fast-Track Cities in Ireland. It concludes with a set of recommendations to inform the development of city implementation plans.

Chapter

2

Methodology

2.1 Introduction

A mixed methods approach was used, combining quantitative and qualitative research methodologies to provide a baseline description of HIV prevention, care and support services, and to document challenges and gaps in HIV service provision in the four Fast-Track Cities in Ireland:

- **Work Package 1 (WP1)** consisted of structured interviews with the HSE Departments of Public Health and the Health Protection Surveillance Centre (HPSC).
- **Work Package 2 (WP2)** involved an online multi-stakeholder consultation using online surveys to gather insights and descriptions of HIV prevention and support services.
- **Work Package 3 (WP3)** collated and synthesised the findings from WP1 and WP2 to present the results and to inform a set of recommendations which will be used to develop implementation plans.

2.2 Project governance and ethics

A Study Advisory Group (SAG) was established by the SHP, which comprised of representatives from the SHP and the Fast-Track Cities steering groups. The role of the SAG was to support and oversee the establishment, progression and successful completion of the study. The SAG met with IQVIA during project initiation and development, providing input into the data collection instruments and, providing feedback on the draft report and findings. The list of members and the Terms of Reference for the SAG can be found in Appendix 2.

The study was submitted to the Research Ethics Committee in the Royal College of Physicians in Ireland (RCPI) and ethical approval was granted in January 2022 (reference number 166).

2.3 Study design

Within **WP1**, qualitative interviews were utilised to allow for more nuanced discussions with HSE Public Health on the available HIV data and resource requirements to develop city-level epidemiological profiles. Two structured interview schedules were developed for the HPSC and Departments of Public Health. Copies of the interview schedules are available in Appendix 3.

The interview schedule was circulated in advance, and five interviews were conducted in February 2022 between IQVIA and a nominated Surveillance Scientist and Specialist in Public Health Medicine with responsibility for HIV in the HPSC and each of the four Departments of Public Health (see Appendix 1). Consent to transcribe and analyse the interview data was sought at the beginning of the interviews.

Within **WP2**, online stakeholder surveys were used to seek the input of stakeholders on the available HIV prevention and support services. The SHP developed lists of key stakeholders and organisations that were deemed relevant to the FTC initiative, and together with IQVIA, developed five stakeholder surveys for:

- Adult public HIV clinical services
- Community organisations and NGOs who provide sexual health and HIV prevention and/or support services
- People living with HIV
- Networks and member organisations for people living with HIV
- HSE and city authorities

2.4 Development of online consultation surveys and participant recruitment

IQVIA and the SHP identified survey topics and drafted a set of questions for each stakeholder group, which were agreed with the SAG. Each survey included closed-ended and open-ended questions. Open-ended questions allowed respondents to provide more detail and nuance in relation to their responses, provide their views on challenges and gaps, and propose suggestions for improvement. The surveys were piloted with relevant members of the Fast-Track City Steering Groups to ensure suitability and comprehensibility. The surveys were uploaded onto the online survey platform *IQVIA Connection*. A web link was generated for each survey which directed participants to the relevant survey.

The SHP was responsible for participant recruitment. In line with best practice, one month prior to the planned online survey distribution, the SHP emailed the members of the FTC Steering Groups detailing the study, timeline and participant requirements. Each stakeholder representative present on the steering group was asked to encourage participation in the surveys among their respective stakeholder group.

When the data collection commenced, the SHP sent stakeholders an individual link to the surveys on the survey platform, *IQVIA Connection*. Surveys were open over a period of three months, from mid-April to mid-July 2022.

Participants were asked to provide explicit consent to each of the consent questions to commence the survey. See Appendix 4 for survey consent form. The SHP sent three reminder emails to each stakeholder group.

The following sections set out the various stakeholder surveys and participant recruitment processes. Each stakeholder survey collected general information (such as location) and demographic information was collected for respondents living with HIV. Participants were not obliged to answer all the questions in a survey, therefore the overall number of respondents varies from question to question. Please see Appendix 4 for each stakeholder survey.

2.4.1 Adult public HIV clinical services

HIV clinic stakeholder survey

A survey of clinical stakeholders was conducted within each of the adult HIV clinical services, on the HIV care provided within their service, the challenges and gaps, and suggestions for improvement.

Questions within this stakeholder survey were broadly aligned to the British HIV Association (BHIVA) Standards of Care 2018[11]. These standards were produced as a reference for commissioning HIV services in the UK. In the absence of HIV standards of care for Ireland, the BHIVA standards provided a reference point against which to assess the quality of HIV care, and were used to develop questions suitable to the Irish healthcare system.

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[11] https://www.bhiva.org/file/KrfaFqLZRlBhg/BHIVA-Standards-of-Care-2018.pdf

The survey covered the following topics:

- HIV testing, diagnosis and prevention
- Person-centred care
- HIV outpatient care and treatment
- Health promotion, prevention and education for people living with HIV
- Complex HIV care
- Psychological care
- HIV across the life course
- COVID-19 and HIV care

Each of the seven adult public HIV services in Ireland were invited to participate (see Appendix 1). The survey link was circulated by email to clinical representatives on the Fast-Track City Steering Groups, who were asked to disseminate the survey link internally, to doctors, nurses and medical social workers in their HIV service. The number of individuals to whom the survey link was sent is not known.

HIV services survey

In addition, a separate piece of work was conducted in March and April 2022 where HIV services were asked to self-assess their service against the BHIVA standards across the following domains:

- HIV testing, diagnosis and prevention
- Person-centred care
- HIV outpatient care and treatment
- Health promotion, prevention and education for people living with HIV
- Complex HIV care and comorbidities
- Psychological care
- HIV across the life course
- Developing and maintaining excellent standards of care, including COVID-19 and HIV care

Each of the seven adult public HIV services in Ireland provided a single response from their service.

Some of the findings from the survey are referenced in this report where they provide further context. Where referenced, the findings appear in a text box. The full set of findings of the adult HIV services survey is provided in full in Appendix 5.

2.4.2 NGOs and community organisations

The survey link was circulated by email to representatives from a range of NGOs and community organisations (n=39). The NGOs and community organisations that were invited to participate comprised of:

- HIV organisations
- Sexual health organisations
- LGBTQI+ organisations
- Addiction and homelessness organisations
- Organisations supporting migrant and refugees
- Youth organisations
- Organisations supporting people engaged in sex work

The survey link was emailed to NGO directors/CEOs or a specific point of contact, who were then asked to circulate the survey link internally, to staff members who provide HIV prevention and/or support services. The number of individuals to whom the survey link was sent is not known.

The survey topics included:

- Funding structures
- Support services for people living with HIV
- HIV prevention interventions

2.4.3 People living with HIV

A survey to capture the views of people living with HIV was developed. Some questions within the survey were adapted from Positive Voices: the national survey of people living with HIV 2017 (Kall M et al., 2020) with consent from Public Health England (now UKHSA). This survey was piloted with members of the FTC Steering Groups who are living with HIV. The survey was also translated into French and Brazilian Portuguese to increase accessibility and participation. The translations were piloted with native speakers, some of whom were living with HIV.

The survey for people living with HIV was open to anyone living with HIV in Ireland who was 18 years of age and over. The weblink for the survey was circulated by email to FTC steering groups, networks and organisations for people living with HIV, NGOs, and other community-based organisations. A shareable QR code was generated which created a direct connection to the online survey. Posters were developed with the QR code and circulated to HIV clinical services and community organisations to aid in promoting the survey. A snowball sampling method was employed whereby FTC Steering Groups, HIV and sexual health organisations, networks and member organisations for people living with HIV and public HIV clinics were encouraged to disseminate the survey link/posters and encourage participation of people living with HIV.

For participants who spoke any other language or who may have had difficulty completing the survey alone, a freephone helpline was made available, where respondents had the option to speak with an interpreter who would assist them in completing the survey. The survey covered the following topics:

- Testing and diagnosis
- Prevention with partners
- Care in General Practice
- HIV clinical care
- Self-management and participation in care
- Health and wellbeing
- Stigma and discrimination
- Community and peer-support services

2.4.4 Member organisations and networks for people living with HIV

All seven member organisations and networks (see Appendix 1) for people living with HIV were invited to complete the survey. The survey link was circulated by email to the HIV network or organisation chair or a member of the network management team. It was requested that each network/organisation submit only one response. The survey covered the following topics:

- Funding and organisational structure
- Activities, services and supports
- Partnerships
- Representation of people living with HIV

2.4.5 Public sector stakeholders

The survey link was circulated by email to stakeholders working in the following authorities and departments in the relevant CHOs for Dublin, Cork, Galway and Limerick (see Appendix 1):

- HSE Health and Wellbeing
- HSE Social Inclusion
- City and County Councils
- Healthy Cities and Counties

It was requested that only one response be submitted per public sector stakeholder group, per their location (city/regional or national level). Those who received the survey link would consult with relevant staff members where necessary, to complete the response. The survey covered the following topics:

- Engagement between city stakeholders
- Support services for people living with HIV
- HIV prevention interventions

2.5 Data analysis and drafting recommendations

Within **WP1**, IQVIA conducted interviews with the Departments of Public Health and the HPSC, which were transcribed using the built-in transcription function in Microsoft Teams and notes were taken during the interviews. The transcriptions were subsequently checked for accuracy. National and regional responses to specific questions in the interview schedule were analysed. Results from WP1 are presented in *Chapter 3: HIV epidemiological profiles*.

Within **WP2**, data were downloaded into Microsoft Excel prior to analysis, which was cleaned and checked for accuracy by IQVIA. Any identifying information contained in open-ended responses was removed.

Frequency tables were developed for each quantitative survey question. Closed survey questions were analysed quantitatively, using descriptive statistics to produce count and frequency data. No inferential statistics were used in the analysis. Open-ended responses on the challenges, gaps and suggestions for improvement, were analysed and grouped by theme.

Both open-ended and closed-ended responses were analysed concurrently, to provide a deeper insight and understanding of the topics.

WP3 involved analysing, collating, and synthesising the findings from both WP1 and WP2. IQVIA conducted a preliminary analysis of the findings and submitted a draft report to SHP. The SHP engaged with stakeholders to validate findings or seek clarifications as required, this was particularly important due to the changing contexts during and post COVID-19. The SHP completed final analytical checks/data verification and finalised the report which was then reviewed by the Study Advisory Group (SAG).

Chapter 9 presents a set of specific recommendations for the FTC Steering Groups to inform decisions on the implementation of the Fast-Track Cities Initiative in Ireland, and a set of recommendations for all relevant HIV stakeholders. All recommendations were developed and agreed by the SAG.

Chapter 3

City boundaries and HIV epidemiological profiles

3.1 Introduction

Interviews were conducted with the local Departments of Public Health for Dublin, Cork, Galway and Limerick, and with the Health Protection Surveillance Centre (HPSC) to review the available HIV data for each of the Fast-Track Cities, and gain an understanding of what is required to develop local HIV epidemiological profiles and the capacity of the HPSC to support this work (See Appendix 3 for interview schedule).

This chapter summarises the Public Health HIV surveillance processes and presents the findings from the interviews with Public Health. As the data were gathered during the COVID-19 pandemic when surveillance processes were affected, further clarification from Public Health was sought at the time of writing the report, to ensure accuracy and relevancy of the findings in the post-COVID-19 context when surveillance processes were returning to normal.

3.2 Participant information

Departments of Public Health

Interviews were conducted jointly with a Specialist in Public Health Medicine and a Surveillance scientist, responsible for HIV surveillance, in each of the four Departments of Public Health (HSE Area)[12] corresponding to the four Fast-Track Cities:

- HSE East (**Dublin**, Wicklow and Kildare)
- HSE South (**Cork**, and Kerry)
- HSE West (**Galway**, Mayo and Roscommon)
- HSE Midwest (**Limerick**, Clare and Tipperary North)

In total, eight individuals were interviewed, four Specialists in Public Health medicine and four Surveillance Scientists.

Health Protection Surveillance Centre (HPSC)

An interview was conducted jointly with a Specialist in Public Health Medicine and a Surveillance Scientist, responsible for national HIV surveillance, in the HPSC.

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[12] These are the Public Health structures that were in place at the time of interview.
The regional departments of Public Health have since been re-structured. The new structure is outlined in:
https://www.hse.ie/eng/services/list/5/publichealth/publichealthdepts/dph/

3.3 Fast-Track Cities: defining geographical boundaries

Prior to this study, the boundaries of the four Fast-Track Cities had not been defined. One of the aims of the project was to define these boundaries, which would be informed by the interviews with the local Departments of Public Health and based on the availability of HIV data at the city and/or county level.

As HIV is a notifiable disease, clinicians and clinical directors of laboratories have a statutory obligation to notify all new HIV diagnoses to the local Department of Public Health. These are called ‘HIV notifications’. All HIV notifications are entered into the Computerised Infectious Disease Reporting (CIDR) system. CIDR is the national IT system for infectious disease notifications in Ireland[13].

HIV notification data are available publicly by HSE Area[14]. As outlined in Section 3.2, a HSE Area may include multiple counties, so HIV notification data are not publicly available at the county level. The county-level data is, however available to the local Departments of Public Health.

When a HIV notification is made to a Department of Public Health, the individual’s home address is provided as part of the patient demographic data. If the individual’s home address is not available, the address of the clinic where the individual was diagnosed is used as a proxy for the home address. Public Health participants highlighted this as a challenge to the accuracy of the data.

Public Health participants across all four cities said that HIV notification data were available at the county level. Once the HIV notification data have been entered onto CIDR, an annual report by county can be extracted from CIDR.

Similarly, participants reported that HIV notification data were available at the city-level, but that providing this was likely to be a more extensive manual exercise as there are multiple address fields in the system. It was also noted that there are no clearly defined geographical city boundaries, that these are subjective.

It was also noted from a data privacy perspective, that if the number of notifications for any agreed boundary (city, county, HSE Area) was less than five, this would be reported as <5 rather than the actual number to ensure maintenance of individual anonymity.

As city boundaries are subjective, and accessing city-level HIV data is likely to require significant Public Health time and resources, using the county boundaries for each of the Fast-Track Cities was deemed the most feasible option to use for the cities from a HIV data perspective.

3.4 Availability and completeness of local HIV data

3.4.1 HIV Notification process and reporting

In Ireland, HIV confirmatory testing is undertaken by the National Virus Reference Laboratory (NVRL), and, more recently, St James’s Hospital (SJH) in Dublin, who began conducting their own HIV confirmatory testing in March 2022. Once a new HIV diagnosis is confirmed, the NVRL and SJH notify this to the relevant Departments of Public Health, by entering the relevant information into the CIDR system.

The NVRL and SJH send a paper or electronic enhanced surveillance form (ESF)[15] to the clinician who requested the HIV confirmation test, usually a HIV/ID/STI physician or, in some instances, a general practitioner (GP). The ESF contains supplementary data fields required for HIV surveillance purposes, including patient details, route of transmission, HIV laboratory results at time of diagnosis, and treatment information. The completed ESFs are returned to the Departments of Public Health and the additional information is then uploaded onto CIDR by a surveillance scientist/assistant.

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[13] https://www.hpsc.ie/cidr/

[14] HPSC HIV Annual reports: https://www.hpsc.ie/a-z/hivandaids/hivdataandreports/

[15] https://www.hpsc.ie/a-z/hivandaids/surveillancedocuments/

3.4.2 Data completeness

Each Department of Public Health was asked to indicate what proportion of ESFs for 2018, 2019 and 2020 had been:

(a) returned to the Department of Public Health; and

(b) entered onto CIDR.

The proportion of ESFs returned to the Departments of Public Health (to end February 2023) are presented in Table 3.1. This data has been updated since the interviews took place, to provide a more accurate picture of the current data completeness. There were delays in entering data onto CIDR during the COVID-19 pandemic, but all ESFs that have been received by Public Health have now been entered onto CIDR.

Table 3.1 Proportion of ESFs returned to Public Health 2018-2020 (to end February 2023).

	2018	2019	2020
PH East	91%	79%	72%
PH South	100%	95%	97%
PH West	100%	96%	54%
PH Midwest	100%	100%	75%

3.4.3 Challenges to data completeness

Surveillance scientists across the four Public Health Departments described the main challenges to data completeness which have been grouped under the following themes:

- delays in the return of the ESFs
- the impact of COVID-19
- the return of partially completed ESFs
- inefficient data collection process

Delays in the return of ESFs

Of the three years reviewed, the highest proportion of ESFs returned was in 2018. Across all three years, the proportion of ESFs returned is lowest in HSE East, who account for the majority of HIV notifications (~70%) each year[16].

The local Departments of Public Health follow up with clinical services where ESFs are outstanding. Interview participants highlighted that the long-term relationships between surveillance scientists and local HIV clinics (nurses, and consultants) was the key factor in the timely return of ESFs.

Impact of COVID-19

The challenges with return of ESFs from 2019 to date, has been exacerbated by the COVID-19 pandemic which commenced in March 2020.

It was reported that many STI/ID/HIV clinical services operated at a reduced capacity during COVID-19 due to staff redeployment within hospitals, which had a knock-on impact on administrative activities such as the completion of ESFs.

The COVID-19 pandemic also impacted on all Departments of Public Health and HPSC, as staff were required to prioritise COVID-19 outbreak response and surveillance.

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[16] https://www.hpsc.ie/a-z/hivandaids/hivdataandreports/

In addition, from July to December 2020, the NVRL paused sending out ESFs due to the increased activity caused by COVID-19. NVRL resumed sending out ESFs in 2021 and a communication was issued to all HIV clinical services to request completion and return of ESFs where possible. In July 2022, the NVRL retrospectively sent out all forms which had not been sent in 2020.

Return of partially completed ESFs

It was reported that ESFs are often returned partially completed. This may happen when the ESF is sent to the GP, who would not have access to the enhanced data and blood results, collected after an individual has been referred to a public HIV clinic and undergone a full HIV clinical assessment. In such situations, GPs are advised by Public Health and NVRL to complete as much data as possible and indicate which HIV clinic the patient has been referred to for HIV care. Public Health then follow up with the relevant clinic to collect any outstanding data. Partially returned ESFs pose a significant challenge for Public Health surveillance when key data fields are missing.

Inefficient data collection process

Participants reported inefficiencies in the data collection process that impact on ESFs being submitted in a timely manner. ESFs are largely paper-based (although sent electronically to some sites), which need to be completed manually by staff within the HIV clinical services, who are already extremely busy. This is compounded in HIV services that do not yet have electronic patient record (EPR) systems, requiring paper-based charts to be located to populate the ESFs.

In the HIV services survey, 7/7 services reported having an agreed policy for completing enhanced HIV surveillance. 4/7 services said they experience delays in completing enhanced surveillance for HIV. Services were asked what would help with timely completion of enhanced HIV surveillance forms, from the following suggestions: direct submission of required data via a secure online portal (n=4); and provision of personnel (n=1).

The completed ESFs are then sent to the local Departments of Public Health, where the data has to be manually entered onto CIDR. The process is labour intensive for both HIV clinical services and the Departments of Public Health.

Prior to the COVID-19 pandemic, a CIDR STI/HIV module was being developed to allow CIDR to flag missing data with the public STI/HIV clinics, so that clinics could then upload the data onto CIDR directly. The development of this module was paused due to the COVID-19 pandemic. Completion of this module, or identification of a similar process, would reduce the manual reporting burden for clinics and local Departments of Public Health and improve data collection.

3.4.4 Barriers to participating in regional HIV surveillance

All local Departments of Public Health indicated that the biggest barrier to their participation in regional HIV surveillance was the limited staff resources, in particular surveillance scientist resources, since many activities require manual intervention and follow-up.

The manual nature of the surveillance process and CIDR itself was also cited as being a barrier to regional HIV surveillance.

3.5 National HIV Surveillance and Reporting

3.5.1 National HIV monitoring and reporting processes

The HPSC is the national surveillance centre. They are responsible for the analysis of the HIV data which is reported to CIDR, and for the monitoring of the national HIV epidemiology and trends. HIV notification data is published weekly on the HPSC website, and detailed epidemiological reports on HIV in Ireland are published annually, usually at the end of the next calendar year once the data has been collected and validated. The annual reports are dependent on the completeness of the data available on CIDR, which is evaluated by HPSC on a regular basis[17].

The HPSC report annual HIV epidemiological data to the European Centre for Disease Prevention and Control (ECDC)[18], who monitor and report on trends across Europe (EU/EEA) and to the World Health Organization (WHO) and UNAIDS, as part of the Global AIDS Monitoring (GAM) Process[19].

3.5.2 National continuum of HIV care

The 90-90-90 targets were established in 2014 by the Joint United Nations Programme on HIV/AIDS (UNAIDS). The aim was that by 2020, 90% of all people living with HIV would be diagnosed, 90% of those diagnosed would be receiving treatment and 90% of those receiving treatment would achieve viral suppression[20]. These testing and treatment targets have now been updated to **95-95-95** by 2025 (UNAIDS, 2021) to keep countries on track to meet the Sustainable Development Goal to end the HIV epidemic by 2030 (SDG3)[21].

The continuum of HIV care is a conceptual framework that enables countries to monitor the critical stages of their HIV testing and treatment response and measure progress against the UNAIDS targets (ECDC, 2022). The latest data published for Ireland relates to 2018. It was estimated that the number of people living with HIV in Ireland at the end of 2018 was approximately 7,200 (95% CI 6200 – 8000). Approximately 90% (95% CI 78%-100%) of people living with HIV are estimated to be diagnosed/know their HIV status, while 10% are undiagnosed. Of those diagnosed, it is estimated that 88% (95%CI 77%-99%) are on antiretroviral therapy (ART) and of those on ART, it is estimated that 95% (95%CI 82%-100%) have an undetectable viral load (HPSC, 2019).

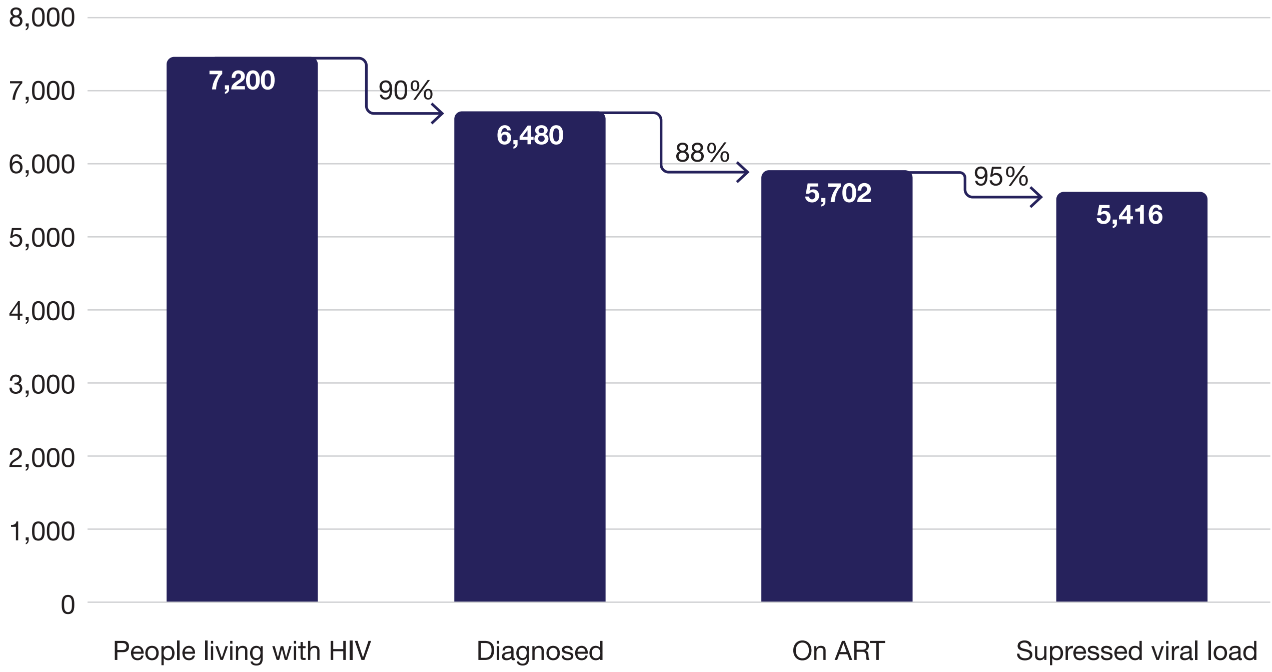

Figure 3.1 Ireland continuum of HIV care 2018.

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17. https://www.hpsc.ie/a-z/hivandaids/hivdataandreports/hivreportsqualityandcompleteness/
18. https://www.ecdc.europa.eu/en/all-topics-zhiv-infection-and-aidssurveillance-and-disease-data/annual-hivaids- surveillance-reports
19. https://www.unaids.org/en/resources/documents/2022/global-aids-monitoring-guidelines
20. UNAIDS. 90-90-90 An ambitious target to help end the AIDS epidemic. Geneva: UNAIDS; 2014.
21. United Nations Sustainable Development Goals (SDGs) https://sdgs.un.org/goals/goal3

The development of national estimates to complete the continuum of HIV care, are coordinated by HPSC using statistical modelling methods and available HIV surveillance data. HPSC work closely with UNAIDS, in particular around the first target (those estimated to be diagnosed/undiagnosed) using Spectrum, the UNAIDS supported modelling tool (HPSC, 2019). HPSC reported considerable difficulty generating this estimate due to the proportion of HIV diagnoses which have been previously diagnosed in a country outside Ireland. The second and third targets are calculated using data collected from HIV clinical services on the number of people living with HIV attending HIV care, who are on treatment and virally supressed. This requires manual data collection from HIV clinical services and was reported to be a very labour intensive process for HIV clinical services in the absence of a HIV cohort database. The last nationally coordinated HIV treatment audit was conducted in 2018 (for 2017 data) (SHCPP, 2018). A further audit is being conducted for 2022 data to provide updated HIV treatment information to support the development of future estimates.

In the HIV services survey, services were asked what would make participation in a nationally coordinated audit in 2022 or 2023 more feasible. The following responses were provided: more time; more personnel; improved IT infrastructure; online platform; data manager; and electronic charts.

3.6 'City' HIV epidemiological profiles

The FTC Implementation Strategy recommends that each city develops its own HIV epidemiologic profile[22]. This means that each city should develop a local continuum of HIV care, based on the agreed city boundaries.

3.6.1 What is required to generate city HIV epidemiological profiles

HIV surveillance data is available from the local Departments of Public Health. This can be provided to Fast-Track Cities, when the city boundaries have been agreed (see Section 3.3).

The estimated number of people living with HIV who are diagnosed/undiagnosed, for each individual Fast-Track City, will require full underlying demographic projections at the sub-national level and a detailed modelling exercise for each city. The creation of sub-national demographic projections and the use of the existing modelling tools to create sub-national estimates need to be further explored. This includes the capacity of those who manage the modelling tools, and the local capacity and resources that would be required to facilitate this.

HIV treatment data (the number of people attending HIV services, on treatment and virally supressed) is also required to develop the HIV epidemiological profiles. This data can be collected from individual HIV clinics, and although there are capacity and IT infrastructure challenges within services to compile this data, a repeat HIV treatment audit is currently ongoing for 2022 data.

3.6.2 HPSC capacity to support development of city epidemiological profiles

The HPSC will support the development of national estimates, when the HIV treatment audit is completed and updated national treatment data is available. The HPSC do not have the capacity to support the development of sub-national estimates at this time. A new biostatistics/modelling unit is to be established in HPSC and may be able to assist with such projects in the future. Requesting support from HPSC, identifying a modelling resource to work on the project and the financial resources required, need further consideration.

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[22] https://www.fast-trackcities.org/implementation-strategy

3.6.3 Challenges

Ireland does not have a national HIV cohort database. A national database would provide updated and timely access to data on people living with HIV in Ireland. The current notification system provides a snapshot of HIV diagnoses at time of diagnosis and does not collect follow-up information on treatment outcomes.

It was stated that there is considerable uncertainty around the estimates produced by UNAIDS due to:

- changes to the environment in recent years: for example introduction of PrEP and changing migration patterns;
- incompleteness or time-varying completeness of epidemiological and treatment data;
- challenges related to the contribution of in-country incidence versus immigrants with a previous HIV diagnosis.

Some counties will have such small numbers that they will not be able to provide valid estimates. A review of what other countries have done for smaller cities should be considered.

3.7 Chapter summary

This chapter summarised the Public Health HIV surveillance processes and presented the findings from the interviews with the local Departments of Public Health for Dublin, Cork, Galway and Limerick, and with the Health Protection Surveillance Centre (HPSC). The findings will inform recommendations on each of the individual Fast-Track City boundaries and the development of local HIV epidemiological profiles.

Chapter 4

Adult public HIV clinical services

4.1 Introduction

An online survey was conducted with adult public HIV clinical services in Ireland to provide a baseline description of HIV care in their service, the supports provided to HIV patients, and to document challenges and gaps in the provision of HIV care. The survey was developed using the BHIVA Standards of Care 2018, and the topics included HIV testing, diagnosis and prevention, person-centred care, HIV outpatient care and treatment, health promotion, prevention and education for people living with HIV, complex HIV care, psychological care, HIV across the life course, COVID-19 and HIV care. The survey was open for a period of three months from mid-April to mid-July 2022. Further information on survey dissemination is described in methodology Section 2.4.1.

This chapter presents the qualitative and quantitative findings from the online survey. Respondents were given the option of answering 'not applicable to my role' and therefore the denominator varies throughout.

4.2 Participant information

There were seven adult public HIV clinics in Ireland at the time of the survey[23]. Four are located in Dublin (Beaumont Hospital, Mater Misericordiae University Hospital, St. James's Hospital, St. Vincent's University Hospital), and one in each of the other Fast-Track Cities (Cork University Hospital, Galway University Hospital and Limerick University Hospital). Doctors, nurses and medical social workers (MSW) in each of these services were invited to participate.

There was at least one response from each HIV clinic, and a total of 36 survey responses were received. The majority of responses (n=26, 72%) came from Dublin-based services, eight (22%) responses came from services in Cork, Galway and Limerick, and two participants (6%) preferred not to say which service they worked for. Fifty percent (n=18) of responses were from nurses, 39% (n=14) from doctors and 8% (n=3) were medical social workers. One respondent (3%) did not specify their role.

The HIV services survey reported that 4/7 adult HIV services had a dedicated medical social worker within their service.

4.3 HIV testing, diagnosis and prevention

4.3.1 Testing and diagnosis

WHO defines late HIV diagnosis as CD4 count <350cells/mm at presentation[24]. Thirty-five healthcare providers (HCPs) responded that they see patients who present with a late HIV diagnosis.

From a list of five potential reasons provided, HCPs were asked about the likelihood of these reasons contributing to a late diagnosis. The most common reasons respondents believed likely or very likely to contribute to late diagnosis were a general lack of awareness of HIV transmission and risk (n=28, 80%),

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[23] These are the adult public HIV clinics that existed at the time of the study. A new HIV clinic opened in Waterford in June 2022.

[24] https://www.who.int/health-topics/hiv-aids

lack of awareness of HIV indicator conditions[25] in healthcare providers (n=28, 80%), and an individual's reluctance to test for HIV (n=27, 77%). Additionally, 57% (n=20) of respondents believed that a healthcare provider's reluctance to offer HIV testing was likely or very likely to contribute to late HIV diagnoses.

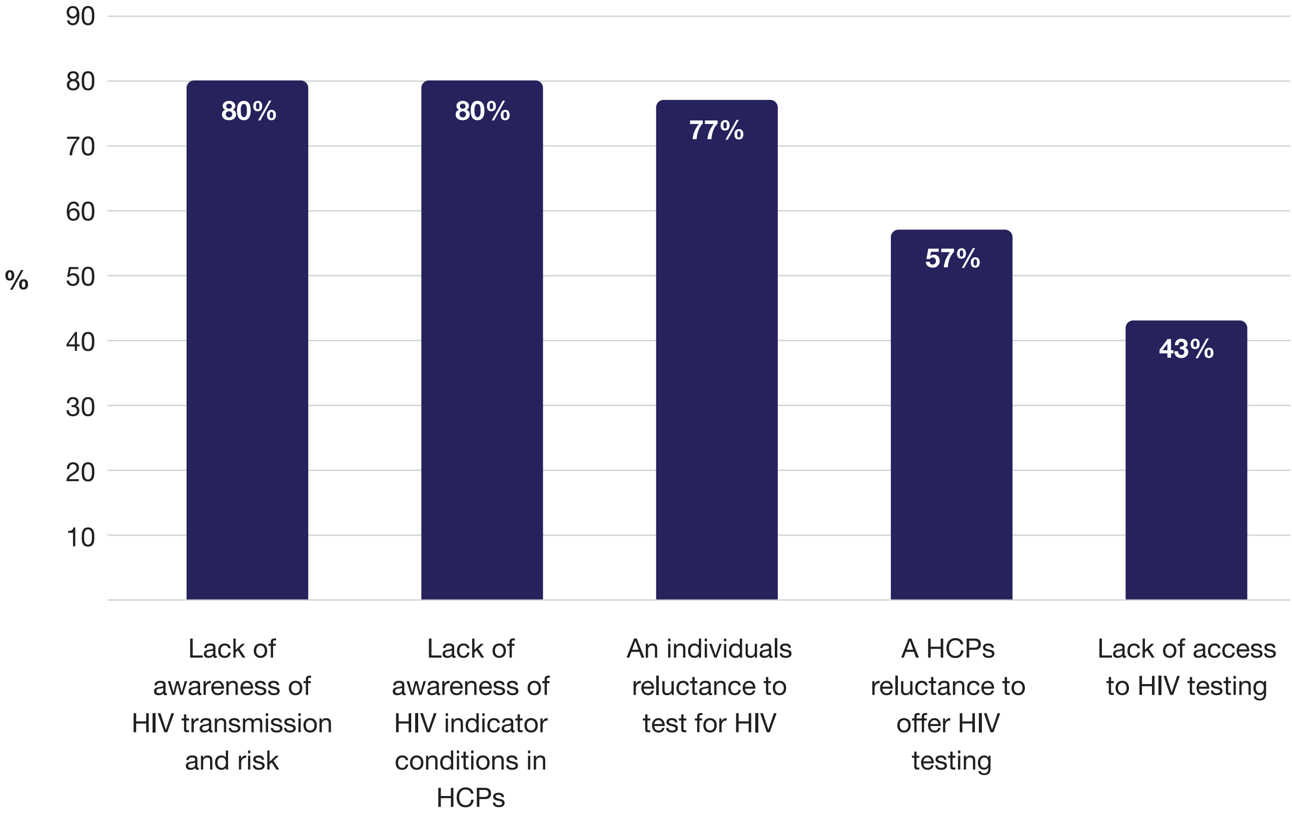

Figure 4.1 Reasons likely or very likely to contribute to late HIV diagnosis.

When asked if there are other important reasons for late HIV diagnosis, 18 HCPs provided open-ended responses. Seven HCPs reiterated the listed options of lack of awareness of HIV risk or indicator conditions, access to or offer of testing. Five HCPs reported stigma/fear of diagnosis as an important reason for late diagnosis. Three HCPs reported challenges to accessing testing specifically for migrants, two relating to challenges in Ireland such as language barriers, awareness of available services, lack of medical card/ limited means to pay for care; and one relating to access to testing/healthcare in the country of origin.

Participants were asked to what extent they believe HIV-related stigma impacts on the timeliness of HIV diagnosis and subsequent engagement in care. All 36 HCPs responded, with 64% (n=23) believing that stigma impacts to a large or very large extent.

From a list of five strategies provided, participants were asked how they thought late HIV diagnosis could be reduced. The majority (72-83%) of HCPs (n=36) agreed that these strategies would help to reduce late diagnoses, see Figure 4.2.

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25. HIV Indicator Conditions: Guidance for Implementing HIV Testing in Adults in Health Care Settings. https://www.eurotest.org/media/0ymdzdvu/guidancepdf.pdf

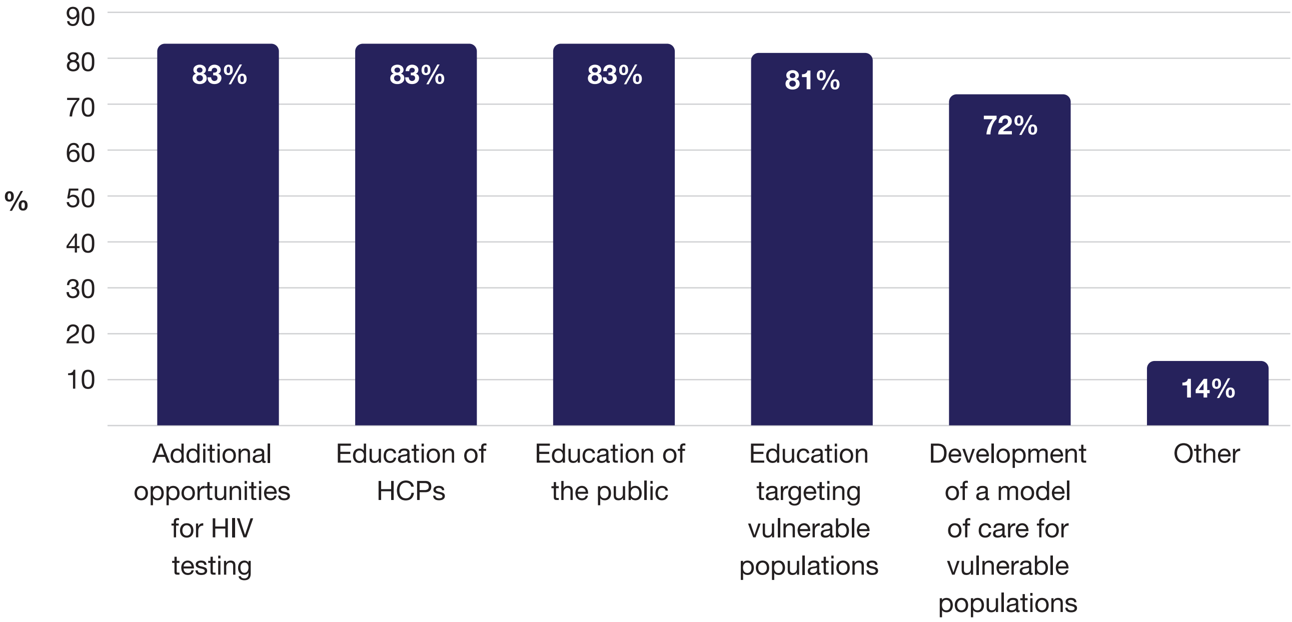

Figure 4.2 Strategies to reduce late HIV diagnosis.

Five HCPs provided other suggestions. Four were aligned to additional opportunities for HIV testing, suggesting an expansion of HIV testing strategies in healthcare settings, such as opt-out testing (e.g. in emergency departments) and community settings. One was aligned to education of the public, suggesting improving awareness around HIV, through better education in schools and more open conversations around HIV.

4.3.2 Prevention with partners

Participants were asked about discussions they have with their patients around prevention of HIV transmission to partners. Participants were asked, from a list of HIV prevention topics provided, which topics they routinely discuss with their patients at time of diagnosis or over time/as required. The majority (83-92%) of HCPs (n=36) reported discussing these four topics routinely with their patients, see Figure 4.3.

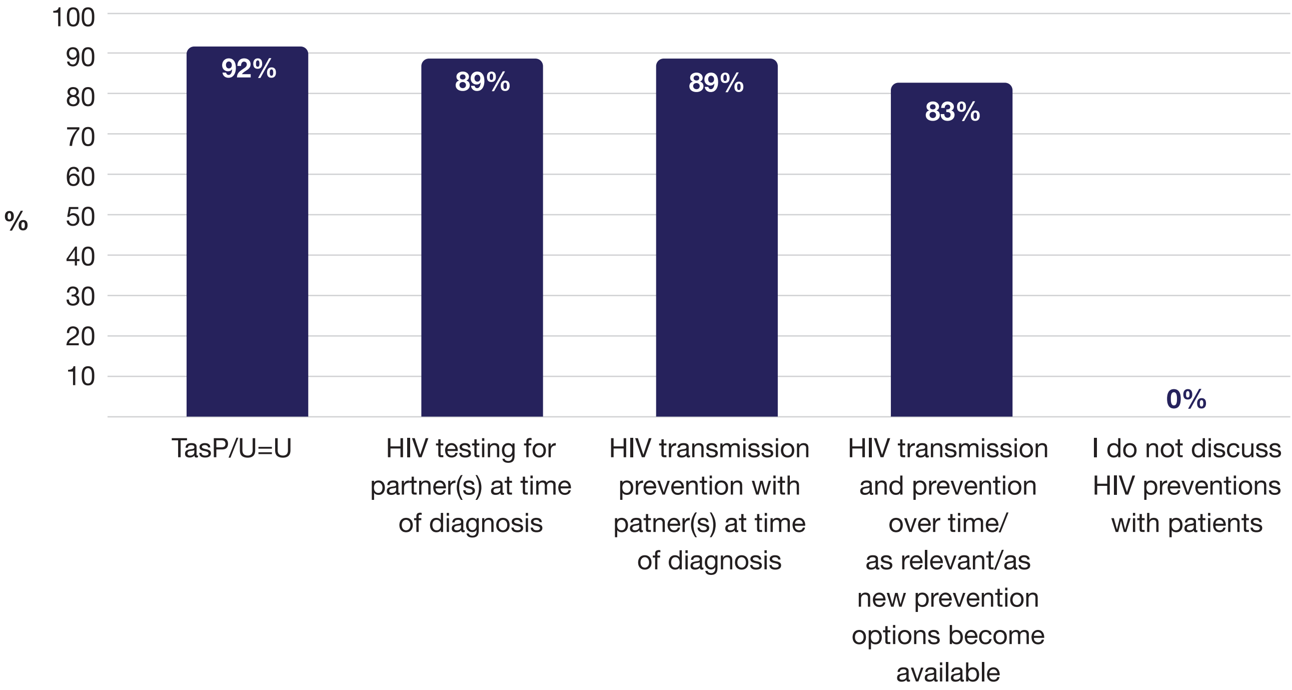

Figure 4.3 HIV prevention with partners; topics routinely discussed with patients.

Participants were invited to provide further open-ended suggestions on how to improve awareness and/or discussions with patients on partner HIV prevention. Five HCPs responded, providing suggestions regarding general HIV awareness (n=3), that this could be improved through education and prevention programmes in schools, universities, primary care and the general population. HCPs also provided suggestions on partner HIV prevention in the HIV clinic setting (n=2), one suggesting that it would be beneficial to have a dedicated sexual health advisor who could take on the role of discussing HIV prevention with patients (acknowledging it is a shared responsibility), and one highlighting that partner HIV prevention should be addressed at every patient visit as people's circumstances and HIV management approaches may change over time.

4.4 Person-centred care

The BHIVA Standards of Care for people living with HIV describes person-centred care as care that is focused on the person and not only on their illness.

4.4.1 Participation of people living with HIV in their care

Respondents were asked about participation of people living with HIV in their care. Of the 36 HCPs, 86% (n=31) agreed or strongly agreed with all three statements provided: that patients need to be more included in decisions around their individual HIV care; in decisions around how overall HIV care is delivered; and that HCPs need to do more to enable patients to self-manage their HIV and overall health and wellbeing.

HCPs were invited to provide open-ended suggestions as to how patients can be more included in decisions around how HIV care is delivered. Seventeen HCPs provided responses. Over half of HCPs (n=9) provided suggestions relating to actively seeking patient feedback (e.g. through national or patient surveys, focus groups, a suggestion box/designated email address) and listening to the feedback.

It was reported in the HIV services survey, that 0/7 services had undertaken a patient experience survey in past 3 years to assess satisfaction with HIV care.

HCPs (n=6) suggested having more time with patients, educating and empowering patients to discuss their care with the care team. This included the development of educational tools for patients and their partners and providing specific counselling and support for newly diagnosed individuals. Additionally, HCPs (n=2) suggested improving patient representation in the relevant HIV care forums, such as on HIV policy or service development groups or through patient representation or advocacy groups.

HCPs were also invited to comment on how they could better facilitate patients to self-manage their HIV through open-ended responses. HCPs (n=6) provided responses relating to improving patient education and support services, including collaboration with community services for additional supports for vulnerable client groups (e.g. literacy) to help them self-manage their HIV.

In the HIV services survey, 7/7 services reported providing language translation services and 4/7 services reported providing sign language services, with an additional service reporting that they do not currently have any patients requiring sign language services, but that it would be provided if required.

HCPs (n=5) suggested that the use of technology could be improved, such as through patient portals or mobile phone apps, where patients could access their test results, monitor their HIV and comorbidities, and access other support tools. HCPs (n=3) stated having more staff resources and time with patients during visits would be beneficial, including more nurses, social workers or on-site peer-support workers. Additional responses included more successful ageing programmes for people living with HIV (n=1) and links with other departments in the hospital (n=1).

4.5 HIV outpatient care and treatment

4.5.1 Access to and retention in care

Based on their clinical experience, participants were asked which of the listed population groups are less likely to achieve/maintain viral suppression. The population groups that HCPs (n=36) felt were less likely to achieve/maintain viral suppression were homeless people (n=32, 89%), followed by people who inject drugs (n=27, 75%) and people from migrant populations (n=19, 53%). Eight (22%) HCPs selected 'other population group' but did not name them.

In the HIV services survey, five services reported that some population groups are less likely to have sustained viral suppression. In addition to homeless people, people who inject drugs and people from migrant populations already mentioned here, services also mentioned patients with medication adherence issues secondary to mental health problems and people with difficult socio-demographic backgrounds.

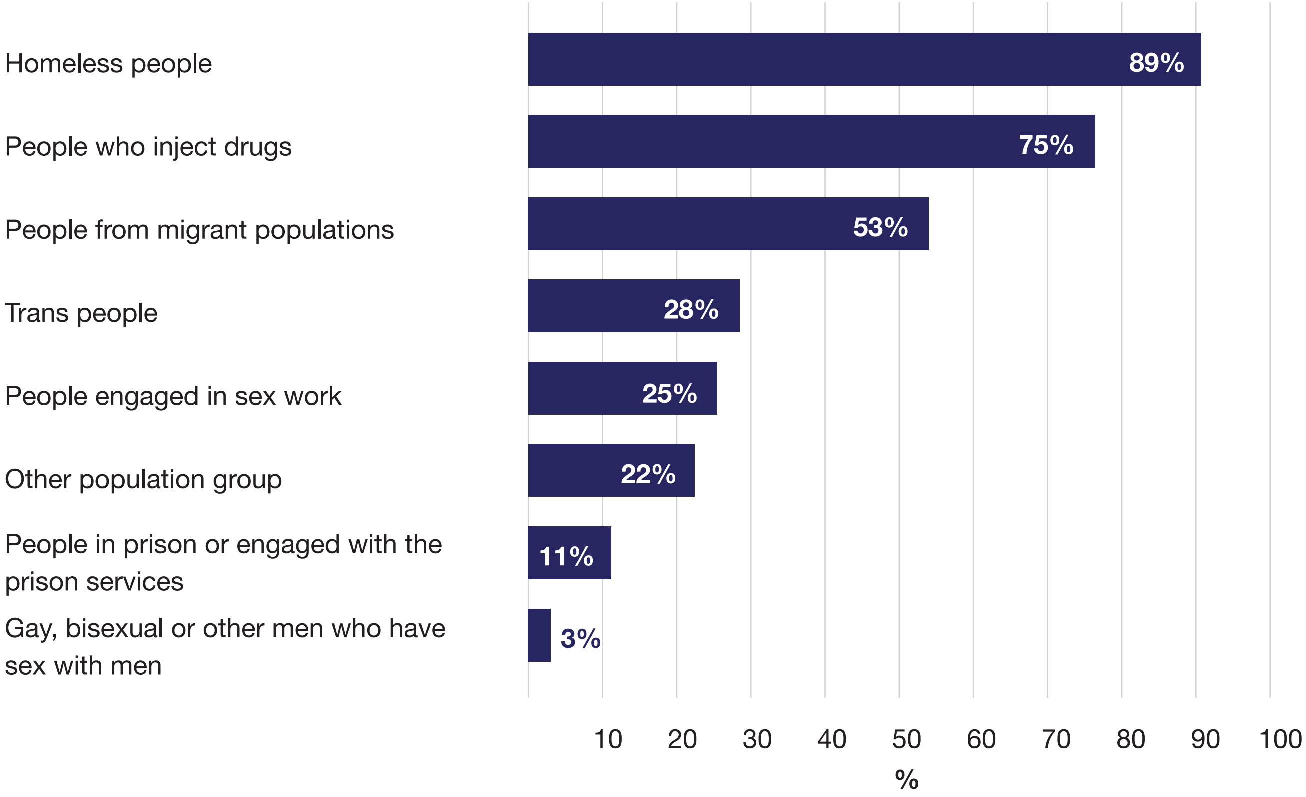

Figure 4.4 Population groups who are less likely to achieve/maintain viral suppression.

Altogether 35 HCPs agreed that additional support is needed to assist vulnerable populations in achieving viral suppression and being retained in care. Of those, 27 provided open-ended suggestions for supports that might be valuable to vulnerable populations in achieving viral suppression and being retained in care. Over half of the suggestions (n=14) related to community supports, such as more key workers and outreach services, to support vulnerable individuals living with HIV in the community, help them navigate the health and social care systems and engage/re-engage with clinical services when required. This included a suggestion of home visits and directly observed therapy (DOT) to support treatment adherence. Ten HCPs suggested more time or resources within HIV clinics to support the diverse needs of vulnerable individuals, such as dedicated HIV nurses/nurse specialists, psychosocial supports, social workers or case managers as part of the multidisciplinary team or have formal links to community services. Four HCPs suggested the co-administration of HIV care within community settings, such as addiction/methadone services, or within prison settings (with coordinated discharge to HIV clinics for those leaving prison). Other suggestions included using peer-support workers (n=4), either in clinic or community settings, addressing the underlying social inclusion issues (n=4), such as deprivation, unemployment, homelessness and addiction, etc., and having information available in various languages for migrants or providing assistance with getting medical cards for their non-HIV medical care needs.

Three other population groups were specifically mentioned in response to this question: gbMSM using chemsex as a vulnerable group; Irish Travellers and that addressing their specific needs might improve retention in care; and adolescents transferring from paediatric to adult services who might require more time and support, including psychological and health advisor support to improve retention in care.

4.5.2 Outpatient care

Participants were asked who they think should be the main healthcare provider (the GP, the HIV clinic or combined care) for the management of comorbidities (e.g., hypertension, dyslipidemia, diabetes) in people living with HIV. Thirty-five HCPs responded, of whom 74% (n=26) answered that comorbidities should be managed through combined care. Six (17%) HCPs indicated that GPs should be the main healthcare provider and three (9%) participants indicated that the HIV clinic should be the main healthcare provider for the management of comorbidities.

HCPs were presented with a list of five potential factors and asked to rate the likelihood that each one would pose a challenge when managing comorbidities. The majority of HCPs (n=33, 92%) believed that three factors were equally likely or very likely to present challenges to managing comorbidities: the patient not being registered with a GP; the patient's ability to pay for GP care; and the patient's ability to pay for medication for comorbidities. Additionally, 31 (86%) HCPs felt that a patient not having disclosed their HIV status to their GP would present challenges to managing comorbidities.

In the HIV services survey, two services estimated that ≥90% of their patients are registered with a GP, three services estimated that between 80-89% of their patients are registered with a GP and two services estimated that 50-79% of their patients are registered with a GP.

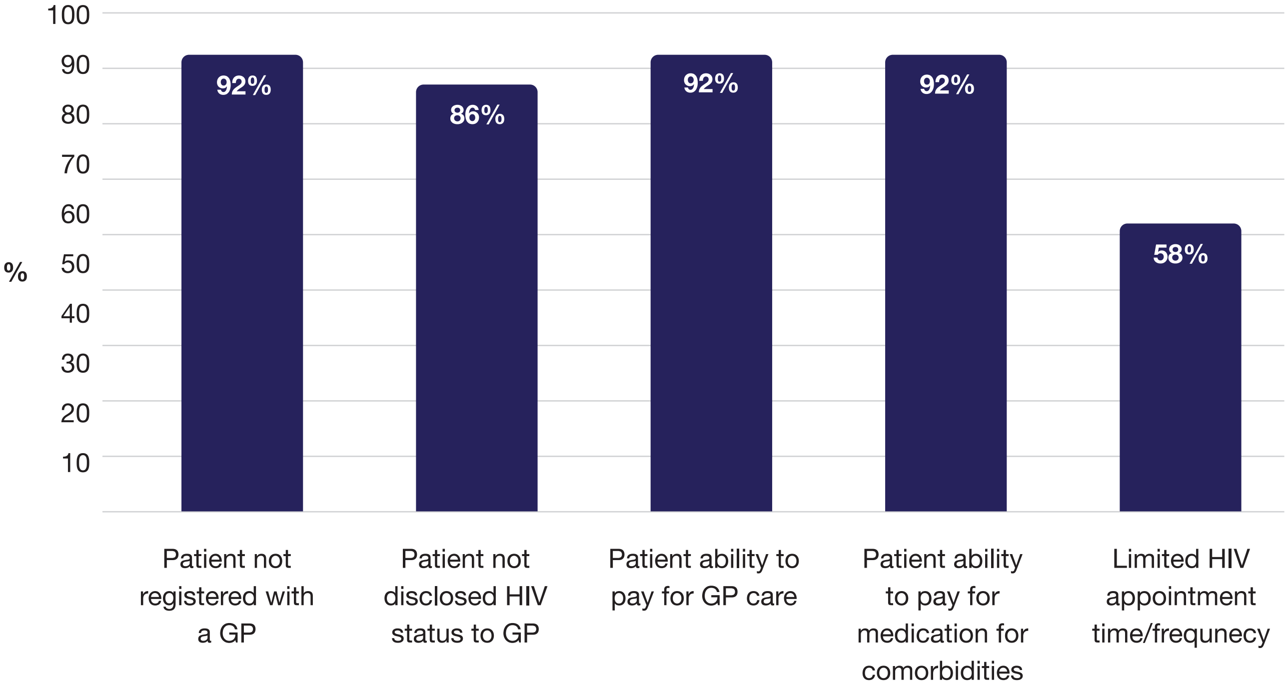

Figure 4.5 Factors likely or very likely to present challenges to managing comorbidities.

Participants were invited to detail other challenges to managing comorbidities and provide open-ended suggestions on how to improve the management of comorbidities. Ten HCPs responded, with four listing other challenges, such as long waiting lists for referral to other services/specialities or difficulty coordinating care, HCP knowledge and comfort in managing general medical conditions and polypharmacy, stable patients only being seen twice a year so controlling some co-morbidities can be difficult unless engaging with the GP, and difficulty keeping track of non-HIV-related healthcare due to lack of a health identifier.

In addition, six HCPs provided suggestions to improve the management of comorbidities, including availability of MSW, physiotherapists and dieticians during outpatient clinics, development of a HIV clinical nurse specialist (CNS) role to provide continuity of care, or development of a proforma to ensure standardisation of care, having resources to better oversee and co-ordinate care between services for complex patients or providing combined clinics/joint patient care with other specialities consulting during HIV clinics to ensure the needs of patients with comorbidities are being met.

The HIV services survey reported that 4/7 adult HIV services had a dedicated medical social worker, 2/7 services had a dedicated clinical nutritional resource and 6/7 services had a dedicated HIV clinical nurse specialist within their service.

4.6 Health promotion services and supports

Participants were asked about health promotion services and supports for patients, in relation to vaccines, STI testing, smoking cessation, and alcohol and recreational drug use. Thirty-four HCPs responded.

4.6.1 Vaccines

Twenty-two (65%) HCPs reported that there are no barriers to providing vaccinations to patients within their HIV clinic and nine (26%) HCPs reported that there are barriers.

Those who reported barriers were invited to detail the barriers and provide open-ended suggestions as to how vaccine access or uptake could be improved. Eight HCPs provided responses, seven of which related to sufficient time, sufficient/dedicated staff, or dedicated clinic space. One service reported that a dedicated vaccine nurse within their service “was a huge help”. Additional barriers mentioned included patients declining vaccines, lack of access to GP vaccine records and unwieldy written documentation systems, suggesting that documentation could be improved with oversight from appointed nurse specialists.

The HIV services survey reported that 6/7 adult HIV services offer vaccines within their service. The service which does not offer vaccines said they inform patients where they can avail of vaccines.

4.6.2 STI testing

Twenty-four (71%) HCPs reported that there are no barriers to providing STI testing to patients within their HIV clinic and ten (29%) reported that there are barriers.

Those who reported barriers were invited to detail the barriers and provide open-ended suggestions as to how STI testing access or uptake could be improved. Nine HCPs provided responses, five of which related to dedicated staff, time or clinic space. Two HCPs reported that STI testing was not available in their HIV clinic, one stating that there was no co-located STI clinic. One HCP stated that STI services are very busy and that STI testing should continue to be prioritised in the HIV clinic as well as offering alternative methods of testing.

4.6.3 Smoking cessation

Participants were asked which smoking cessation supports, from a list of three options, are available to patients. Thirty (88%) HCPs reported that they refer patients to local smoking cessation services (e.g. HSE stop smoking advisors), 25 (74%) HCPs reported brief interventions/making every contact count (MECC) and 19 (56%) HCPs reported signposting to national smoking cessation supports (e.g. QUIT.ie, QUIT phone service). Two HCPs (6%) responded ‘other’, stating that in-house smoking cessation services were available in their hospital.

Participants were invited to provide open-ended suggestions on other supports that would be useful to promote smoking cessation. One HCP responded that having resources within services would be very helpful as so many patients continue to smoke.

It was reported in the HIV services survey that the proportion of patients who would benefit from smoking cessation support services was from 10% to >40%.

4.6.4 Alcohol and recreational drug use

Participants were asked which supports for the reduction of problematic alcohol and drug use, from a list of three options, are available to patients. Thirty-one (86%) HCPs reported that they refer patients to addiction support services, 26 (72%) HCPs reported brief interventions/MECC and 23 (64%) HCPs reported signposting to drug and alcohol supports and/or services (e.g. Ask About Alcohol). Two HCPs (6%) responded ‘other’, both stating that referral to on-site medical social workers for assessment and support was available and one stating that referral to Liaison Psychiatry was available onsite also.

It was reported in the HIV services survey that the proportion of patients who would benefit from an agreed care pathway to drug and alcohol services was between 10% and 25%.

Participants were invited to provide open-ended suggestions on other supports that would be useful to reduce alcohol and drug use. Six HCPs provided responses, three highlighting challenges, such as lack of dedicated in-house addiction support services, that addiction services are more likely to address drugs rather than problematic alcohol use, that there are fewer resources available for alcohol dependency. Three HCPs provided suggestions, including more timely access to addiction counselling, more (and more accessible) peer-support workers, and more information and training on chemsex for clinical staff.

4.7 Complex HIV care

As outcomes for people living with HIV improve, participants were asked if they have concerns for retention of medical and nursing skills for the provision of in-patient care for patients presenting with advanced HIV and HIV-related opportunistic infections. Thirty-four HCPs responded, half (n=17) of whom were concerned about the retention of medical and nursing skills as HIV outcomes improve, 13 (38%) HCPs responded that they were not concerned and 4 (12%) HCPs were unsure.

When asked for open-ended suggestions on how to ensure the retention of medical and nursing skills for management of advanced HIV and HIV-related opportunistic infections, 19 HCPs provided responses. The majority (n=14) provided suggestions relating to education and training, with some specific suggestions including regular resources to fund educational opportunities and continuous professional development for staff, participation in conferences, case presentations/teaching-based discussions of advanced/complex cases (within clinic team and at external forums such as grand rounds and conferences), continued specialist training opportunities for medical and nursing with as much clinical exposure as possible, and the suggestion of a HIV/ID postgraduate course.

Two HCPs mentioned that they see enough complex in-patients or late presenters to maintain their skills, although one suggested that it might be beneficial to have an opportunity to work at different centres to facilitate cross-learning. One HCP mentioned that complicated cases occur infrequently and highlighted the importance of reviewing these cases as part of continuous education and learning.

Four HCPs suggested centralising complex HIV care (in particular inpatient care) to large centres with sufficient volume to maintain provider skillset, including working in networks to facilitate transfer of care to the centres as required.

BHIVA standards recommend HIV inpatient care networks to ensure optimisation of skill sets and provision of care. Participants were asked if they would support the development of HIV inpatient care networks in Ireland. Nearly all 36 HCPs (n=33, 92%) were supportive and three (8%) were unsure.

4.8 Psychological care

From a list of four options provided, participants were asked what proportion of their patients would benefit from psychological support to improve emotional wellbeing and mental health.

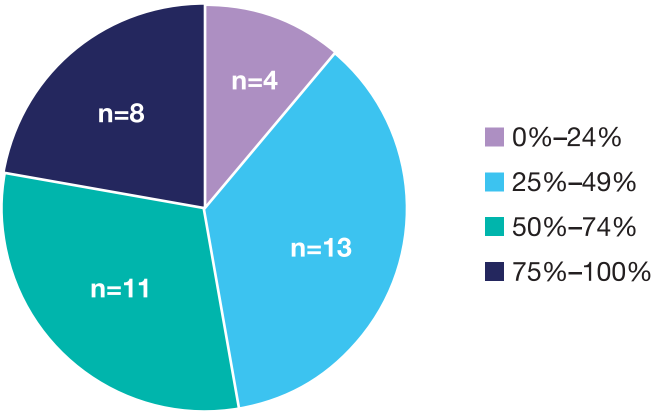

Figure 4.6 Number of HCPs who selected the specific proportion of patients who would benefit from psychological support.

Of the 36 HCPs who responded, 19 reported that more than half of their patients would benefit from psychological support, see Figure 4.6.

When asked how the emotional wellbeing and mental health of patients could be improved in their HIV service, 29 HCPs provided open-ended responses. Twelve HCPs stated that having dedicated psychology support/dedicated psychologist on-site in the HIV clinic and three HCPs stated that better access to or referral pathways to psychology would improve patient mental health and wellbeing. Ten HCPs said that having dedicated or additional staff resources in their clinic would help, including a dedicated counsellor/counselling service (n=6), MSW (n=6), or CNS (n=3); with a further three respondents suggesting that having more time with patients would help. Additionally, six respondents suggested more timely and better access to support services, including community mental health services.

The HIV services survey reported that 1/7 adult HIV services had a dedicated psychologist within their service; 5/7 services had an agreed care pathway for mental health assessment and management; and 3/7 services had access to dedicated psychological services to support people attending their service. Of the four services which do not have access to dedicated psychological services, all reported that a dedicated psychological resource would benefit their patients.

Participants were asked to identify the challenges or barriers for patients to access psychological care or support services and how access could be improved. Twenty-nine HCPs provided open-ended responses, 22 of whom listed challenges or barriers, relating to lack of a dedicated psychologist/limited psychology resources (n=8), the cost or lack of funding for a psychology resource (n=2) and limited access to community counselling services (availability and affordability) (n=8). Additionally, three respondents mentioned the patients' reluctance to engage with psychological supports as a barrier. Fifteen respondents provided open-ended suggestions to how access could be improved, these related to having a dedicated (or funding for) psychology resource (n=3), dedicated/additional clinic resources (counselling/MSW/CNS) (n=3), better or more timely access and referral pathways (n=3), and online support services or virtual clinics (n=2). Focusing on outpatient mental health care and support (n=1) and the provision of free community-based services (n=1) were also suggested.

The HIV services survey reported that 4/7 adult HIV services had a dedicated medical social worker and 6/7 services had a dedicated HIV clinical nurse specialist within their service.

4.9 HIV across the life course

4.9.1 Young adults and adolescents living with HIV

Participants were asked if there are any challenges in transitioning adolescents to adult HIV care and 35 HCPs provided responses. Twenty-five (71%) HCPs responded 'yes', that there are challenges in transitioning adolescents to adult HIV care, 7 (20%) said that there were no challenges and three (9%) were unsure.

The HIV services survey reported that 3/7 services had an agreed pathway for young adults and adolescents living with HIV who are transitioning their care to adult services.

When asked what the challenges were, 17 HCPs provided open-ended responses describing the many challenges. The majority (n=14) highlighted challenges relating to the transition from a paediatric to an adult service itself. HCPs (n=3) described paediatric services as a more protected and supportive environment where patients are used to more time for consultations. The challenges described in transitioning to an adult service included that adult clinics are busier, more impersonal and intimidating (n=6), patients are suddenly treated as an adult and given more responsibility (n=3), there are high DNA (did not attend) rates, especially in the early days of transitioning to adult services, with patients needing time to adjust (n=2), the fear of moving service can lead to lack of engagement (n=1) and that the young adults knowledge of HIV can be overestimated by the provider (n=1).

Additionally, three HCPs highlighted challenges relating to the adolescence period. They noted that it is a difficult time in the young person's life, a time of great change where they are trying to find their place in society, and where there is often resistance to what is perceived as authority. Two HCPs highlighted challenges relating to medication adherence, such as resistance, polypharmacy or body image issues like weight gain that may be associated with HIV treatment.

Participants were invited to provide open-ended suggestions on how to improve support to adolescents transitioning to adult care, and 17 HCPs provided responses. The main suggestions were having dedicated staff resources (key workers/MSW/CNS) to support the transition and ensure continuity of care (n=7) and having a dedicated clinic (at a quieter time) for young adults (n=6). One respondent suggested a visit to the adult service to meet the team and having a tour of the clinic in advance of their first appointment would be beneficial, with another respondent saying their service already offered this. It was also suggested that young adults would benefit from psychology support or mental health resources (n=2) or that peer-support (n=2) would be helpful.

4.9.2 Older age

Participants were asked if they see challenges and gaps in addressing the medical and social care needs of ageing patients (65 years and older) living with HIV. Thirty (86%) HCPs responded that they see challenges and gaps in addressing the needs of ageing patients, one (3%) said that they do not and four (11%) were unsure.

The HIV services survey reported that 2/7 services had an agreed pathway for referring patients >65 years to geriatric medicine services; and 2/7 services said they routinely refer patients >65 years to geriatric medicine services.

Participants were invited to provide open-ended suggestions on how the challenges and gaps could be improved and 19 HCPs provided responses. The most common suggestion (n=8) was a joint HIV and geriatric clinic or gerontology involvement in HIV care, with one respondent stating they were addressing this challenge through a joint HIV and medicine for the elderly clinic within their service. Other suggestions included better links with GPs and other specialities (who manage comorbidities) (n=4), better long-term care options and links with community care/nursing homes (n=3), and more flexible or remote HIV care or monitoring (n=2) for patients with reduced mobility, including a suggestion that growing older with HIV needs to be better researched and documented.

4.10 COVID-19 and HIV care

The COVID-19 pandemic had a significant impact on how clinical services were delivered in Ireland, resulting in service adaptations as service providers worked to try and meet the needs of patients. Participants were asked to describe the positive and negative changes in HIV care delivery that arose from service adaptations during the COVID-19 pandemic.

Twenty-six participants provided responses on the positive changes in HIV care delivery and in addition, many respondents described the impact of these changes. The most common response (n=12) was the establishment of virtual HIV clinics (phone/video consultations) for suitable patients, resulting in reduced clinic appointments and waiting times. Respondents described service efficiencies to improve clinic flow, such as stricter appointment times (n=8) and pre-clinic triage/assessment (n=5) which have led to a more streamlined service, including faster pharmacy, nursing and social work services, less busy waiting areas, reduced waiting times and improved patient experience. Additionally three respondents mentioned ART delivery options for patients where required and one respondent mentioned an expansion of the nurse’s role which has resulted in more providers and improved waiting times.

In the HIV services survey, 5/7 services said that the COVID-19 pandemic provided their service the opportunity to introduce changes to improve efficiency and service delivery. These efficiencies are listed in question 86, Appendix 5

Twenty-six participants provided responses on the negative changes in HIV care delivery that arose from service adaptations during the COVID-19 pandemic. Eleven respondents described challenges or negative outcomes relating to the move from face-to-face to virtual HIV clinics. Reduced face-to-face services resulted in missed appointments and missed opportunities for STI screening, smears, vaccines or other supports, such as psychological support, as well as reduced monitoring and less comprehensive management of comorbidities. While some respondents said that virtual appointments may be preferred by some patients, some respondents described virtual consultations as less thorough or less enjoyable for both patient and provider. Three respondents mentioned other challenges regarding the clinical care of patients, two referring to poorer access to (shared) GP care and one to worsening waiting times for referral to other specialist services. Two respondents mentioned the loss of clinic space or walk-in services since COVID-19 and one mentioned that there was now an increased expectation of service flexibility.

Additionally, five respondents described the negative impacts of COVID-19 on their patients, such as fear, social isolation and anxiety. Fear of getting COVID-19 resulted in some patients (particularly those severely immunocompromised) being afraid to attend clinic and missing medication, and increased anxiety resulting in weight gain, higher alcohol and drug use in some patients. Seven respondents listed other general COVID-19 related challenges, such as reduced access to STI/HIV testing and increased late diagnosis, reduced laboratory turn-around times and delayed results, disjointed care from GPs, hospital visitor restrictions and the resulting challenges for patients, family and friends.

In the HIV services survey, services were asked about the greatest concerns for their service throughout the COVID-19 pandemic. Responses are listed in question 87, Appendix 5.

4.11 Chapter Summary

This chapter presented the findings from the 36 respondents who completed the survey for adult public HIV clinical services. HIV clinical service providers highlighted a range of challenges and gaps to the provision of HIV care to people living with HIV, alongside suggestions for service improvement. The findings will inform recommendations at the end of the report and the subsequent development of city implementation plans.

Chapter
5

NGO and community organisations

5.1 Introduction

An online survey was conducted with NGOs and community organisations who provide HIV prevention interventions and support services for people living with HIV, to provide a baseline description of the available services and funding structures, and to document the challenges and gaps. The survey was open for a period of three months from mid-April to mid-July 2022, further information on the survey topics covered and dissemination can be found in the methodology Section 2.4.2.

This chapter presents the qualitative and quantitative findings from the online survey.

5.2 Participant information

Thirty-nine organisations were invited to participate in the survey and the survey was open to all managers, staff and volunteers involved in providing HIV prevention and support services. A total of 43 responses were received.

Participants were asked in which location(s)[26] they provide their HIV prevention and/or support work and to name the organisation they work for. The number of responses is outlined, by location and organisation in Table 5.1.

Table 5.1. Number of NGO survey responses by location and organisation (n=43).

Location (responses)	Organisation	Number of responses
Cork (n=9)	Sexual Health Centre Cork	6
	Gay Project Cork	1
	Foróige	1
	Did not specify	1
Dublin (n=6)	Merchants Quay Ireland	1
	Foróige	1
	Outhouse	1
	SAOL	1
	ACET	1
	Did not specify	1
Dublin/National (n=9)	HIV Ireland	9
Limerick/National (n=4)	GOSHH	4
Galway (n=3)	Sexual Health West	2
	Simon Communities of Ireland	1
Dublin & Limerick (n=1)	Ana Liffey Drug Project	1
National (n=11)	Foróige	9
	Sex Workers Alliance Ireland	1
	SafetyNet	1
Total responses		**43**

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[26] Respondents could select multiple options and were advised to select the county(ies) where they (as the survey respondent) provide their HIV prevention and/or support work, and to select the 'national' option if their organisation has a national remit.

Most of the organisations are specifically aligned to one of the four Fast-Track Cities, even where they also have a national remit. Three organisations selected the 'national' option and provide services across many of the Fast-Track Cities.

From a list of 10 options, respondents were also asked to select their role(s) within their organisation. Selection of multiple options was permitted. The responses are presented in Table 5.2.

Table 5.2 Role(s) of the respondents within their organisation (n=43).

Role	Number of respondents[27]
Support worker	11
Director/CEO or equivalent	10
Manager	9
Other please specify	7
Community worker	5
Outreach worker	4
Health promotion worker	3
Community tester	2

Roles named by those who selected 'other' were: youth justice worker (n=3), youth worker (n=1), communications and administration (n=1), trainer (n=1), and training officer (sexual health promotion) (n=1).

5.3 Funding structures

Respondents who indicated that they were the Director, CEO or equivalent (n=10) of the organisation, were asked about core funding, funding for support services for people living with HIV, and funding for HIV prevention interventions. Responses were received from Directors/CEOs whose organisations provide services across all four cities, Dublin (n=3), Dublin/National (n=1), Cork (n=2), National (n=2), Limerick/National (n=1) and Galway (n=1).

For all questions on funding sources, respondents were asked where their organisation accessed funding, from a list of eight options provided:

- National HSE Social Inclusion Office
- Local HSE Social Inclusion Office
- National HSE Health and Wellbeing (e.g. SHP)
- CHO HSE Health & Wellbeing
- Local Authorities (City and County Councils)
- Healthy Ireland
- Not applicable
- Other

Selection of multiple options per question was permitted.

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[27] Total individual responses exceed 43 as 6 respondents identified themselves as having multiple roles within their NGO.

5.3.1 Core Funding

Respondents were asked if their organisation receives core funding (defined as funding that covers organisational costs, including building, overheads, administration costs, and management staff). Nine respondents selected 'Yes', while the remaining participant who did not select 'Yes' explained that their organisation did receive core funding but that there was no single body or statutory body as a group that covered their core costs. This participant's responses to questions about core funding have therefore been included alongside the responses of those who did select 'Yes'. One respondent who selected 'Yes' when asked if their organisation received core funding did not provide any further details about the source of the core funding so the remainder of this section is composed of the responses of nine respondents in total.

Respondents were asked to report where they accessed core funding between 2019 and 2021. The Local HSE Social Inclusion Office was the most frequently selected funder per year. The sources of funding are outlined in Figure 5.1.

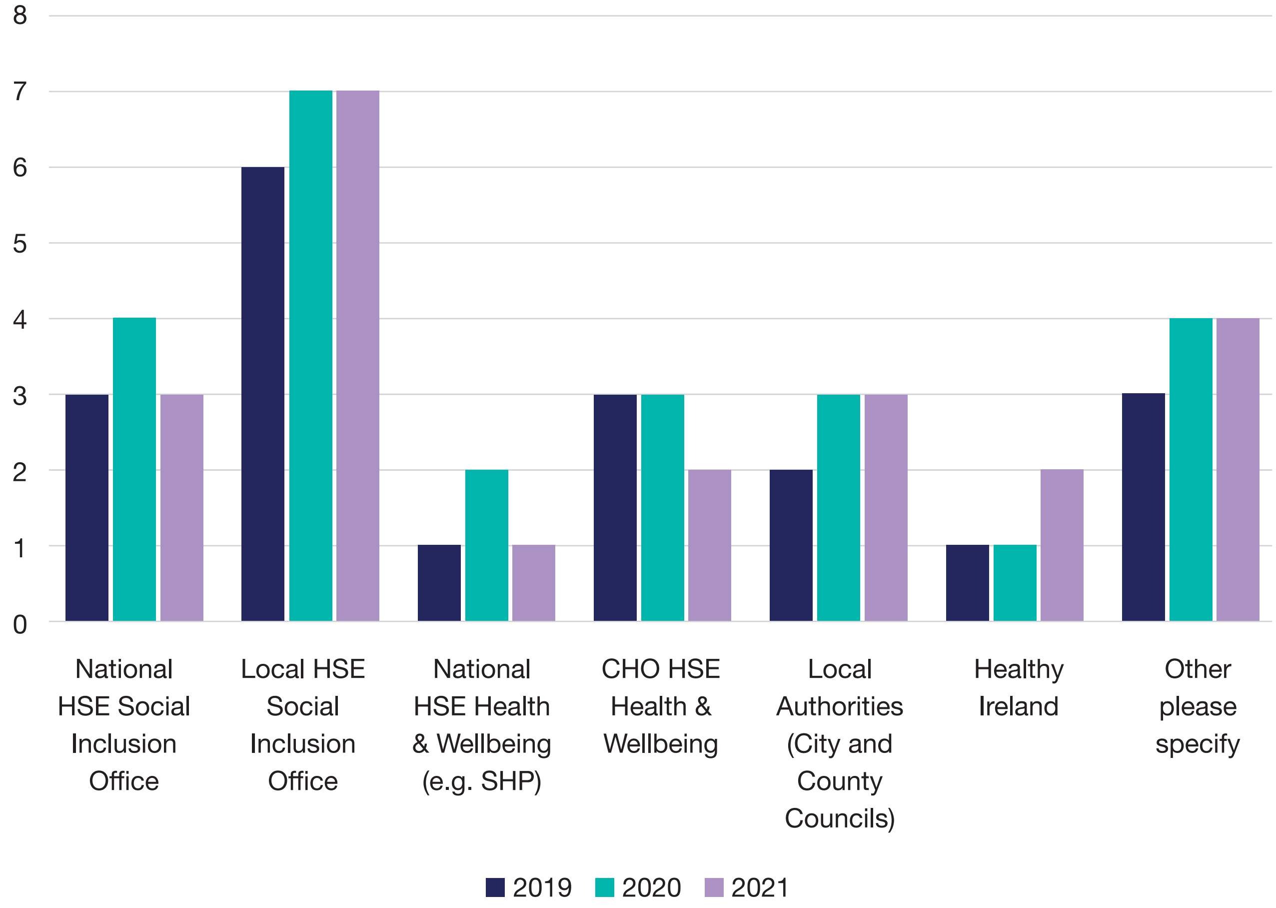

Figure 5.1. Sources of core funding accessed by organisations between 2019 and 2021.

The other funding sources mentioned by respondents were: Pobal (n=2), the Department of Justice (n=1), Rethink Ireland (n=1), and Tusla (n=1). One respondent outlined the complexity of their funding: 'Other core funders include individuals, corporate bodies, philanthropic bodies, churches as well as other statutory bodies not listed above. Benefit-in-kind from volunteers. No single body nor statutory bodies as a group provide core funding which exhaustively 'covers' core costs.'

When asked to estimate the average whole time equivalent (WTE) staff covered by core funding between 2019 and 2021 eight respondents reported WTE ranging between 1.1 and 11 WTE.

5.3.2 Funding for support services for people living with HIV

Of the ten Directors/CEOs who responded to the funding section, six reported they accessed funding for support services for people living with HIV between 2019 and 2021. Three respondents reported that this did not apply to their organisation and one participant did not provide any information. From the six responses received, the main source of funding for support services for people living with HIV was Local HSE Social Inclusion Offices. The sources of funding are outlined in Figure 5.2.

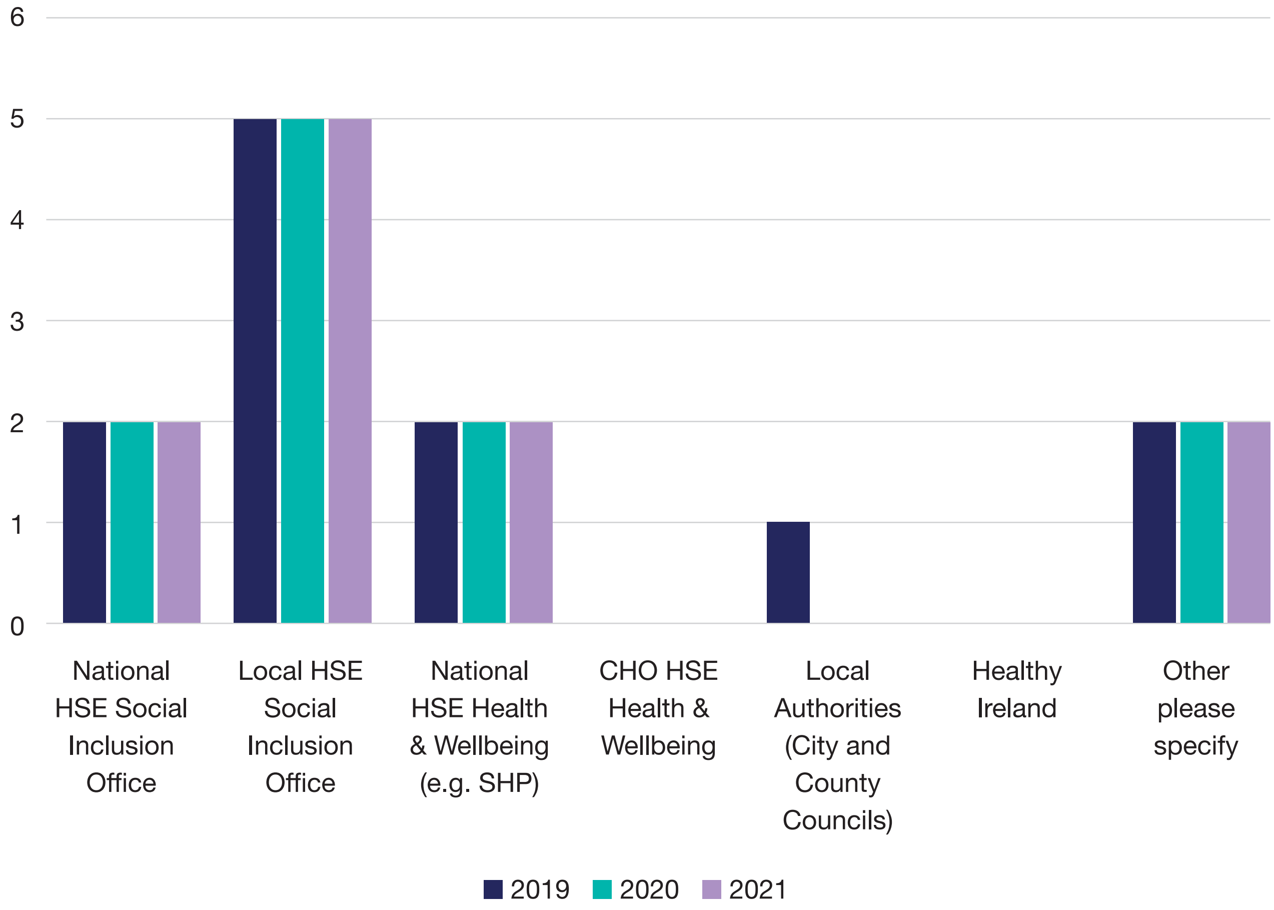

Figure 5.2 Sources of funding for support services for people living with HIV provided to organisations between 2019 and 2021.

Two respondents mentioned other sources of funding, one mentioned the Department of Social Protection, corporate and philanthropic funding, the other mentioned individuals, corporate bodies, philanthropic bodies and churches.

When asked to estimate the average WTE covered by funding for support services for people living with HIV between 2019 and 2021, five respondents reported a range of between 1 and 4 WTE.

5.3.3 Funding for HIV prevention

Of the ten Directors/CEOs who responded to the funding section, eight reported that their organisation accessed funding for HIV prevention interventions between 2019 and 2021. One respondent indicated that this was not applicable to their organisation. The sources of funding are outlined in Figure 5.3.

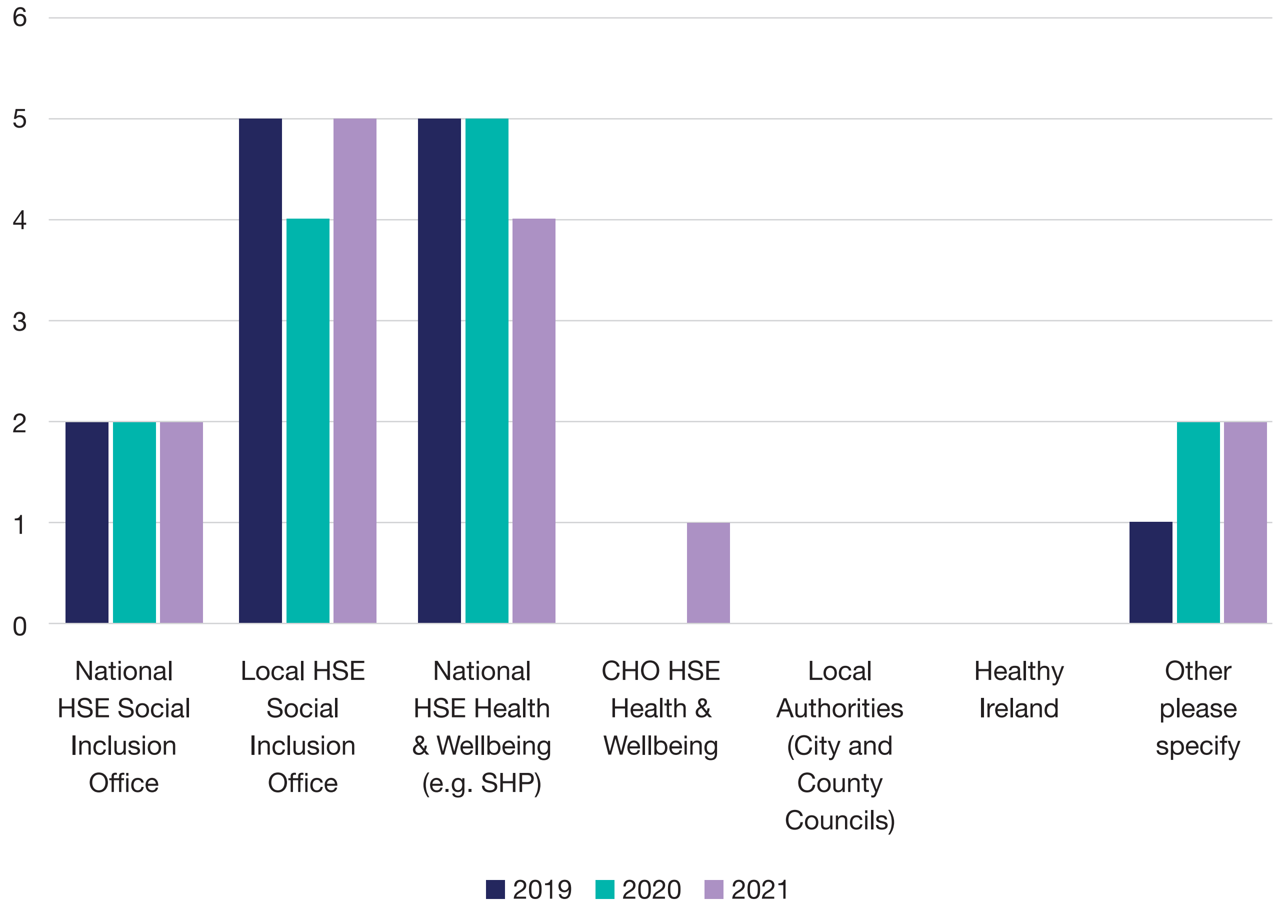

Figure 5.3 NGO sources of funding for HIV prevention interventions provided to organisations between 2019 and 2021.

From the eight responses received, National HSE Health and Wellbeing and Local HSE Social Inclusion Offices were the main sources of funding for HIV prevention interventions. Two respondents mentioned other sources of funding, one mentioned corporate and philanthropic funding, the other mentioned individuals, corporate bodies, philanthropic bodies and churches.

When asked to estimate the average WTE covered by HIV prevention funding between 2019 and 2021, six respondents reported a prevention range of between 1.1 and 5.5 WTE.

5.3.4 Funding challenges and gaps

Directors/CEOs and equivalents were asked if it has become more difficult to access funding for HIV support and/or prevention over the past two years since COVID-19. Five respondents answered yes, four responded no and one did not provide a response. Of the five respondents who reported that accessing funding had become more difficult, four were based in Dublin.

The participants were given the option of providing open-ended comments on the challenges and gaps in the availability or accessibility of funding for HIV support and prevention and how it could be improved. Six participants reported challenges/gaps and two provided suggestions for improvement.

The challenges and gaps reported were:

- Reduced availability of corporate and philanthropic funding, HIV is less of a priority (n=2);
- Unclear structures for accessing funding, funding opportunities not well communicated (n=1);
- No increase in funding for HIV support services over the period 2019-2021 (n=1);

- Difficulty securing funding for pilots which are necessary for proof of concept (n=1);
- A focus on particular population groups such as gbMSM, impacts on other marginalised groups (n=1);
- The current rise in the cost of living will make accessing donations more challenging (n=1);
- Insufficient funding restoration (n=1);
- Lack of HIV specific funding, that it is included within the broader sexual health remit (n=1);
- Dependence on HSE funding for infectious disease screening (including HIV) for asylum seekers and migrants (n=1).

The suggestions for improvement were:

- Increase core funding to ensure the proper management and administration of programmes and maintain effective service delivery. This includes meeting rising overhead costs (n=1);
- Increase funding for support services to meet existing needs and innovative service delivery (e.g. a national peer-support services, counselling and psychotherapy) (n=1);
- Improve access to funding from the CHO areas to help meet the demand for support services for people living with HIV in these areas. This includes peer support, one to one support, and counselling/psychotherapy (n=1);
- Report on the numbers attending HIV clinical services, to inform support needs by location (n=1).

5.4 HIV prevention and support services

All respondents (regardless of role) were asked which area(s) of HIV they worked in. Twenty (46.5%) respondents said that they work solely in HIV prevention, three (7%) said that they work solely in the provision of support services for people living with HIV, and twenty (46.5%) said they work in both HIV prevention and support for people living with HIV (Table 5.4).

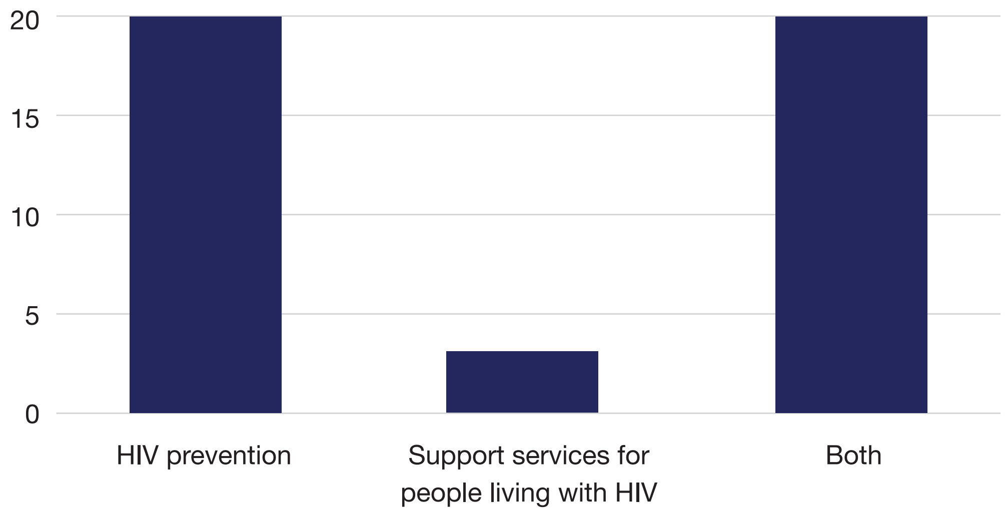

Figure 5.4 Areas of HIV work engaged in by respondents (n=43).

5.4.1 Support services for people living with HIV

This section outlines responses received from the survey respondents who said they provide support services for people living with HIV (n=23). Respondents were asked to report what support services they provide, from a list of 19 options, as listed in Table 5.5. Of the 23 respondents who said they provide support services, five responded to this question, three were from the same Dublin/National organisation, one was from a different Dublin-based organisation, and one was from a Cork-based organisation.

Table 5.3 Types of support services provided to people living with HIV (n=5).

Type of support service	n[28]
Advice/support in relation to stigma or discrimination	5
Advice or support to access HIV clinical care	5
Advice or support to access other health services	5
Advice or support to access other outreach/community services (such as drug/addiction, homelessness, etc.)	5
Information on HIV prevention, viral suppression, U=U	5
Practical information/resources (leaflets/websites) on living well with HIV	5
Advice/support on disclosing your HIV status	4
Sexual health information	4
Other please specify	4
Advice/support to access social welfare services (benefits, housing, etc.)	3
Counselling	3
Financial or legal information and support	3
High level HIV advocacy	3
HIV treatment advice (medications, how to take your tablets on time/correctly, side effects, etc.)	3
Safe space(s) to meet peers	3
Advice/support on immigration issues, accessing migrant support services	2
Advice on further education or employment	2
Peer-support group(s)	2
Seminars/classes on living well with HIV	2

Services most widely reported by the five respondents relate to the provision of general information and advice, with more specialised information such as legal or financial information provided less frequently. The four respondents who reported that they provide 'other' support services to people living with HIV mentioned a biennial conference for people living with HIV (n=1), fundraising policy (n=1), other community support (n=1), linking into hospital services (n=1), advocacy (n=1) and bereavement and emotional support (n=1).

When asked to report on the gaps in the provision of support services for people living with HIV, 19 (83%) participants provided open-ended responses:

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[28] Respondents were asked to tick all options that apply.

- Limited and inequitable availability of community support services (such as peer support) for those living with or affected by HIV, those living in rural areas or within specific populations such as migrant populations and people who use(d) drugs (n=8);
- Lack of supports to assist specific populations to attend clinical care and pathways between clinical and support services (n=4);
- Limited availability of and pathways for mental health supports such as counselling and psychotherapy (n= 3);
- No HIV consultant in University Hospital Limerick, requiring some clients to travel to other cities for medical treatment (n=3);
- Gaps in the availability of information and health promotion resources on living well with HIV, including dealing with stigma (n=2);
- Lack of specialist legal support for issues that affect people living with HIV (n=1);
- Clinic appointments being issued by letter, fear of clients living in shared accommodation that letters will be read by others (n=1);
- Lack of social groups and meet ups (n=1);
- Not all HCPs knowledge is up to date, online/e-learning does not suit everyone (n=1);
- Lack of sexual health information within the education system (n=1).

When asked about the main challenges in the provision of community support services to people living with HIV, 22 (96%) provided open-ended responses:

- HIV-related stigma in the general population and self-stigma prevents many people living with HIV being reached (in particular the migrant population) or accessing support services (n=9);
- Lack of funding, for core/administration costs, for staff and programme resources to deliver and develop services further (n=8);
- Meeting the needs of marginalised populations, including those living in rural areas, migrant populations or those hidden due to stigma (n=5);
- Accessibility and pathways to clinics/services (n=2);
- Undiagnosed HIV/delayed access to testing (n=2);
- Lack of dedicated space for the provision of local peer support, counselling and psychotherapy services (n=2);
- Structural and social issues/inequalities faced by many service users such as housing, addiction, increasing cost of living (n=2);
- Limited research and understanding on the varied needs of people living with HIV, including psychosocial and healthcare needs (n=2);
- Lack of information about the different population groups accessing HIV clinical services, in order to adapt support services (n=1);
- Medication compliance (n=1);
- Lack of female HIV advocates or activists (n=1).

Participants were invited to provide open-ended suggestions on how community support services for people living with HIV could be improved. Sixteen (70%) responded with the suggestions below:

- Increase funding to improve the availability of HIV support services, including funding for member organisations, peer-support programmes, mental health supports and supporting those marginalised or living in rural areas access HIV treatment and support services (n=7);
- Improve referral pathways and collaboration between HIV clinics and community support services, in particular for new HIV diagnoses (n=4);
- Conduct research, e.g. on clinic accessibility, the intersection between HIV and structural/social issues, provision of services internationally (n=3);
- Increase the number and types of support groups available, professional and peer-support groups, including training of peer-support workers (n=3);
- Improve the involvement of people living with HIV in decision-making and in service development and delivery (n=2);
- Provide broader education and communication on HIV to relevant sectors to help reduce stigma around HIV and sexual health (e.g. community development, health and social care professionals) (n=2);
- Increase HIV resources and availability of education and training for service providers and healthcare professionals (n=2);
- Improve the availability of information on statutory sources of funding, including at local level (n=1);
- Provide up-to-date information on all events for people living with HIV across Ireland and establish more formal channels to facilitate better sharing of information (n=1);
- Development of multi-agency support services (n=1);
- Deliver early interventions, e.g. with schools, families, people who inject drugs (n=1);
- Increased advocacy and information services for people living with HIV who face discrimination (n=1);
- Improve networking opportunities for service providers (n=1);
- Improve accessibility to services, e.g. regional medical checks or telemedicine (n=1);
- Consider the provision of language-specific clinics e.g. Ukrainian (n=1);
- A volunteer-led after-hours and weekend helpline (n=1);
- Increase funding to support adult education, further and higher education and employment activation (n=1).

Participants were also asked if there were any COVID-related challenges that continue to impact on their organisations' ability to provide HIV support services. One third of participants (n=8, 35%) reported a residual impact of COVID-19 on their service provision, with seven providing open-ended responses to elaborate further on this. Two respondents mentioned ongoing reduced capacity in service provision, while another two mentioned concerns about vulnerability to COVID-19 among people living with HIV, especially those who are unvaccinated, and that this was impacting on the support they receive. Other challenges identified were: provider exhaustion (n=1), a lack of research on the impact of COVID-19 on migrant and lower socio-economic communities (n=1), concern about future waves of COVID-19 (n=1), rapid testing only resuming in March 2022 (n=1), and a lack of knowledge about services that have fully resumed (n=1).

5.4.2 HIV prevention interventions

This section reports on the responses received from the survey respondents who said they provide HIV prevention interventions (n=40). Respondents were asked which population groups they target for HIV prevention interventions from a list provided. The responses are displayed in Figure 5.5. Respondents could select multiple population groups.

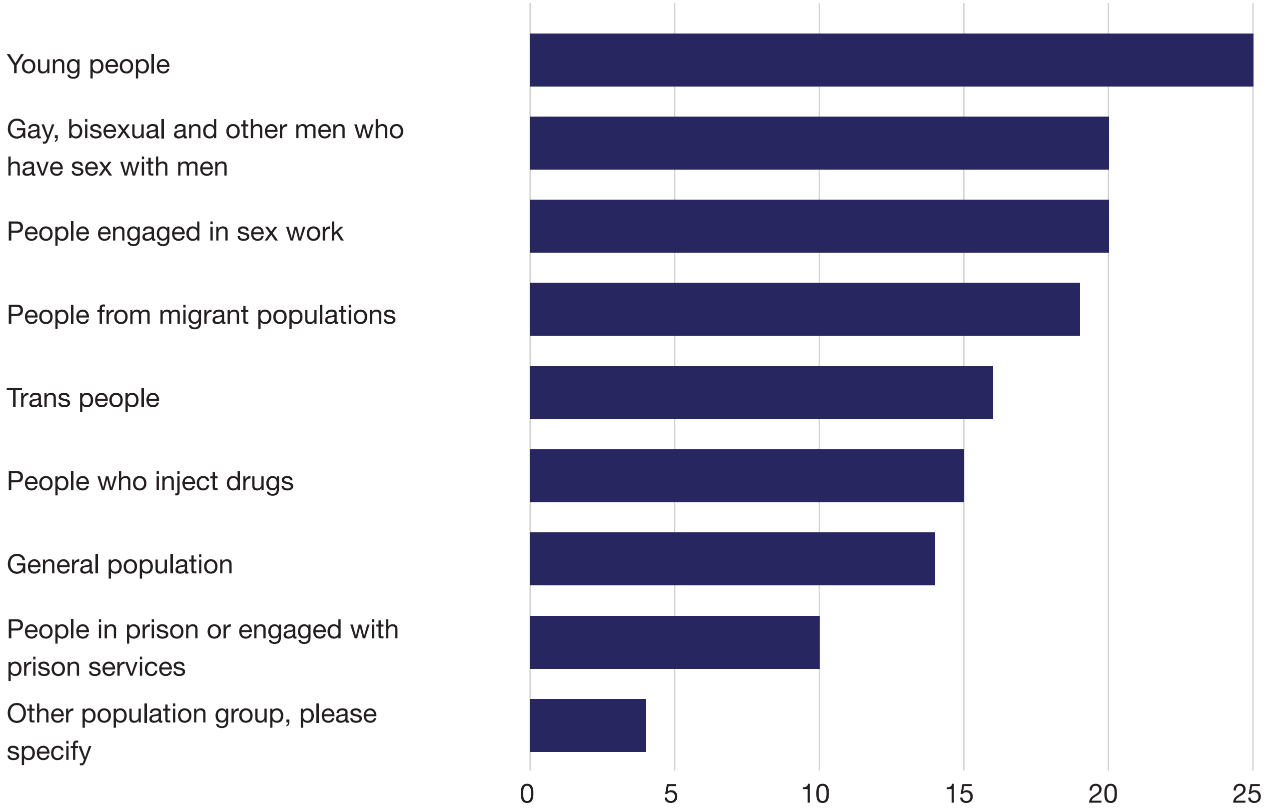

Figure 5.5 Population groups targeted for HIV prevention interventions (n=40).

Those who selected 'Other population group, please specify' noted that they provide HIV prevention interventions to professionals/staff who work with people/groups who may be vulnerable to HIV (n=2), women who use drugs, women engaged in sex work, and women recently released from prison (n=1), and people with disabilities (n=1).

Respondents were asked to report which HIV prevention interventions they provide, from a list of 12 options, for each of the population groups they target. There was also an option to describe any 'other' interventions they may provide that were not on the list. The number of respondents who provide each of the HIV prevention interventions is presented in Figure 5.6, by population group.

Table 5.4 Provision of HIV prevention interventions by population group.

	General population	Young people	gbMSM	Trans people	People who inject drugs	People from migrant populations	People engaged in sex work	People engaged with prison services	Other population group
	n=14	n=25	n=21	n=16	n=15	n=19	n=20	n=10	n=4
Information and advice on HIV transmission and prevention	13	22	21	16	14	18	19	9	4
Health promotion and risk reduction education	13	19	20	15	14	17	19	9	4
Information on HIV prevention interventions	13	20	21	16	13	17	19	8	4
Provision of condoms and lubricant	12	13	21	15	11	16	18	7	4
STI testing and treatment	6	5	8	6	8	10	10	4	2
HIV testing and counselling	13	10	20	15	12	18	18	7	2
Information on harm reduction	7	11	17	14	12	13	18	8	4
Harm reduction interventions	3	4	4	3	5	3	5	2	2
Information on HIV treatment as prevention, U=U	13	11	20	15	12	17	18	8	4
HIV treatment adherence support	9	4	11	9	6	9	11	4	2
Community outreach	12	10	17	13	10	13	16	7	2
Other prevention intervention	0	2	4	1	3	3	3	0	1

The ‘other’ HIV prevention interventions that respondents said they provided in addition to those on the list, are described in Table 5.6, by population group.

Table 5.5 Other HIV prevention interventions.

Population group	‘Other’ HIV prevention interventions
Young people (n=2)	Referrals to Guide Clinic for treatment and adherence support (n=1)
	Did not specify (n=1)
Gay, bisexual and other men who have sex with men (n=2)	Referrals to Guide Clinic for treatment and adherence support (n=1)
	Chemsex support (n=1)
	STI testing and counselling offered from Outhouse in collaboration with both GMHS and MPOWER at HIV Ireland. We act as the community-based setting in which this work takes place (n=1)
Trans people (n=1)	STI testing and counselling offered from Outhouse in collaboration with both the Gay Men’s Health Service (GMHS) and MPOWER at HIV Ireland. We act as the community-based setting in which this work takes place (n=1)
People who inject drugs (n=3)	Referrals to Guide Clinic for treatment and adherence support (n=1)
	Peer support (n=1)
	Prevention work as previously described, but more defined by 'where' it takes place than 'what' is offered. For example, people's homes at a kitchen table. (n=1)
People from migrant populations (n=3)	Referrals to Guide Clinic for treatment and adherence support (n=1)
	Peer support (n=1)
	Prevention work as previously described, but more defined by 'where' it takes place than 'what' is offered. For example, faith communities at a weekend event. (n=1)
People engaged in sex work (n=3)	Referrals to Guide Clinic for treatment and adherence support (n=1)
	Peer support (n=1)
	STI testing and counselling offered from Outhouse in collaboration with both GMHS and MPOWER at HIV Ireland. We act as the community-based setting in which this work takes place. (n=1)
Other population group: People with disabilities (n=1)	Did not specify (n=1)

When asked to report on the gaps in the provision of HIV prevention interventions, 30 participants (75%) provided open-ended responses:

- Insufficient availability of PrEP services to meet demand (n=11);
- Limited provision of information and education on sexual health and HIV for young people, in formal and non-formal education settings, including training for teachers (n=7);
- Insufficient sexual health and HIV prevention interventions and supports, particularly for specific populations including migrant populations (especially those who do not speak English or are new to Ireland), those living in a homeless setting and older people (n=6);

- Insufficient availability of (community-based) HIV testing (n=5);
- Insufficient awareness raising and prevention campaigns, in general and for specific populations including migrant populations, older people and those engaged with the prison service (n=3);
- Insufficient staffing/resources for NGOs to cover a large geographical catchment (n=2);
- Insufficient access to PEP, in particular out of hours and in locations other than emergency departments (n=3);
- Limited funding/resources for health promotion/HIV information and prevention campaigns, including budget for translation of information (n=2);
- The U=U message can be hard to understand. Research on how best to communicate the U=U message in the Irish context (n=1);
- Insufficient number of healthcare professionals working in this sector (n=1);
- Availability of safe smoking and injecting paraphernalia in prison (n=1);
- Availability of good public health information and accessible training to improve the skills of frontline staff to better support key population groups, including issues such as harm reduction and mental health (n=1);
- Changes in the provision of clinic- and community-based services following the COVID-19 pandemic continues to be challenge (n=1).

When asked about the main challenges to the provision of HIV prevention interventions, 30 participants (75%) provided open-ended responses:

- Engaging individuals who may not understand/admit their risk, or specific population groups such as migrant populations with language barriers or different cultural beliefs (n=10);
- Stigma and discrimination among the general population, in rural areas and among service/healthcare providers (n=9);
- Insufficient funding, resources and space for NGOs to provide sustainable services that meet the diverse needs of communities (n=5);
- Insufficient access to PrEP and promoting PrEP to individuals who are then unable to access it (n=3);
- (Incorrect) online information (n=2);
- Lack of understanding/up-to-date knowledge about HIV in community and service providers (n=2);
- Lack of young person’s clinics, for people aged under 17 years (n=1);
- Gardaí using condoms as evidence of sex work (n=1);
- Transport and costs to travel to community services (n=1);
- Negative shadow cast by initial inadequate response to AIDS (n=1).

Participants were invited to provide open-ended suggestions on how HIV prevention interventions could be improved. Twenty-one (52.5%) responded with the suggestions below:

- Improve HIV awareness, communications and campaigns, for example through mainstream media coverage, social media or education in schools (n=7);
- Increase funding/resources, including multi-annual funding, funding for additional staff, expansion of outreach services in rural locations and to cover travel expenses (n=5);
- Continue and expand community (rapid) HIV testing (n=2);
- Improve availability of PrEP (n=2);
- Increase peer-led services (n=1);
- Make information available in multiple languages and provide interpreters at point of care (n=1);

- Provide training on cultural competence to clinic staff working with gbMSM and trans people (n=1);
- Facilitate one to one work and group sessions for young people (n=1);
- Remove the age restriction for the HSE home testing service to improve access to testing for young people (n=1);
- Prevent Gardaí from using condoms as evidence (n=1).

The final question asked if there were any COVID-related challenges that continue to impact on their organisations ability to provide HIV prevention interventions, to which nine (23%) participants responded yes, providing open-ended responses to elaborate further on this. Six respondents mentioned ongoing reduced access to HIV prevention interventions or face-to-face services, and working towards a return to full service delivery. Other challenges identified included: provider exhaustion (n=1), a lack of research on the impact of COVID-19 on migrant and lower socio-economic communities (n=1), concern about future waves of COVID-19 (n=1), an increase in the demand for Relationship and Sexuality Education in schools after being missed during COVID (n=1), delays in the development of the next Sexual Health Strategy and HIV Fast-Track Cities implementation plans (n=1) and the COVID-19 pandemic pushing HIV even further off the radar (n=1).

5.5 Chapter summary

This chapter presented the findings from the 43 respondents who completed the survey for NGOs and community organisations. Respondents outlined a range of challenges and gaps relating to funding and the provision HIV prevention services and support services to people living with HIV, alongside suggestions for service improvement. The findings will inform recommendations at the end of the report and the subsequent development of city implementation plans.

Chapter 6

People living with HIV

6.1 Introduction

An online survey was conducted with people living with HIV who were aged 18 years and above and living in Ireland to gather insights on their opinions on the services and supports available to them, and to document challenges and gaps. The survey topics included testing and diagnosis, prevention with partners, care in general practice, HIV clinical care, self-management and participation in care, health and wellbeing, stigma and discrimination and community and peer-support services. The survey was open for a period of three months from mid-April to mid-July 2022. Further information on survey dissemination is described in methodology Section 2.4.3.

This chapter presents the qualitative and quantitative findings from the online survey.

6.2 Participant information

Seventy people living with HIV participated in the survey. Of these, 71% (n=50) were male and 61% identified as gay (n=43). Of those who provided their age (n=54) two thirds (65%) were over the age of 40. The median age of respondents was 46, and ages ranged from 20 to 73. The average age at time of HIV diagnosis was 33. There was good geographical spread among participants with responses from people living in 18 counties across Ireland. Altogether 57% (n=40) were born in Ireland and 41% were born outside of Ireland (from 13 different countries). One respondent did not cite their country of birth. Table 6.1 presents the demographic profile of survey respondents.

Table 6.1 Demographic profile of survey respondents.

Demographic Characteristic	Response	n	%
Age	20-29	3	4
	30-39	16	23
	40-49	16	23
	50-59	10	14
	60+	9	13
	Not provided	16	23
Gender	Female	14	20
	Male	50	71
	Non-binary	3	4
	In another way	0	0
	Prefer not to say	3	4

Demographic Characteristic	Response	n	%
Sexuality	Straight/heterosexual	18	26
	Gay or lesbian	43	61
	Bisexual	6	9
	Other	0	0
	Prefer not to say	1	1
	Not provided	2	3
Region of birth	Ireland	40	57
	Europe (excluding Ireland)	12	17
	Africa	7	10
	South America	5	7
	North America	3	4
	Asia	2	3
	Middle East	0	0
	Not provided	1	1
Year of HIV diagnosis	2020-2021	11	16
	2010-2019	25	36
	2000-2009	21	30
	1990-1999	8	11
	1980-1989	5	7
Region of HIV diagnosis	Ireland	50	71
	Europe (excluding Ireland)	12	17
	Africa	3	4
	USA and Canada	2	3
	Asia	1	1
	Middle East	1	1
	South America	1	1
Attending HIV clinical service	Yes	66	94
	No	4	6
Registered with a GP	Yes	60	86
	No	8	12
	Don’t know	1	1
	Not provided	1	1

From the 70 respondents, 71% (n=50) were diagnosed with HIV in Ireland, and 27% (n=20) were diagnosed outside of Ireland. Just over half of respondents (n=36, 52%) were diagnosed with HIV between 2010 and 2021, and just under half (n=34, 48%) were diagnosed in 2009 or before. Of those diagnosed pre-2009, 18% (n=13) were diagnosed between 1980 and 1999. Ninety-four per cent (n=66) of respondents reported currently attending a HIV clinical service for HIV care and treatment, of these, 59% (n=39) are attending a Dublin-based service. Eighty-seven per cent (n=60) of respondents are registered with a GP (Table 6.1).

6.3 HIV testing and diagnosis

Participants were asked where they first tested positive for HIV. Sixty-four of the 69 respondents were diagnosed in a clinical setting, the most common location was in a public STI clinic (41%). Overall results are presented in Table 6.2.

Table 6.2 Location of test when first tested positive.

Location	Number	%
Public STI clinic	29	41%
GP/Primary care	11	16%
Hospital as an outpatient	11	16%
Community/mobile testing site	3	4%
Hospital emergency department	3	4%
Hospital as an inpatient	5	7%
Antenatal clinic	2	3%
Blood donation	1	1%
Unspecified medical setting	2	3%
Home sampling (take own sample and send to lab)	2	3%
Self-testing (do own rapid HIV test and get an immediate result)	0	0%
Prison	0	0%
Drug or addiction services	0	0%

Participants were asked to select from a list of five potential reasons why someone might delay testing for HIV, multiple responses could be selected. The most commonly selected answer was HIV-related stigma (n=54, 77%), followed by fear of receiving a positive result (n=51, 73%). The third most commonly selected response was a lack of knowledge about HIV transmission and individual risk for HIV (n=48, 69%). Access to HIV testing and reluctance of providers to offer HIV testing were selected by 26 (37%) and 19 (27%) respondents respectively (Figure 6.1).

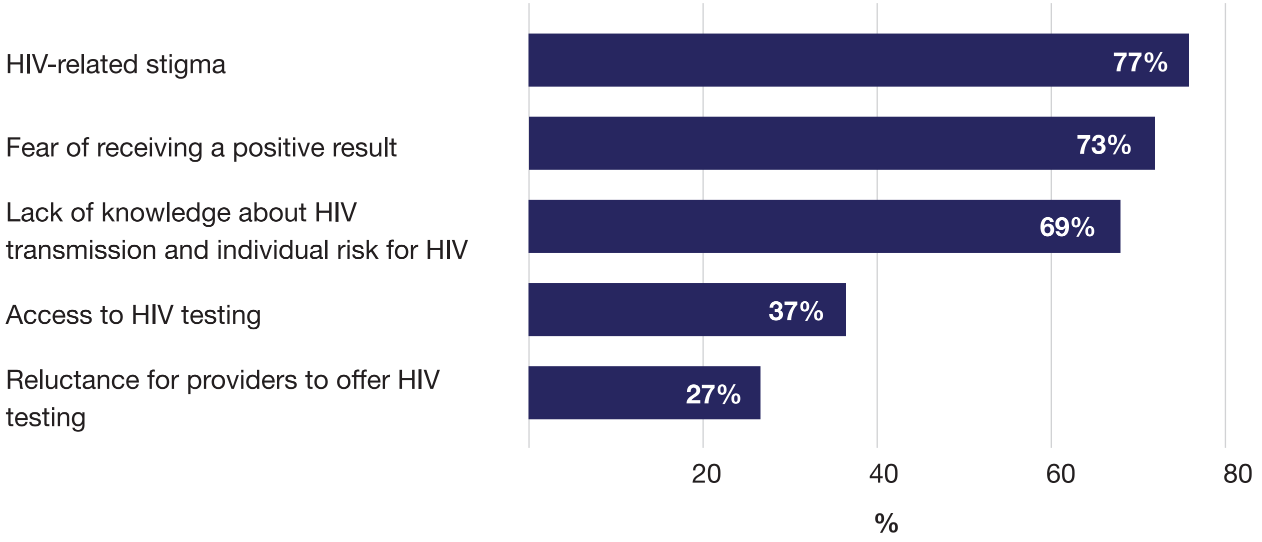

Figure 6.1 Reasons why someone may delay testing for HIV (n=70).

Four respondents described other factors that may make someone delay testing for HIV, two mentioned that having a test for HIV might impact ability to obtain insurance, one participant mentioned lack of knowledge around availability of testing and another mentioned that, at the time, no treatment was available and so testing was futile.

Respondents were invited to describe what might make it easier for someone to test for HIV and therefore be diagnosed sooner, 56 individuals provided open-ended responses to this question. Respondents felt very strongly that HIV testing should be normalised and considered in an opt-out basis in healthcare settings, and that HIV testing should be included in general health checks. It was also suggested that STI clinics be made more accessible (e.g. extended opening hours). All other suggestions are outlined in Table 6.3.

Table 6.3 Suggestions for how to make HIV testing easier.

Suggestions	Frequency
Increase HIV testing availability, expand access and capacity, normalise HIV testing including provision of opt-out testing	31
Make Information On HIV Available, Including HIV Awareness And Stigma Reduction Campaigns	16
Improve education around HIV prevention and treatment, incorporate into school curricula	10
Improve knowledge of U=U, HIV treatment and prevention medications	7
Improve general awareness that HIV can affect all populations	3
More efforts to reach underserved populations	3
Ensure services are discreet	2
HIV is not different to other diseases – portray HIV like other long-term chronic illnesses	1
Invest in community leaders	1
Establish a peer helpline	1

Participants were asked if they were referred to, or provided with information on accessing services, at the time of their diagnosis. Four options were provided and respondents could tick all that applied to them. Out of the 70 respondents, 79% (n=55) were referred to or provided with information on accessing HIV clinical services, overall results are presented in Figure 6.2.

Some 34% (n=24) were provided information on or referral to counselling or psychological supports, 24% (n=17) to peer support and 21% (n=15) to NGO or community organisations. Two participants said that they were not referred to or given information on accessing any services as no treatment was available at the time.

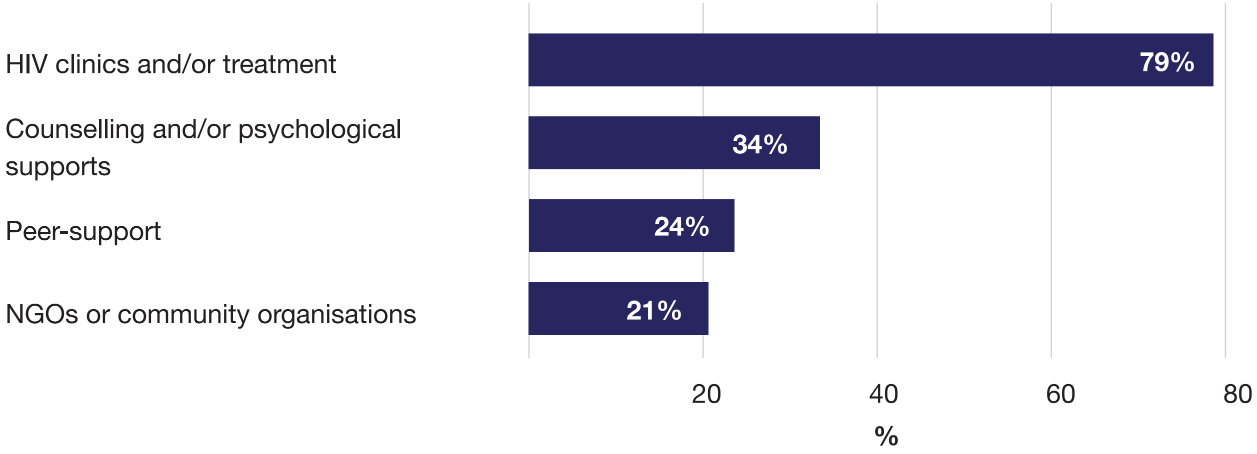

Figure 6.2 Percentage of respondents who were referred to, or provided information on accessing services at time of diagnosis (n=70).

6.4 Prevention with partners

The statement *U=U* or *undetectable = untransmittable*, relates to the fact that a person on HIV treatment with undetectable viral load cannot pass on HIV through sex. Almost all of the respondents (n=69, 99%) had heard of the U=U statement, with 80% (n=56) strongly believing and 14% (n=10) somewhat believing the statement (Figure 6.3).

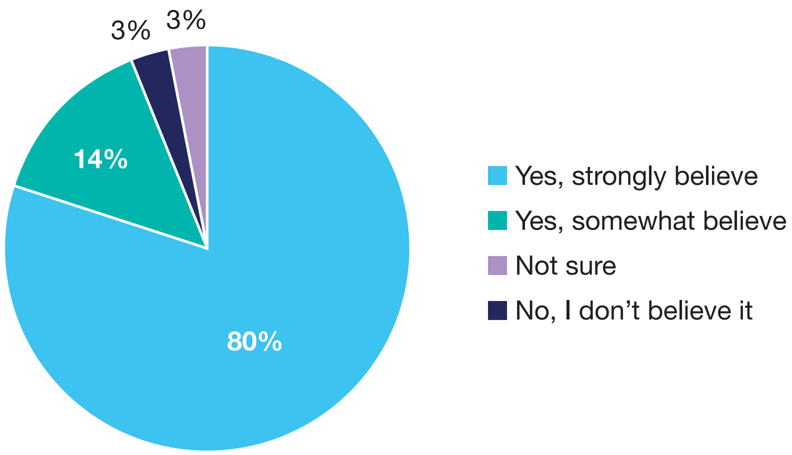

Figure 6.3 Do you believe the U=U statement? (n=70).

When asked how the statement made them feel about their own HIV status more than half stated that it made them feel much better (54%, n=37), 17 felt better (25%) and eleven felt the same about their status (16%), two felt worse (3%) and two others felt much worse (3%). Participants were invited to provide their thoughts on the U=U statement, 36 participants provided responses, themes are presented in Table 6.4.

Table 6.4 Thoughts on U=U.

Theme	n	Sample quote
U=U is not well understood by the public, and needs promotion	7	I know what undetectable is and U=U but a lot of people do not and the ones that do are sceptical and not willing to trust you are undetectable.
Feels positive/life changing/ empowering/provides emotional stability/improves confidence	5	HIV affects no one but me. It is empowering.
Relationship benefits/enjoy sex/confidence with partners	5	It is sexually liberating. I no longer have fear of passing on HIV to my partner.
Good, it helps, it's powerful	4	I feel like a normal person again.
It hasn't reduced stigma	3	U=U doesn't change anything. Worst yet, nowadays since the U=U campaign, I get asked about my VL for things that are not a HIV risk to anyone regardless of my VL.
It can help to reduce stigma	3	It is an excellent initiative to break down barriers related to HIV stigma.
Sceptical, hesitant to believe fully	3	I don’t fully feel convinced about it, and worry about passing it to someone.
Some HCPs aren't aware of it/ it hasn't changed attitudes	3	HIV stigma is the same including from the HSE and doctors/ pharmacists.
May make people careless	2	Makes men think they are invincible and can do what they like but they forget about the other reasons they should protect themselves against all other STIs.
Simple and effective message	2	I think the simplicity of it is perfect… U=U to me is a very effective slogan for its message.

The most common response received from participants was that U=U is not understood by the public and requires promotion. Participants stated that U=U made them feel more positive about life, that it had a positive impact on their relationships and sex life. There were mixed responses about the impact of the U=U on HIV-related stigma with equal numbers believing that it has the potential to reduce stigma or that it had not reduced stigma. There were a few negative observations with three participants sharing that some HCPs are not aware of U=U and that it has not changed attitudes towards people living with HIV.

6.5 Care in general practice

Respondents were asked if they were registered with a GP. Sixty-nine responded to this question: 87% (n=60) were registered with a GP; 12% (n=12) were not; and 1% (n=1) did not know. Of the 60 individuals who are registered, 98% (n=59) reported that their GP is aware of their HIV status.

Participants were provided with five statements about their experiences with their GP, and were asked for their viewpoint. Overall, 70% (n=39) reported that they strongly agreed or agreed that their GP knows enough about their HIV condition and treatment. Seventy-nine per cent (n=41) of participants strongly agreed or agreed that they are comfortable discussing their HIV with their GP, and 74% (n=41) strongly agreed or agreed that their GP is as involved as they want them to be in their HIV care. Fifty-seven per cent (n=31) of respondents strongly agreed or agreed that their HIV specialist and their GP communicate well regarding their health. Thirty-seven per cent of participants (n=17) strongly agreed or agreed that they do not attend their GP on a regular basis due to the cost of attending, however 63% (n=29) strongly disagreed or disagreed with this statement, meaning that cost was not a barrier for attending the GP for these 29 individuals. Figure 6.4 presents these findings.

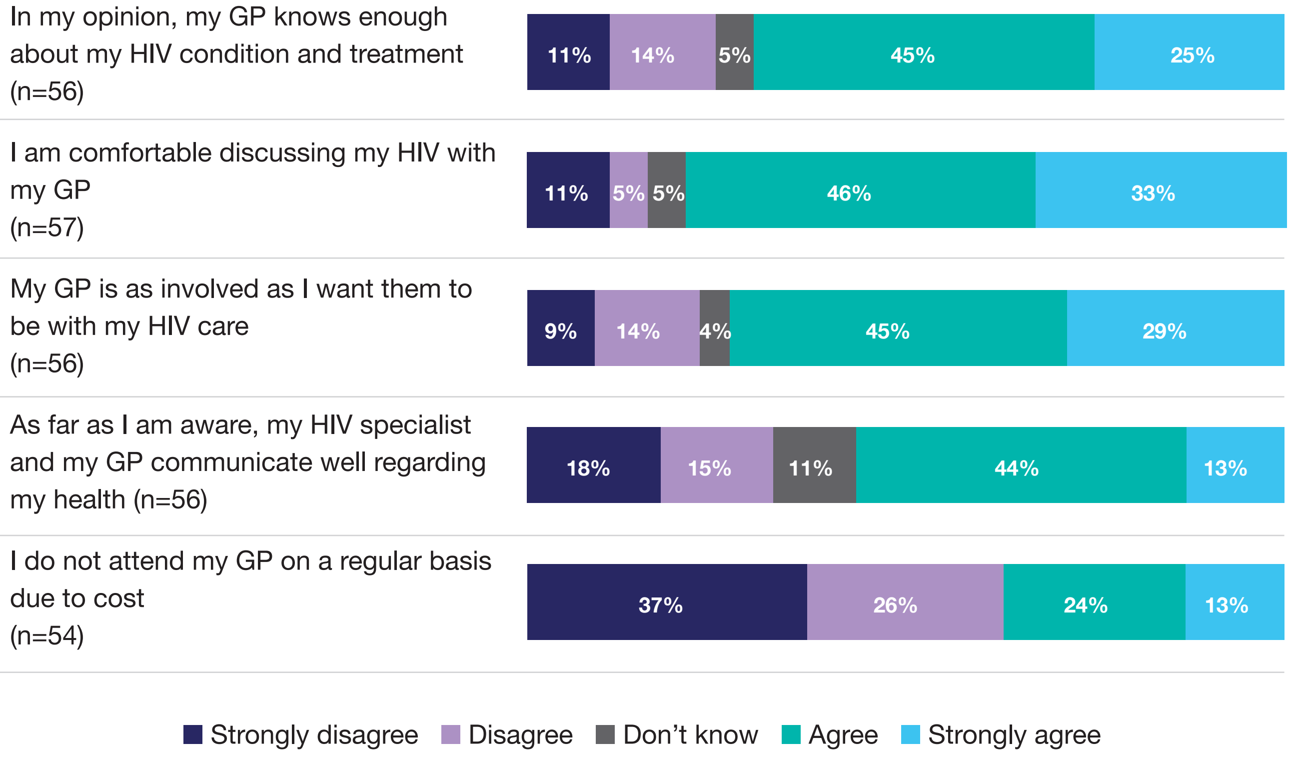

Figure 6.4 Experiences with general practitioners.

6.6 HIV clinical care

Participants were asked how satisfied they were with their HIV clinical care. Overall, 83% (n=53) reported being satisfied or very satisfied with their clinical care, 11% (n=7) reported being dissatisfied or very dissatisfied. Figure 6.5 presents the overall results.

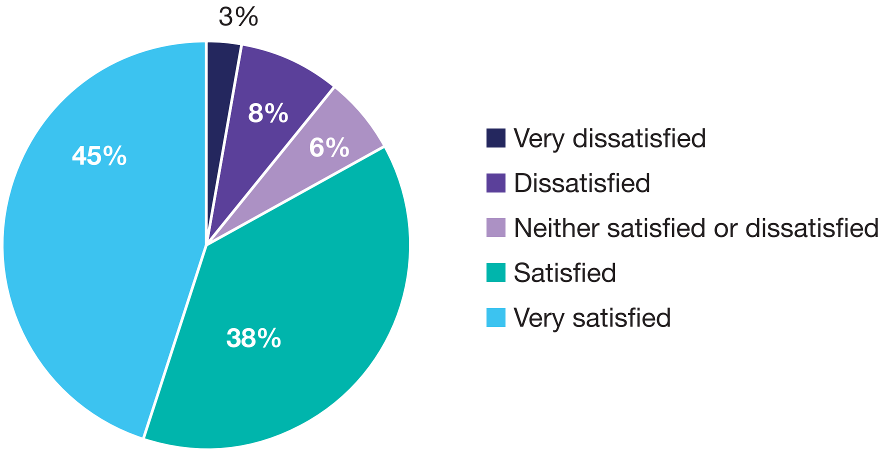

Figure 6.5 Satisfaction with HIV clinical care (n=64).

HIV-related support needs

Respondents were asked if they had needed or received specific HIV supports. A list of seven supports were provided and respondents were asked if they had received it, needed it but could not get it, needed it but did not try to get it, needed it but did not know about it, or did not need it.

The proportion of 'need' was defined as the percentage of respondents who stated they needed or received a service, out of all those who responded to each question. The proportion of 'unmet need' was defined as the percentage of respondents who did not receive a specific support, out of those who stated they needed it (the three options above).

The most commonly reported need overall was for HIV treatment advice. Nearly all (n=59, 94%) of respondents indicated that they needed this, of whom, the majority (n=51, 86%) stated that they had received this advice. Similarly, 85% (n=53) said they needed information about living with HIV, of whom, 83% (n=44) of respondents said this need was met, and 65% (n=41) of respondents said they needed professional help to take their HIV tablets on time or correctly, of whom, 85% (n=35) said that they had received this help.

Three quarters (n=48, 75%) of respondents said they needed peer support or social contact with other people with HIV, of these, 67% (n=32) said this need was unmet. Additionally, 55% (n=35) of respondents reported needing help disclosing their HIV status and this need was unmet for 60% (n=21) of those who needed it. Seventy per cent (n=45) of respondents said they needed help managing long-term conditions or comorbidities, and half (n=23, 51%) reported this need was unmet. Figure 6.6 presents the level of met and unmet need for HIV-related supports among those reporting a need.

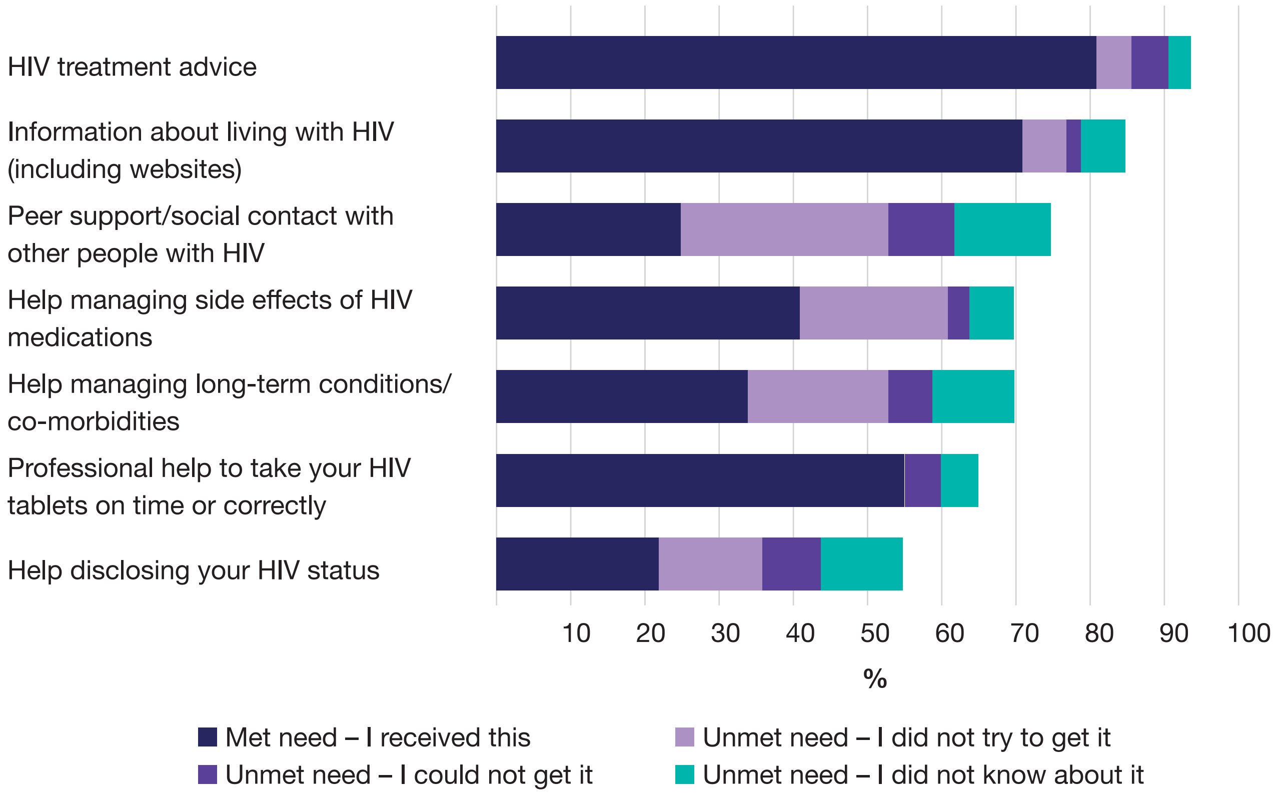

Figure 6.6 Met and unmet HIV-related support needs, amongst overall reported need.

When participants reported that they could not get the support they needed from HIV clinics, they were given the option of elaborating why they thought this was the case. Twenty participants provided open-ended responses, which are grouped in Table 6.5.

Table 6.5 Reasons why participants could not get support from HIV clinics.

Theme	n	Sample Quote
HIV clinic reluctant to acknowledge side effects from HIV medication, experience of side effects dismissed, reluctant to change medication despite availability of alternative drugs	6	When I first attended the HIV clinic, I needed to take my meds every day at the same time. I was told there might be some side effects but honestly this was just a very brief comment. My first meds had real bad side effects and I was told for a year and a half that I would get used to them before the clinic agreed to change my meds, even though I asked time after time.
Information not provided at HIV clinics	4	I had to find out about the info myself. It wasn't given at the clinic.
Not informed about peer-support at clinics	3	In Ireland I have never been offered peer support. I have been repeatedly warned by medical professionals NOT to seek peer support or have any contact with other people with HIV due to the stigma I would experience.
Too focused on the medical treatment of HIV, holistic care is overlooked	3	Many times HIV is treated like a one tablet a day and you're fine illness. Often times clinics don't consider a wholesome treatment for HIV.
Information or support not available at time of diagnosis	3	It was not available when I was diagnosed. As in there were no proper peer-support groups. By proper I mean trained, structured, etc.
Lack of time at appointments to discuss other issues and needs	2	A lot of the time the clinics are too busy to care about these.
Did not know how or where to access information or support	1	
Told to go to GP to get help with side effects from HIV medication	1	
Frequent clinical rotation of doctors who have no interest in HIV	1	
Poor connectivity with GPs in terms of coordinating treatment	1	
Closure of support service in the area	1	
COVID-19	1	

One participant described how it took time to build confidence to establish a good relationship with their clinic. One participant also expressed a wish for more support managing long-term conditions/ comorbidities ‘even without asking, I would love to have them talk to me about this.’

Respondents were asked if their satisfaction with their HIV clinical care had changed in the past two years since COVID-19. The majority (n=44, 68%) reported that their satisfaction remained the same. Eleven participants (17%) reported that their satisfaction had increased, and ten (15%) reported that their satisfaction had decreased.

The 21 participants who had reported a change in their satisfaction since COVID-19, were invited to describe why their satisfaction had changed and what could be improved. Eighteen open-ended responses were received, some were directly related to COVID-19 (Table 6.6) and others were related to changes in satisfaction around HIV care in general (Table 6.7).

Table 6.6 COVID-19 related changes in HIV care satisfaction.

Increased satisfaction	**Frequency**
Improved efficiency and less waiting time	4
Staff aimed to provide best care possible and very proactive	2
HIV clinic offered better general healthcare help and support compared to GP	1
Decreased satisfaction	
Nurse only visits during early COVID-19	1
Harder to access services	1
The improved efficiency during early COVID-19 is gone	1
Other comments	
Problems that patients were experiencing for years were immediately solved when same issues began affecting staff during COVID-19	1

Table 6.7 General comments on change in HIV care satisfaction.

Improved satisfaction	**Frequency**
Very supportive staff	1
More confident about own HIV status	1
Provide more than HIV care (e.g. vaccines, STI testing)	1
Decreased satisfaction	
Lack of connectivity between HIV clinics and peer-support	1
Constantly seeing new doctors and consultants is exhausting and intrusive	3

Participants were invited to provide open-ended suggestions on how general HIV care or treatment could be improved. Thirty-seven participants provided responses, which are grouped into suggestions in Table 6.8.

Table 6.8 Suggestions for how HIV care or treatment could be improved.

Suggestions	n	Sample quote
Improved and/or automatic access to counselling and peer-support on-site	8	I think everyone should receive some counselling and support automatically. I was completely alone with my diagnosis for years, in a very dark place.
Consistent consultant and doctors at each clinic visit, improve continuity of care	6	I've been attending clinic since 2015 and have rarely seen the same doctor.
Improved clinic infrastructure and aesthetics	5	These are spaces we have to attend all our lives and there should be a sense of warmth and belonging. Clinic X is particularly grim.
Improved waiting times, including at the clinic pharmacy	5	My normal wait is 4 hours in hospital and I work full time so I have to lie about appointments.
Extend opening hours/ increase flexibility, improve clinic contactability and administrative support	5	It would be helpful if there was a HIV contact number where any problems that occurred between clinic appointments could be discussed.
Improved confidentiality in waiting areas, and pharmacy medication collection areas	5	I am always slightly mortified that this [medication] is discussed openly and not in a separate room. I'm pretty sure this is not GDPR compliant too?
Allow time for discussing HIV medication, side effects and other treatments	4	I've attended the clinic and found that my medication has already been prescribed - despite the fact that I might've wanted to discuss changing treatment. I've never been given information on availability of treatments.
Electronic/digital communication of appointments and test results	3	I don't want a letter coming to my door every time for an appointment people should be able to opt for email or text messages.
Promotion of support services/ groups and resources	3	They still don't adequately promote outside resources like Sexual Health Clinics and support groups.
HIV-related and stigma reduction education for HCPs including GPs, pharmacists and dental staff	3	Re-education should be mandatory all pharmacies and GP on HIV so when they do come into contact with us it's not like time travel back to 1985. Also, do something about dental care.
Less judgemental attitude from staff	2	Staff can be unhelpful and quite judgemental. If I were really ill I would not want to be under their care.
Decentralised HIV care to the community	2	Care and treatment could be decentralised to Primary Care centres in smaller towns across Ireland.
Address staff shortages and clinic resourcing as patient care is being compromised	2	A permanent consultant is needed badly in [X clinic]…Staff try their best but are up against it.

Suggestions	n	Sample quote
Learn from centres of excellence abroad	2	I'd also definitely take a leaf out of the 56 Dean Street book - Option E is a great initiative. Being able to attend for bloods then get an email within a couple of weeks, whatever the result, is a great service.
Establish patient advocacy groups led by people living with HIV	1	
Give patients time to digest their diagnosis before launching into health promotion advice	1	
GPs could do bloodwork	1	
Ensure all relevant services are provided at the HIV clinic, remove the need to travel to different places	1	
Participation in own care, joint decision-making	1	
Allow for open and honest discussions around risks of drug taking	1	

Participants emphasised the need for automatic access to counselling and peer support, especially at time of diagnosis, and to improve continuity of HIV care by having consistent consultants and doctors when attending appointments. Several participants described their clinics and waiting areas as ‘particularly grim’, ‘grubby’, ‘depressing’ and ‘daunting’, and said that these areas should be made to feel more welcoming. Participants regularly described waiting for hours to be seen in clinic, and that this wait time is just not feasible or acceptable. Lack of confidentiality was cited as an ongoing issue.

Three participants reported that they had no suggestions for improvement as their HIV clinic offers the holistic healthcare that is needed ‘I cannot fault the service of the staff from security guards at the door to the nurses and doctors.’ Another participant acknowledged the outstanding work of nurses at their HIV clinic ‘nursing staff are phenomenal and are better sources of support than anything else’.

6.7 Self-management and participation of people living with HIV in their care

Participants were asked if they agreed or disagreed with a series of six statements about their experience and participation in their care within their HIV clinic. Figure 6.7 presents the overall results.

Overall, the majority of respondents agreed/strongly agreed that their clinics provide them with enough information about their HIV, and that information was provided in an understandable format. Eighty per cent (n=51) feel supported to self-manage their HIV, and 62% (n=47) agreed that they are involved in decisions about their HIV treatment and care. Sixty-eight per cent (n=44) reported having enough time at appointments to cover everything that needed discussed, compared to 30% (n=19) who reported not having enough time at appointments. Sixty-nine per cent (n=44) agreed that staff listen carefully to what they had to say, although 28% (n=17) disagreed with this.

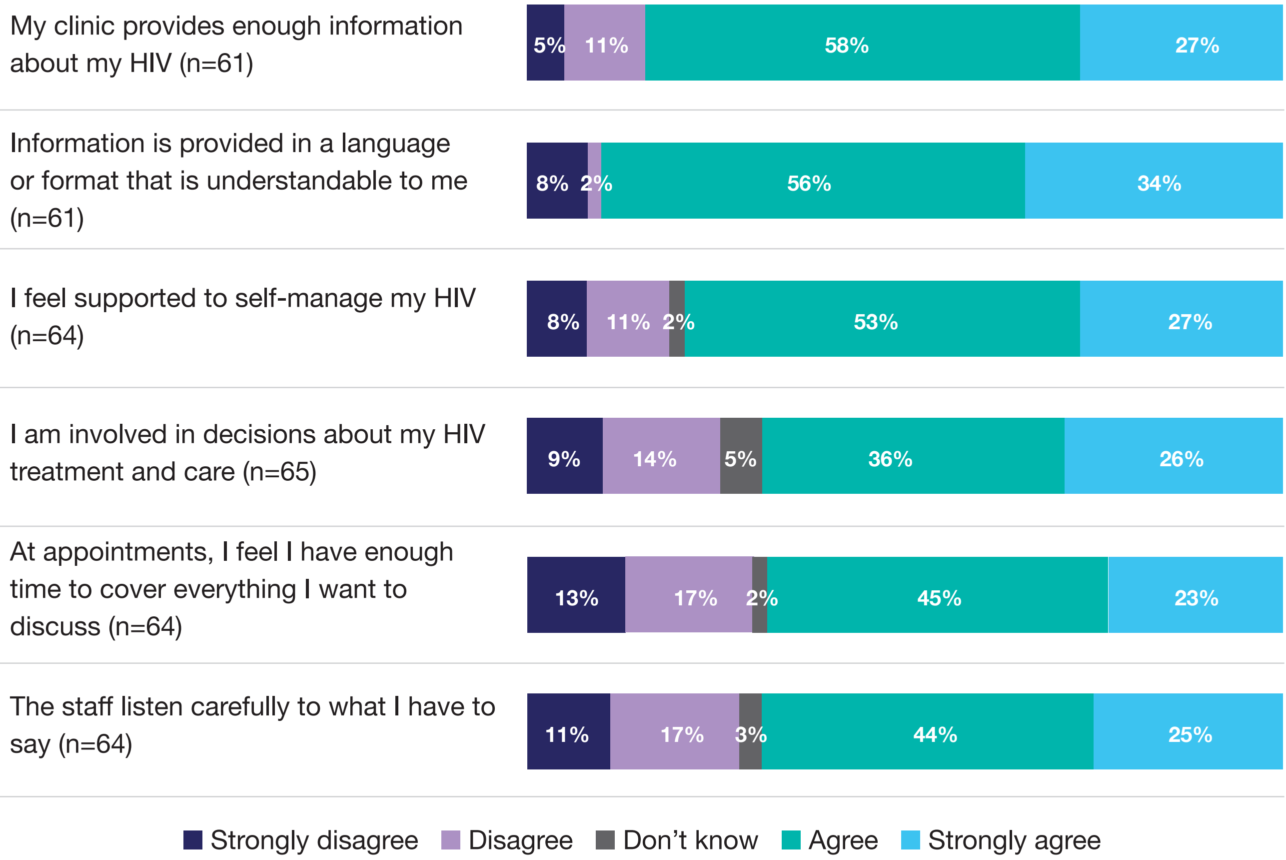

Figure 6.7 Experience and participation of people living with HIV in their HIV clinics.

Participants were asked if they would like to be more involved in their HIV care, and be more supported to self-manage their HIV to which 67% (n=42) said yes, and 33% (n=21) said no.

Participants were given the option of providing information on the challenges to self-managing their HIV and for suggestions to improve involvement in their HIV care. Eighteen open-ended responses were received which are grouped by challenges in Table 6.9 and by suggestions in Table 6.10.

From the 18 responses, nine respondents described challenges, four reported no challenges to self-managing their HIV. One other participant reported that they are quite happily living with HIV.

Table 6.9 Challenges to self-managing HIV.

Challenges	n	Sample quote
Unable to discuss or disclose HIV with GP or family	3	How can I healthily self-manage my HIV if I never tell my family or people I am living with. Living in fear all the time of them finding my meds and asking what they are for.
Lack of mental health supports	3	We know how this [mental health issues] affects linkage/retention to care, adherence, etc., and yet mental health checks are not utilised.
Not involved in HIV care decisions, feel unable to discuss other HIV treatment options with HCP	2	There's also the problem that often I go in and my medication is already prescribed and issued. It sometimes makes me uneasy about even asking about other regimes, as being difficult or rocking the boat.
Lack of consistency in healthcare provider at appointments affecting quality of care	1	
Lack of support for comorbidities and other conditions	1	
Feel talked down to at appointments	1	
HCPs not up to date on latest HIV treatments and medications	1	
HIV care lacks support systems and information on disclosure and accessing various health services	1	
Time at appointments is not utilised well – too much time spent discussing previous results	1	

Twelve people provided open-ended suggestions for how to improve involvement in HIV care, which are presented in Table 6.10.

Table 6.10 Suggestions for how to improve involvement in HIV care.

Suggestions	n	Sample quote
Access to mental health care, counselling and peer support	4	There really should be wrap-around supports embedded in the clinic (including peer support) for those early days.
Broader help and support for other health conditions and comorbidities	3	I have [X condition] more support in this area would help.
Provision of information on living well with HIV and HIV disclosure	2	The clinic can and should provide information on good websites that provide ongoing information on a number of different aspects of living well with HIV. I had to find them myself, sites that give you information on interaction of other meds with your HIV. Sites that inform you on ways to bring up and talk to your GP about your HIV.
HCPs to involve patients in discussions on (advancements) in HIV treatments, side effects and general health	2	More conversations about why I am moving to different meds or why I should do this or that.
Consistent consultants and doctors at each visit	1	
Information on drug-drug interactions	1	
General social welfare support	1	
Would prefer HIV care from GP	1	
Advice and support on how to talk about HIV with GP	1	
Access to a social worker to work though challenges	1	
Provision of lifestyle support (e.g. smoking cessation, diet)	1	
Appropriate use of time at appointments – not spending so much time looking at historical results	1	

Many challenges and suggestions in Tables 6.9 and 6.10 echo suggestions made in Table 6.8, with improving access to mental healthcare and peer-support being the main suggestion alongside improving access to broader help and support for other health conditions and comorbidities. One respondent reported that NGOs and support groups are vital for those who have not disclosed their HIV status to family or people they live with.

6.8 Health and wellbeing

This section asked about the broader health-related needs of participants, and whether these were being met. A list of 13 services and supports were provided, and participants were asked if they had received it, needed it but could not get it, needed it but did not try to get it, needed it but did not know about it, or did not need it.

The proportion of 'need' was defined as the percentage of respondents who stated they needed or received a service, out of all those who responded to each question. The proportion of 'unmet need' was defined as the percentage of respondents who did not receive a specific support, out of those who stated they needed it (the three options above).

The most commonly reported need overall was for STI testing (at the HIV clinic), 87% (n=59) of respondents indicated that they needed this, of whom, the majority (n=52, 88%) stated that they had received STI testing. Sixty-nine per cent (n=48) said they needed help or advice regarding their sex life, and 69% (n=46) needed condoms and lubricant, of whom 60% (n=29) and 78% (n=36 respectively) reported that this need was being met.

The HIV services survey reported that 7/7 services had condoms and lubricant available to patients.

Two thirds (n=42, 62%) reported the need for help to manage weight, of which 57% (n=24) reported that this need was unmet.

The HIV services survey reported that 2/7 services had a dedicated clinical nutritional resource. The five services which do not have a dedicated clinical nutrition resource said that a dedicated resource would be beneficial for their patients.

Forty-four per cent (n=29) of respondents said they needed help to stop smoking, this need was unmet for 55% (n=16) of those who needed it. A third (n=20, 33%) of respondents reported a need for home health services, of these 90% (n=18) said this need was unmet. Just under a third (n=20, 30%) said they needed alcohol counselling or treatment, of whom 55% (n=11) reported an unmet need. Twenty-two per cent (n=14) reported a need for chemsex support and this need was unmet for 79% (n=11) of those who needed it. A fifth (n=13, 20%) said they needed drug counselling or treatment and 16% (n=10) reported a need for drug detox or maintenance treatment, the unmet need was 62% (n=8) and 70% (n=7) respectively.

Nineteen per cent (n=12) reported needing family planning or advice on getting pregnant, and half (n= 6, 50%) reported this need was unmet. Eighteen per cent (n=11) said they needed contraception and this need was unmet for 45% (n=5) of those who needed it. Fifteen per cent (n=9) said they needed information or advice on menopause, of whom 89% (n=8) reported this need was unmet.

In the HIV services survey, 4/7 services reported having a pathway for conception assessment and management. 4/7 services reported having a pathway for contraceptive assessment and management and one service said that it would be beneficial to have a women's health/contraception specialist in clinic. 4/7 services reported having a pathway for menopause assessment and management and one service said that a menopause clinic would be ideal.

Figure 6.8 presents the level of met and unmet need for health-related services and support amongst those reporting a need.

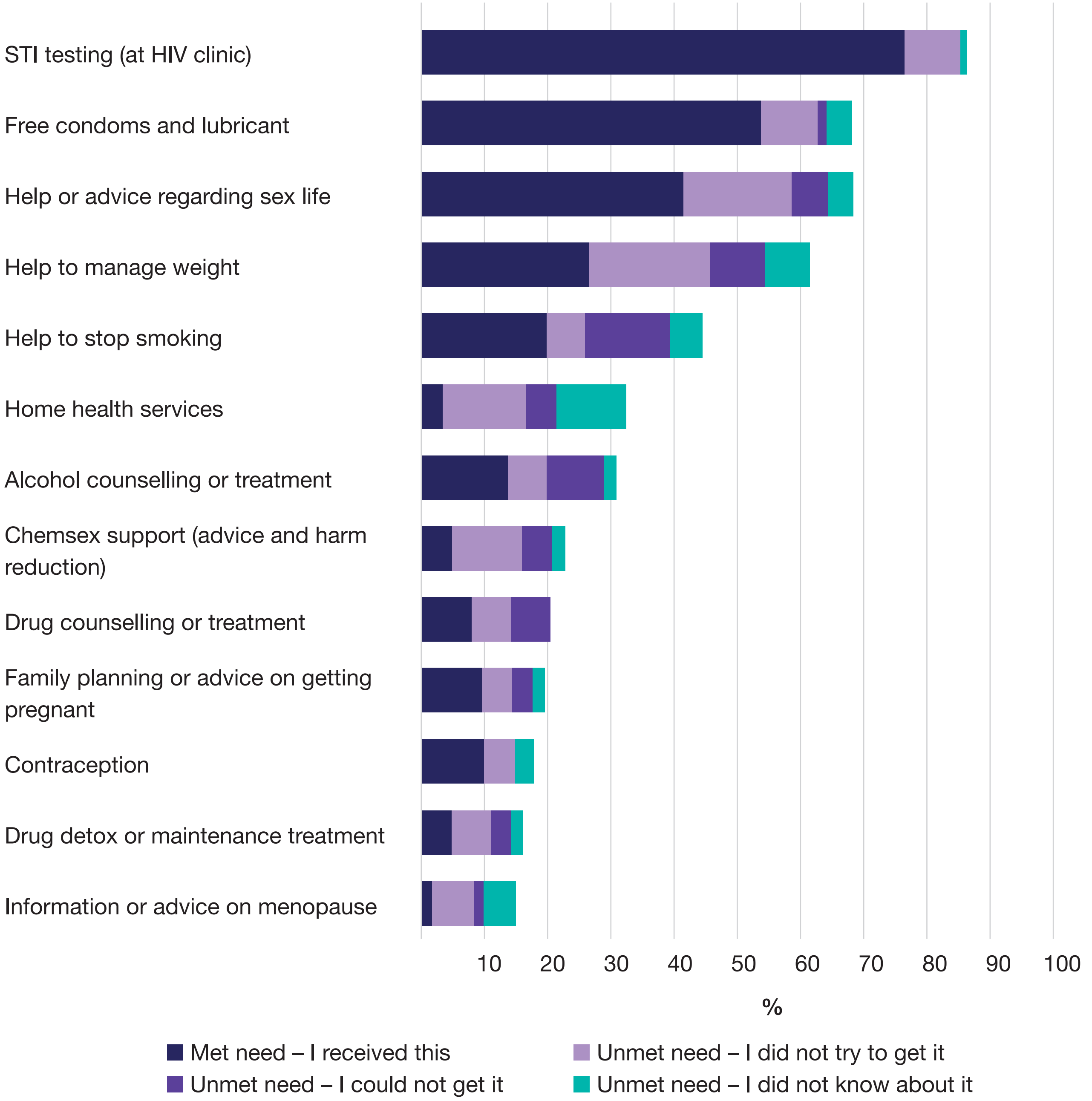

Figure 6.8 Met and unmet health-related services and support needs, amongst overall reported need.

When participants reported that they could not access the services and supports they needed, they were given the option of elaborating why they thought this was the case. Some 21 people responded to the question, reasons are grouped in Table 6.11.

Table 6.11 Reasons why participants could not get the services and supports they needed.

Theme	n	Sample quote
Service not available in HIV clinics	9	Mental health support, peer support, access to vaccinations not available in clinics.
Dismissive staff in HIV clinics	4	When I was experiencing weight gain as a side effect of a medication I was advised I should snack less and maybe go to Weight Watchers.
Have never been offered a service or support in that area	3	Never been asked.
Service was not of good quality	2	Had the most ridiculous dietary consultation once. I knew as much as the dietician. Pathetic.
Long waiting lists	2	When I did ask for mental health support I was waiting a long time for an appointment.
Told service not available at HIV clinic and to go to GP	2	I spoke to my doctor at clinic and said it's not their area and I need to go to GP.
COVID-19	1	
Funding cuts resulting in service closures	1	

One participant mentioned that they do not access some supports through their HIV clinic, but do so via their local peer-support service.

Participants were asked if they would like to provide open-ended suggestions on how access to services and supports could be improved. Sixteen responses were received which are grouped into suggestions in Table 6.12.

Table 6.12 Suggestions for improving access to services and supports.

Suggestions	n	Sample quote
Improve communication of, signposting to and pathways into various supports and services	4	It's all about communication and accessibility of information to the community about the different health care services.
Embed supports within HIV clinics and NGOs	3	Various support groups should work together with the clinics.
Establish or increase provision of local services	3	More local services.
More flexible appointments (clinic days, online platforms to make/ amend appointments)	2	Flexibility in appointments. Ability to make online amendments on internet.
Improve accessibility for those with disabilities, those with infants, those who are elderly etc.	2	Accessibility for disabled and mother's with babies.
Increase time and resourcing during appointments	2	More time with nurses /consultants
Increase access to chemsex support and information	1	
Look to international centres of excellence	1	
Invest in the mental health and wellbeing of all people living with HIV	1	
Ensure all population groups have a voice in service delivery	1	
HIV-related stigma training across the whole health system	1	
Provision of free parking	1	
Provision of HIV friendly dental care	1	
Have LGBTQIA friendly staff	1	

6.9 Stigma and discrimination

Participants were provided with four statements on perceived or experienced HIV-related stigma in a healthcare setting, and if they had experienced this. In general, the majority of respondents have not avoided seeking healthcare when they needed it (69%, n=46), or felt they had been refused healthcare or had a medical treatment delayed (59%, n=41). In comparison, more respondents felt that they have been treated differently to other patients (28% experiencing this more than a year ago, and 19% in the past year). Similar proportions of respondents worried that they would be treated differently to other patients in the past year (32%, n=22), more than a year ago (33%, n= 23), and had not worried that they would be treated differently to other patients 35% (n=24). Overall results are presented in Figure 6.9.

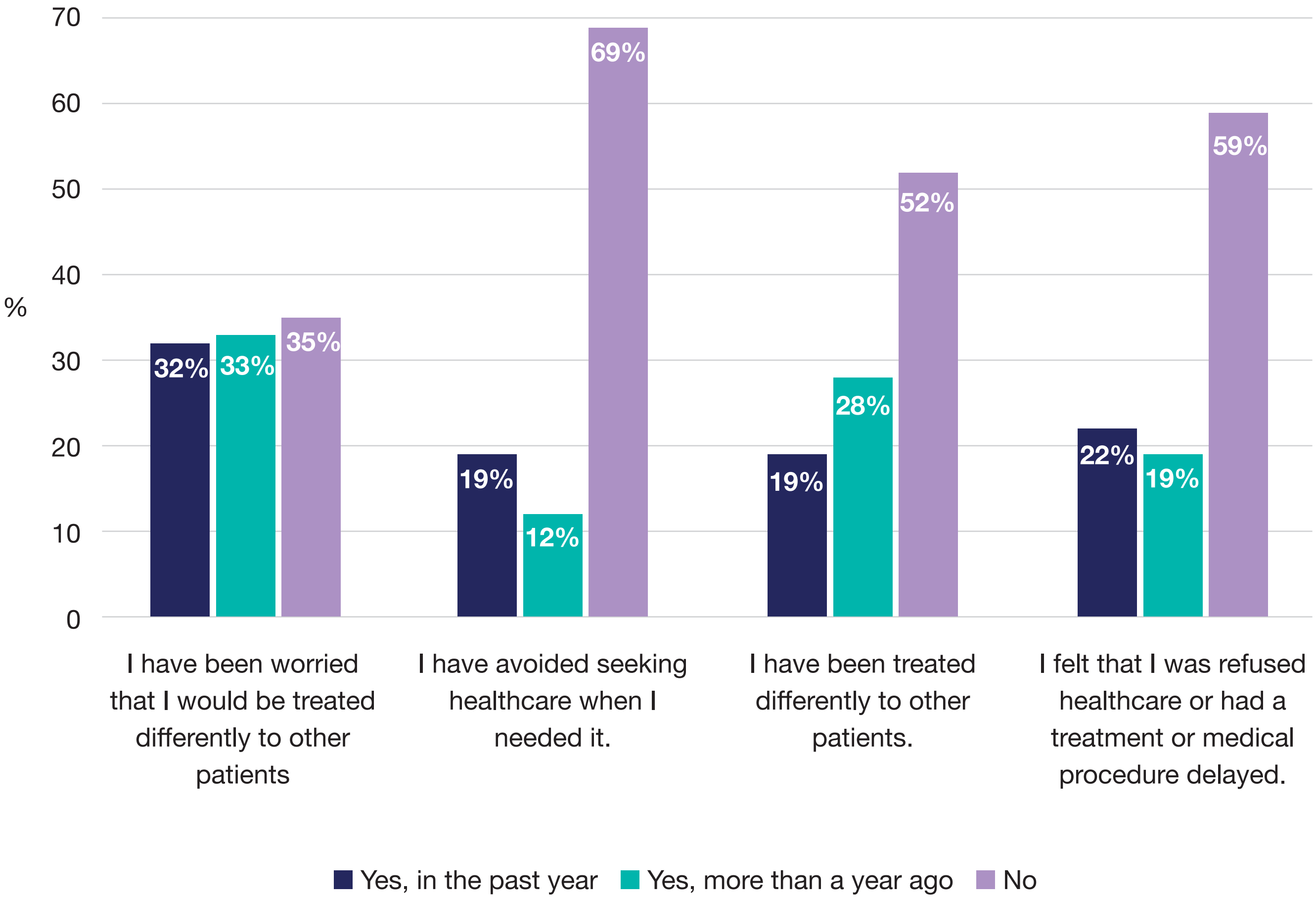

Figure 6.9 Experience of HIV-related stigma in the healthcare setting.

6.10 Community HIV support services

Many support services for people living with HIV are provided by HIV or sexual health NGOs, community organisations, and HIV member organisations. Participants were asked if they had contact with HIV or Sexual Health NGOs, community organisations or HIV member organisations in the past five years. Over half of participants (54%, n=37) confirmed that they had contact with a HIV or Sexual Health NGO, or HIV member organisation for any reason in the past five years (Table 6.13).

Table 6.13 Organisations accessed by people living with HIV in the past five years (n=37).

Organisation	Number of participants who contacted them	Organisation	Number of participants who contacted them
HIV Ireland	30	ACT UP Cork	5
Positive Now	12	Positive Cork	4
ACT UP Dublin	11	Gay Project Cork	4
Plus Friends	7	AMACH! LGBT Galway	2
Sexual Health Centre Cork	7	LGBT Ireland	2
Positive Life	6	ACET	1
Sexual Health West	6	BelongTo	1
Outhouse	6	The National Women's Group	1
GOSHH	5	Transgender Equality Network of Ireland (TENI)	1

Participants were asked if they were currently attending a HIV support group, one fifth confirmed that they were (21%, n=15). When asked who manages the support group, 13 participants provided details;

- Positive Cork
- Plus Friends
- Positive Now
- GOSHH
- HIV Ireland
- Sexual Health Centre Cork
- The National Women's Group

Participants were asked how important community HIV support services were for their health and wellbeing (Figure 6.10). Half of participants (52%, n=36) reported that community HIV support services were important or very important for their health and wellbeing, 24% (n=17) said that community support services were somewhat important and slightly important, and 24% (n=17) reported that they were not important.

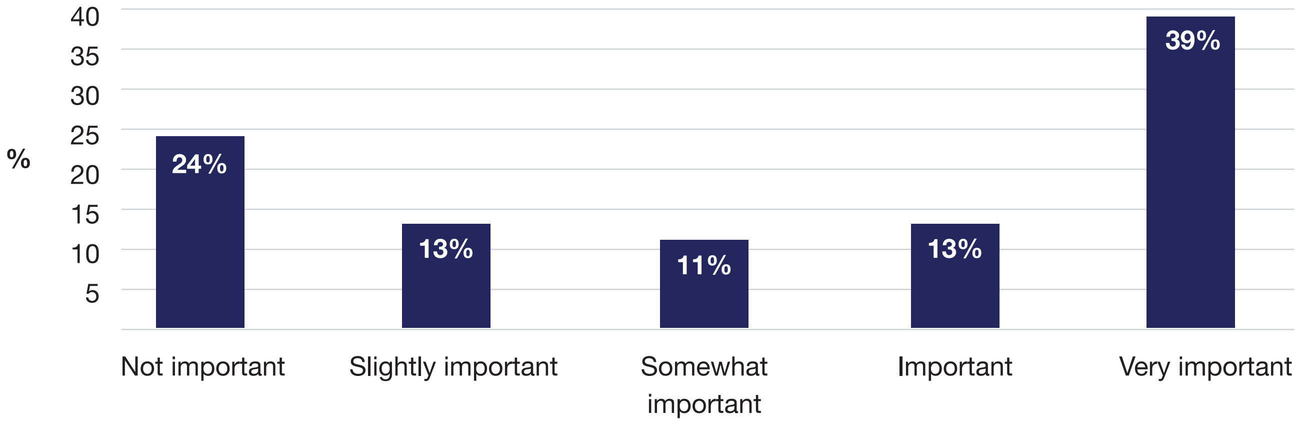

Figure 6.10 Importance of community HIV support services for health and wellbeing.

Community-related HIV support needs

A list of 17 community-related HIV services and supports were provided, and participants were asked if they had received it, needed it but could not get it, needed it but did not try to get it, needed it but did not know about it, or did not need it.

The proportion of 'need' was defined as the percentage of respondents who stated they needed or received a service, out of all those who responded to each question. The proportion of 'unmet need' was defined as the percentage of respondents who did not receive a specific support, out of those who stated they needed it (the three options above).

Information on HIV and sexual health

Seventy-six per cent (n=52) of respondents reported a need for practical information and resources on living well with HIV, 73% (n=38) of whom reported that this need was met. Sixty-eight per cent (n=46) needed information on partner HIV prevention, viral suppression and U=U, of these 63% (n=30) said this need was met. Sixty-three per cent (n=43) needed seminars or classes on living well with HIV and 60% (n=26) reported this need was unmet. Sixty-six per cent (n=45) said they needed sexual health information of whom 67% (n=30) said this need was met.

Healthcare support

Sixty-five per cent (n=42) of respondents said they needed advice or support to access HIV clinical care, of whom 71% (n=30) received this. Similarly, 65% (n=45) reported needing HIV treatment advice, with 67% (n=30) reporting that this need was met. Sixty-one per cent (n=40) reported the need for advice or support to access other health services, of whom 50% (n=20) received this.

Psychosocial support

Sixty-eight per cent (n=45) of respondents reported a need for a peer-support group, of whom just over half (n=23, 51%) reported this need being met. Sixty-seven per cent (n=44) said they needed a safe space to meet peers, with 64% (n=28) reporting this need was unmet. Two thirds (n=43, 66%) reported a need for counselling, of whom 51% (n=22) said this need was unmet. Sixty-three per cent (n=41) said they needed advice or support in relation to stigma or discrimination, this need was unmet for 56% (n=23) of those who needed it. Just over half of respondents (n=35, 55%) reported a need for advice and support on disclosing their HIV status, with 66% (n=23) unmet need.

Social welfare support

Fifty-eight per cent (n=37) reported a need for advice or support to access social welfare services, of whom 76% (n=28) reported this need was unmet. Similarly, 58% (n=38) said they needed financial or legal information and support, for whom 74% (n=28) said this need was unmet. Forty-one per cent (n=26) needed advice on further education or employment, this need was unmet for 88% (n=23) of those who needed it. Advice or support to access other outreach or community services (such as drug/addiction, homelessness, etc.) was needed by 38% (n=24), of whom 75% (n=18) did not have this need met. Lastly, 26% (n=16) needed advice or support on immigration issues/ help to access migrant support services with three quarters (n=12, 75%) saying this need was unmet.

Figure 6.11 presents the level of need that was met and unmet for services and support by community support services, amongst those reporting a need.

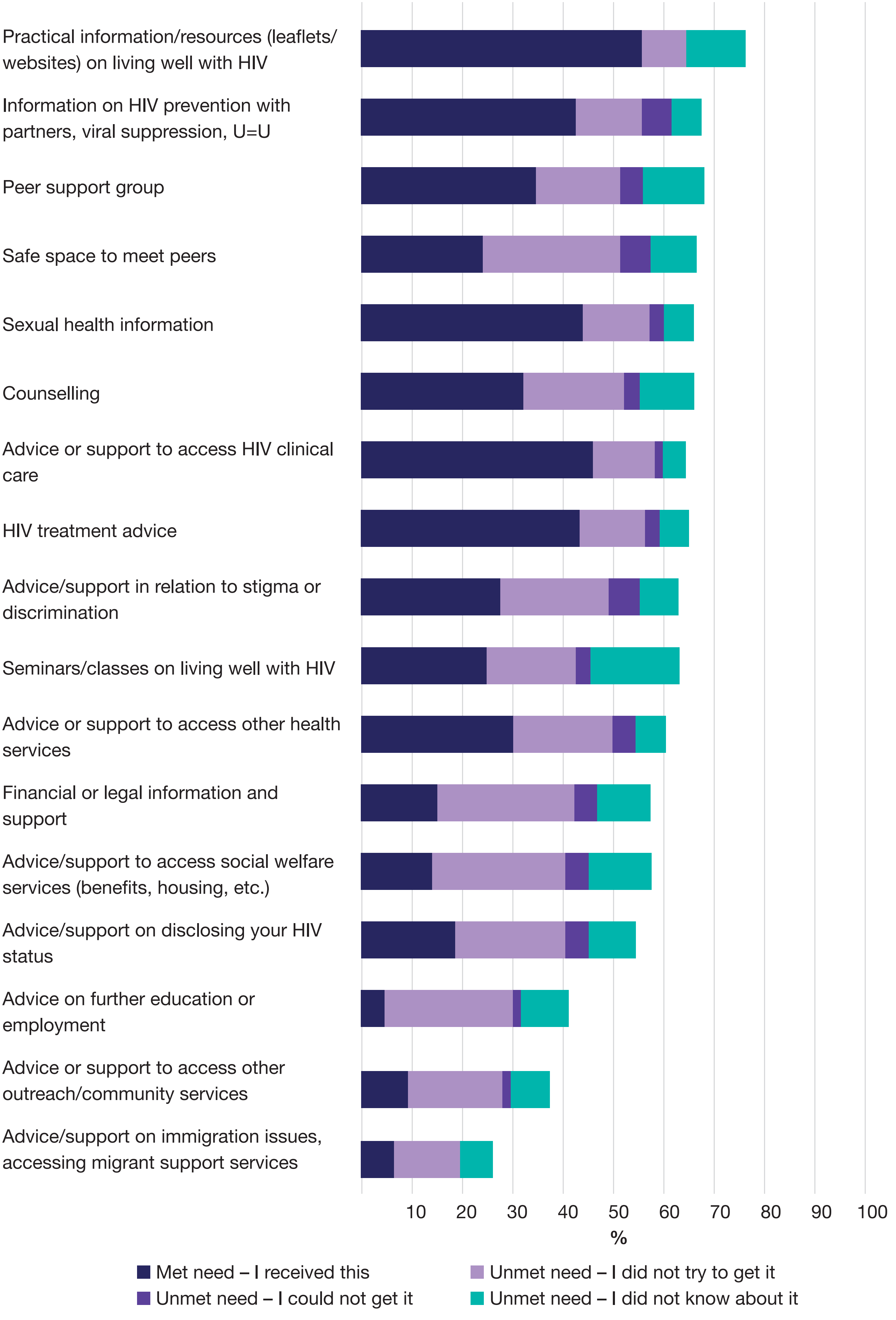

Figure 6.11 Met and unmet community-related support needs, among overall reported need.

Participants who reported that they had needed support but had been unable to access it, were asked to outline the reasons why they could not access the support. Table 6.14 outlines reasons provided by 15 respondents.

Table 6.14 Reasons why participants could not get the community-related supports they needed.

Reason	n	Sample quote
Not available	5	It wasn't available at the time.
Provision of poor or inadequate services	4	Support is poor. Lots of people making money and not providing proper services.
Did not know services existed despite needing them/unable to access services despite trying	4	If they were offered, they were done so without publicity in that I could not locate the services despite repeated tries.
Certain population groups are overlooked	2	I feel the HSE put money into peer support for lgbtq but not enough for other communities.
Closure of services	1	
Had to find out information for themselves	1	
Ignored by professionals despite seeking support	1	
Worried about personal safety if status exposed	1	

Respondents were asked if there were other community supports not listed above, that they received or that would be useful to them. Seven people responded, four individuals responded with supports that would be useful to them:

- Establishing a service similar to 56 Dean Street, London
- Peer-to-peer education
- Transport to peer support
- Patient advocacy groups in clinics
- Funding for stress relief

Three individuals described four other supports that they had availed of:

- Community support from GOSHH
- PozVibe Podcast giving a platform to voices of people living with HIV
- Individual support from a peer-mentor
- The MPOWER Programme at HIV Ireland

Participants were asked over the past two years (since COVID-19) if it had become difficult to access community HIV support services, 66% (n=45) said no, and 34% (n=23) said that it had become more difficult. Eighteen participants provided further detail regarding accessing community HIV support services during COVID-19, with the majority describing reduced frequency and ability to meet face-to-face, or closure of certain services. One participant commented that Zoom had limited the availability of certain services, but had helped to expand access to others.

Participants were provided with a list of nine statements on their general experience with community HIV support services, and were asked to what extent they agreed with the statements (Figure 6.12). Of the nine statements, the highest level of agreement (76%) was in relation to information and services being provided in a language or format that is understandable to them, and the area with the lowest level of agreement (44%) was opening hours/times of services being convenient.

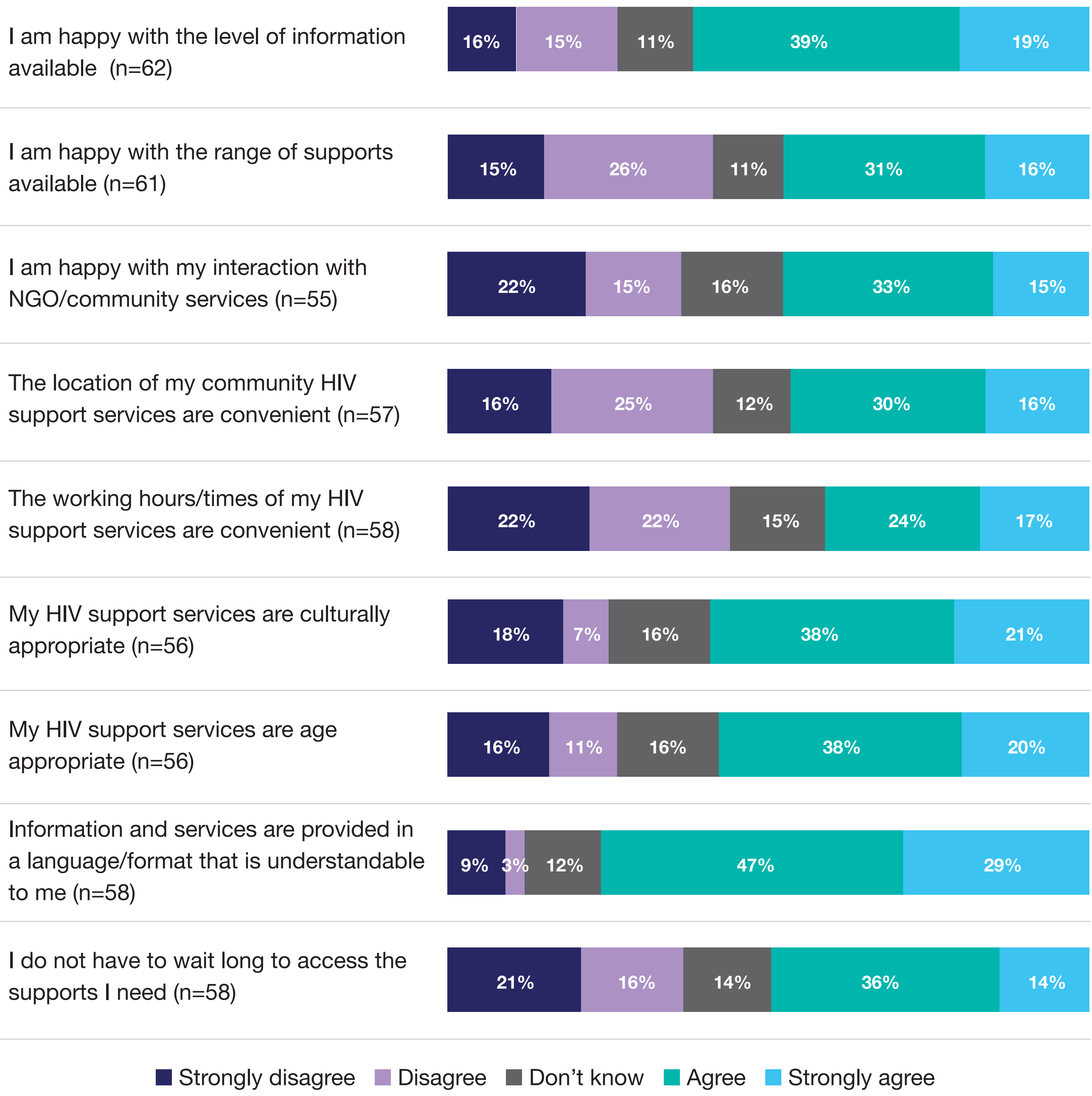

Figure 6.12 Experience within community support services.

Participants were asked for open-ended suggestions for how community HIV support services could be improved, ten individuals provided suggestions that are outlined in Table 6.15.

Table 6.15 Suggestions for how community support services could be improved.

Suggestions	n	Sample quote
Increase funding for provision of local services and supports	7	More funding hiring and training into a fully inclusive HIV support programme.
Events that cater to different age ranges, and events that are not only held in Dublin	4	it's mostly limited to meets in Dublin and I don't want to travel to talk to peers.
Address the lack of diversity and lack of cultural competency in organisations, employ people living with HIV	3	Diversity is extremely lacking in HIV organisations. Whether it is the people working in them or on their board. There are no steering committees. How can support services and HIV programmes be truly culturally competent?
Promote, advertise and signpost to the services	2	If they are available they are well hidden away.
Offer more flexible opening hours, difficult for people to attend services within 9-5 times	2	My local NGO is opened Monday to Friday 9am to 5pm. But many people living with HIV work during the week, so they should be opened on Sat. One suggestion I have is, The NGO could allow the HIV support Group to work out of their building either on Sat or in the evening.
Address waiting lists and increase appointment availability with community supports	2	More appointments.

Two respondents said that community supports did not really exist ‘we will talk about improving it when it comes into existence’, and another said that they were not aware of any community supports.

Most of the suggestions and comments here are mirrored in other areas of the chapter, including improving funding, signposting to services, more flexible service hours, increasing peer and social events, and meaningful representation of people living with HIV within organisations.

It must also be noted that some respondents voiced their dissatisfaction at continuously being asked to participate in research and surveys, and felt that there have been little to no improvements in care, support, systems or policies as a result of research. This again highlights the importance of meaningful representation of people living with HIV within research that affects them, and the importance of using existing research to develop and deliver effective services.

6.11 Chapter summary

This chapter presented the findings from the 70 respondents who completed the survey for people living with HIV. Respondents outlined a range of challenges and gaps to the provision of clinical HIV care, broader health and wellbeing support services and community support services. Respondents also provided suggestions for improving service provision. The findings from this chapter will inform recommendations at the end of the report and the subsequent development of city implementation plans.

Chapter

7

Member organisations and networks for people living with HIV

7.1 Introduction

An online survey was conducted with member organisations and networks for people living with HIV in Ireland to provide a baseline description of their organisations, describe the work they do, the supports provided to people living with HIV, and to document challenges, gaps and suggestions for improvement. The survey topics included organisational structure and size, funding, activities, services and supports, partnerships and representation of people living with HIV. The survey was open for a period of three months from mid-April to mid-July 2022. Further information on survey dissemination is described in methodology Section 2.4.4.

This chapter presents the qualitative and quantitative findings from the online survey.

7.2 Participant information

All five existing member organisations and two networks were invited to participate, requesting that one person, the chair or a member of the management team, respond on behalf of the organisation or network. A response was received from each organisation and network.

7.3 Member organisations for people living with HIV

The five participating member organisations were Positive Now, Positive Cork, Plus Friends, The National Women's Group and Positive Life (Northern Ireland). These organisations comprise solely for and of people living with HIV.

Table 7.1 List of member organisations.

Member organisation	Description
Positive Now	An all-Ireland network that provides education and support to people living with HIV, and ensures that their voices are represented at all levels of society.
Plus Friends	A national social group for people living with HIV.
Positive Life (NI)	A Northern Ireland based member organisation, who in partnership with HIV Ireland and Positive Now, are piloting a national HIV peer-support programme.
The National Women's Group	A national social group for women living with HIV.
Positive Cork	A Cork-based peer-support group for people living with HIV.

7.3.1 Organisational structure and size

Participants were asked to indicate how many members are currently in their organisation and to outline the organisation's governance structure (Table 7.2).

Table 7.2 Overview of membership and governance structure of member organisations.

Member organisation	Number of members	Registered charity	Governance structure
Plus Friends	427	No	Informal
Positive Now	412	No	Semi-formal
Positive Life (NI)	220	Yes	Formal
The National Women's Group	26	No	Informal
Positive Cork	<20	No	Informal

The organisations range in size from under 20 to over 400 members. The largest organisation is Plus Friends with 427 members, and the smallest organisation is Positive Cork with less than 20 members. Positive Life (NI) is the only organisation with charitable status and therefore has a formal governance structure with a CEO, board of trustees and staff members. Positive Now has a semi-formal governance structure with a volunteer coordinator and a team of four other volunteers who manage day-to-day activities. Three of the organisations have an informal governance structure and manage themselves.

7.3.2 Funding

Member organisations were asked how their work was funded or supported.

Positive Now and The National Women's Group reported receiving funding from HIV Ireland, while HIV Ireland seek funding from donors to support the work of these two voluntary organisations. Positive Life (NI) receive funding from Public Health Agency, the Department of Health (NI) and the National Lottery. Positive Cork and Plus Friends do not receive any funding.

Member organisations were asked if the funding or support they receive (regularly, occasionally or does not) cover the following costs:

- Network chair/management time costs
- Activity-related member/volunteer time costs
- Activity-related member/volunteer expenses (travel costs, etc.)
- Rent/office/meeting space
- Administration costs (phone, computer, utilities, etc.)
- Advocacy work
- Activities to support people living with HIV

Members were also asked to describe any other activities/work that their funding covers.

Positive Life (NI) was the only organisation which reported that all the listed costs are either covered regularly or occasionally. For Positive Now and The National Women's Group, costs are covered regularly or occasionally for activity-related members/volunteer expenses and for activities to support people living with HIV. One of these organisations also reported receiving regular funding for administration costs, refreshment costs for social group activities and that they were provided access to a meeting space at no cost within the NGO premises. Besides Positive Life (NI), no member organisation had funding that covered costs for advocacy work; or time costs for management, members or volunteers, so this work is done at their own expense.

Member organisations were asked about the challenges and gaps in relation to accessing funding. The main challenge reported was not being registered as a charity, as unregistered organisations are unable to access funding from the HSE/Government. Charity registration was described as a lengthy and involved process and this would not be feasible for many of the member organisations. Unregistered organisations are therefore dependant on NGO funding. Additional challenges include funding being provided on an annual basis which can lead to breaks in services/activities between funding cycles; and difficulty securing funding for certain costs or activities, such as administration costs, promotional material, project work and events. It was also noted that many social events are held for members in Dublin and the cost of staying overnight in Dublin is prohibitive and prevents members attending.

Member organisations were asked for open-ended suggestions to improve access to funding. Suggestions included becoming a registered charity; having access to multi-annual funding to support continuity of services; and having government funding available or a defined funding stream to support the running/administration costs of the member organisation, stating this would benefit the services they provide and the partner NGOs. One organisation suggested that improving the relationship with their local NGO, might help to improve access to funding for their work, stating this could be achieved by people living with HIV working or volunteering with the NGO or being represented on the Board.

7.3.3 Activities, services and supports

Member organisations were asked to select the activities, services and supports they provide, from a pre-defined list. Table 7.3 lists the type of activity and the number of organisations that provide them.

Table 7.3 Activities, services and supports provided by member organisations.

Activity	Number of organisations
Addressing HIV-related stigma and discrimination	5
Advice or support to access HIV clinical care	5
Advice or support on HIV disclosure	5
Social activities/events	5
Peer support group meetings	4
Signposting to community-based peer-support	4
HIV advocacy	3
Information on HIV transmission and prevention	3
Information on HIV prevention with partners, viral suppression, U=U	3
Signposting to counselling services	3
Advice or support to access other health services	3
Advice on HIV treatment	2
Advice on further education or employment	2
Legal information/support	1
Information/resources (leaflets/websites) on living well with HIV	1
Counselling services	1
Advice or support to access other outreach/community services	1
Advice or support to access social welfare services	1
Advice or support on immigration issues, accessing migrant support services	1

Responses demonstrated that member organisations provide a broad range of activities, services and supports for people living with HIV. The most common activities, reported by all five organisations were addressing HIV-related stigma and discrimination; social activities/events; advice or support to access HIV clinical care and HIV disclosure.

Three organisations specified that they provide services that were not in the pre-defined list above. This includes the previously mentioned national peer-support pilot programme run in partnership between Positive Now, Positive Life and HIV Ireland. One organisation mentioned supporting members who may be experiencing feelings of isolation that can follow a HIV diagnosis, another, supporting one another and keeping each other up to date on the latest HIV research and developments.

Member organisations were asked about the challenges and gaps in relation to the availability and delivery of services and supports. All five organisations provided open-ended responses to this question and funding was universally cited as being the biggest challenge. Similar to the funding section, respondents stated that not having some level of unrestricted funding (funding that a group can use at their own discretion for any of the organisation's purposes) made it difficult to address needs as they arise. While most activities can be covered through existing funding applications, sometimes funding for particular events needs to be applied for separately and accessing this was reported to be challenging and described as 'trying to put a square peg in a round hole'. Funding being restricted to a specific timeframe or activity, was also reported to disrupt service continuity, or the planning of future activities. For example, when a particular strand of funding comes to an end, this may result in the end of those services unless replacement funding is sourced.

A number of other challenges were mentioned by respondents. Travel and childcare costs, and access to childcare were reported to be barriers for member participation in events/services or supports. As a result of HIV-related stigma, some members may not be ready, or may never choose to share their status with family, friends or colleagues. This means that attending dedicated HIV member events or access services or supports for people living with HIV, requires careful planning by members if they have not disclosed their HIV status. One organisation reiterated that it is important to recognise that the needs of women living with HIV can be hugely different from gbMSM living with HIV. Lack of communication and the working relationship between the local sexual health NGO, local HIV clinic and member organisation was also described as a challenge in supporting people living with HIV in the region.

Member organisations were asked for open-ended suggestions for how the availability and delivery of HIV-related activities, services and supports could be improved. As in the funding section, improving funding streams or access to more flexible funding for member organisations was suggested to improve continuity of services and the ability to respond to needs as they arise. Two organisations suggested that there should be more collaboration between HIV clinical services and member organisations, and that clinics should provide more information on, and refer individuals to available peer-support groups. It was also suggested that better integration between all of the local HIV services (HIV clinical services, NGOs, and member organisations) would enhance services and pathways that are provided to people living with HIV in the area. This included improving representation of people living with HIV at the local service level. Another suggestion included the establishment of patient advocacy groups within HIV clinics, the provision of outreach services outside of cities, and out of hours counselling and support services.

Member organisations noted that at the time the survey was conducted, COVID-19 affected their ability to meet in-person, and required them to provide services in a hybrid online and face-to-face format which required an additional investment in equipment.

7.3.4 Partnerships

Member organisations were asked who they collaborate with through provision of a pre-defined list of possible HIV partner organisations and departments. Table 7.4 lists the types of HIV partner organisations and the number of member organisations who said they collaborate with them

Table 7.4 Collaboration of member organisations with other organisations/departments.

HIV partner organisations and departments	Number of member organisations
Other member organisations and networks	5
HIV clinical services	4
HIV/sexual health NGOs	3
Local Authorities (City and County Councils)	2
Other NGOs (addiction, homeless, migrant, etc.)	1
Local Community Development Committees	1
HSE Health & Wellbeing (e.g. SHP, local CHO office)	1
Other	1
HSE Social Inclusion (e.g. addiction, homeless, migrant support services, local CHO office)	0
Healthy Cities and Counties	0

All organisations reported that they collaborate with other member organisations and networks. Four organisations collaborate with HIV clinical services, and three with HIV and sexual health NGOs, and two collaborate with local authorities. One member organisation collaborates with HSE Health and Wellbeing, and another organisation said they collaborate with Local Community Development Committees and other NGOs for example those that provide addiction, homelessness and migrant services. One organisation reported collaborating with other HIV partners, namely international organisations including those based in the UK and Sweden. No member organisations collaborate with HSE Social Inclusion or Healthy Cities and Counties.

7.3.5 Representation of people living with HIV

Respondents were asked if they felt that people living with HIV are sufficiently represented in relevant national and local forums. Only one organisation responded that people living with HIV are sufficiently represented. Two organisations responded that people living with HIV are not sufficiently represented and two responded that they ‘don’t know’.

Organisations were asked about the challenges to representation of people living with HIV in working groups and forums. The organisation that responded that people living with HIV are sufficiently represented, reported that it remains a challenge to be heard and to have a presence. The other four organisations reported a variety of challenges. It was cited that while many people living with HIV would be interested in participating in working groups or at local and national forums, many do not feel equipped or lack the confidence to do so. This can result in a feeling of tokenism, rather than meaningful participation. It was noted that if representatives of people living with HIV do not have a good working knowledge of the issues affecting all communities, this may result in them representing their own views to the detriment of others.

It was also noted that although many individuals choose to remain anonymous, this should not prevent their voices being heard. HIV-related stigma across all spheres of society was cited as a challenge due to the lack of knowledge about HIV prevention and treatment among HCPs' (outside of those involved in the provision of HIV care) and the general public. The resulting fear of experiencing HIV-related stigma, was cited as a barrier to people living with HIV participating in relevant fora.

Respondents were asked for open-ended suggestions on how representation could be improved. Capacity building programmes or interventions for people living with HIV were suggested, to improve knowledge and confidence, and allow for meaningful participation of people living with HIV in working groups and local/national fora. This includes how to better engage with and capture the views of the whole HIV community, to ensure those who are representing people living with HIV are representing the needs of all people living with HIV. It was also suggested that it would be beneficial to audit HIV-related NGOs and government committees on their policies on including people living with HIV in the decision-making process.

Combatting broader HIV-related stigma was suggested, focussing on both HCPs and the general public. This included more training for HCPs on HIV and the needs of people living with HIV, and continued provision of HIV education and awareness interventions, to ensure the general public are informed about HIV. It was also suggested that there should be a more formal peer-support role for people living with HIV who could attend HIV clinical services and provide more prompt peer support to those who may want it, in particular for those newly diagnosed, and provide information on the available community supports. Finally, it was suggested that there should be improved representation of people living with HIV within HIV NGOs through staff/volunteer members, or through representation on the Board.

7.4 Networks for people living with HIV

The two networks who participated in the survey were ACT Up Dublin and ACT Up Cork. These networks describe themselves as a non-partisan group of individuals committed to direct action to end the HIV crisis.

7.4.1 Summary of networks

There are less than 20 members in both of the networks, some of whom are living with HIV. Neither of the networks are a registered charity, so both have an informal governance structure, one describing this as non-hierarchical and consensus based. One network reported that, at the time of the survey, the network was not operational, as the network was in the process of being established at the time of the COVID-19 pandemic.

The networks were asked how their work was funded or supported, and what costs this funding covered. One of the networks reported accessing their own funding from the community and individuals. This funding occasionally covers costs relating to: activity-related member/volunteer expenses; advocacy work; activities to support people living with HIV; and posters and materials for design work. The other network reported receiving no funding to support their work. In regards to challenges and gaps to accessing funding, one responded that there were none, as the costs are small.

The networks were asked to select the activities, services and supports they undertake from the same pre-defined list. Although one network was not operational at the time, both networks generally provide the same types of activities: information on HIV transmission, prevention, viral suppression and U=U; addressing HIV-related stigma and discrimination; HIV advocacy; social activities and events; information on living well with HIV; and advice or support to access health services. In regards to the challenges and gaps, one network noted that access to the PrEP programme for new individuals is a challenge. COVID-19 was also reported to have affected their work, presenting challenges to in-person meetings, and community outreach. The other network noted that they were just becoming established when COVID-19 occurred.

When asked about collaboration with other HIV partner organisations/departments, both networks reported collaborating with other networks and member organisations, and HSE Health and Wellbeing (e.g. SHP, local CHO office). One of the networks also collaborates with HIV and sexual health NGOs, and other NGOs (addiction, homeless, migrant, etc.). When asked about representation of people living with HIV, both networks did not feel that people living with HIV are sufficiently represented in relevant national and local forums.

7.5 Chapter summary

This chapter presents the results from five member organisations and two networks. Participants described their organisational structures, funding arrangements, the activities, services and supports provided to people living with HIV, the associated challenges and gaps and suggestions for improvement. Representation of people living with HIV, and suggestions for improving representation was also discussed. The findings from this chapter will inform the recommendations set out at the end of the report and the subsequent development of city implementation plans.

Chapter 8

City-level public sector structures

8.1 Introduction

There are a variety of different public sector structures across the four cities that are relevant to the Fast-Track Cities Initiative. This includes local city authorities, Healthy City and Counties and HSE departments, who are responsible for a range of local and national services, and liaise with various other agencies and NGOs in providing services and funding.

An online survey was conducted with the relevant public sector stakeholders across the four cities to describe the existing public sector structures for each of the Fast-Track Cities and to inform recommendations as to where the Fast-Track Cities Initiative may best fit within the existing structures. The survey topics included engagement between city stakeholders, support services for people living with HIV and the available funding, and HIV prevention interventions and the available funding. The survey was open for a period of three months from mid-April to mid-July 2022 and further information on survey dissemination is described in methodology Section 2.4.5.

This chapter presents the qualitative and quantitative findings from the online survey.

8.2 Participant information

Twenty-seven stakeholders aligned to Dublin, Cork, Galway, Limerick or the national level, were invited to participate. These stakeholders included HSE Health & Wellbeing, HSE Social Inclusion, City and County Councils, and Healthy Cities and Counties. A representative was invited to respond on behalf of each stakeholder, though in some instances more than one response was received as some respondents were affiliated to more than one stakeholder. A total of 21 respondents reported affiliation with 24 stakeholders as shown in Table 8.1.

Table 8.1 Stakeholder affiliations reported by participants.

County/Region	Stakeholder	Area	n[29]
Cork (n=3)	HSE Health and Wellbeing	CHO 4	1
	HSE Social Inclusion	CHO 4	2
	City and County Councils	Cork City Council	1
		Cork County Council	2
	Healthy Cities and Counties	Cork	2
Dublin (n=7)	HSE Health and Wellbeing	CHO 6	2
		CHO 7	2
		CHO 9	2
	HSE Social Inclusion	CHO 6	1
		CHO 9	1
	City and County Councils	Dún Laoghaire-Rathdown County Council	1
		Fingal County Council	1
	Healthy Cities and Counties	Dublin	4
Galway (n=6)	HSE Health and Wellbeing	CHO 2	3
	HSE Social Inclusion	CHO 2	2
	City and County Councils	Galway City Council	1
		Galway County Council	3
	Healthy Cities and Counties	Galway	2
Limerick (n=3)	HSE Health and Wellbeing	CHO 3	1
	HSE Social Inclusion	CHO 3	1
	City and County Councils	Limerick City and County Council	1
	Healthy Cities and Counties	Limerick	1
National (n=2)	HSE Health and Wellbeing	National Health and Wellbeing	1
	HSE Social Inclusion	National Social Inclusion Office	1

All four cities have local HSE Health and Wellbeing and HSE Social Inclusion offices, which are affiliated to the Community Health Organisation (CHO) structures[30]. There are national HSE Health and Wellbeing and Social Inclusion Offices also. The local authorities differ across the four cities, in that, Dublin has one city and three county councils, Cork and Galway have separate city and county councils and Limerick has a joint city and county council. All four cities are part of the National Healthy Cities and Counties initiative. More information is available on the city stakeholders in Appendix 1.

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[29] Total n exceeds 21 as some participants selected multiple options.

[30] In 2023, the Government of Ireland commenced the phased introduction of six Regional Health Areas (RHAs) within the HSE, which will replace the Community Health Organisations (CHOs).

8.3 Engagement between city stakeholders

Participants were asked if there are structures in place to facilitate engagement between the city stakeholders, to which 19 said yes, and two responded that they did not know.

Respondents were asked, from a list of six options provided, what regional structures are in place to facilitate engagement between stakeholders. The most frequently selected option was Local Community Development Committee (LCDC) networks and meetings (n=15). This was closely followed by Regional Healthy Ireland meetings and networks (n=12), primary care and community healthcare network meetings (n=10) and regional HSE networks or meetings (n=8), with regional HIV networks or meetings being the least frequently selected response (n=2) (Figure 8.1).

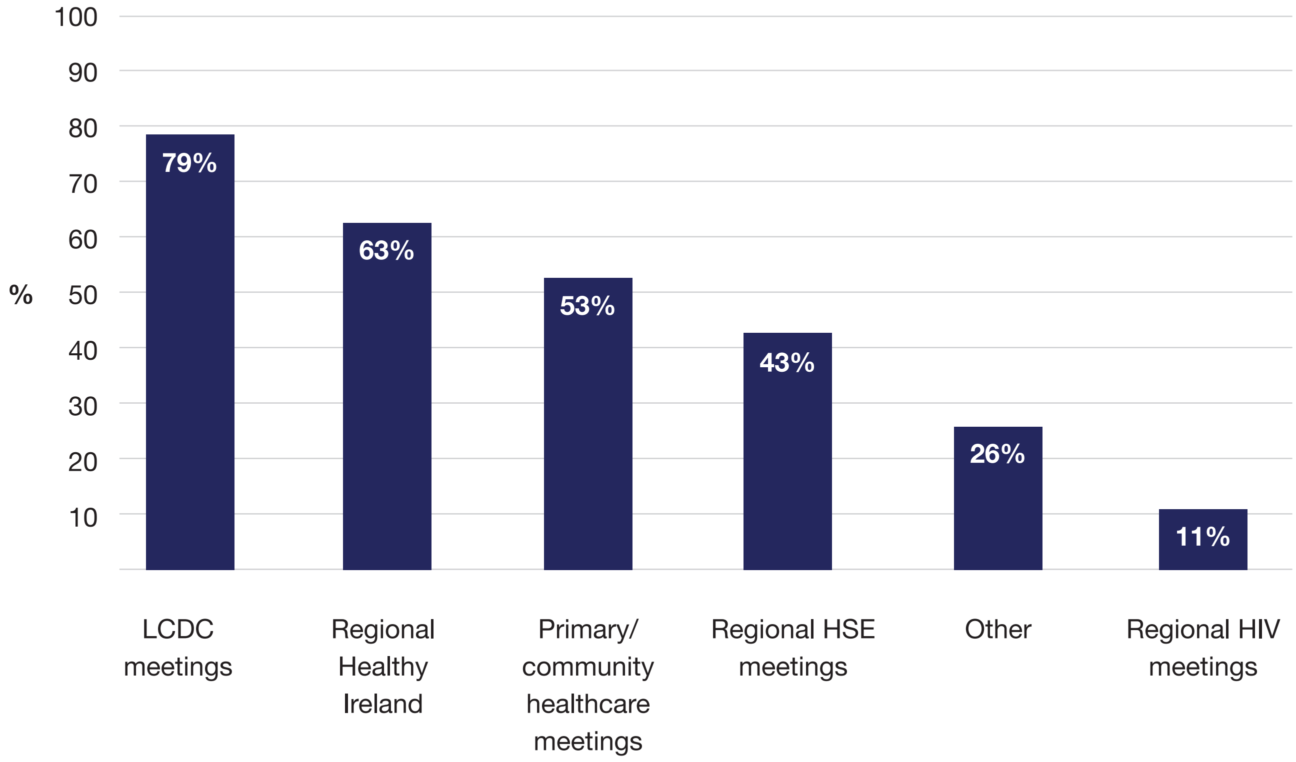

Figure 8.1 Regional structures in place to facilitate engagement between statutory organisations (n=19).

Five participants also provided open-ended responses outlining other regional structures where there is engagement between stakeholders, listed below. Each structure was named only once.

- Community Response Forum
- Connecting for Life
- Cork LGBT Interagency Group
- Children and Young People's Services Committees
- Fast-Track City Steering Groups
- Healthy Dublin Coordinators Meeting
- LCDC & Health and Wellbeing Sub-Committee Meetings/Networks
- LEADER
- National Health and Wellbeing meetings
- National Working Groups (Clinical, Public Health and community)
- Youth Health Service

When asked if there are any existing multi-stakeholder HIV groups/fora that would be relevant for the Fast-Track Cities Initiative to engage with, five participants responded. Responses listed the following groups/fora: Galway Sexual Health Forum, Community Healthcare West and the Healthy Ireland Sexual Health Sub-Group. In addition, some respondents listed a number of HIV-related organisations that it would be relevant for their city to engage with.

8.4 Support services for people living with HIV

Stakeholders were asked if they provide direct support for people living with HIV, to which 18 stakeholders indicated that they do not provide direct support, one was unsure and two stated that they did provide direct support services for people living with HIV. However, open-ended comments provided by these two stakeholders described the nature of this support indicating that they did not provide direct support services, but provided funding to NGOs or directed individuals to relevant services. Thus the responses of these two participants were re-coded to ‘no’, bringing the total number of stakeholders reporting that they did not provide direct support services to people living with HIV to 20.

8.4.1 Funding for support services

Stakeholders were asked if they currently provide funding to NGOs or community organisations for activities/services to support people living with HIV, to which nine (43%) said they did provide funding, nine (43%) said they did not provide funding, and three (14%) said they did not know.

Stakeholders who provide funding for HIV support services were asked to list the NGOs and community organisations they provide funding to, from a list of 33 options provided. Table 8.2 lists each of the NGOs and community organisations and details the number of stakeholders who reported providing funding to them for HIV support services.

Table 8.2. The number of stakeholders who provide funding to the listed NGOs and community organisations for HIV support services (n=9).

NGO/community organisation	Sources of funding
Foróige	3 or 4 sources
GOSHH	
Sexual Health West	
Simon Communities of Ireland	
Transgender Equality Network of Ireland	
AkiDwA	2 sources
AMACH! LGBT Galway	
Ana Liffey Drug Project	
Cairde	
Coolmine TC	
HIV Ireland	
Irish Family Planning Association	
Peter McVerry Trust	
SafetyNet	
Sexual Health Centre Cork	
Tabor Group	

NGO/community organisation	Sources of funding
ACET	1 source
BeLongTo	
The Bridge Project	
Chrysalis Community Drug Project	
Gay Project Cork	
LINC	
Merchants Quay Ireland	
NASC	
SAOL	
UISCE	

The participants were also given the opportunity to include any other NGO/community organisation that was not listed. One participant indicated that they also provide funding to the Voice of New Communities and the Paddy McGrath Housing Project.

Stakeholders were asked if they have funding available that NGOs/community organisations can access/apply for, to support people living with HIV. Three stakeholders (14%) reported that funding is always available, while seven (33%) reported that funding is 'sometimes' available. A further eight stakeholders (38%) reported that no funding is available for application by NGOs/community organisations for the provision of HIV support services, and the remaining two (10%) did not know. One participant did not respond to this question. A breakdown of the responses by stakeholder is presented in Table 8.3.

Table 8.3. Funding availability for HIV support services by stakeholder region/area (n=20).

Stakeholder affiliation	Area/region	Funding always available (n=3)	Funding sometimes available (n=7)	Funding not available (n=8)
HSE Health and Wellbeing	Galway (CHO 2)	✓	✓	-
	Limerick (CHO 3)	-	-	✓
	Cork (CHO 4)	-	-	-
	Dublin (CHO 6)	-	-	✓
	Dublin (CHO 7)	-	-	✓
	Dublin (CHO 9)	-	✓	✓
	National	✓	-	-
HSE Social Inclusion	Galway (CHO 2)	✓	-	-
	Limerick (CHO 3)	-	-	✓
	Cork (CHO 4)	-	✓	-
	Dublin (CHO 6)	-	-	✓
	Dublin (CHO 9)	✓	-	-
	National	-	✓	-
Councils	Cork City Council	-	✓	-
	Cork County Council	-	✓	-
	Dublin Dún Laoghaire-Rathdown County Council	-	-	✓
	Dublin Fingal County Council	-	✓	-
	Galway City Council	✓	-	✓
	Galway County Council	-	-	✓
	Limerick City & County Council	-	✓	-
Healthy Cities and Counties	Cork	-	✓	-
	Dublin	✓	✓	✓
	Galway	✓	✓	-
	Limerick	-	✓	-

The ten stakeholders who reported that funding is always or sometimes available were asked if funding is restricted to specific interventions or activities. Eight participants responded with seven indicating that funding allocation for service provision is dependent on scheme guidelines as dictated by the source e.g. Healthy Ireland, the National Lottery or Sláintecare, with only one stakeholder indicating the funding they provide is unrestricted.

8.4.2 Challenges and gaps

The participants were asked to provide open-ended comments on the challenges and gaps in the provision of support services for people living with HIV or if they had any suggestions on how to improve support services for people living with HIV. Two participants reported challenges and six provided suggestions for improvement.

Reported challenges were:

- That marginalised groups are the most at risk and most effected by HIV and that they can experience barriers to accessing support services for people living with HIV (n=1);
- CHO7 was mentioned as having a very poor level of support services available and that there was insufficient awareness about HIV in the community (n=1).

The suggestions for improvement were:

- Support services should be co-designed with services users and organisations (n=2);
- Need to define the most appropriate organisations for provision of funding and what falls under remit of sexual health or social inclusion (n=1);
- Need to improve links with existing health promotion programmes and self-management supports, such as the HSE Living Well Programme[31], that could be adapted for those living with HIV (n=1);
- Need for clear pathways to primary care and chronic disease services, possibly supported by a community connector/health promoter role (n=1);
- Education programmes for health and social care professionals on HIV prevention and health promotion for people living with HIV (n=1);
- A support group is needed in CHO7 for those living with HIV (n=1);
- The work underway in Cork city (unspecified) was mentioned as a good model of practice (n=1).

8.5 HIV prevention interventions

A list of nine HIV prevention interventions was provided to inform this section of the survey:

1. Information and on HIV transmission and prevention
2. Health promotion and risk reduction education
3. Information on HIV prevention interventions (condoms, PEP, PrEP)
4. Provision of (free) condoms and lubricant
5. STI testing and treatment
6. HIV testing and counselling
7. Information on harm reduction
8. Harm reduction interventions (needle and syringe programmes and opioid substitution therapy)

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[31] HSE Living Well Programme www.hse.ie/LivingWell and information leaflet on: https://www.hse.ie/eng/health/hl/selfmanagement/living-well-programme/living-well-booklet-interactive.pdf

9. HIV treatment and adherence support, to prevent onward transmission

Stakeholders were asked if they provide direct HIV prevention interventions to the following list of key population groups:

- Gay, bisexual and other men who have sex with men
- Trans people
- People who inject drugs
- People from migrant populations
- People engaged in sex work
- People in prison or engaged with prison services

The majority of participants (n=19, 90%) indicated that they do not provide direct HIV prevention interventions to these key population groups. One participant said they provide all listed HIV prevention interventions to all key population groups. The one participant who responded ‘other’ (national) said that they provide three of the HIV prevention interventions to all population groups (not just key populations): provision of free condoms and lubricant (to services/organisations) via the National Condom Distribution Service and Information on HIV transmission and prevention and Information on HIV prevention interventions via sexualwellbeing.ie and communication resources and campaigns.

8.5.1 Funding for prevention interventions

Stakeholders were asked if they currently provide funding to NGOs or community organisations for HIV prevention interventions with key populations, to which ten (48%) reported that they do not provide funding, seven (33%) reported that they do provide funding and four (19%) reported that they did not know.

Stakeholders who provide funding for HIV prevention interventions were asked to indicate which key population groups funding is provided for, with an additional response option that funding is not restricted to individual key population groups. Six of the seven respondents indicated that funding is not restricted to individual key population groups, one of whom selected all key population groups in their response also. One stakeholder indicated that they provide HIV prevention funding for four key population groups (people engaged in sex work; people from migrant populations; trans people; and gbMSM).

Stakeholders who said that they provide funding for HIV prevention interventions were asked to list the NGOs and community organisations they provide funding to, from the same list of 33 options provided. Table 8.4 lists each of the NGOs and community organisations and details the number of stakeholders who reported providing funding to them for HIV prevention interventions.

Table 8.4. The number of stakeholders who provide funding to the listed NGOs and community organisations for HIV prevention interventions (n=7).

NGO/community organisation	Sources of funding
HIV Ireland	3 sources
Sexual Health West	
ACET	2 sources
Ana Liffey Drug Project	
GOSHH	
LINC	
Sexual Health Centre Cork	
AkiDwA	1 source
Cairde	
Coolmine TC	
Foróige	
Gay Project Cork	
Merchants Quay Ireland	
NASC	
Outhouse	
SafetyNet	
Simon Communities of Ireland	
Tabor Group	
Transgender Equality Network of Ireland	

The participants were also given the opportunity to include any other NGO/community organisation that was not listed, one additional organisation was named, that being the Gay Health Network.

Stakeholders were asked if they have funding available that NGOs or community organisations can apply for/access for HIV prevention interventions with key populations. Only one stakeholder reported that funding is always available, ten (48%) reported that funding is sometimes available and ten (48%) reported that funding is not available, as presented in Table 8.5.

Table 8.5. Funding availability for HIV prevention interventions by stakeholder region/area (n=21).

Stakeholder affiliation	Area/region	Funding always available (n=1)	Funding sometimes available (n=10)	Funding not available (n=10)
HSE Health and Wellbeing	Galway (CHO 2)	-	✓	-
	Limerick (CHO 3)	-	-	✓
	Cork (CHO 4)	-	-	✓
	Dublin (CHO 6)	-	-	✓
	Dublin (CHO 7)	-	-	✓
	Dublin (CHO 9)	-	✓	✓
	National	✓	-	-
HSE Social Inclusion	Galway (CHO 2)	-	✓	-
	Limerick (CHO 3)	-	-	✓
	Cork (CHO 4)	-	✓	✓
	Dublin (CHO 6)	-	-	✓
	Dublin (CHO 9)	-	✓	-
	National	-	✓	-
Councils	Cork City Council	-	✓	-
	Cork County Council	-	✓	✓
	Dublin Dún Laoghaire-Rathdown County Council	-	-	✓
	Dublin Fingal County Council	-	✓	-
	Galway City Council	-	-	✓
	Galway County Council	-	✓	✓
	Limerick City & County Council	-	✓	-
Healthy Cities and Counties	Cork	-	✓	✓
	Dublin	-	✓	✓
	Galway	-	✓	-
	Limerick	-	✓	-

The eleven stakeholders who reported that funding is always or sometimes available, were asked to indicate for which key population groups funding is available or if funding is not restricted to individual key population groups. Nine respondents indicated that funding is not restricted to individual key population groups, one of whom selected all key population groups in their response and one of whom selected people from migrant populations in their response also. One respondent selected ‘other’, stating that funding would be available ‘under the terms of the Healthy Ireland Round 4 and/or SICAP’.

When asked to describe their funding mechanisms or structures, ten stakeholders provided the following descriptions. The national Health and Wellbeing office said that funding was provided annually through a (Section 39) grant agreement[32] process and the national Social Inclusion office said that funding is generally provided to the CHO areas, who then manage the service arrangements with the local providers, and that HSE funding is applied for through the Section 39 application form. Three CHO stakeholders said that funding was available through HSE Section 39 funding and the HSE National lottery grant scheme[33] with one additional CHO stakeholder saying that funding was available by way of an ‘application form’. The Healthy City stakeholders said that Healthy Ireland funding is available through various community grants (n=1) and that funding is delivered in rounds and that ‘partner organisations and their projects are funded as part of an approved Programme of Work’ (n=1). The city and county councils said that funding for community groups is available mainly for capital or programme costs and that deadlines apply (n=1) and that eligibility is determined by the individual scheme requirements (n=1).

8.5.2 Challenges and gaps

Lastly, stakeholders were asked their opinion on the challenges and gaps in regards to HIV prevention interventions for key populations, to which seven provided open-ended responses, two reporting challenges and six providing suggestions for improvement, with some respondents providing multiple suggestions.

The challenges reported were:

- That the annual funding structure limits NGO staff recruitment options (n=1);
- That there are no dedicated funded health promotion posts within the CHO to support HIV prevention interventions (n=1).

The suggestions for improvement were:

- Improve interagency collaboration, between statutory, community and voluntary service providers, across the different sectors to address population health issues, and support interagency action plans (n=2);
- Targeted support for HIV prevention interventions is required for some population groups, such as homeless, those with substance use problems especially those who inject drugs, those engaged in sex work, transgender people and undocumented migrants (n=1);
- Need to develop bespoke approaches/information for different populations with a view to health literacy and cultural norms (n=1);
- Comprehensively address the unique prevention and care needs of trans women and men (n=1);
- Ethnicity data should be routinely collected and analysed to identify gaps in service delivery and inform the development of targeted interventions (n=1);
- Greater promotion of U=U among healthcare professionals (n=1);
- Review relevant survey findings and engage with the applicable services users and providers (n=1);

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[32] https://www.hse.ie/eng/services/publications/non-statutory-sector/section-39-documentation.html

[33] https://www2.hse.ie/services/schemes-allowances/lottery-grants/national-lottery-grants/

- Use of websites for the dissemination of information, e.g. www.drugs.ie;
- The completion of a scoping exercise in the CHO7 area to identify knowledge and practice gaps in relation to the area of HIV;
- Greater promotion of community HIV testing (e.g. in local bars/community organisations) in the CHO7 area (n=1);
- Need to promote and support programmes for health and wellbeing in Dublin Dún Laoghaire-Rathdown area (n=1).

8.6 Chapter summary

This chapter presents the findings from 27 respondents aligned to public sector structures. Participants described the existing engagement between stakeholders in their regions, local funding arrangements for HIV prevention and support services and the associated challenges and gaps and suggestions for improvement. The findings will help each Fast-Track City decide where the initiative best fits within their existing structures and will inform the recommendations set out at the end of the report and the subsequent development of city implementation plans.

Chapter 9

Study recommendations

The following sections set out a brief study summary, an overview of the study's strengths and limitations, a set of specific recommendations for the FTC Steering Groups and a set of recommendations for all relevant HIV stakeholders. All recommendations set out in this chapter have been developed and agreed by the Study Advisory Group.

9.1 Study summary

This study describes the existing HIV-related structures and the HIV prevention, care and support services available across the four Fast-Track Cities, as well as outlining the current challenges and gaps, and providing suggestions for improvement.

The primary objective of this study was to gather information to inform the work of the FTC Steering Groups and the development of their local FTC implementation plans. The information presented in this report should be considered by all stakeholders working in HIV policy and the provision of HIV care and prevention interventions in Ireland.

9.2 Study strengths and limitations

This study has a number of strengths and limitations. This large multi-stakeholder research study is the first of its kind to bring together information from Public Health, service providers and people living with HIV in Ireland. Data collection was completed by an independent company. There was strong engagement and participation in the surveys, and the inclusion of open-ended response options allowed for the documentation of further depth on the topics. The survey for clinical HIV services was developed in alignment with the BHIVA Standards of Care 2018.

There are a number of limitations worth noting. COVID-19 may have reduced the number of survey responses received. Time has lapsed since data collection was conducted in 2022. Additional challenges, such as a recent increase in people living with HIV coming to Ireland, has placed additional pressure on existing services, and this may not be reflected in survey responses. Nonetheless, the findings of the study are still relevant as the HIV prevention and support landscape has not significantly changed since data collection. The demographic profile of the 70 respondents living with HIV may not be representative of all people living with HIV, and it is unknown if people living with HIV who did not participate in the study hold different views, have different experiences, and have other unmet needs that are not documented in this report. Similarly, it is not known if the responses from HCPs working in HIV clinical services are fully representative of all HCPs working in HIV services, but the findings in the HIV stakeholder survey are broadly supported by the findings in the HIV services survey, which has been referenced where appropriate within this report and is available to read in full in Appendix 5.

While the study wasn't designed to provide in-depth information on other health-related services and supports beyond HIV-specific care and supports, nonetheless, some issues on specific topics did emerge, like access to women's services. Further information on specific barriers and concerns for people living with HIV in associated health domains would be useful to better design such services and respond to people's needs.

9.3 Recommendations for the FTC steering groups

It is proposed that the cities of Dublin, Cork, Galway and Limerick, take ownership of their local FTC initiatives. Each of the four cities has a FTC Steering Group which comprises representation from relevant local HIV and city stakeholders. The SHP will continue to support the initiative by remaining on the city steering groups and supporting collaboration between cities and with the Department of Health. The capacity of the FTC Steering Groups to deliver on the initiative will be dependent on the successful sourcing of funding for the management of the initiative and for the improvement of local HIV services and supports.

The following recommendations were developed to support each FTC Steering Group make evidence-based decisions on the management of the HIV FTC initiative in Ireland, and to support the development of local FTC implementation plans.

The FTC Steering Groups should:

- Develop local FTC implementation plans, in consultation with local stakeholders, for the next three years based on the findings of the study and include budget considerations within these plans.
- Ensure that people living with HIV are appropriately represented on the steering groups in the development of the FTC implementation plans and their delivery. Implementation plans should give careful consideration to barriers such as HIV-related stigma that may prevent people living with HIV from participating and that may impact on service delivery.
- Seek funding opportunities through national and regional HSE processes and through other/external funding mechanisms, as appropriate.
- Align the initiative to national strategies and collaborate to identify areas where they can work together across the cities, to leverage efficiency and avoid duplication.
- Use county geographical boundaries to define the HIV Fast-Track City boundaries, as these are the most feasible geographical boundary at present. HIV data is available at the county level and the county boundaries are more relevant to the existing public sector structures as well as the delivery of HIV prevention, care and support services.
- Determine the local governance and management structures for the implementation of the initiative in each city, in consultation with local authorities and HIV stakeholders.
- Explore the feasibility, capacity and resources required to develop city-level epidemiological profiles with the regional and national departments of Public Health.

9.4 Recommendations for HIV stakeholders

In addition to the above recommendations for the FTC Steering Groups, the following set of recommendations was agreed by the SAG to inform the FTC Steering Groups in the development of their city-level implementation plans. These recommendations should also be taken into consideration by all relevant stakeholders in their work to improve the provision of HIV care and support services, and the availability of HIV prevention interventions in Ireland.

The city steering groups will be required to review the recommendations listed below, and in collaboration with local stakeholders, agree their relevance within the local context, and prioritise them within their local FTC implementation plans.

The current epidemiological HIV context also requires consideration in the development of implementation plans and service planning, where the number of individuals living with HIV seeking care and support in Ireland has increased significantly in recent years, in part due to individuals coming to Ireland seeking international protection, to study and work, and new infections occurring in Ireland. This has increased the workload within HIV clinical services and increased the demand for community support services.

Similar findings were reported throughout the study by many different stakeholder groups and therefore the recommendations have been grouped by theme.

Representation of people living with HIV

- Representation of people living with HIV in relevant national and local forums needs improvement and it is likely that achieving this will require capacity building programmes or interventions to improve the capacity and confidence of people living with HIV to meaningfully participate and be able to more broadly represent the diverse community of people living with HIV.
- People living with HIV should be more involved in service design and delivery. This is heavily reliant on volunteers and consideration needs to be given to how volunteers can be better supported to improve their participation.

HIV-related stigma

- More work is required at both national and local levels to combat all aspects of HIV-related stigma among the general population and among service/healthcare providers. This includes work to remove stigma as a barrier to HIV testing or accessing services. All stakeholders should consider HIV-related stigma in all aspects of service planning and delivery, which will require collaboration between national and local stakeholders and researchers.

HIV-related funding

- Funding was identified as an issue that needs to be addressed across the HIV continuum. Funding is required for staff resources and IT infrastructure within HIV clinics and Public Health Departments, and to expand community HIV prevention interventions and support services for people living with HIV.
- The reported funding challenges and gaps for NGOs/community organisations who provide community prevention and support services should be considered. The reported challenges and gaps related to issues such as core (administration) funding costs, the funding needs of HIV member organisations, sustainability of funding for support services, and the additional costs associated with meeting the needs of diverse or marginalised communities.
- More transparent local funding mechanisms are required, both for (sexual) health and social inclusion funding, to improve access to appropriate and efficient local funding, and to enable community organisations to meet the needs of their communities.

HIV surveillance data

- Public HIV clinics, local Departments of Public Health and HPSC require sufficient resourcing to meet national HIV surveillance requirements. This includes having appropriate IT infrastructure and sufficient staff resources to gather and analyse the regional and national HIV surveillance data.
- Locally available information, on the numbers and population groups attending HIV clinical services and on the new HIV notifications, would be useful to inform local support needs and service planning.

HIV clinical care

- There is a need to improve the provision of person-centred HIV care within clinical services, such as improving the time available to patients to discuss and manage their individual care needs and to support patients to better self-manage their HIV and overall health and wellbeing. This requires having sufficient and dedicated staff resources within HIV clinics, such as counsellors, MSWs and CNS.
- The areas of complex HIV care and the management of comorbidities require further consideration, such as the need for dedicated resources during clinics or for joint/coordinated care. This includes psychology care and supports, and addressing the needs of patients as they become older. Improved referral pathways are required within clinical services as well as to community supports, such as counselling and peer-support groups.
- HIV clinic infrastructure and flexibility in access to care could be improved, including consideration of the use of technology, for example the establishment of a patient portal to better access/monitor their results.

Support services for people living with HIV

- Individuals and/or marginalised groups may require additional supports to improve retention in care and maintain viral suppression. This includes community supports (more key workers and outreach services), more time/resources within HIV clinics (dedicated HIV nurses/nurse specialists, psychosocial supports, social workers) and co-administration of HIV care within community settings (addiction/prison settings).
- The availability of HIV support services through NGOs/community organisations and HIV member organisations should be improved, in particular peer-support programmes, counselling and mental health supports. This should take into consideration the local needs of marginalised or rural communities, the provision of local services and outreach and making safe spaces available for peers to meet.

Collaboration between services and stakeholders

- Improved bi-directional communication and collaboration is required between all local HIV services (HIV clinical services, NGOs, member organisations and peer-support groups) in order to enhance information and pathways on services available to people living with HIV. This includes information on social events for people living with HIV. As the FTC initiative supports multi-stakeholder engagement, it may be an ideal mechanism for information exchange and coordination between local stakeholders.
- Signposting and referral pathways should be improved, between local HIV services and existing health promotion programmes, self-management and social welfare supports, primary care and chronic disease services.

HIV testing

- Late HIV diagnoses remains a challenge and could be reduced through the expansion of HIV testing strategies. For HCPs, this includes education on HIV transmission and testing, such as indicator condition testing, to improve the offer of HIV testing in clinical settings. For individuals (and specific population groups), this includes education on HIV transmission, U=U, HIV-related stigma and the expansion of HIV testing strategies, including community HIV testing, to improve HIV testing uptake.

HIV prevention interventions

- Expansion of HIV prevention interventions should take into consideration bespoke/targeted interventions to reach specific population groups.
- Access to local HIV clinical, surveillance and ethnicity data could be improved and utilised to inform the development of targeted interventions.
- Challenges in relation to accessing specific HIV prevention interventions were highlighted throughout the report, such as improving access to PrEP services as a priority, and improving access to PEP, in particular out of hours and in locations other than emergency departments.

Communications and campaigns

- Delivery of HIV awareness and prevention campaigns should continue, including U=U messaging, to improve knowledge among the general public, HCPs and specific population groups (including in different languages). Care needs to be taken in the development of HIV messaging to not inadvertently increase HIV-related stigma. This highlights the importance of including people living with HIV in service planning and delivery.

Education and training

- Gaps in knowledge and understanding of HIV transmission were reported to impact on individuals accessing HIV prevention interventions or testing for HIV. It is important that education resources for young people include up-to-date information on HIV/STI prevention.
- Improved HIV education resources are required, as well as increased availability of training for service providers and healthcare workers. Regular HIV knowledge updates for professionals would be useful, to support the consistency of messaging to service users.

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Appendices

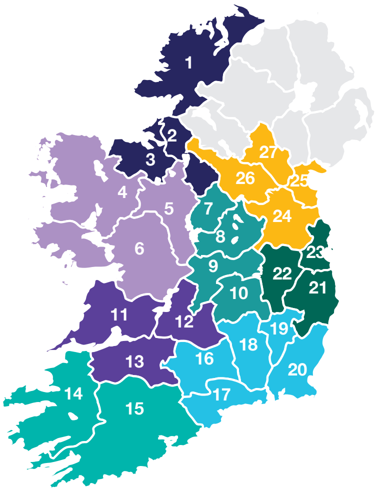
Appendix 1: Fast-Track Cities stakeholder consultation information

Departments of Public Health

At the time of the data collection, there were eight Departments of Public Health covering the Republic of Ireland. The Departments of Public Health East, West, South and Midwest were included in this scoping study.

Table 1A List of HSE Public Health Areas with corresponding map

HSE Public Health Areas and Counties	
HSE West	Mayo (4), Roscommon (5) and **Galway (6)**
HSE Midwest	Clare (11), Tipperary North (12) and **Limerick (13)**
HSE South	Kerry (14) and **Cork (15)**
HSE East	Wicklow (21), Kildare (22) and **Dublin (23)**



In 2023, the Government of Ireland commenced the phased introduction of six Regional Health Areas (RHAs) within the HSE.

HSE Health Protection Surveillance Centre (HPSC)

The Health Protection Surveillance Centre (HPSC) is Ireland's specialist agency for the surveillance of communicable diseases and is responsible for monitoring and reporting national communicable disease trends.

Public HIV clinical services

At the time of the scoping study, HIV care was provided in nine hospital settings. A new HIV clinical service commenced in University Hospital Waterford in June 2022.

The seven adult HIV services that participated in the study are located in Dublin, Cork, Galway and Limerick:

- Beaumont Hospital Dublin
- Mater Misericordiae University Hospital Dublin
- St. James's Hospital Dublin
- St. Vincent's University Hospital Dublin
- Cork University Hospital
- Galway University Hospital
- Limerick University Hospital

There is a joint paediatric HIV service in:

- Children's Health Ireland Crumlin
- Temple Street Hospital

NGOs and community organisations

- HIV organisations
- Sexual Health organisations
- LGBTQI+ organisations
- Addiction and homelessness organisations
- Organisations supporting migrants and refugees
- Youth organisations
- Organisations supporting sex workers

Member organisations for people living with HIV

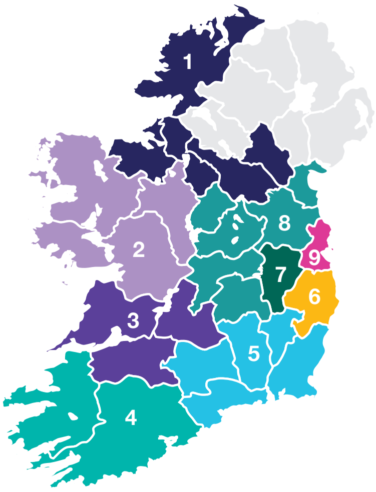
- Positive Now
- The National Women's Group
- Positive Cork
- Positive Life
- Plus Friends

Networks for people living with HIV

- ACT UP Dublin
- ACT UP Cork

HSE Community Healthcare Organisations

Ireland was divided into nine community healthcare organisations (CHO), prior to the RHA restructuring. CHOs link primary, mental and social care providers as well as supporting population-based health and wellbeing. The heads of service for CHO 2, 3, 4, 6, 7 and 9 were invited to participate in the stakeholder consultation.



HSE Social Inclusion

HSE Social Inclusion provides a range of services to support vulnerable groups which includes key populations who may be more vulnerable to HIV. HSE Social Inclusion predominantly provides funding to NGOs within the community and voluntary sectors also manages HSE drug and alcohol services. Social Inclusion in CHO 2, 3, 4, 6, 7, 9 and the National Social Inclusion Office were invited to participate in the stakeholder consultation.

HSE Health and Wellbeing

HSE Health and Wellbeing focuses on enabling people to stay healthy and well, reducing health inequalities and protecting people from threats to their health and wellbeing. From a national perspective, the SHP participated in the stakeholder consultation.

Local Authorities

There are 31 local authorities in Ireland. Local authorities are multi-purpose bodies responsible for delivering a broad range of services. The following local authorities were invited to participate in the stakeholder consultation.

- Cork
    - Cork City Council
    - Cork County Council
- Dublin
    - Fingal County Council
    - Dún Laoghaire-Rathdown County Council
    - South Dublin County Council
    - Dublin City Council
- Galway
    - Galway City Council
    - Galway County Council
- Limerick
    - Limerick City and County Council.

Healthy Cities and Counties

Healthy Cities and Counties of Ireland support Local Authorities to implement the Healthy Ireland Framework. The National Healthy Cities and Counties of Ireland Network has representatives from government departments, the HSE, the Institute of Public Health, the Federation of Irish Sport and local political and community representatives. The following Healthy Cities and Counties were invited to participate in the stakeholder consultation;

- Healthy Cork City
- Healthy Cork County
- Healthy Dublin City
- Healthy Fingal
- South Dublin County Council
- Healthy Dún Laoghaire-Rathdown
- Healthy Galway
- Healthy Limerick

Appendix 2: Study Advisory Group members and terms of reference

Membership

Professor Fiona Lyons, Clinical Lead/Medical Director, HSE Sexual Health Programme

Caroline Hurley, Project Manager, HSE Sexual Health Programme

Dr Nicola O’Connell, Research Manager, HSE Sexual Health Programme

Dr Éadaoin Butler, former Acting Research Manager, HSE Sexual Health Programme

Rachael Metrustry, Project Officer, HSE Sexual Health Programme

Professor Jack Lambert, Consultant in Infectious Diseases, Mater Misericordiae University Hospital, Dublin

Stephen O’Hare, Executive Director, HIV Ireland

Dr Martin Davoren, Executive Director, Sexual Health Centre Cork

Study Advisory Group Terms of Reference

- Support and oversee the establishment, progression and successful completion of the scoping study
- Provide input and sign off data collection instruments developed by the research team
- Meet with the research team at scheduled times and key intervals
- Review and provide feedback on draft reports
- Attend steering group meetings as required

Appendix 3: Work Package 1. Interview schedules for HPSC and Departments of Public Health

Interview schedule: Local Departments of Public Health

1. HIV notification data (diagnosis) is currently reported nationally by HSE Area, which includes multiple counties.
    - **a.** Can HIV notification data be separated at the county level?
    - **b.** Can HIV notification data be separated at the city level?
    - **c.** If yes, is it possible to provide this HIV data annually for FTC monitoring and reporting purposes? (note: Public Health are looking to report annually on county data in the future, so this may be something that becomes routine)
2. Data completeness
    - **a.** What proportion of the enhanced surveillance forms have been returned to your Dept of PH for each year 2018, 2019, 2020?
    - **b.** What proportion of the enhanced surveillance forms have been entered on CIDR in your Dept of PH in 2018, 2019, 2020?
3. What are the barriers to improving the HIV completeness data?
4. Are there any barriers to participating in regional HIV surveillance within your department?

Interview schedule: Health Protection Surveillance Centre (HPSC)

1. How is national HIV monitoring data collected?
2. How is the national HIV continuum of care generated? (the national HIV 90-90-90 epidemiological profile)
3. What data/modelling technique would be required to generate city/county epidemiological profiles?
4. Is the required data available?
5. If no, can this data be collected? Or could proxy data be used?
6. If yes, what is your capacity to support the regional Departments of Public Health to generate this?
7. What is the broader capacity of the HPSC at present to do modelling and statistical work, and what are the barriers/challenges in conducting this work?

Appendix 4: Work Package 2. Stakeholder Consultation Surveys

Survey information and consent form

You are being invited to take part in a research study carried out by IQVIA on behalf of the HSE Sexual Health and Crisis Pregnancy Programme (SHCPP)*.

The purpose of this study is to provide a baseline description of HIV prevention, care and support services across the four Fast-Track Cities in Ireland and to document challenges and gaps. The information gathered from key stakeholders will be used to develop a Fast-Track Cities report which will be published on www.sexualwellbeing.ie. The report will support the development of city implementation plans for the Fast-Track Cities in Ireland.

This survey takes approximately X minutes to complete. There is the option throughout the survey to provide detailed responses and feedback. You have the right to refuse to answer questions or close the survey at any time prior to submission.

Why is this study being done?

In 2019, the cities of Dublin, Cork, Galway and Limerick, signed up to the Fast-Track Cities Initiative. The Fast-Track Cities Initiative is a global partnership between cities and municipalities around the world and four core partners – the International Association of Providers of AIDS Care (IAPAC), the Joint United Nations Programme on HIV/AIDS (UNAIDS), the United Nations Human Settlements Programme (UN-Habitat), and the City of Paris, in collaboration with the network of cities. The initiative's aim is to build upon, strengthen, and leverage existing HIV programs and resources to accelerate locally coordinated, city-wide responses to end the HIV epidemic by 2030.

The purpose of this study is to provide a baseline description of HIV prevention, care and support services across the four Fast-Track Cities in Ireland and document challenges and gaps. The study will provide the evidence base for the establishment of the Fast-Track Cities Initiative and will inform the development of city implementation plans.

Who is responsible for this study?

IQVIA is conducting this study on behalf of the SHCPP who is commissioning the study. IQVIA is an independent research organisation. The research is compliant with local Data Protection Laws and Market Research Society's Code of Conduct including European Society for Opinion and Market Research (ESOMAR), European Pharmaceutical Market Research Association (EphMRA) and all other relevant national codes of practice. This study has received ethical approval from the Royal College of Physicians Ireland (RCPI), reference number 166.

Privacy Notice and Data Protection

Please find all details regarding your privacy and data protection here: Link to privacy notice.

Consent to Future Uses

Your answers to this survey will be anonymised and anonymous responses will be sent to the SHCPP with your consent, after the end of the study to allow for comparative analysis should future studies be conducted on this topic.

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* In 2024, the Sexual Health and Crisis Pregnancy Programme (SHCPP) became the Sexual Health Programme (SHCPP)

Where can I get further information?

If you have any further questions about the study or if you need any further information now or at any time in the future, please contact:

Name: Rachael Metrustry

Address: HSE Sexual Health and Crisis Pregnancy Programme

Consent form

I confirm that I have read and understood the information about this research project and give informed consent to have my responses processed as part of this research.

☐ Yes
☐ No

I understand that once I have completed the survey and submitted my responses they cannot be withdrawn.

☐ Yes
☐ No

I give permission for anonymous data to be stored by the SHCPP for possible future publication and research related to the current study

☐ Yes
☐ No

HIV clinic stakeholder survey

General information

Q1. What service do you work for?

1. Beaumont Hospital
2. Mater Misericordiae University Hospital
3. St James's Hospital
4. St Vincent's University Hospital
5. Cork University Hospital
6. University Hospital Galway
7. University Hospital Limerick
8. Other, please specify: FREE TEXT BOX
9. Prefer not to say

Q2. What is your role?

1 Doctor
2 Nurse
3 Medical Social Worker

HIV Testing diagnosis and prevention

Testing and diagnosis – Sub-heading

Q3. Do you see patients who present with a late HIV diagnosis[1]?

[1] Late diagnosis defined as CD4 count of <350cells/mm3 at presentation

1 Yes
2 No
3 N/A to my role

Q4. Of the potential reasons listed below for late diagnosis, please tick the box that is closest to your viewpoint.

[Show if Q3=1]

MATRIX QUESTION: Very unlikely, unlikely, likely, very likely, don't know, N/A to my role

1 An individual's reluctance to test for HIV
2 Lack of awareness of HIV transmission and risk
3 Lack of access to HIV testing
4 A healthcare provider's reluctance for to offer HIV testing
5 Lack of awareness of HIV indicator conditions in healthcare providers

Q5. Are there other important reasons for late HIV diagnoses? Please detail.

FREE TEXT BOX

Q6. To what extent do you believe HIV-related stigma impacts on timeliness of HIV diagnosis and subsequent engagement in care?

DISPLAY LIKERT SCALE: To a very little extent, to a little extent, to some extent, to a large extent, to a very large extent, N/A to my role.

Q7. How do you think late HIV diagnosis could be reduced? Tick all that apply

1. Education of the public
2. Education of healthcare providers
3. Education targeting vulnerable populations
4. Additional opportunities for HIV testing
5. Development of a model of care for vulnerable populations
6. Other, please specify: FREE TEXT BOX
7. N/A to my role

Prevention with partners – Sub-heading

Q8. Which of the following prevention topics do you routinely discuss with patients? Tick all that apply.

1. HIV testing for partner(s) at time of diagnosis
2. HIV transmission and prevention with partners at time of diagnosis (e.g. PEP, PrEP, condoms)
3. HIV transmission and prevention over time/as relevant/as new prevention options become available
4. TasP/U=U
5. I do not discuss HIV prevention with patients
6. Other, please specify: FREE TEXT BOX
7. N/A to my role

Q9. If you would like to provide suggestions on how to improve awareness and/or discussions on HIV prevention with partners, please detail.

FREE TEXT BOX

Person – centred care

Participation of people living with HIV in their care – Sub-heading

Q10. Please read the following statements about person - centred care and rate your level of agreement with each statement.

MATRIX QUESTION: Strongly disagree, Disagree, Neither disagree nor agree, Agree, Strongly Agree, N/A to my role.

1. We need to include patients more in decisions around their individual HIV care.
2. We need to include patients more in decisions around how overall HIV care is delivered.
3. We need to do more to enable patients to self-manage their HIV and overall health and wellbeing.

Q11. If you would like to comment about how we could improve how patients can be included more in decisions around how overall HIV care is delivered, please detail. FREE TEXT BOX

Q12. If you would like to comment about how we could better facilitate patients to self-manage their HIV, please detail. FREE TEXT BOX

HIV outpatient care and treatment

Access to and retention in care – Sub-heading

Q13. In your experience, which of the following population groups are less likely to achieve/maintain viral suppression? Tick all that apply.

1. Gay, bisexual, and other men who have sex with men (gbMSM)
2. Trans people
3. Homeless people
4. People engaged in sex work
5. People from migrant populations
6. People who inject drugs
7. Individuals in prison or engaged with prison services
8. Any other population group: FREE TEXT BOX
9. N/A to my role

Q14. Is additional support needed to assist vulnerable populations in achieving viral suppression and being retained in care?

1. Yes
2. No
3. Don’t know
4. N/A to my role

Q15. What support do you think would be valuable to vulnerable populations in achieving viral suppression and being retained in care? [Show if Q14=1]

FREE TEXT BOX

Outpatient care – Sub-heading

Q16. For management of comorbidities (for e.g., hypertension, dyslipidemia, diabetes) in people living with HIV, who do you think should be the main healthcare provider?

1. GP
2. HIV service
3. Combined care
4. N/A to my role

Q17. How likely are the factors listed below to present challenges to managing comorbidities?

Please tick the box that is closest to your viewpoint.

MATRIX QUESTION: Very unlikely, unlikely, likely, very likely, don’t know, N/A to my role

1. Patient not registered with a GP
2. Patient not disclosed HIV status to GP
3. Patient ability to pay for GP care
4. Patient ability to pay for medication for comorbidities
5. Limited HIV appointment time/frequency

Q18. If you feel there are other important challenges to managing comorbidities and/or would like to provide suggestions on how to improve the management of comorbidities, please detail. FREE TEXT BOX

Health promotion services and supports

Vaccines – Sub-heading

Q19. Are there barriers to providing vaccinations to patients within your HIV service?

1. Yes
2. No
3. Don’t know
4. N/a to my role

Q20. What are the barriers and how could vaccine access or uptake be improved? Please detail. [Show if Q19=1] FREE TEXT BOX

STI testing – Sub-heading

Q21. Are there barriers to providing STI testing to patients within your HIV clinic?

1. Yes
2. No
3. Don't know
4. N/a to my role

Q22. What are the barriers and how could STI testing access or uptake be improved? Please detail.[Show if Q21=1] FREE TEXT BOX

Smoking cessation - Sub-heading

Q23. Which smoking cessation supports are available to your patients? Please tick all that apply.

1. Brief interventions, making every contact count (MECC)
2. Referral to local smoking cessation services e.g HSE Stop Smoking Advisors
3. Signposting to national smoking cessation supports e.g. QUIT.ie, QUIT phone service.
4. Other, please specify: FREE TEXT BOX
5. N/A to my role

Q24. If you would like to provide suggestions on other supports that would be useful to promote smoking cessation, please detail. FREE TEXT BOX

Alcohol and recreational drug use - Sub-heading

Q25. Which of the following are available to your patients to support the reduction of problematic alcohol and drug use? Please tick all that apply

1. Brief interventions, making every contact count (MECC)
2. Referral to addiction support service
3. Signposting to drug and alcohol supports and/or services e.g. Ask About Alcohol
4. Other, please specify: FREE TEXT BOX
5. N/A to my role

Q26. If you would like to provide suggestions on other supports that would be useful to reduce alcohol and drug use, please detail. FREE TEXT BOX

Complex HIV care

Q27. As outcomes for people living with HIV improve, do you have concerns for retention of medical and nursing skills for provision of inpatient care for patients presenting with advanced HIV/HIV related opportunistic infections?

1. Yes
2. No
3. Don't know
4. N/A to my role

Q28. How do you think we can ensure retention of medical and nursing skills for management of advanced HIV and HIV related opportunistic infections? FREE TEXT BOX

Q29. BHIVA standards recommend HIV inpatient care networks to ensure optimisation of skill sets and provision of care. Would you support the development of HIV inpatient care networks in Ireland?

1. Yes
2. No
3. Don't know
4. N/A to my role

Psychological care

Q30. What proportion of your patients would benefit from psychological support to improve emotional wellbeing and mental health?

1. 0% - 24%
2. 25% - 49%
3. 50% - 74%
4. 75% - 100%
5. N/A to my role

Q31. How could the emotional wellbeing and mental health of patients be improved within your HIV service? FREE TEXT BOX

Q32. What are the challenges/barriers for patients to access psychological care or support services and how could access be improved? FREE TEXT BOX

HIV across the life course

Young adults and adolescents living with HIV - Subheading

Q33. Are there any challenges in transitioning adolescents to adult HIV care?

1. Yes
2. No
3. Don't know
4. N/a to my role

Q34. What are the challenges? FREE TEXT BOX

Q35. If you would like to provide suggestions on how to improve support to adolescents transitioning to adult care, please detail. FREE TEXT BOX

Older Age – Subheading

Q36. Do you see challenges and gaps in addressing the medical and social care needs of ageing patients (65 years and older) living with HIV?

1. Yes
2. No
3. Don't know
4. N/A to my role

Q37. If you would like to provide suggestions on how these gaps and challenges could be improved, please detail. FREE TEXT BOX

COVID-19 and HIV care

With the COVID-19 pandemic, there have been many changes to how healthcare is being delivered, such as a move to online/remote consultations.

Q38. Please describe the **positive changes** in HIV care delivery that arose from service adaptations during the COVID-19 pandemic. FREE TEXT BOX

Q.39. Please describe the **negative changes** in HIV care delivery that arose from service adaptations during the COVID-19 pandemic. FREE TEXT BOX

DISPLAY CLOSE-OUT PAGE

This survey is complete. Thank you for participating in this study.

NGO and community organisations survey

General Information

Q1. Does your organisation provide dedicated HIV prevention and/or support work?

1. Yes
2. No → Close out of survey.
   Close-out message: This survey is complete. Thank you for participating in this study

Q2. In which location(s) do you provide HIV prevention and/or support work?
Select national if your organisation has a national remit.

Select the county(ies) where you (as the survey respondent) provide HIV prevention and/or support work. Tick all that apply.

1. Dublin
2. Cork
3. Limerick
4. Galway
5. National

Q3. What is the name of the organisation you work for?

1. ACET
2. AkiDwA
3. AMACH! LGBT Galway
4. Ana Liffey Drug Project
5. BeLongTo
6. Cairde
7. Chrysalis Community Drug Project
8. Coolmine TC
9. Foróige
10. Gay Project Cork
11. GOSHH
12. HIV Ireland
13. Irish Family Planning Association
14. Irish Refugee Council
15. LGBT Ireland
16. LINC
17. Merchants Quay Ireland
18. NASC
19. National Youth Council of Ireland
20. Outhouse
21. Peter McVerry Trust
22. Rialto Community Drugs Team
23. SafetyNet

24. SAOL
25. Sexual Health Centre Cork
26. Sexual Health West
27. Sex Workers Alliance Ireland
28. Simon Communities of Ireland
29. SpunOut.ie
30. Tabor Group
31. The Bridge Project
32. Transgender Equality Network of Ireland
33. UISCE
34. Other, please specify: FREE TEXT BOX

Q4. What is your role with this organisation?

1. Support Worker → Route to Q20
2. Counsellor → Route to Q20
3. Outreach worker → Route to Q20
4. Health Promotion Worker → Route to Q20
5. Community Worker → Route to Q20
6. Community Tester → Route to Q20
7. Rapid HIV Testing volunteer → Route to Q20
8. Manager → Route to Q20
9. Director/CEO/ or equivalent → Route to Q5
10. Other, please specify: FREE TEXT BOX

Core Funding

[1] Core funding would cover organisational costs – building, overheads, administration costs, management staff, etc.

Q5. Does your organisation receive core funding?

1. Yes → Route to Q6
2. No → Route to Q10

Q6. Where did your organisation access core funding in 2019? Tick all that apply.

1. National HSE Social Inclusion Office
2. Local HSE Social Inclusion Office
3. National HSE Health & Wellbeing (eg SHCPP)
4. CHO HSE Health & Wellbeing
5. Local Authorities (City and County Councils)
6. Healthy Ireland
7. Not applicable
8. Other, please specify:
   FREE TEXT BOX

Q7. Where did your organisation access core funding in 2020? Tick all that apply.

1. National HSE Social Inclusion Office
2. Local HSE Social Inclusion Office
3. National HSE Health & Wellbeing (eg SHCPP)
4. CHO HSE Health & Wellbeing
5. Local Authorities (City and County Councils)
6. Healthy Ireland
7. Not applicable
8. Other, please specify:
   FREE TEXT BOX

Q8. Where did your organisation access core funding in 2021? Tick all that apply.

1. National HSE Social Inclusion Office
2. Local HSE Social Inclusion Office
3. National HSE Health & Wellbeing (eg SHCPP)
4. CHO HSE Health & Wellbeing
5. Local Authorities (City and County Councils)
6. Healthy Ireland
7. Not applicable
8. Other, please specify:
   FREE TEXT BOX

Q9. What was the average Whole Time Equivalent (WTE) covered by core funding between 2019 and 2021?FREE TEXT BOX

Funding for Support Services for People Living with HIV

Q10. Where did your organisation access funding for support services for people living with HIV in 2019? Tick all that apply.

1. National HSE Social Inclusion Office
2. Local HSE Social Inclusion Office
3. National HSE Health & Wellbeing (eg SHCPP)
4. CHO HSE Health & Wellbeing
5. Local Authorities (City and County Councils)
6. Healthy Ireland
7. Not applicable
8. Other, please specify:
   FREE TEXT BOX

Q11. Where did your organisation access funding for support services for people living with HIV in 2020? Tick all that apply.

1. National HSE Social Inclusion Office
2. Local HSE Social Inclusion Office
3. National HSE Health & Wellbeing (eg SHCPP)
4. CHO HSE Health & Wellbeing

5. Local Authorities (City and County Councils)
6. Healthy Ireland
7. Not applicable
8. Other, please specify:
   FREE TEXT BOX

Q12. Where did your organisation access funding for support services for people living with HIV in 2021? Tick all that apply.

1. National HSE Social Inclusion Office
2. Local HSE Social Inclusion Office
3. National HSE Health & Wellbeing (eg SHCPP)
4. CHO HSE Health & Wellbeing
5. Local Authorities (City and County Councils)
6. Healthy Ireland
7. Not applicable
8. Other, please specify:
   FREE TEXT BOX

Q13. What was the average WTE covered by this funding between 2019 and 2021? FREE TEXT BOX

Funding for HIV Prevention

Q14. Where did your organisation access funding for HIV prevention interventions in 2019? Tick all that apply

1. National HSE Social Inclusion Office
2. Local HSE Social Inclusion Office
3. National HSE Health & Wellbeing (eg SHCPP)
4. CHO HSE Health & Wellbeing
5. Local Authorities (City and County Councils)
6. Healthy Ireland
7. Not applicable
8. Other, please specify:
   FREE TEXT BOX

Q15. Where did your organisation access funding for HIV prevention interventions in 2020? Tick all that apply

1. National HSE Social Inclusion Office
2. Local HSE Social Inclusion Office
3. National HSE Health & Wellbeing (eg SHCPP)
4. CHO HSE Health & Wellbeing
5. Local Authorities (City and County Councils)
6. Healthy Ireland
7. Not applicable
8. Other, please specify:
   FREE TEXT BOX

Q16. Where did your organisation access funding for HIV prevention interventions in 2021? Tick all that apply

1. National HSE Social Inclusion Office
2. Local HSE Social Inclusion Office
3. National HSE Health & Wellbeing (eg SHCPP)
4. CHO HSE Health & Wellbeing
5. Local Authorities (City and County Councils)
6. Healthy Ireland
7. Not applicable
8. Other, please specify:
   FREE TEXT BOX

Q17. What was the average WTE covered by this funding between 2019 and 2021? FREE TEXT BOX

Q18. In your opinion, has it become more difficult to access funding for HIV support and/or prevention over the past two years since COVID-19?

1. Yes
2. No

Q19. What are the challenges or gaps in the availability or accessibility of funding for HIV support and/or prevention and how could it be improved? Please detail. FREE TEXT BOX

General Information

Q20. Which areas of HIV do you work in? Tick all that apply.

1. Support services for people living with HIV → Route to Q21
2. HIV prevention → Route to Q26

Support for People Living with HIV

Q21. Please select the support services that you provide for people living with HIV. Tick all that apply.

- **a.** Practical information/resources (leaflets/websites) on living well with HIV
- **b.** Seminar /classes on living well with HIV
- **c.** HIV treatment advice (medications, how to take your tablets on time/correctly, side effects, etc.)
- **d.** Information on HIV prevention, viral suppression, U=U
- **e.** Sexual health information
- **f.** Peer-support group(s)
- **g.** Safe space(s) to meet peers
- **h.** Counselling
- **i.** Advice or support to access HIV clinical care
- **j.** Advice or support to access other health services
- **k.** Advice or support to access other outreach/community services (such as drug/addiction, homelessness, etc.)
- **l.** Financial or legal information and support
- **m.** Advice/support in relation to stigma or discrimination
- **n.** Advice/support on disclosing your HIV status

- **o.** Advice/support to access social welfare services (benefits, housing, etc.)
- **p.** Advice on further education or employment
- **q.** Advice/support on immigration issues, accessing migrant support services
- **r.** High level HIV advocacy
- **s.** Other, please specify: FREE TEXT BOX

Q22. If there are gaps in the provision of support services for people living with HIV, please highlight the gaps you feel are most important (this can be where a service isn't provided at all, or is insufficient to meet the demand). FREE TEXT BOX

Q23. What are the main challenges in the provision of community support services to people living with HIV? FREE TEXT BOX

Q24. If you would like to provide suggestions on how community support services for people living with HIV could be improved, please detail: FREE TEXT BOX

Q25. Are there important COVID-related challenges that are still impacting on your organisation's ability to provide HIV support services for people living with HIV?

1. Yes, please specify: FREE TEXT BOX
2. No

HIV Prevention

Q26. Which populations do you target for HIV prevention interventions? Tick all that apply.

1. General population
2. Young people
3. Gay, bisexual and other men who have sex with men
4. Trans people
5. People who inject drugs
6. People from migrant populations
7. People engaged in sex work
8. People in prison or engaged with prison services
9. Other, please specify:

FREE TEXT BOX

Q27 to **Q35** Please select which HIV prevention interventions are provided. Tick all that apply.

[SEPARATE QUESTION FOR EACH POPULATION SELECTED]

- **a.** Information and advice on HIV transmission and prevention
- **b.** Health promotion and risk reduction education
- **c.** Information on HIV prevention interventions (condoms, PEP, PrEP)
- **d.** Provision of (free) condoms and lubricant
- **e.** STI testing and treatment
- **f.** HIV testing and counselling
- **g.** Information on harm reduction
- **h.** Harm reduction interventions (needle and syringe programmes and opioid substitution therapy)

- **i.** Information on HIV treatment as prevention (TasP), U=U
- **j.** HIV treatment and adherence support
- **k.** Community outreach
- **l.** Other: FREE TEXT BOX

Q36. If there are gaps in the provision of HIV prevention interventions, please highlight the gaps you feel are most important (this can be where a service isn't provided at all or is insufficient to meet the demand). FREE TEXT BOX

Q37. What are the main challenges in the provision of HIV prevention interventions? FREE TEXT BOX

Q38. If you would like to provide suggestions on how HIV prevention interventions could be improved, please detail: FREE TEXT BOX

Q39. Are there important COVID-related challenges which are still impacting on your ability to provide HIV prevention interventions?

1. Yes, please specify: FREE TEXT BOX
2. No

DISPLAY CLOSE-OUT PAGE

This survey is complete. Thank you for participating in this study.

People living with HIV survey

General Information

Q1. Are you living with HIV?

☐ Yes
☐ No

Q2. In which year were you diagnosed with HIV?

Please select a year.

Q3. In which country were you diagnosed with HIV?

Please select a country

Q4. Do you attend a HIV clinic (for HIV care and treatment)?

☐ Yes
☐ No

Q5. In what county is your HIV clinic located:

☐ Dublin
☐ Cork
☐ Galway
☐ Limerick
☐ Other, please specify:

Testing and diagnosis

Q6. When you first tested positive for HIV, where did you have the test?

☐ Public STI clinic
☐ General practice (GP)/Primary Care
☐ Community/mobile testing site
☐ Hospital emergency department
☐ Hospital as an inpatient
☐ Hospital as an outpatient
☐ Antenatal Clinic
☐ Blood donation
☐ Unspecified medical setting
☐ Home sampling (Take own sample and send to lab)
☐ Self-testing (Do own rapid HIV test and get an immediate result)
☐ Prison
☐ Drug/addiction services
☐ Other location, please specify

Q7. Why do you think someone might delay testing for HIV? Tick all that apply.

☐ Lack of knowledge about HIV transmission and individual risk for HIV
☐ Fear of receiving a positive result
☐ HIV stigma
☐ Access to HIV testing
☐ Reluctance for providers to offer test
☐ Other, please specify:

Q8. What might make it easier for someone to test for HIV and therefore be diagnosed sooner?
FREE TEXT BOX

Q9. At the time of your diagnosis, were you referred to, or provided information on accessing the following services? Tick all that apply.

☐ HIV clinic and/or treatment
☐ HIV peer-support network and/or services
☐ Non-governmental organisations (NGOs)/Community organisations
☐ Counselling and/or psychological support
☐ Other, please specify:

Prevention with partners

Q10. Have you heard of the following statement:

A person on HIV treatment with an undetectable* viral load cannot pass on HIV through sex, known as undetectable = untransmittable (U=U).

** Also known as virally suppressed, this means the virus is not detectable in your blood or the test result is less than 200 copies/mL*

☐ Yes
☐ No

Q11. Do you believe the above U=U statement ‘A person on HIV treatment with an undetectable viral load cannot pass on HIV through sex’ to be true?

☐ Yes, strongly believe
☐ Yes, believe somewhat
☐ No, I don’t believe it
☐ Not sure
☐ I don’t understand what undetectable means

Q12. How does the U=U statement make you feel about your own HIV status?
Please rate on a scale from 1-5, where 1 is much worse and 5 is much better.

Much worse	Worse	The same	Better	Much better
☐	☐	☐	☐	☐

Q13. If you wish, please use the space below to tell us about your thoughts on this statement.
FREE TEXT BOX

General Practitioner (GP) care

Q14. Are you registered with a GP?

☐ Yes
☐ No
☐ Don't know

Q15. Does your GP know your HIV status?

☐ Yes
☐ No
☐ Don't know

Q16. Here are some statements about your experience with your GP. Please tick the box that is closest to your viewpoint.

	Strongly disagree	Disagree	Agree	Strongly Agree	Don't know	N/A
In my opinion, my GP knows enough about my HIV condition and treatment	☐	☐	☐	☐	☐	☐
I am comfortable discussing my HIV with my GP	☐	☐	☐	☐	☐	☐
My GP is as involved as I want them to be with my HIV care	☐	☐	☐	☐	☐	☐
As far as I am aware, my HIV specialist and my GP communicate well regarding my health	☐	☐	☐	☐	☐	☐
I do not attend my GP on a regular basis due to cost (I do not have a medical card)	☐	☐	☐	☐	☐	☐

HIV Clinical Care

Q17. In general, how satisfied are you with your HIV clinical care?

Very satisfied	Satisfied	The same	Dissatisfied	Very dissatisfied
☐	☐	☐	☐	☐

Q18. In general, have you needed and/or received the following support. For each of these, please tick the box that is closest to your experience.

	I have received this	I needed this but could not get it	I needed this but did not try to get it	I needed this but did not know about it	I did not need this
Information about living with HIV (including websites)	☐	☐	☐	☐	☐
HIV treatment advice	☐	☐	☐	☐	☐
Professional help to take your HIV tablets on time or correctly	☐	☐	☐	☐	☐
Help managing side effects of HIV medications	☐	☐	☐	☐	☐
Peer support/social contact with other people with HIV	☐	☐	☐	☐	☐
Help disclosing your HIV status	☐	☐	☐	☐	☐
Help managing long-term conditions/ comorbidities	☐	☐	☐	☐	☐

Q19. You mentioned you couldn’t get the support needed, please tell us the reason(s) why. Free text box

Q20. In the past two years (since COVID-19), has your satisfaction with your HIV clinical care changed?

☐ Yes, it has decreased
☐ Yes, it has increased
☐ No, it is about the same

Q21. Why has your satisfaction changed and what could be improved? Free text box

Q22. If you would like to provide suggestions on how HIV care or treatment could be improved in general, please detail. Free text box

Self- management & participation of people living with HIV in their care

Q23. Here are some statements about your experience and participation with your HIV clinic. Please tick the box that is closest to your viewpoint.

	Strongly disagree	Disagree	Agree	Strongly Agree	Don't know	N/A
My clinic provides enough information about my HIV	☐	☐	☐	☐	☐	☐
Information is provided in a language or format that is understandable to me	☐	☐	☐	☐	☐	☐
I feel supported to self-manage my HIV	☐	☐	☐	☐	☐	☐
I am involved in decisions about my HIV treatment and care	☐	☐	☐	☐	☐	☐
At appointments, I feel I have enough time to cover everything I want to discuss	☐	☐	☐	☐	☐	☐
The staff listen carefully to what I have to say	☐	☐	☐	☐	☐	☐

Q24. Would you like to be more involved in your HIV care, and be supported to self-manage your HIV?

1 ☐ Yes
2 ☐ No

Q25. If you would like to provide more information on challenges to self-managing your HIV, or provide suggestions on how you could be more involved or supported, please detail. Free text box

Health and wellbeing

Maintaining health and wellbeing is important for people living with HIV, to support a good quality of life and reduce potential impacts on health in later years. This section asks about your healthcare and other needs, and whether these are being met.

Q26. In general, have you needed and/or received the following services or support?

For each of these, please tick the box that is closest to your experience.

	I have received this	I needed this but could not get it	I needed this but did not try to get it	I needed this but did not know about it	I did not need this
Help to manage weight	☐	☐	☐	☐	☐
Help or advice regarding your sex life	☐	☐	☐	☐	☐
Free condoms and lubricant	☐	☐	☐	☐	☐
STI testing (at your HIV clinic appointment)	☐	☐	☐	☐	☐
Help to stop smoking	☐	☐	☐	☐	☐
Alcohol counselling or treatment	☐	☐	☐	☐	☐
Drug counselling or treatment	☐	☐	☐	☐	☐
Chemsex support (advice and harm reduction)	☐	☐	☐	☐	☐
Drug detox or maintenance treatment	☐	☐	☐	☐	☐
Contraception	☐	☐	☐	☐	☐
Family planning or advice on getting pregnant	☐	☐	☐	☐	☐
Information/advice on menopause	☐	☐	☐	☐	☐
Home health services	☐	☐	☐	☐	☐

Q27. You mentioned you couldn’t get the support needed, please tell us the reason(s) why. Free text box

Q28. If you would like to provide suggestions on how access to health services could be improved, please detail. Free text box

Stigma & discrimination

Q29. Because of your HIV status, have you experienced any of the following experiences in relation to a healthcare setting?

	No	Yes, in the past year	Yes, more than a year ago
I have been worried that I would be treated differently to other patients	☐	☐	☐
I have avoided seeking healthcare when I needed it	☐	☐	☐
I have been treated differently to other patients	☐	☐	☐
I felt that I was refused healthcare or had a treatment or medical procedure delayed	☐	☐	☐

Community and peer-support

Many support services for people living with HIV are provided by HIV or Sexual Health NGOs (community organisations) or networks for people living with HIV.

Q30. Have you had contact with a HIV/ Sexual Health NGO, or HIV Network for any reason in the past 5 years?

☐ Yes
☐ No

Q31. Please name the NGO(s)/ HIV Networks you had contact with. (Tick all that apply)

☐ ACET
☐ ACT UP Cork
☐ ACT UP Dublin
☐ AMACH! LGBT Galway
☐ BelongTo
☐ Gay Project Cork
☐ GOSHH
☐ HIV Ireland
☐ Irish Family Planning Association
☐ LGBT Ireland
☐ LINC
☐ Outhouse
☐ Plus Friends
☐ Positive Cork
☐ Positive Life
☐ Positive Now
☐ Sexual Health Centre Cork
☐ Sexual Health West
☐ The National Women's Group
☐ Transgender Equality Network of Ireland (TENI)
☐ Other, please specify:

Q31. Do you currently attend a HIV support group?

☐ Yes
☐ No

Q33. Who manages the group?

☐ ACET
☐ ACT UP Cork
☐ ACT UP Dublin
☐ AMACH! LGBT Galway
☐ BelongTo
☐ Gay Project Cork
☐ GOSHH
☐ HIV Ireland
☐ Irish Family Planning Association
☐ LGBT Ireland
☐ LINC
☐ Outhouse
☐ Plus Friends
☐ Positive Cork
☐ Positive Life
☐ Positive Now
☐ Sexual Health Centre Cork
☐ Sexual Health West
☐ The National Women's Group
☐ Transgender Equality Network of Ireland (TENI)
☐ Other, please specify:

Q34. Overall, how important would you say community HIV support services have been for your health and wellbeing?

☐ Not important
☐ Slightly important
☐ Somewhat important
☐ Important
☐ Very important

Q35. In your engagement with community HIV support services, have you needed and/or received the following services or support?

For each of these, please tick the box that is closest to your experience.

	I have received this	I needed this but could not get it	I needed this but did not try to get it	I needed this but did not know about it	I did not need this
Practical information/ resources (leaflets/ websites) on living well with HIV	☐	☐	☐	☐	☐
Seminar/classes on living well with HIV	☐	☐	☐	☐	☐
HIV treatment advice (medications, how to take your tablets on time/correctly, side effects, etc.)	☐	☐	☐	☐	☐
Information on HIV prevention, viral suppression, U=U	☐	☐	☐	☐	☐
Sexual health information	☐	☐	☐	☐	☐
Peer-support group	☐	☐	☐	☐	☐
Safe space to meet peers	☐	☐	☐	☐	☐
Counselling	☐	☐	☐	☐	☐
Advice or support to access HIV clinical care	☐	☐	☐	☐	☐
Advice or support to access other health services	☐	☐	☐	☐	☐
Advice or support to access other outreach/community services (such as drug/addiction, homelessness, etc.)	☐	☐	☐	☐	☐
Financial or legal information and support	☐	☐	☐	☐	☐
Advice /support in relation to stigma or discrimination	☐	☐	☐	☐	☐
Advice /support on disclosing your HIV status	☐	☐	☐	☐	☐
Advice/support to access social welfare services (benefits, housing, etc.)	☐	☐	☐	☐	☐
Advice on further education or employment	☐	☐	☐	☐	☐
Advice /support on immigration issues, accessing migrant support services	☐	☐	☐	☐	☐

Q36. You mentioned you couldn’t get the support needed, please tell us the reason(s) why.

Q37. If there are other important community supports (not listed above) that you received or would be useful to you, please detail. Free text box

Q38. Over the past two years (since COVID-19), has it become more difficult to access the community HIV support services that you need?

☐ Yes, please specify:
☐ No

Q39. Here are some statements about your experience with community HIV support services. Please tick the box that is closest to your viewpoint.

	Strongly disagree	Disagree	Agree	Strongly Agree	Don't know	N/A
I am happy with the level of information available	☐	☐	☐	☐	☐	☐
I am happy with the range of supports available	☐	☐	☐	☐	☐	☐
I am happy with my interaction with NGOs/ community services	☐	☐	☐	☐	☐	☐
The location of my community HIV support services are convenient	☐	☐	☐	☐	☐	☐
The working hours/times of my HIV support services are convenient	☐	☐	☐	☐	☐	☐
My HIV support services are culturally appropriate	☐	☐	☐	☐	☐	☐
My HIV support services are age appropriate	☐	☐	☐	☐	☐	☐
Information /services are provided in a language/format that is understandable to me	☐	☐	☐	☐	☐	☐
I do not have to wait long to access the supports I need	☐	☐	☐	☐	☐	☐

Q40. If you would like to provide suggestions on how community support services could be improved, please detail. FREE TEXT BOX

Demographics

Q41. In which year were you born?

Q42. How do you identify your gender?

☐ Female (including trans woman)
☐ Male (including trans man)
☐ Non-binary
☐ In another way
☐ Prefer not to say

Q43. Is your gender identity the same as the sex you were assigned at birth?

- ☐ Yes
- ☐ No
- ☐ Prefer not to say

Q44. Which of the following best describes how you think of yourself?

- ☐ Straight/Heterosexual
- ☐ Gay or Lesbian/Homosexual
- ☐ Bisexual
- ☐ Other, please specify:
- ☐ Prefer not to say

Q45. What is your ethnic group/background?

- ☐ **White**
  - ☐ Irish
  - ☐ Irish Traveller
  - ☐ Roma
  - ☐ Any other white background
- ☐ **Black or Black Irish**
  - ☐ African
  - ☐ Any other Black background
- ☐ **Asian or Asian Irish**
  - ☐ Chinese
  - ☐ Indian/Pakistani/Bangladeshi
  - ☐ Any other Asian background
- ☐ **Other, including mixed background**
  - ☐ Arab
  - ☐ Mixed, please specify
  - ☐ Other, please specify
  - ☐ Prefer not to say

Q46. What county do you currently live in? Please select from list

Q47. What is your country of birth? Please select from list

This survey is complete. Thank you for taking the time to complete the survey. We really appreciate your insights.

Member organisations and networks for people living with HIV survey

General information:

Q1. Are you affiliated with a HIV member organisation or network?

1 Yes
2 No → Closeout of survey.
Close-out message: Thank you for your interest. We are sorry, you do not meet the criteria to participate in this survey. We appreciate your time and hope you will continue to participate in our surveys in future.

Q2. What is the name of the organisation/network that you are affiliated with? (Multiple Select option)

1 Positive Now and the All – Ireland Network
2 Positive Cork
3 ACT UP Dublin
4 ACT UP Cork
5 Positive Life
6 Plus Friends
7 The National Women's Group
8 Other, please detail: FREE TEXT BOX

Q3. How many members does your organisation/ network have? Please estimate if you don't know the exact figure. FREE TEXT BOX

Q4. How many members are living with HIV? Please estimate if you don't know the exact figure. FREE TEXT BOX

Funding and organisational structure

Q5. Is your organisation/network a registered charity?

1 Yes
2 No
3 Don't know

Q6. Please describe the governance structure of the organisation/network. FREE TEXT BOX

Q7. How is the work of your organisation/network funded/supported? Tick all that apply.

Please use the text box for additional details.

1 We access/receive our own funding – please detail from whom. FREE TEXT BOX
2 We collaborate with a partner who accesses external funding to support our work – please name the partner and external funding source/donor. FREE TEXT BOX
3 We collaborate with a partner who supports our work from their own funding – please name the partner. FREE TEXT BOX
4 We receive ad-hoc funding/support for specific network activities – please detail from whom over the last 2 years. FREE TEXT BOX
5 We receive no funding or support for our work
6 Don't know

Q8. What does the funding/support you receive cover? Tick all that apply.

MATRIX QUESTION: regularly, occasionally, not covered

1. Organisation/network chair/management time costs
2. Activity-related member/volunteer time costs
3. Activity-related member/volunteer expenses (travel costs, etc.)
4. Rent/office/meeting space
5. Administration costs (phone, computer, utilities, etc.)
6. Advocacy work
7. Activities to support people living with HIV

Q9. Please use the free text box to describe any other activities/work that the funding you receive covers. FREE TEXT BOX

Q10. What are the challenges and gaps in relation to accessing funding/support for the work of your organisation/network? FREE TEXT BOX

Q11. If you would like to provide suggestions on how access to funding/support could be improved, please detail: FREE TEXT BOX

<u>Activities, services and supports</u>

Q12. Which HIV-related activities/services/supports does your organisation/network undertake? Tick all that apply.

- **a.** HIV advocacy
- **b.** Legal information/support
- **c.** Addressing HIV-related stigma and discrimination
- **d.** Information on HIV transmission and prevention
- **e.** Information/resources (leaflets/websites) on living well with HIV
- **f.** Information on HIV prevention with partners, viral suppression, U=U
- **g.** Advice on HIV treatment (medications, how to take your tablets on time/correctly, side effects, etc.)
- **h.** Network-led peer-support group meetings
- **i.** Signposting to community-based peer-support groups
- **j.** Social activities/events
- **k.** Network-led counselling services
- **l.** Signposting to counselling services
- **m.** Advice or support to access HIV clinical care
- **n.** Advice or support on HIV disclosure
- **o.** Advice or support to access other health services
- **p.** Advice or support to access other outreach/community services (such as drug/addiction, homelessness, etc.)
- **q.** Advice or support to access social welfare services (benefits, housing, etc.)
- **r.** Advice on further education or employment
- **s.** Advice or support on immigration issues, accessing migrant support services
- **t.** Other, please specify:

Q13. What are the challenges and gaps in relation to the availability and delivery of HIV-related activities/

services/supports? FREE TEXT BOX

Q14. If you would like to provide suggestions on how the availability and delivery of HIV-related activities/services/supports could be improved, please detail: FREE TEXT BOX

Q15. Are there important COVID-related challenges that are impacting your work?

1 Yes, please specify: FREE TEXT BOX
2 No

Partnerships

Q16. Which of the following does your Network collaborate with? Tick all that apply.

a. Other HIV Networks
b. HIV/sexual health non-governmental organisations (NGOs)
c. Other non-governmental organisations (NGOs) (addiction, homeless, migrant, etc.)
d. Other Local Community Development Committees
e. HIV Clinical Services
f. HSE Health & Wellbeing (e.g. SHCPP, local CHO office)
g. HSE Social Inclusion (e.g. addiction, homeless, migrant support services, local CHO office)
h. Local Authorities (City and County Councils)
i. Healthy Cities and Counties Initiative
j. Other, please specify:

FREE TEXT BOX

Q17. Do you feel that people living with HIV are sufficiently represented in relevant in national and local fora?

1 Yes
2 No
3 Don’t know

Q18. What are the main challenges to representation of people living with HIV in working groups/fora? FREE TEXT BOX

Q19. If you would like to provide suggestions on how representation of people living with HIV could be improved, please detail: FREE TEXT BOX

DISPLAY CLOSE-OUT PAGE

This survey is complete. Thank you for participating in this study.

City level public sector structures survey

General Information

Q1. In which area do you work?

1. Cork
2. Dublin
3. Galway
4. Limerick
5. National

Q2. Which stakeholder group are you affiliated with? Tick all that apply.

HSE Health & Wellbeing

a. CHO 2
b. CHO 3
c. CHO 4
d. CHO 6
e. CHO 7
f. CHO 9
g. National H&W

HSE Social Inclusion

h. CHO 2
i. CHO 3
j. CHO 4
k. CHO 6
l. CHO 7
m. CHO 9
n. National Social Inclusion Office

City and county councils

o. Cork City Council
p. Cork County Council
q. Limerick City & County Council
r. Galway City Council
s. Galway County Council
t. Dublin City Council
u. Fingal County Council
v. South Dublin County Council
w. Dún Laoghaire- Rathdown County Council

Healthy Cities and Counties

x. Dublin
y. Cork
z. Galway
aa. Limerick

Q3. Are there existing structures in place to facilitate engagement between (the above) city stakeholders/authorities?

1	Yes	➔ ROUTE TO Q4
2	No	➔ ROUTE TO Q5
3	Don't know	➔ ROUTE TO Q5

Q4. What regional structures are in place to facilitate engagement between city stakeholders/authorities? Tick all that apply.

1 Regional HIV networks/meetings
2 Regional HSE networks/meetings
3 Local Community Development Committee (LCDC) networks/ meetings
4 Regional Healthy Ireland (Cities, Counties, Community networks/meetings)
5 Primary Care/Community Healthcare Network meetings
6 Other, please specify: FREE TEXT BOX

Q5. Are there any existing multistakeholder HIV groups/fora (that may include statutory and non-statutory bodies) that you think would be relevant for the Fast-Track Cities Initiative to engage with, please list: FREE TEXT BOX

__Support for people living with HIV__

Q6. Do you provide direct support services for people living with HIV?

1	Yes	➔ ROUTE TO Q7
2	No	➔ ROUTE TO Q8
3	Don't know	➔ ROUTE TO Q8

Q7. Please describe the type of support services you provide for people living with HIV? FREE TEXT BOX

Q8. Do you currently provide funding to NGOs or community organisations for activities/services to support people living with HIV?

1	Yes	➔ Route to Q9
2	No	➔ Route to Q10
3	Don't know	➔ Route to Q10

Q9. Please list the NGOs/community organisations you provide funding for.

1. ACET
2. AkiDwA
3. AMACH! LGBT Galway
4. Ana Liffey Drug Project
5. BeLongTo
6. Cairde
7. Chrysalis Community Drug Project
8. Coolmine TC
9. Foróige
10. Gay Project Cork
11. GOSHH

12. HIV Ireland
13. Irish Family Planning Association
14. Irish Refugee Council
15. LGBT Ireland
16. LINC
17. Merchants Quay Ireland
18. NASC
19. National Youth Council of Ireland
20. Outhouse
21. Peter McVerry Trust
22. Rialto Community Drugs Team
23. SafetyNet
24. SAOL
25. Sexual Health Centre Cork
26. Sexual Health West
27. Sex Workers Alliance Ireland
28. Simon Communities of Ireland
29. SpunOut.ie
30. Tabor Group
31. The Bridge Project
32. Transgender Equality Network of Ireland
33. UISCE
34. Other, please specify:

Q10. Do you have **funding available** that NGOs/community organisations can access/apply for to support people living with HIV?

1	Yes, always	➔ ROUTE TO Q11
2	Yes, sometimes	➔ ROUTE TO Q11
3	No	➔ ROUTE TO Q12
4	Don't know	➔ ROUTE TO Q12

Q11. Is your available funding restricted to specific interventions or activities, if so please describe. FREE TEXT BOX

Q12. If you have any thoughts on challenges or gaps in the provision of support services for people living with HIV and/ or have suggestions on how to improve support services for people living with HIV, please detail. FREE TEXT BOX

HIV prevention

Q13. Do you provide **direct** HIV prevention services for key populations? Tick all that apply.

1 Gay, bisexual and other men who have sex with men (gbMSM)
2 Trans people
3 People who inject drugs
4 People from migrant populations
5 People engaged in sex work
6 People in prison or engaged with prison services
7 Other, please specify:
8 Don't know
9 No

Q14-20. Please select which, if any, HIV prevention interventions are provided for this population? Tick all that apply. [SEPARATE QUESTION FOR EACH POPULATION SELECTED]

1 Information and on HIV transmission and prevention
2 Health promotion and risk reduction education
3 Information on HIV prevention interventions (condoms, PEP PrEP)
4 Provision of (free) condoms and lubricant
5 STI testing and treatment
6 HIV testing and counselling
7 Information on harm reduction
8 Harm reduction interventions (Needle and syringe programmes and opioid substitution therapy)
9 HIV treatment and adherence support, to prevent onward transmission
10 Other, please specify:

Q21. Do you currently **provide funding** to NGOs or community organisations for HIV prevention interventions with key populations?

1	Yes	➜ ROUTE TO Q22
2	No	➜ ROUTE TO Q24
3	Don't know	➜ ROUTE TO Q24

Q22. Please indicate for which key populations funding is provided. Tick all that apply.

1 Funding is not restricted to individual key population
2 Gay, bisexual and other men who have sex with men (gbMSM)
3 Trans people
4 People who inject drugs
5 People from migrant populations
6 People engaged in sex work
7 People in prison or engaged with prison services
8 Other, please specify:

Q23. Please list the NGOs or community organisations you provide funding to for HIV prevention interventions.

a. ACET
b. AkiDwA
c. AMACH! LGBT Galway
d. Ana Liffey Drug Project
e. BeLongTo
f. Cairde
g. Chrysalis Community Drug Project
h. Coolmine TC
i. Foróige
j. Gay Project Cork
k. GOSHH
l. HIV Ireland
m. Irish Family Planning Association
n. Irish Refugee Council
o. LGBT Ireland
p. LINC
q. Merchants Quay Ireland
r. NASC
s. National Youth Council of Ireland
t. Outhouse
u. Peter McVerry Trust
v. Rialto Community Drugs Team
w. SafetyNet
x. SAOL
y. Sexual Health Centre Cork
z. Sexual Health West
aa. Sex Workers Alliance Ireland
bb. Simon Communities of Ireland
cc. SpunOut.ie
dd. Tabor Group
ee. The Bridge Project
ff. Transgender Equality Network of Ireland
gg. UISCE
hh. Other, please specify: FREE TEXT BOX

Q24. Do you have **funding available** that NGOs or community organisations can apply for/access, for HIV prevention interventions with key populations?

1	Yes, always	→ ROUTE TO Q25
2	Yes, sometimes	→ ROUTE TO Q25
3	No	→ ROUTE TO Q27

Q25. Please indicate for which key populations: Tick all that apply.

1 Funding is not restricted to individual key population
2 Gay, bisexual and other men who have sex with men (gbMSM)
3 Trans people
4 People who inject drugs
5 People from migrant populations
6 People engaged in sex work
7 People in prison or engaged with prison services
8 Other, please specify:

Q26. Please describe the funding mechanism/structure, or if this is for specific activities. FREE TEXT BOX

Q27. If you have any thoughts on the challenges or gaps in HIV prevention interventions with key populations and how to improve these, please detail. FREE TEXT BOX

DISPLAY CLOSE-OUT PAGE

This survey is complete. Thank you for participating in this study.

Appendix 5: Survey of adult HIV clinical services

Fast – Track Cities survey of adult HIV clinical services

July 2022

Background

In 2019, Dublin, Cork, Galway and Limerick signed up to the Fast-Track Cities Initiative (FTCi). The initiative's aim is to build upon, strengthen, and leverage existing HIV programs and resources to accelerate locally coordinated, city-wide responses to achieve the following UNAIDS 2030 targets;

- 95% of people living with HIV knowing their HIV status.
- 95% of people who know their HIV-positive status on HIV treatment.
- 95% of people living with HIV on HIV treatment with suppressed viral loads.
- Zero stigma and discrimination.

Steering groups have been established for each of the four Fast-Track Cities. The steering groups comprise representatives from sexual health and HIV organisations, people living with HIV, public adult HIV clinical services, HSE Sexual Health and Crisis Pregnancy Programme (SHCPP)*, HSE Departments of Public Health, HSE Health Protection Surveillance Centre (HPSC), HSE Health & Wellbeing departments, HSE Social Inclusion, Local City and County Councils and the Department of Health, who will support and establish the implementation of the initiative in each city.

Methods

In 2021, the HSE Sexual Health and Crisis Pregnancy Programme (SHCPP) commissioned a HIV Scoping Study of available HIV data, services and support in the four Fast-Track Cities, to provide the evidence base for both the establishment of the FTC Initiative, and the work of the Steering Groups in the development of city-level epidemiological profiles and implementation plans. As part of this study, the SHCPP surveyed each of the adult public HIV clinical services in Ireland to obtain an estimate of care. In absence of Irish standards, the British HIV Association Standards of Care for People Living with HIV, 2018 was used, and a range of outcomes were selected to develop questions. Where applicable, the BHIVA target is presented with the questions. Ethical approval from the Royal College of Physicians of Ireland was obtained for the study, reference number: RECSAF 166.

All adult public HIV services in Ireland were invited to participate and it was requested that only one response be submitted per service. Those who received the survey would consult with relevant staff members where necessary, to complete the response. The survey was open from March to April 2022. Each service provided a response (n=7). Descriptive results are displayed in aggregate format under the following headings;

- Baseline HIV service description
- HIV testing, diagnosis and prevention
- Person-centred care
- HIV outpatient care and treatment
- Health promotion, prevention and education for people living with HIV
- Complex HIV care and comorbidities

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* In 2024, the Sexual Health and Crisis Pregnancy Programme (SHCPP) became the Sexual Health Programme (SHCPP)

- Psychological care
- HIV across the life course
- Developing and maintaining excellent standards of care

Results

Results are presented in graphical format where there are differences across services. Numbers on y-axis indicate number of HIV services.

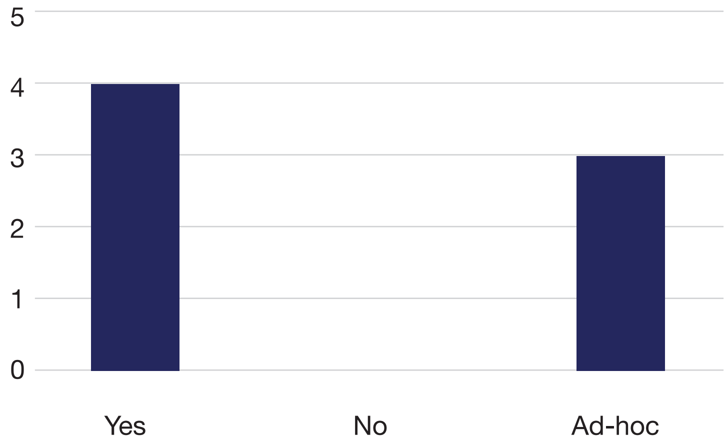
Baseline Service Description

1. How many patients are registered with your service for HIV care?
   - Adult HIV clinical services reported a range of 220 to 5,990 patients registered for care.

2. In your service do you have a dedicated:
   - Pharmacist: 7/7 services
   - HIV clinical nurse specialist: 6/7 services
   - Medical social worker: 4/7 services
   - Psychologist: 1/7 services

HIV testing, diagnosis and treatment

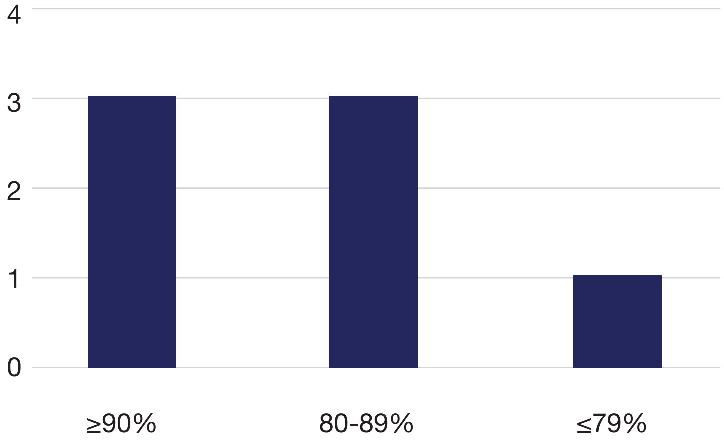
3. In your service do you undertake a ‘look back’ of previous engagement with healthcare services for all new patients diagnosed late (CD4 count <350 cells/mm3) or very late (CD4 count <200 cells/mm3 or AIDS)?
   - BHIVA target: 95% of services.



4. In your service, do you routinely offer HIV testing to partners of those newly diagnosed with HIV?
   - 7/7 services routinely offer HIV testing to partners of those newly diagnosed with HIV.

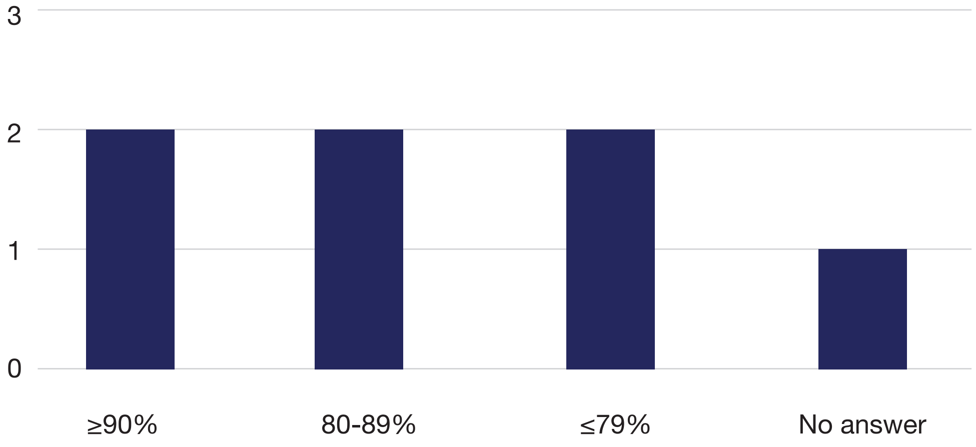
5. In your service, what is the estimated proportion of people with documented evidence of having had a discussion about HIV transmission and prevention (PEPSE, PrEP, condoms)?

- BHIVA target: 90%.



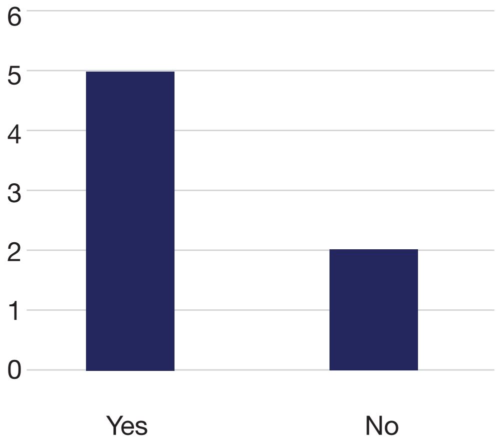
6. In your service, for people with sustained viral suppression (at least 6 months) what is the estimated proportion with documented evidence that they have been advised that they cannot transmit HIV to their sexual partners?

- BHIVA target: 90%.

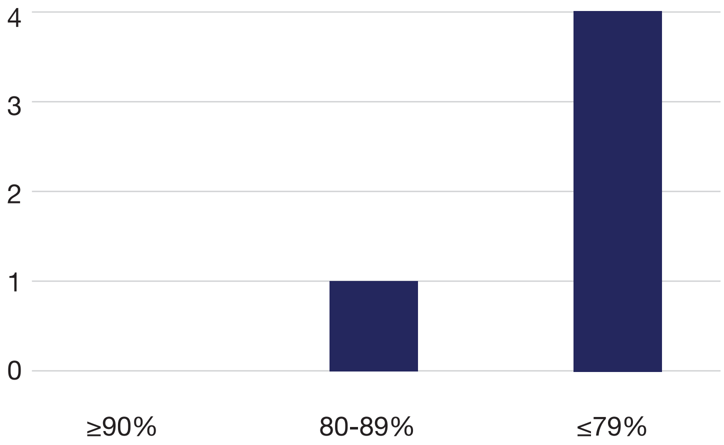


Person - centred care

7. In your service is there equality and diversity training available to staff members?



8. Of the five services that have equality and diversity training available, what is the estimated proportion of staff who have completed this training?



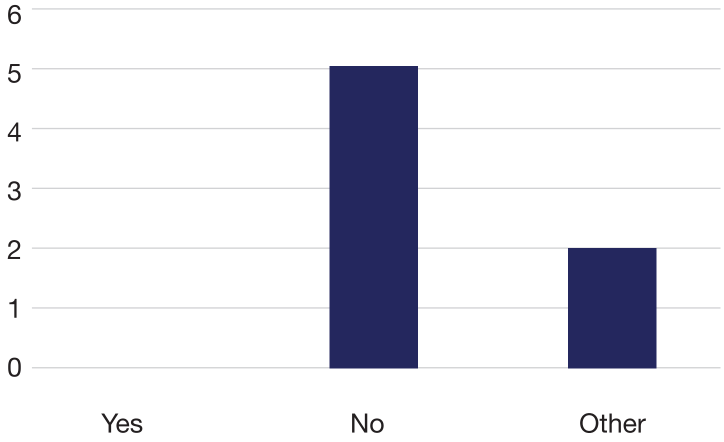
9. In your service have you undertaken a patient experience survey in past 3 years to assess satisfaction with HIV care across medical departments?

- 0/7 services have undertaken a patient experience survey in past 3 years to assess satisfaction with HIV care across medical departments.

10. In your service have you undertaken a patient experience survey in the past 3 years that includes experience of HIV-related stigma?

- 0/7 services have undertaken a patient experience survey in the past 3 years that includes experience of HIV-related stigma.

11. In your service is there routine participation of people living with HIV, as individuals or through representatives, in service design and delivery?



Service comments:

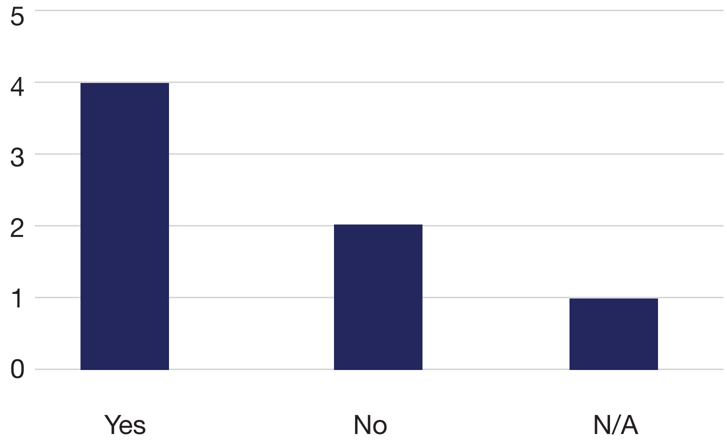
i) Looking to formalise a structure, on-site comment cards available to all.

ii) Comments during consultations are taken on board.

12. In your service do you provide language translation services/interpreters?

- 7/7 services provide language translation services.

13. In your service do you provide sign language translation services for individuals who are hearing impaired?



Service comments:

The service which said N/A does not currently have any patients requiring sign language services. Sign language services would be provided if required.

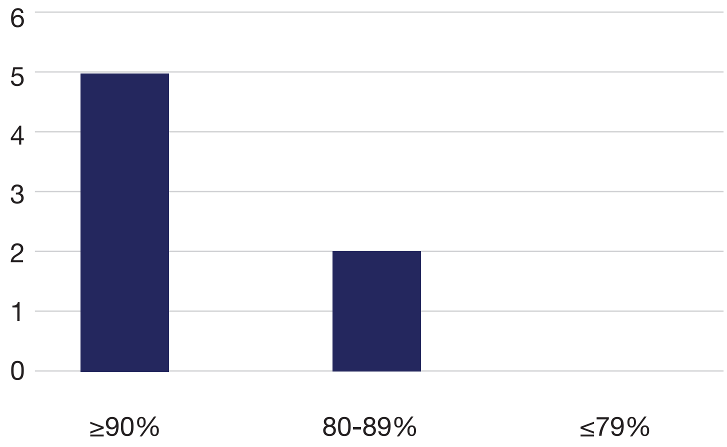
HIV outpatient care and treatment

14. In your service what is the estimated proportion of new HIV referrals that are seen within 2 weeks of appointment request?

- BHIVA target: 90%.
- 7/7 services reported that **≥90%** of new HIV referrals are seen within 2 weeks of appointment request.

15. In your service what is the estimated proportion of people newly diagnosed with HIV who are offered referral for peer support?

- BHIVA target: 90%.

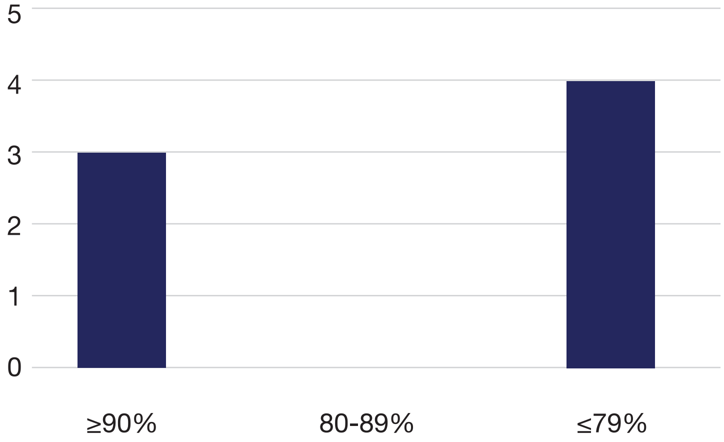


16. In your service what is the estimated proportion of newly diagnosed patients with documented evidence of a clinical assessment and who are offered the opportunity of starting ART within a month of attending for care?

- BHIVA target: 90%.
- 7/7 services reported that **≥90%** of newly diagnosed patients have documented evidence of a clinical assessment and are offered the opportunity of starting ART within a month of attending for care.

17. In your service what is the estimated proportion patients with documented evidence that the results of HIV viral load, CD4 count, HIV resistance assay, were available within 2 weeks of specimen collection?

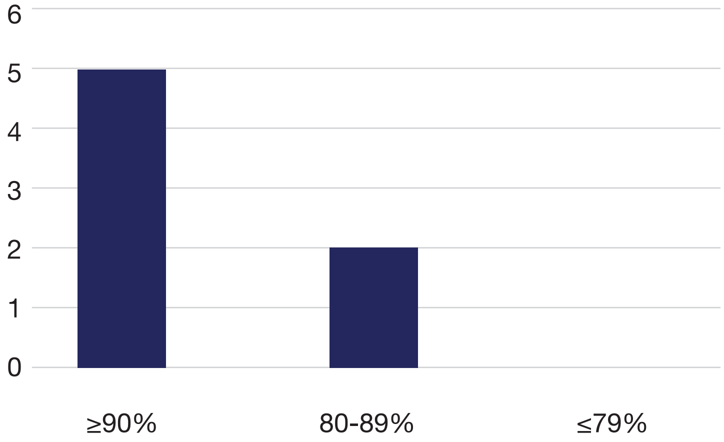
- BHIVA target: 90%.



Services noted that HIV resistance assays take 4-6 weeks (this includes services that replied ≥90%).

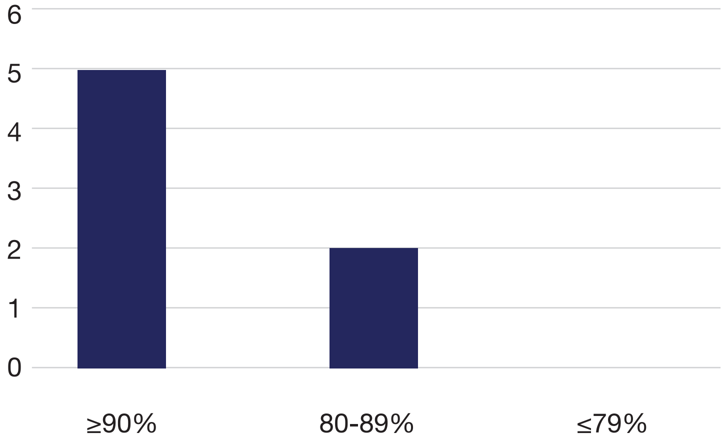
18. In your service what is the estimated proportion of **newly diagnosed** adults (who have not died or transferred their care) retained in care in the year following diagnosis?

- BHIVA target: >90%.



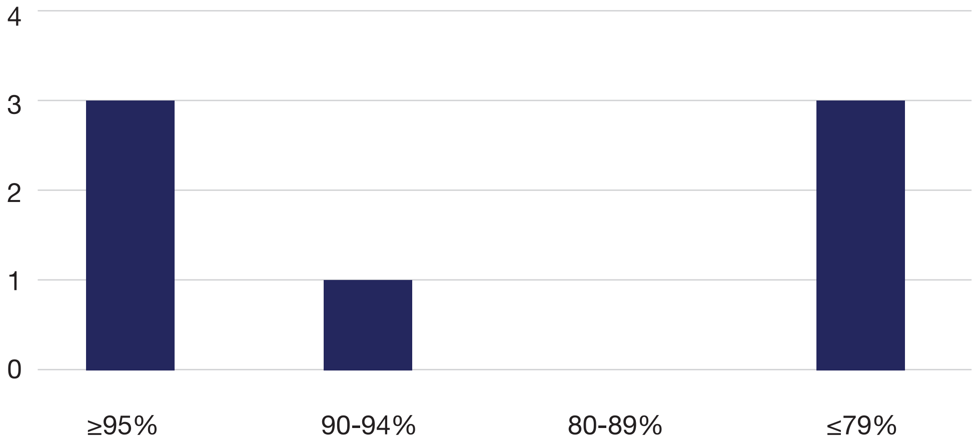
19. In your service what is the estimated proportion of people registered for care (who have not died or transferred their care) who have accessed HIV clinical services within the past 12 months?

- BHIVA target: 90%.

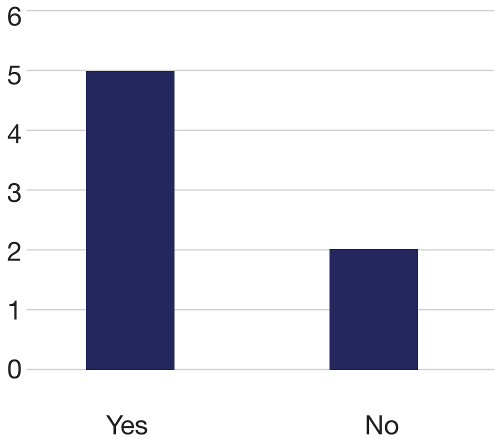


20. In your service what is the estimated proportion of people who have not accessed HIV clinical services within the past 12 months i.e., lost to follow up (who have not died or transferred their care) in whom there is documented evidence of efforts to re-engage them?

- BHIVA target: 95%.



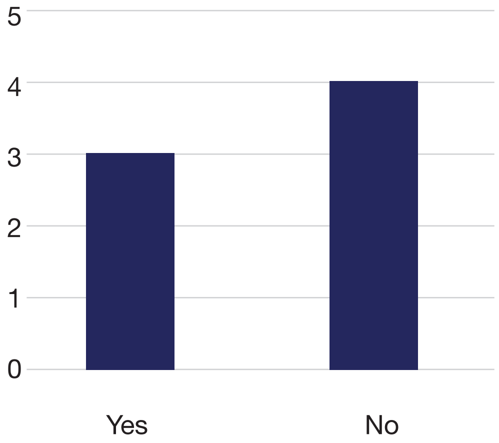
21. In your service do you have a specific lost to follow up policy?



22. In your service, what is the estimated proportion of people in your service on ART?

- 7/7 services reported that the proportion of people who are on ART is **≥94%**.

23. In your service, are some population groups less likely to be on ART?



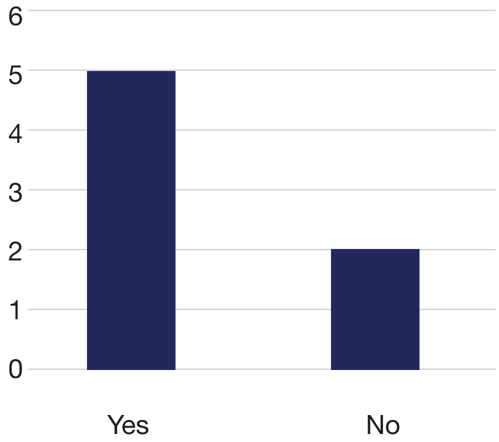
24. Of the three services who reported that some population groups are less likely to be on ART, these included:

- Homeless individuals
- People from migrant populations
- People who inject drugs
- People with acute mental health problems
- People with difficult socio-demographic backgrounds

25. In your service, what is the estimated proportion of people with sustained viral suppression (at least 6 months)?

- 7/7 services reported that the proportion of people with sustained viral suppression (at least 6 months) is **≥90%**.

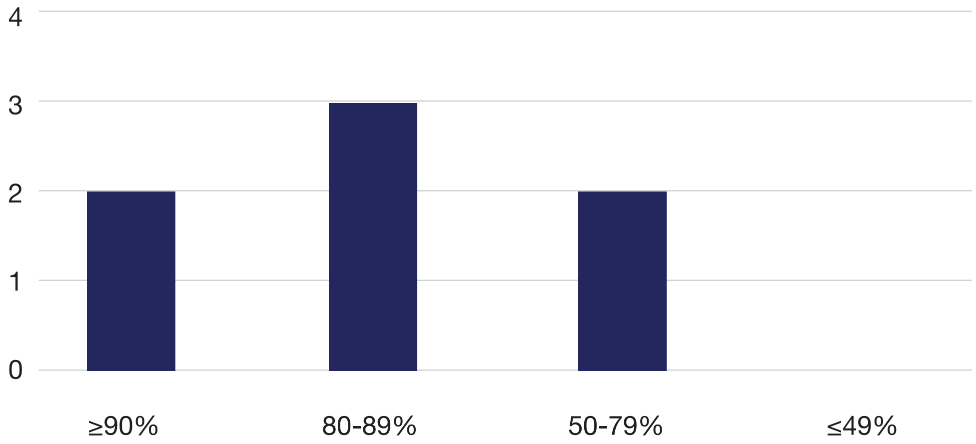
26. In your service, are some population groups less likely to have sustained viral suppression?



27. Of the five services who reported that some population groups are less likely to have sustained viral suppression, these included:

- Individuals from migrant populations
- Homeless individuals
- People who inject drugs
- Patients with medication adherence issues secondary to mental health problems
- People with difficult socio-demographic backgrounds

28. In your service what is the estimated proportion of people who are registered with a GP?



29. Do patients without a medical card/GP visit card experience challenges in paying for GP care?

- 7/7 services reported that patients without a medical card/GP visit card experience challenges in paying for GP care.

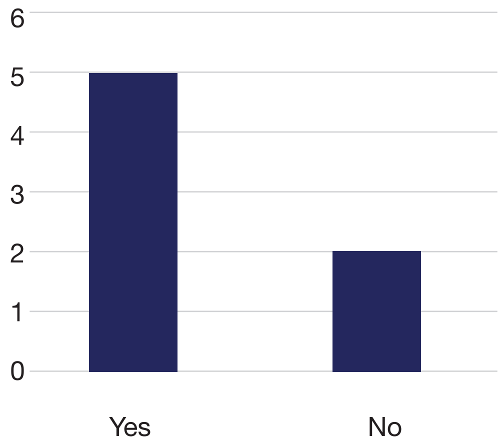
30. Services estimated the proportion of patients who experience challenges in paying for GP care to be between **5% and 30%**.

31. Do patients in your care experience challenges in paying for medication for comorbidities?

- 7/7 services reported that patients experience challenges in paying for medication for comorbidities.

32. Services estimated the proportion of patients who experience challenges in paying for medication for comorbidities to be between **5% and 30%**.

33. Do patients in your care prefer **not** to disclose their HIV status to their GP?



34. Services estimated that between **7% and 50%** of patients preferred not to disclose their HIV status to their GP.

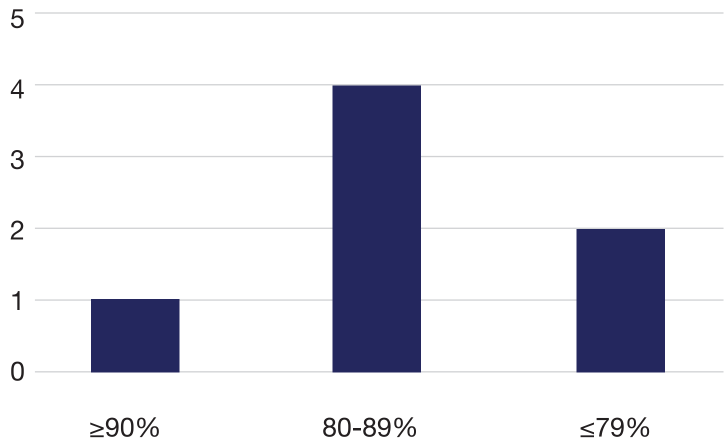
- Services outside Dublin noted a greater proportion of patients who prefer not to disclose their status to their GP.

35. In your service, do you have an agreed pathway for people on ART who experience viral rebound (defined as confirmed measurable HIV viral load of more than 200 copies/mL) who were previously suppressed or where viral suppression is not achieved after treatment initiation?

- 7/7 services have an agreed pathway for people on ART who experience viral rebound who were previously suppressed or where viral suppression is not achieved after treatment initiation.

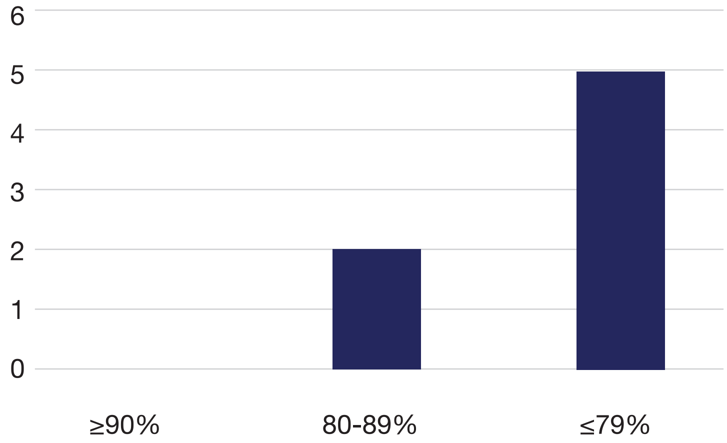
36. In your service what is the estimated proportion of people who can get pregnant, with documented evidence of a discussion around current reproductive choice and contraception over a 15-month period?

- BHIVA target: 90%.

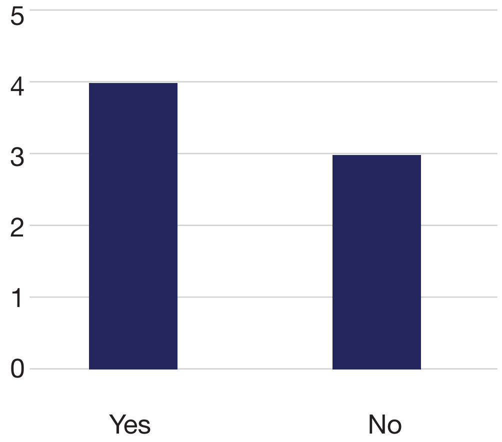


37. In your service what is the estimated proportion women and trans men aged 45–56 years old with documented discussion about menopause and enquiry about symptoms?

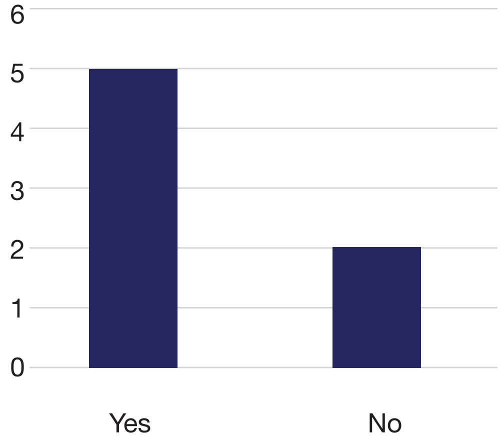
- BHIVA target: 90%



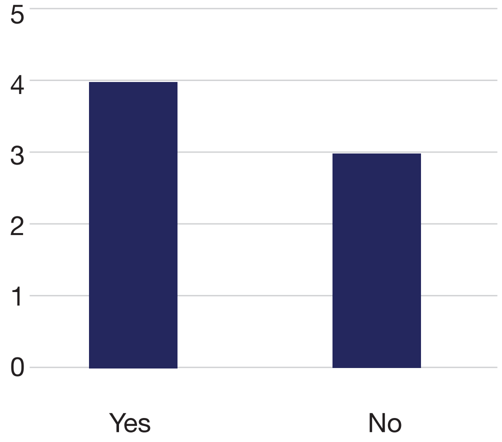
38a. In your service is there a pathway for contraceptive assessment and management?



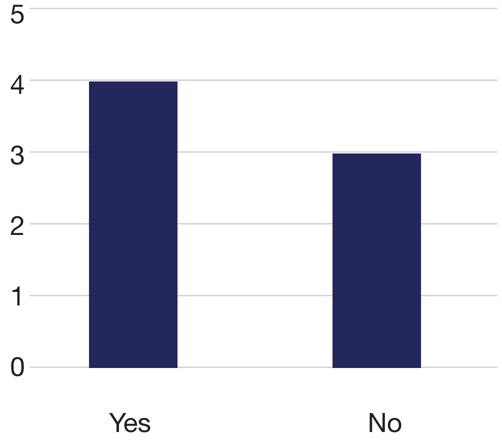
38b. In your service is there a pathway for conception assessment and management?



38c. In your service is there a pathway for fertility assessment and management?

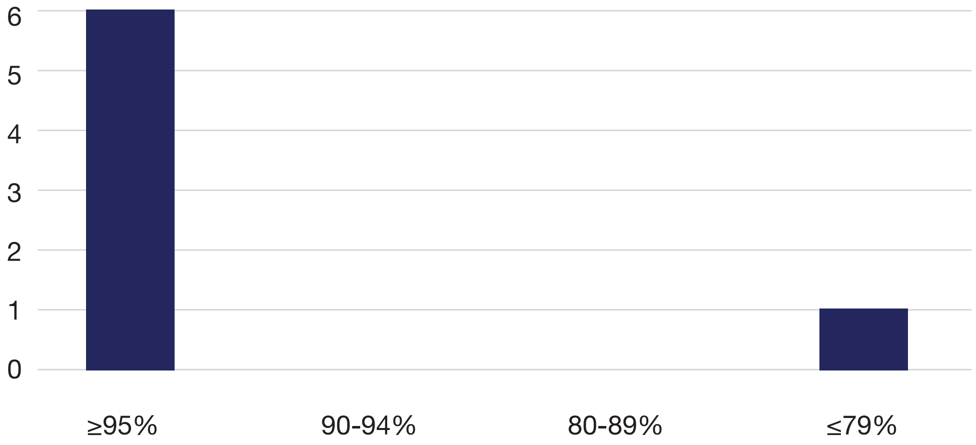


38d. In your service is there a pathway for menopause assessment and management?



39. In your service what is the estimated proportion of pregnant people with documented evidence that care plans, to be employed by the multidisciplinary team, are in place? The care plan should cover pre-, intra- and postpartum care and paediatric follow-up and should be available at the point of care.

- BHIVA target: 95%

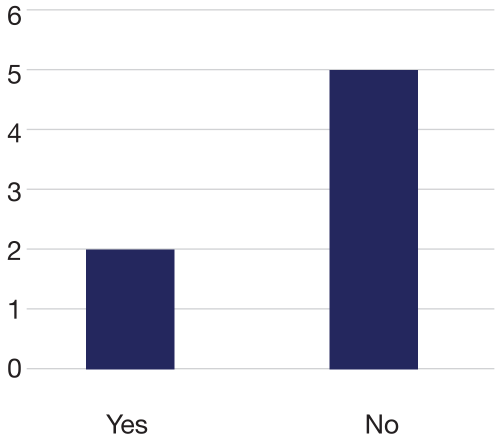


Services included the following comments at the end of this section:

- It would be beneficial to have a women's health/ contraception specialist in clinic (n=1).
- A menopause clinic would be ideal, and also an >50s clinic (n=1).

Health promotion, prevention and education for people living with HIV

40. In your service do you have a dedicated clinical nutritional resource to support patients in maintaining a healthy BMI?



41. The five services which do not have a dedicated clinical nutrition resource said that a dedicated resource would be beneficial for their patients.

42. Services reported that the proportion of patients that do, or would benefit from a dedicated clinical nutrition resource to be between **20 and 50%**.

43. In your service do you have or offer referral to smoking cessation support services?

- 7/7 services have, or offer referral to smoking cessation support services.

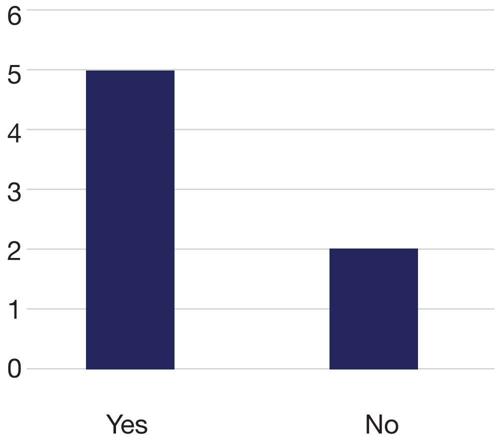
44. All services replied yes to 43, so 44 (if no to 43, is this a service you patients would benefit from?) is not relevant.

45. Services reported that the proportion of patients that benefit from smoking cessation support services to be from **10% to >40%**.

46. In your service do you inform people requiring cervical screening that they should avail of routine screening at least annually?

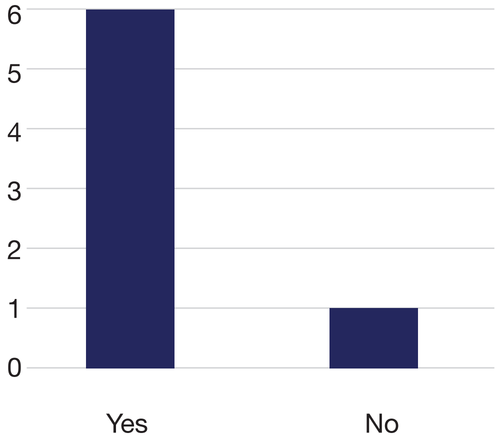
- 7/7 services inform people requiring cervical screening that they should avail of routine screening at least annually.

47. In your service do you offer annual cervical screening to eligible persons?



48. Of the five services who offer annual cervical screening, the approximate number of eligible people who have cervical screening performed per annum ranged from **30 to 280**.

49. Do you offer vaccines in your service?



50. The service which does not offer vaccines, informs patients where they can avail of vaccines.

51. Of the 6 services who provide vaccines;

- 6/6 offer annual influenza
- 6/6 offer Hepatitis A
- 6/6 offer Hepatitis B
- 6/6 offer Pneumococcus
- 6/6 offer HPV vaccine
- 4/6 offer MMR for non-immune
- 4/6 offer VZV for non-immune

52. In your service are condoms and lubricant made available to patients?

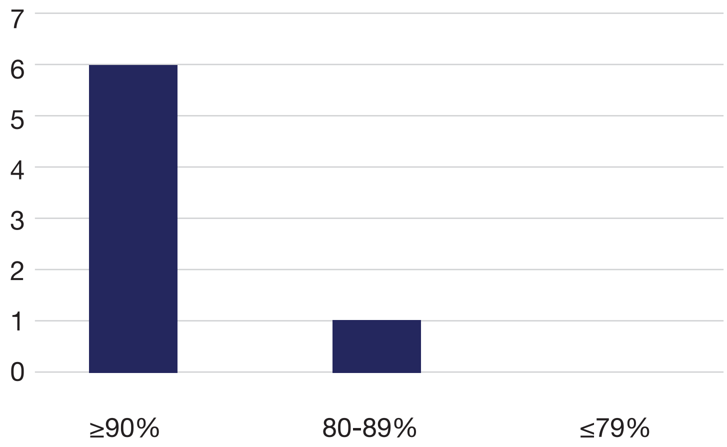
- 7/7 services make condoms and lubricant available to patients.

53. In your service what is the estimated proportion of **new HIV attendees** with documented evidence that a sexual history has been taken and a sexual health screen has been offered within 4 weeks of first attendance?

- BHIVA target: 90%.
- 7/7 services estimated proportion of new HIV attendees with documented evidence that a sexual history has been taken and a sexual health screen has been offered within 4 weeks of first attendance is **≥90%**.

54. In your service what is the estimated proportion of people with documented evidence that a sexual history has been taken and a sexual health screen has been offered at least once a year?

- BHIVA target: 90%.

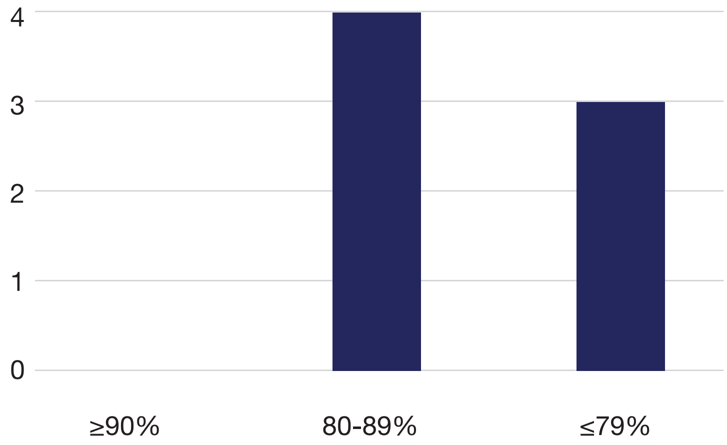


55. In your service what is the estimated proportion of gbMSM with documented evidence of syphilis and hepatitis C screening at least annually?

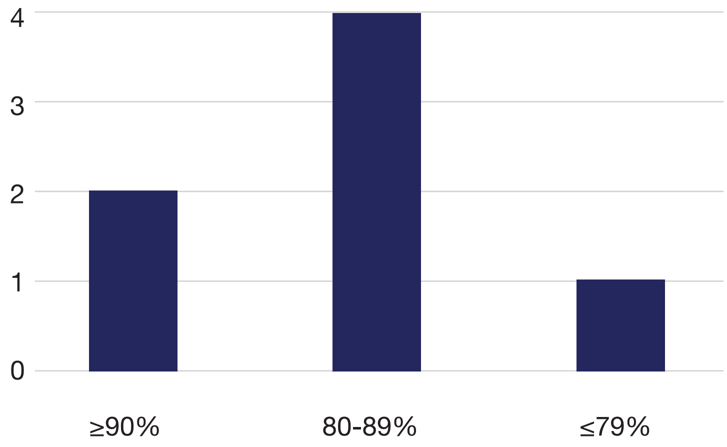
- BHIVA target: 90%.
- 7/7 services reported that the estimated proportion of gbMSM who have documented evidence of syphilis and hepatitis C screening at least annually to be **≥90%**.

56. In your service what is the estimated proportion people with documented evidence of a discussion about recreational drug use (including chemsex), at least annually?

- BHIVA target: 90%

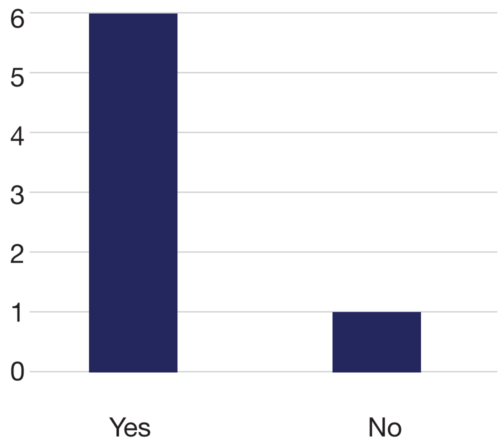


57. In your service what is the estimated proportion people with documented evidence of a discussion about alcohol use at least annually?



58. In your service, is there an agreed care pathway to drug and alcohol support services?

- BHIVA target: 95% of services.



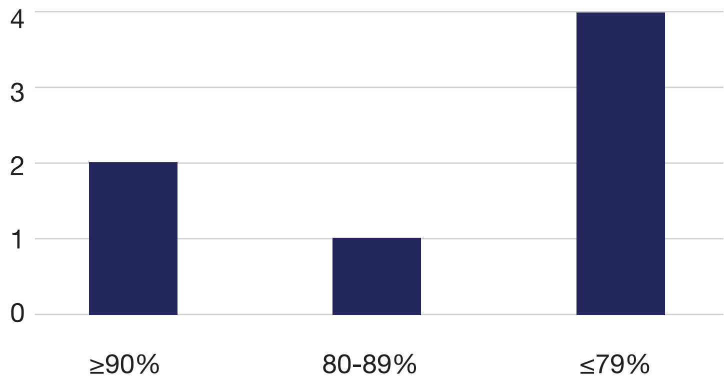
59. The service which does not have a care pathway to drug and alcohol services noted that it would be beneficial to have one.

60. Services reported that the proportion of patients that benefit from an agreed care pathway to drug and alcohol services to be between **10 and 25%**

Complex HIV care and comorbidities

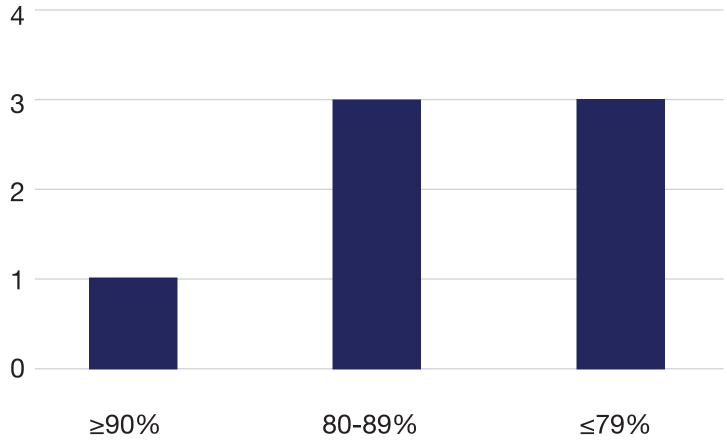
61. In your service what is the estimated proportion of people aged over 40 years with 10-year cardiovascular disease risk calculated within 1 year of first presentation?

- BHIVA target: 90%



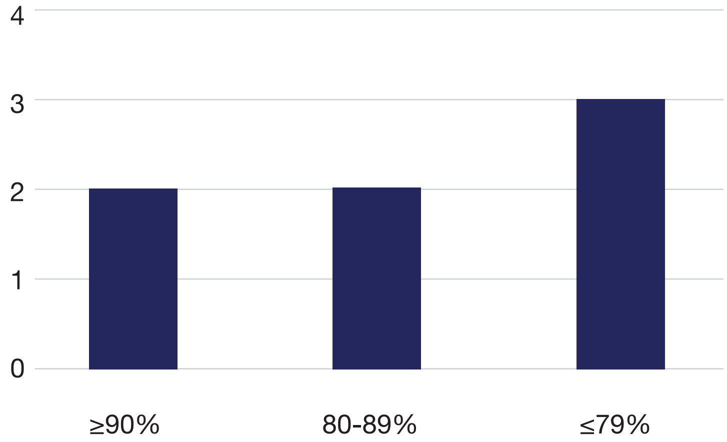
62. In your service what is the estimated proportion of people aged over 40 years with 10-year cardiovascular disease risk calculated within the last 3 years?

- BHIVA target: 90%



63. In your service what is the estimated proportion of people aged over 50 years and all post-menopausal women and trans men with documented evidence of bone fracture risk assessment within the last three years?

- BHIVA target: 90%.



64. In your service what is the estimated proportion of people newly diagnosed with HIV from high- and medium-risk countries with documented screening for latent TB?

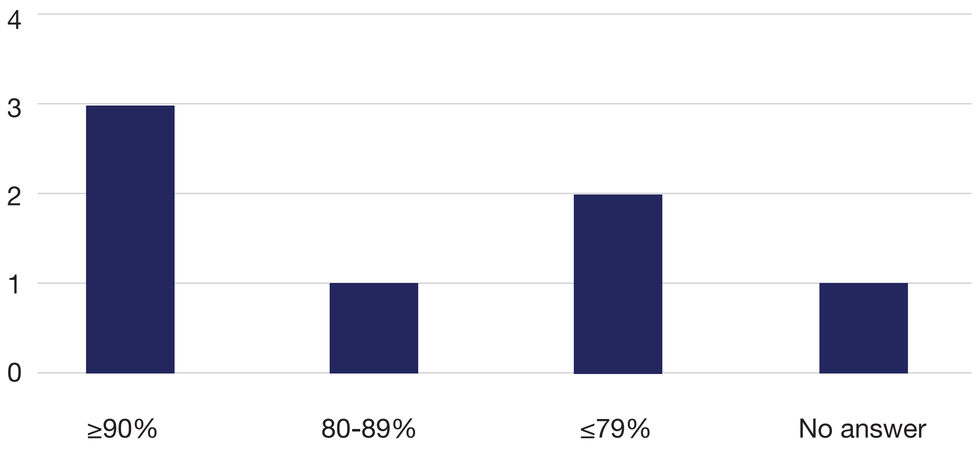
- BHIVA target: 90%.
- 7/7 services reported that the estimated proportion of people newly diagnosed with HIV from high- and medium-risk countries with documented screening for latent TB to be **≥90%**.

65. In your service what is the estimated proportion of people with documented screening for hepatitis B and C at time of HIV diagnosis or first clinic appointment?

- BHIVA target: 95%.
- 7/7 services reported that the estimated proportion of people with documented screening for hepatitis B and C at time of HIV diagnosis or first clinic appointment to be **≥95%**.

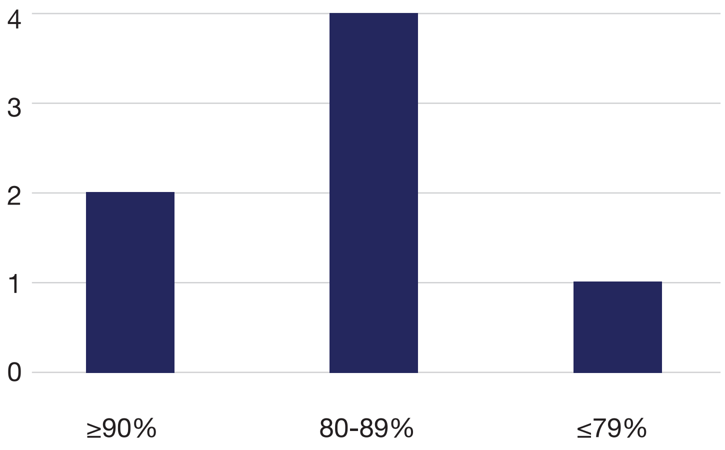
66. In your service what is the estimated proportion of people who are co-infected with hepatitis B and/or C with documented assessment of liver staging?

- BHIVA target: 90%

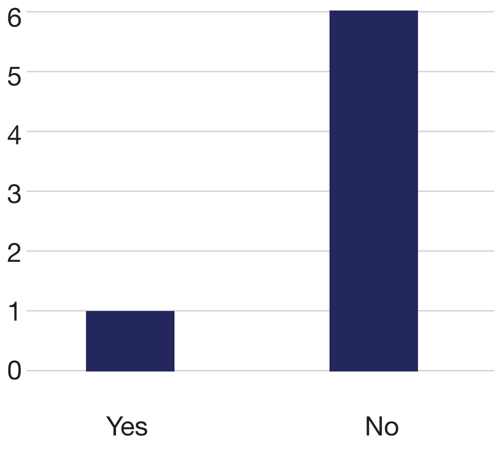


67. In your service what is the estimated proportion of people with cirrhosis (regardless of cause) with documented hepatocellular carcinoma screening in past 12 months?

- BHIVA target: 90%

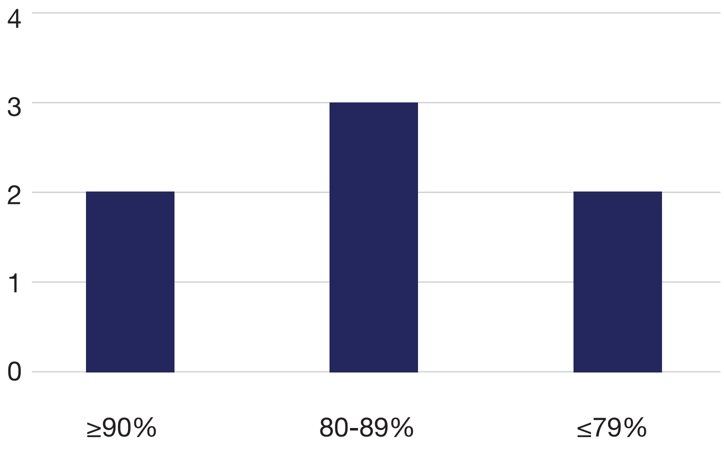


68. In your service do you have a nominated oncology specialist for HIV related malignancies and AIDS defining malignancies?

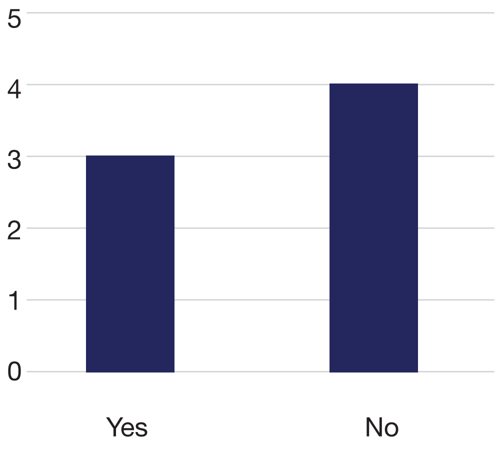


69. For patients requiring inpatient care for HIV related illnesses what is the estimated proportion of people admitted to your service within 24 hours of request for transfer from another institution?

- BHIVA target: 90%.



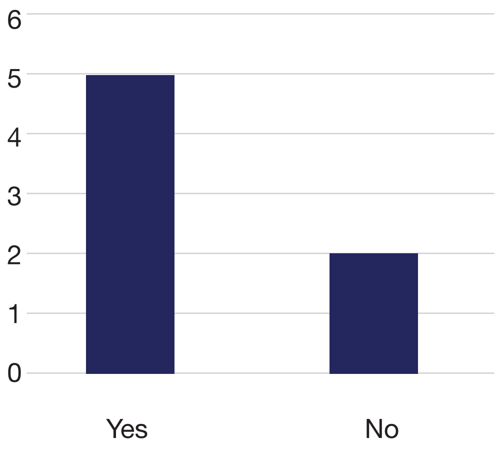
70. In your service is there 24-hour HIV specialist consultant cover for the management of HIV?



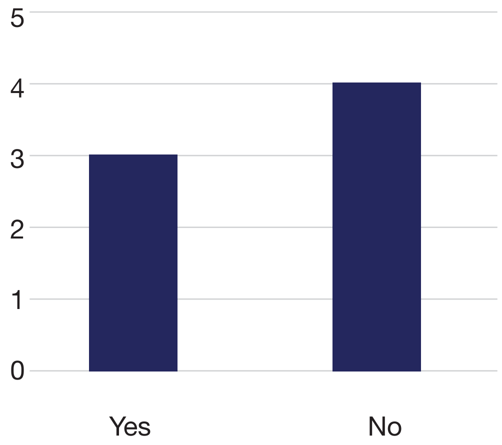
Psychological care

71. In your service is there an agreed care pathway for mental health assessment and management?

- BHIVA target: 95% of services.



72. In your service do you have access to dedicated psychological services to support people attending your service?

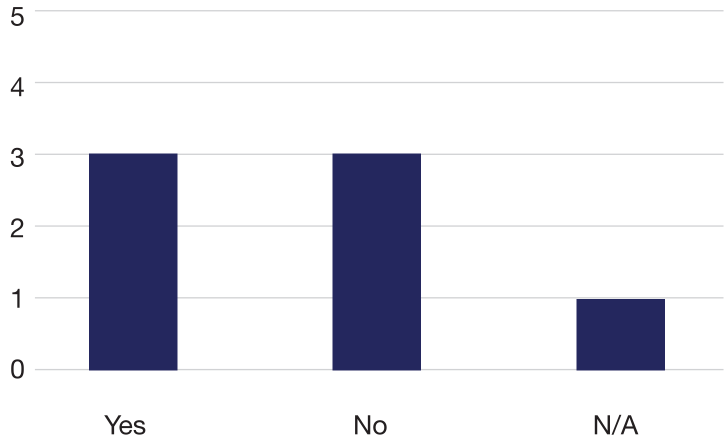


73. The four services which do not have access to dedicated psychological services all reported that a dedicated psychological resource would benefit their patients.

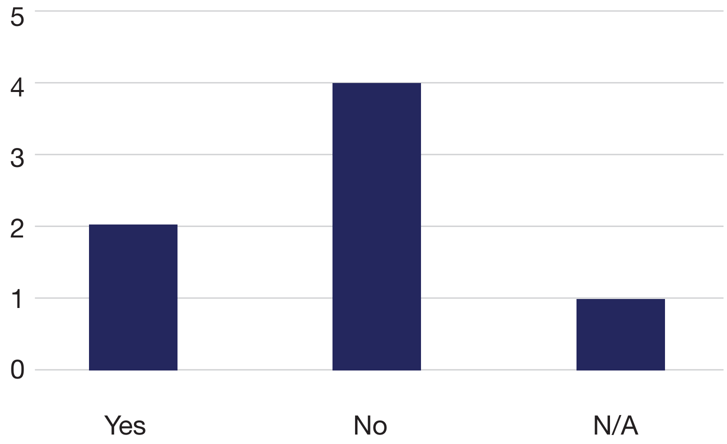
74. The estimated proportion of patients that do, or would benefit from a dedicated psychological service ranged from between **7% and 50%**.

HIV across the life course

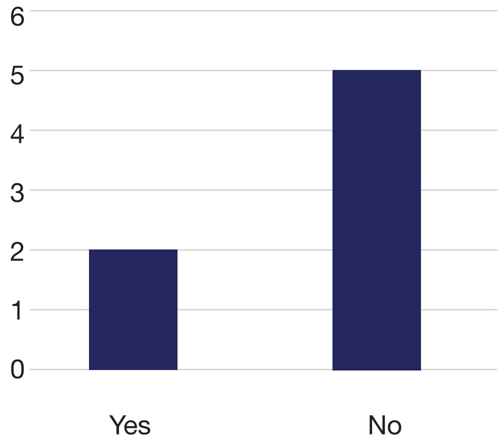
75. In your service do you have an agreed pathway for young adults and adolescents living with HIV who are transitioning their care to adult services?



76. In your service do you have an agreed pathway for referring patients >65 years to geriatric medicine services?



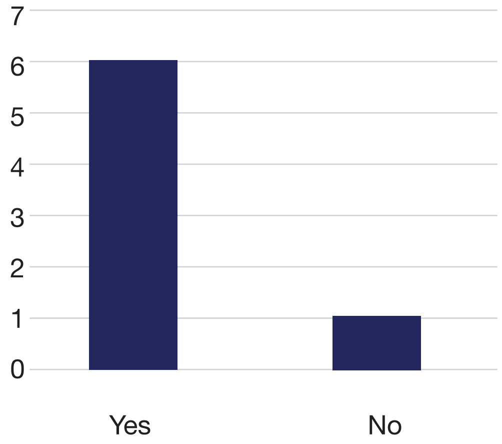
77. In your service do you routinely refer patients >65 years to geriatric medicine services?



Developing and maintaining excellent standards of care

78. In your service do you undertake local audits related to the delivery of HIV care?

- BHIVA target: 95% of services



79. Services listed the following standards that were applied when conducting local audits:

- BHIVA
- EACS
- NHIVNA
- KPI 95-95-95
- Patient experience quality survey
- ‘Varied international standards’

80. Should the same standards for HIV care be used across all adult HIV services?

- 7/7 services agreed that the **same standards for HIV care** should be used.

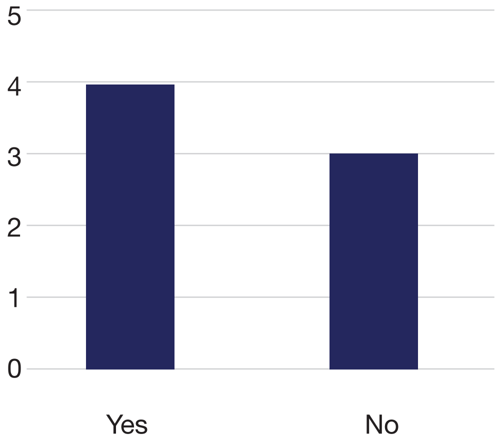
81. To make participation in a nationally coordinated audit in 2022 or 2023 feasible, services listed the need for the following resources;

- More time
- More personnel
- Improved IT infrastructure
- Online platform
- Data manager
- Electronic charts

82. Does your service have an agreed policy for completing enhanced surveillance for HIV?

- 7/7 services have an agreed policy for completing enhanced HIV surveillance.

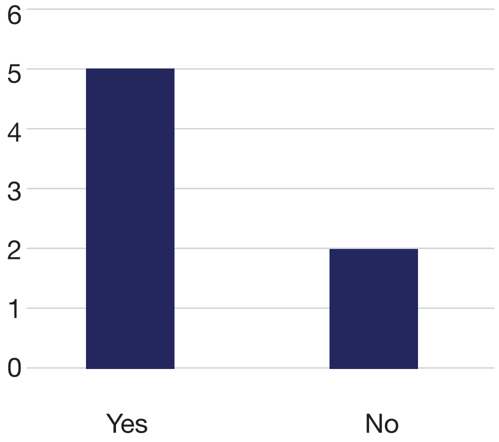
83. Does your service experience delays in completing enhanced surveillance for HIV?



84. Services were asked what would help with timely completion of enhanced HIV surveillance forms from the following two option:

- Direct submission of required data via a secure online portal (n=4)
- Provision of personnel (n=1)

85. Has the pandemic provided your service an opportunity to introduce changes to improve efficiency and service delivery?



86. Services detailed the following improvements in efficiency and service delivery;

- Pre-clinic triage system in place
- Pre-clinic dispensing of medication
- Postage of medications and prescriptions
- Role expansion of nursing staff to include patient 6/12 reviews
- Virtual clinics/ virtual reviews
- Timed appointments
- On-site pharmacy
- Splitting of HIV clinics across 2 sessions

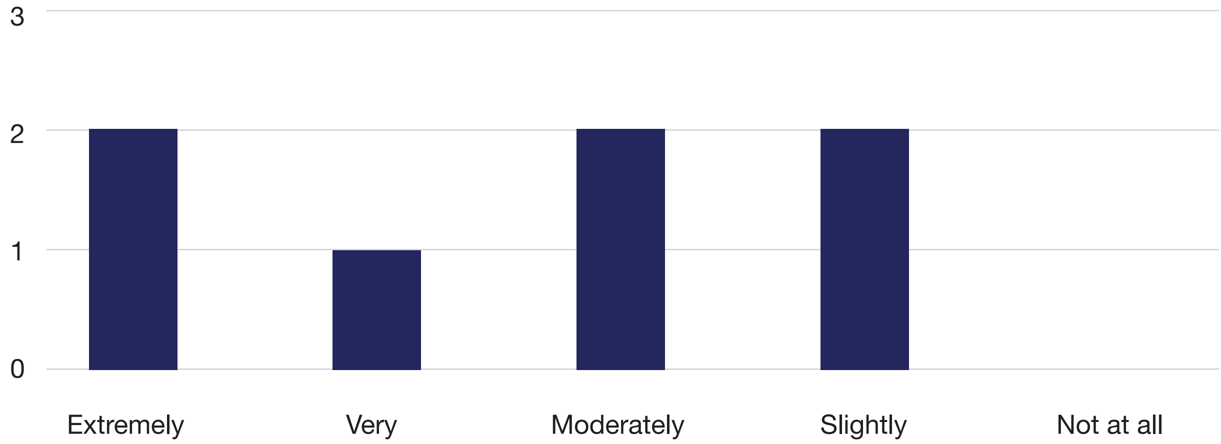
87. Throughout the COVID-19 pandemic, what have been the greatest concerns for your service?

- Difficulties for patients accessing service
- Fear of delayed testing and diagnosis
- Safety fears for staff and patients
- Missed opportunities to follow up on clinical concerns
- Delays in lab results
- Increased patient fear/anxiety
- Continuity of patient care
- Trying to manage patients with complicated psychosocial/clinical backgrounds virtually
- Managing disruptions (patient/staff illnesses/absences)
- Ensuring patients had medication when clinics were limiting numbers and patients had COVID-19

88. How did access to your service change throughout COVID-19?

- Virtual reviews, pre-assessments and clinics
- Minimising of consult times and services
- Prioritising medication dispensing
- Limited STI screening
- No cervical cytology offered
- No vaccines available
- Decreased waiting room capacity
- 2 services mentioned they continued to provide F2F services throughout the pandemic
- 1 service mentioned those with complex medical/psychosocial issues were always seen where possible

89. To what extent are lab turn-around-times negatively impacted by the COVID-19 pandemic?



FAST-TRACK
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