London's HIV Voluntary and Community Sector

Responding and rebuilding after COVID-19

Chester Howarth

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directory of social change

Funded by
NHS

In partnership with
FAST-TRACK CITIES

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Published by the Directory of Social Change (Registered Charity no. 800517 in England and Wales)

Registered address: Directory of Social Change, First Floor, 10 Queen Street Place, London EC4R 1BE

Tel: 020 4526 5995
Email: research@dsc.org.uk

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This report was commissioned and funded by the NHS in partnership with Fast-Track Cities London.

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Digital edition first published 2023

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Cover and text design by Kate Griffith

All images used for this report are courtesy of Fast-Track Cities London

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Foreword

The COVID-19 pandemic has brought unprecedented challenges to organisations worldwide, including those dedicated to supporting people affected by HIV in London. The intersection of HIV and the pandemic has created a unique set of circumstances, impacting heavily on people affected by HIV and London's HIV voluntary and community organisations. Fast-Track Cities London commissioned this independent report from the Directory of Social Change to delve into the state of HIV voluntary and community organisations in London since the initial impact of the pandemic, examining the challenges faced both by people affected by HIV and organisations supporting them, and looking at the changes made in response to the pandemic.

The emergence of COVID-19 forced HIV voluntary and community organisations in London to swiftly realign their priorities and allocate resources accordingly. Many organisations experienced a reduced availability of funding and volunteers, which posed significant challenges. With increased demands on healthcare systems, some organisations had to redirect resources to support the immediate healthcare response to the pandemic, impacting their ability to provide comprehensive services to individuals affected by HIV. This reallocation of resources often meant postponing or cancelling less urgent programmes, such as community outreach and prevention initiatives.

The pandemic also prompted a rapid shift to virtual platforms for service provision, communication and support. HIV voluntary and community organisations in London quickly embraced remote technologies to continue their essential work during lockdowns and restrictions. Telehealth consultations, virtual support groups and online counselling sessions became the norm, ensuring continuity of care while adhering to social distancing guidelines. However, it is important to note that not all individuals affected by HIV had access to the necessary technology or stable internet connection, creating new disparities and challenges in reaching and engaging marginalised communities.

Traditional fundraising events, which rely on in-person gatherings, had to be cancelled or postponed indefinitely due to social distancing measures. As a result, organisations experienced a decline in financial support, which affected their ability to sustain ongoing programmes and provide crucial support services. Some organisations innovatively turned to virtual fundraising campaigns, leveraging social media and digital platforms to connect with donors and raise funds. However, despite these efforts, the financial strain caused by the pandemic continues to pose a significant challenge for HIV voluntary and community organisations in London.

Through the work of the Fast-Track Cities London HIV improvement collaborative, many HIV voluntary and community organisations in London forged partnerships with other organisations, including NHS trusts. These alliances aimed to share resources, knowledge and expertise in order to maximise the impact of their services. The collaborative facilitated the development of creative solutions and improved access to essential resources. By working together, organisations could better address the complex needs of their clients and adapt to the changes brought about by COVID-19. Such partnerships will continue to be crucial as HIV voluntary and community organisations navigate the recovery phase and build resilience for future challenges.

The COVID-19 pandemic has profoundly impacted the state of HIV voluntary and community organisations in London. There is more demand for support than previously and less funds available. The situation is further aggravated by the increases in the cost of living that are affecting every organisation's running costs and the ability to recruit and retain staff. However, through resilience, innovation and collaboration, HIV voluntary and community organisations have continued to provide essential support to people affected by HIV. As the world emerges from the pandemic, it is crucial to sustain and strengthen these organisations, ensuring that their vital work continues to positively impact the lives of those affected by HIV in London. Fast-Track Cities London Leadership Group welcomes this research and the recommendations within it and will work with the HIV voluntary and community sector to ensure its sustainability in the future.

Professor Jane Anderson, Co-Chair of Fast-Track Cities London, Consultant Physician and Director of the Centre for the Study of Sexual Health and HIV, Homerton University Hospital

Professor Kevin Fenton, Co-Chair of Fast-Track Cities London, Regional Director of Public Health England London and Regional Director of Public Health for NHS London

About the Directory of Social Change

At the Directory of Social Change (DSC), we believe that the world is made better by people coming together to serve their communities and each other. For us, an independent voluntary sector is at the heart of that social change, and we exist to support charities, voluntary organisations and community groups in the work they do. Our role is to:

- **provide practical information** on a range of topics, from fundraising to project management, in both our printed publications and our e-books;
- **offer training** through public courses, events and in-house services;
- **research funders** and maintain a subscription database, *Funds Online*, with details on funding from grant-making charities, companies and government sources;
- **offer bespoke research** to voluntary sector organisations in order to evaluate projects, identify new opportunities and help make sense of existing data;
- **stimulate debate and campaign** on key issues that affect the voluntary sector, particularly to champion the concerns of smaller charities.

DSC's researchers are experts in undertaking charity sector research to inform policy and practice. Our bespoke and commissioned research is led by the needs of our clients, and our policy work supports the wider voluntary sector. To find out more about DSC's research services, visit us online at www.dsc.org.uk/research or get in touch with us via research@dsc.org.uk to see how DSC's research can help you and your organisation.

About the author

CHESTER HOWARTH

Chester joined DSC in 2020 and works as a Senior Researcher, primarily on DSC's bespoke research projects. He has been the lead author on several publications, including two reports within DSC's *Focus On* series and within DSC's ongoing research on the impacts of socio-economic change on charities.

Chester has also led the development of DSC's online interactive resources, which provide a new way of disseminating the latest data on armed forces charities.

Prior to joining DSC, Chester worked as a research assistant, supporting projects on child poverty and well-being and co-authoring articles published in academic journals. He also has experience working as a freelance consultant to a group of children's charities and undertaking research with a statutory health organisation.

Acknowledgements

The author would like to thank all the organisations that were involved throughout this research project.

Special thanks go to the members of the steering group – representatives from The Food Chain, METRO Charity, National AIDS Trust, Positive East and Terence Higgins Trust – who have provided guidance and expertise throughout.

Special thanks also go to the individuals and organisations that completed surveys and participated in focus groups, which included – among a range of other organisations – Catholics for AIDS Prevention and Support (CAPS), House of Rainbow CIC and Positively UK.

The author is thankful to Dean Renshaw for additional research, and Jay Kennedy, Stuart Cole and Rhiannon Doherty for research support. Editorial work was carried out by Hazel Bird.

Executive summary

About this report

This report presents new research conducted by the Directory of Social Change (DSC) in partnership with Fast-Track Cities (FTC) London. In 2018, FTC London agreed four goals to achieve by 2030 (FTC London, 2023a). Since then, the COVID-19 pandemic has emerged, impacting people affected by HIV (see 'Terminology' on page xvii) in London as well as the voluntary and community sector organisations that are key to providing support to those people.

This research aims to shed light on whether and how the needs of people affected by HIV in London have changed following the onset of the COVID-19 pandemic. It also investigates the resilience of voluntary and community sector organisations and their readiness to respond. DSC hopes this report will be used by funders, practitioners and policymakers to help voluntary and community sector organisations to continue supporting people affected by HIV in London.

Research methods

There were three strands to DSC's research methodology:

- **A survey of people affected by HIV:** During October and November 2022, DSC and the project steering group promoted DSC's online and paper survey. This survey received responses from 40 individuals, all of whom accessed care or services for HIV in London.
- **A survey of voluntary and community sector organisations:** From January to March 2023, this survey was shared directly with organisations identified by DSC as providing support for people affected by HIV in London. Altogether, it received responses from 41 organisations.
- **Focus groups with voluntary and community sector organisations:** In March 2023, DSC's researchers facilitated two online focus groups with representatives from 18 voluntary and community sector organisations, including five organisations from the project steering group.

Key findings

The needs of people affected by HIV in London

Changing, diverse and complex needs

- Needs around mental health and well-being had changed the most following the COVID-19 pandemic: 90% of the people surveyed said this area was more important because of the pandemic and, on average, 72% of voluntary and community sector organisations said demand for support had increased since before the pandemic.
- The voluntary and community sector organisations said demand was typically increasing or staying the same across a wide range of topics: only 4 of the 36 different types of support in

DSC's survey showed decreased demand among 10% or more of respondents, suggesting diverse and potentially increasingly complex needs.

Mental health and well-being

- As noted above, needs around mental health and well-being had risen in importance for the overwhelming majority of the people DSC surveyed. Support around social isolation and loneliness was most widely considered very important in this area (65%), followed by access to counselling or therapy (56%).
- The voluntary and community sector organisations had seen widespread increased demand (reported by 88%) for support with social isolation and loneliness. Their representatives described how the COVID-19 pandemic had created and exacerbated problems such as disconnection from social and health support networks.

Finances, poverty and social issues

- Needs around finances, poverty and social issues had risen in importance because of the COVID-19 pandemic for 78% of the people DSC surveyed. The respondents widely considered a number of issues to be very important, including support with fuel poverty (58%), poor-quality housing (58%), accessing benefits (55%) and homelessness (55%).
- The voluntary and community sector organisations had seen widespread increases in demand for various types of support around finances and poverty, including accessing benefits (81%), accessing food (74%) and homelessness (71%).

Other areas of need

- Needs around migration and immigration had risen in importance because of the COVID-19 pandemic for just under half (47%) of the people DSC surveyed.[1] The voluntary and community sector organisations had seen widespread increases in demand for support in areas such as accessing immigration-related legal aid (78%) and good-quality immigration advice (77%). They described how migration status can intersect with or compound needs such as isolation and loneliness, and create challenges for access to appropriate support services.
- For the people DSC surveyed, needs around living with HIV were more likely to have stayed about the same (62%) than to have risen in importance (35%) because of the COVID-19 pandemic. However, support around ageing well with HIV was widely considered very important (66%), as was getting appropriate care from a GP (66%).
- Despite needs around living with HIV being less likely to have risen in perceived importance, voluntary and community sector organisations described how other increasingly important issues can still interact with aspects of living with HIV, such as financial or mental health difficulties taking priority over and interfering with adherence to treatment.

[1] Migration and immigration were included in DSC's survey to reflect both impermanent and permanent movement, respectively.

The resilience of voluntary and community sector organisations

Capacity to deliver support

- Overall, demand for support was reported to be higher than before the onset of the COVID-19 pandemic for most (60%) of the voluntary and community sector organisations surveyed. The average increase in demand for support was 25%.
- While the voluntary and community sector organisations were mostly meeting demand in each area of need, this was typically with no spare capacity (from 27% to 45% of respondents).
- A notable minority (upwards of 15%) of voluntary and community sector organisations were falling significantly short of meeting demand within each of the areas of need, particularly support around finances, poverty and social issues. This presents a potential barrier to improving health, quality of life and well-being for people living with HIV.

Income, expenditure and financial security

- The voluntary and community sector organisations had overwhelmingly (88%) seen increased expenditure compared to before the onset of the COVID-19 pandemic – but only half (50%) had seen increased income.
- A clear majority (71%) of the voluntary and community sector organisations had used reserves to meet operating costs during the past three years, potentially reducing their financial resilience.
- Voluntary and community sector organisations were concerned about declining public interest in HIV as an issue – and income from public donations was more widely considered very important (62%) than income from local government (53%) or the NHS (48%).
- Concerningly, financial security had become significantly worse than it was before the onset of the COVID-19 pandemic for just over one-quarter (28%) of the voluntary and community sector organisations surveyed by DSC, but it had improved significantly for a notable minority (14%).

Challenges and opportunities

Risks to meeting beneficiary needs

- Significantly increasing beneficiary need was already a reality for more than half (57%) of the voluntary and community sector organisations surveyed, and significantly increasing beneficiary numbers were a concern for over two-fifths (44%).
- Other relatively widespread immediate risks to meeting beneficiary needs were a reduction in volunteers (39%), burnout among paid staff (38%) and reductions in paid staff (35%).
- Close to half of the voluntary and community sector organisations surveyed said that their organisation was at risk of closing permanently within either one year (28%) or two or more years (17%). This raises concerns around meeting FTC London's 2030 goals, in which voluntary and community sector organisations play a key role.

Challenges facing voluntary and community sector organisations

- Challenges around staff and volunteers included difficulties recruiting new staff and volunteers because of, for example, changing priorities among potential staff and volunteers and declining interest in the HIV sector. Burnout, one of the risks included in DSC's survey of organisations, arises from a complex set of circumstances, including that staff and volunteers can themselves be affected by HIV and be impacted by changes to their socio-economic circumstances.

- Challenges around meeting the needs of people affected by HIV included designing support and services that can meet the need for social connection, reaching and supporting a diverse population within which some groups may feel marginalised, and increasingly complex needs.

- Voluntary and community sector organisations had concerns about how far the needs of people affected by HIV are understood by funders and commissioners, such as integrated care systems, local authorities and independent funders. Particular areas of concern were providing funding for support in relation to subjective needs, such as social connection and faith. The organisations' representatives also voiced concerns over the sustainability of funding in terms of it being project based and not being able to cover core costs, such as expenses related to physical premises.

- Voluntary and community sector organisations described challenges making onwards referrals to statutory services alongside demand arising from limited statutory support, which could create challenges in terms of increasing numbers of beneficiaries and the complexity of their needs.

Opportunities for voluntary and community sector organisations

- The opportunities presented by collaboration was a key theme emerging from DSC's focus groups and the survey of voluntary and community sector organisations.

- Voluntary and community sector organisations felt that collaboration could help the sector better meet the needs of people affected by HIV – for example, through referrals that draw on the unique strengths and expertise of different organisations – and observed that it can even keep organisations functioning in difficult financial circumstances.

- Voluntary and community sector organisations recognised that collaboration requires strong relationships, which in turn require time and resources as well as the right funding incentives and may be challenging to build between the voluntary sector and statutory sector.

Recommendations

FTC London should facilitate ongoing information-sharing, intelligence-sharing and policy development through collaboration

1. Raise awareness of which voluntary and community sector organisations support people affected by HIV in London and what they do.

2. Create working groups around policy and workshops for practitioners to facilitate an inclusive and ongoing dialogue between diverse voluntary and community sector organisations.

FTC London should influence funders to better meet the needs of people affected by HIV in London

3. Develop guidance to help funders and commissioners understand how to ensure their funding is available to all types of voluntary and community organisation.
4. Help to foster a funding environment which encourages and strengthens collaboration between voluntary and community sector organisations.
5. Help to reform funding and commissioning practices to repair and prevent further erosion of the financial resilience of voluntary and community sector organisations.
6. Provide guidance and training on creating effective funding applications.
7. Undertake dedicated research on the distribution and nature of funding for HIV voluntary and community sector organisations in London.

FTC London should support the voluntary and community sector to recruit and retain paid staff and volunteers

8. Create a workforce development fund for training and practical support on the recruitment and retention of paid staff and volunteers.
9. Raise the profile of work in the HIV voluntary and community sector among potential staff and volunteers, and support a diverse workforce of staff and volunteers to enter the sector.
10. Support voluntary and community sector organisations to improve paid staff and volunteers' well-being.

Introduction

Context

The needs of people living with HIV

Over the decades since the early 1980s, when AIDS – the syndrome resulting from the human immunodeficiency virus, known as HIV – was first identified, significant advances in treatment and therapy have improved the health outcomes of people living with HIV (Lowbury, 2021, p. 40). Today, with appropriate treatment, people with HIV can expect to live about as long as the population more broadly (Popping et al., 2021, p. 2). Indeed, the proportion of people aged 50 or older who are living with diagnosed HIV has approximately doubled during the past decade, from 25% in 2012 to 48% in 2021 (UK Health Security Agency, 2022a, fig. 9).

In the UK, for almost two in every five people who access care for HIV, London is where they do so (Lowbury, 2021, p. 10). The city was the first in the world to achieve the Joint United Nations Programme on HIV/AIDS's '95–95–95' targets for 2025, which are part of working towards the elimination of HIV. Specifically, in London, 95% of people living with HIV are aware of their status; of these people, 98% are on treatment; and, of those, 97% are virally suppressed, which means their treatment is working and they cannot transmit the virus (Lowbury, 2021, p. 42).

As a result of improved treatment and health outcomes among people living with HIV, a focus on improving physical, mental, emotional and social well-being has risen in importance (Popping et al., 2021, p. 2). While most people living with HIV have high levels of physical, mental, emotional and social well-being, levels of well-being across these domains are generally lower for people living with HIV than among the general public, particularly in relation to mental health (Popping et al., 2021).

Indeed, symptoms of depression and anxiety have been reported by around half of all people living with HIV in England, which is substantially higher than the rate among the broader population. This is reflected across other indicators, making mental ill health 'a primary concern among people with HIV' (Kall et al., 2020, p. 12). HIV-related stigma has been linked to mental health difficulties and is an important aspect of HIV that separates it from other long-term conditions (Lowbury, 2021, pp. 60–61).

The results from a large, representative survey of people living with HIV in England and Wales showed that HIV-related services and help are what people living with HIV most commonly need access to – and, positively, are needs that are met for the vast majority of people (Kall et al., 2020, p. 67). Nevertheless, areas of support such as managing other long-term conditions – it is common for people living with HIV to have multiple health conditions – are not met for around one-third of people living with HIV (Changing Perceptions Project Team, 2018, p. 16). This is a particularly important consideration for the diverse population of people growing older with HIV (Terence Higgins Trust, 2017).

Almost two-thirds of people living with HIV need broader health-related services and help, but these needs are met for only about half (Kall et al., 2020, p. 67). For example, in the large survey described above, in relation to mental health, only two-fifths of people needing a psychologist or counsellor received this help, and only half of people needing stress management received this form of support (Kall et al., 2020, p. 70). Similar findings can be seen for needs around weight management and advice regarding sex.

Looking more broadly, just under half of people living with HIV reported having a social or welfare need, but almost two-thirds of these needs were not met (Kall et al., 2020, p. 67). For example, approximately one-fifth of people living with HIV needed services or help in relation to loneliness or social isolation, but they had the highest level of unmet need (75%) among those assessed (Kall et al., 2020, p. 69). Meanwhile, just under one-quarter of people living with HIV needed housing support, but this was unmet in around half of those cases (Kall et al., 2020, p. 70).

The outline above takes a broad approach. However, when thinking about the needs of people living with HIV, it is important to emphasise that these 'are complex, change over time and go beyond the day-to-day management of HIV' (Changing Perceptions Project Team, 2018, p. 13). This reflects the fact that while certain demographic groups are more at risk, people living with HIV come 'from all backgrounds and walks of life' (Changing Perceptions Project Team, 2018, p. 3) and include both younger and older people (Terence Higgins Trust, 2017).

The support ecosystem for people living with HIV

Because of the non-clinical nature of many needs experienced by people living with HIV, it is important to keep in mind that NHS and other clinical services are only one part of the ecosystem of support. Other types of support commonly considered essential by service providers and clinicians include peer support, psychosocial support, and information, advice and advocacy (National AIDS Trust, 2017, p. 14).

Effectively providing support across the wide range and complexity of needs requires a range of different organisations, including voluntary and community sector organisations (see 'Terminology' on page xvii). Accordingly, support from voluntary and community sector organisations has been and continues to be an important aspect of policy frameworks for commissioning services (NHS England, 2014, 2021).

Indeed, there is a history of voluntary and community sector organisations being involved in HIV-related support. This is rooted in 'a time when medication could not provide solutions', which meant 'clinicians, activists and patients learnt together how to manage HIV' (Lowbury, 2021, p. 49). Community engagement therefore became central to HIV care; this included support from voluntary and community sector organisations, which remain central to the support services received by people living with HIV (National AIDS Trust, 2017, p. 13).

Previous estimates suggest that close to one-fifth (17%) of people living with HIV in London access support from services provided by charity or voluntary organisations each year and around two-fifths (38%) of people living with HIV in London have accessed such support at some point. Moreover, almost all of those who had used support services in London said these were important to their health and well-being, with almost two-thirds (63%) saying they were very important, which was higher than in other regions of England (Kall et al., 2020, p. 64).

However, the same survey found that accessing HIV support services has become more difficult in recent years. Indeed, evolving circumstances, including cuts in local authority funding for non-legally mandated voluntary and community services and the impact of the COVID-19 pandemic on the sector's infrastructure, have affected charitable and voluntary organisations' ability to provide support and meet needs (Lowbury, 2021, p. 73).

About Fast-Track Cities London

Fast-Track Cities (FTC) London is a partnership of four signatory organisations: the Mayor of London, NHS England, Public Health England (now the UK Health Security Agency) and London Councils (FTC

London, 2023a). FTC London's Leadership Group has representation from a variety of organisations, including voluntary and community sector organisations, as well as people with lived experience of HIV (FTC London, 2023b).

Together, this partnership of organisations that make up FTC London has committed to specific goals for London by 2030, which – as given on FTC London's website – are:

- End new HIV infections in the capital by 2030.
- End HIV-related stigma and discrimination.
- Stop preventable deaths from HIV-related causes.
- Work to improve the health, quality of life and well-being of people living with HIV across the capital. (FTC London, 2023a)

About this report

Background

This research, conducted by the Directory of Social Change (DSC) in partnership with FTC London, is intended to provide insights for practitioners, policymakers, funders and commissioners around the changing needs of people affected by HIV in London and the ability of voluntary and community sector organisations to respond. The report presents new evidence that aims to help to foster understanding, focused on the following research questions:

- What are the changing needs of people affected by HIV in London since the initial impact of the COVID-19 pandemic?
- How do these changing needs relate to the achievement of FTC London's goals?
- What are the challenges anticipated by voluntary and community sector organisations serving the people affected by HIV in London?
- How resilient are voluntary and community organisations, and how ready are they to respond to these challenges?

Structure of the report

Chapter 1 focuses on the needs of people affected by HIV. This chapter uses data from a survey of people affected by HIV. The survey was carried out by DSC to provide insights on which areas of need have become more or less important because of the COVID-19 pandemic and how important various types of issue and support are to affected people at present. The chapter also draws on data from a survey DSC carried out with voluntary and community sector organisations to better understand how demand for support has changed relating to similar sets of issues and types of support.

Chapter 2 turns to the resilience and readiness of voluntary and community sector organisations. This chapter draws on data from DSC's survey of voluntary and community sector organisations to help illuminate the extent to which organisations are more or less able to meet demand across different areas of need. It also covers organisations' changing financial situation.

Chapter 3 focuses on the challenges and opportunities facing voluntary and community sector organisations. This chapter is informed by in-depth qualitative data from DSC's focus groups, as well as data from DSC's survey of voluntary and community sector organisations, and aims to provide insights around the nature of the challenges facing organisations and their prevalence in the sector. It also aims to elucidate what opportunities are available and how challenges might be overcome.

Chapter 4 details the conclusions and recommendations from the research. This final chapter brings together the multiple strands of this research project, providing a comprehensive overview of the findings and setting out recommendations grounded in the evidence that DSC has gathered.

As detailed in the 'Methodology' section below, DSC's researchers employed a mixed-methods approach to this research. Throughout this report, data from DSC's survey of people affected by HIV is presented in green boxes; data from DSC's survey of voluntary and community sector organisations is presented in blue boxes; and quotes from DSC's focus groups with voluntary and community sector organisations are presented in purple boxes.

Terminology

This report uses a few key terms that may require some context and explanation. It uses the term **people living with HIV** to refer to people who are HIV positive. This term is used at specific points throughout this report – for example, when appropriate in reference to other research.

Meanwhile, the term **people affected by HIV** is broader, including people who are at risk of HIV but not necessarily HIV positive. This term refers to people who access or use HIV-related clinical or support services, such as those who may be at greater risk of HIV and therefore access information or advice, such as around prevention – for example, advice on PrEP (pre-exposure prophylaxis) medicine – or testing. This broader term is used in the context of DSC's surveys and is particularly relevant to DSC's survey of people affected by HIV, in which all the respondents accessed care or services for HIV in London (see figure A.1, in the appendix) but were not necessarily living with HIV.

This report also employs the term **voluntary and community sector organisations** to refer primarily to a range of formal organisations including registered charities (in this context, charities registered with the Charity Commission for England and Wales (CCEW)); charitable incorporated organisations (CIOs); community interest companies (CICs) that are not for profit; and CICs and social enterprises that can make profit. However, DSC's methodology (described below) does not explicitly exclude informal (i.e. non-registered) voluntary and community sector organisations. This report focuses on voluntary and community sector organisations that support people living with or affected by HIV in London – unless otherwise stated, that is the focus throughout.

Methodology

Survey of people affected by HIV

DSC's researchers worked with a steering group of charities and NHS staff to develop a survey of people affected by HIV in London. The survey was intended primarily to provide insights about which needs have become more or less important following the onset of the COVID-19 pandemic, and which issues or topics of support are important to people affected by HIV. During October and November 2022, DSC and the project steering group promoted the online survey using social media; in total, DSC received valid responses from 40 individuals (including four paper-based responses gathered by the project's steering group).

Quotes from the respondents appear throughout the report to supplement and complement the quantitative findings. These quotes generally appear as they were written. However, where necessary, minor alterations have been made to improve the readability. Where changes have been made, care has been taken not to alter the original meaning.

Characteristics of the participants

The respondents to DSC's survey of people affected by HIV were asked to provide background demographic information about themselves. This was to help build a better understanding of the extent to which the varied communities affected by HIV in London are represented among the respondents. A comparison with official statistics for people accessing HIV care in London (UK Health Security Agency, 2022b) suggests the respondents are broadly representative in terms of age but under-representative of women and people from Black and other minority ethnic groups.

The overall respondent profile can be summarised as follows (see figures A.1–A.6, in the appendix, for further detail):

- **Accessing HIV support:** all (100%) of the respondents stated that they accessed care or services for HIV in London.
- **Age:** there were more older respondents than younger respondents. About half (52%) of the respondents were aged between 55 and 64, and only a significant minority were aged between 16 and 24 or between 25 and 34 (8% each).
- **Gender:** most (75%) of the respondents identified as male and 12% identified as female.
- **Ethnicity:** while more than half (57%) of the respondents identified as English, Welsh, Scottish, Northern Irish or British, a large minority reported a different ethnic background.
- **Country of birth:** most (78%) of the respondents had been born in the UK and a significant minority had been born in a range of different countries.
- **Where support is most often accessed:** the respondents most commonly accessed support in Camden (24%), Kensington and Chelsea (16%) or Westminster (13%) and least commonly accessed support in Redbridge or Islington (3% each).

Survey of voluntary and community sector organisations

DSC's researchers also developed, in collaboration with the steering group described above, a survey of voluntary and community sector organisations that provide support to people affected by HIV in London. The survey focused mostly on changes (since before the onset of the pandemic) around demand for support and services in key areas, changes around the financial situation of organisations, and the challenges and opportunities facing organisations. During January to March 2023, the survey was shared directly with organisations identified by DSC as providing support in this area. Altogether, it received responses from 41 organisations (a 44% response rate).[2]

[2] DSC's researchers identified voluntary and community sector organisations that support people affected by HIV in London through a keyword search of charitable objects for charities registered with CCEW. The resulting organisations (N=64) were reviewed by the steering group for this project; members of the steering group drew attention to additional voluntary and community sector organisations (N=2). DSC's researchers also identified additional voluntary and community sector organisations that had specific HIV-related support services or programmes and a presence in London (N=27) from among the organisations published on HIV Lens (HIV Lens, 2023). In total, 93 organisations were identified.

Quotes from the respondents appear throughout the report to supplement and complement the quantitative findings. These quotes appear as they were written. However, where necessary, minor alterations have been made to improve the readability. Where changes have been made, care has been taken not to alter the original meaning.

Characteristics of the participants

The respondents to DSC's survey of voluntary and community sector organisations were asked to provide background information about their organisation and their beneficiaries. A comparison limited to charities that could be linked to data from CCEW suggests the charities surveyed were slightly under-representative of financially smaller charities.

The overall respondent profile can be summarised as follows (see figures A.7–A.11, in the appendix, for further detail):

- **Type of organisation:** the overwhelming majority (85%) of the respondents were registered charities or CIOs, but a notable minority (15%) were not-for-profit CICs.
- **Charity size:** almost half (47%) of the charities which had published accounts on the CCEW website were small (annual income below £100,000), one-third (33%) were medium (annual income between £100,000 and £1 million) and one-fifth (20%) were large (annual income above £1 million).
- **Where support is provided:** more than two-thirds (71%) of the respondents supported people affected by HIV in London and outside London, while close to one-third (29%) supported people affected by HIV in London only.
- **Percentage of support in London (among those who provided support in and outside London):** the (median) average percentage of support dedicated to people affected by HIV in London was 75%, with a minimum of 9% and a maximum of 98%.
- **Where support is provided in London's sub-regions:** all key sub-regions were represented, and the respondents most commonly supported people affected by HIV in central London (83%) and least commonly in North London (61%).
- **Demographics of people supported:** the respondents supported people of Black or other minority ethnicities (92%), women (80%), heterosexual men (65%), gay and bisexual men (62%), trans people (57%) and people who use drugs intravenously (40%).

Focus groups with voluntary and community sector organisations

DSC's researchers chaired two online focus groups, one on 16 March 2023 (with seven participants) and one on 21 March 2023 (with 11 participants). Each focus group lasted for 1 hour and 30 minutes. The participants were mostly recruited through DSC's survey of voluntary and community sector organisations (discussed above) but two participants were recruited directly through the steering group for this research project. In total, 5 of 18 participants represented organisations on this project's steering group; for transparency, these cases are marked throughout but are not identified individually for reasons of confidentiality.

The focus groups were intended to encourage discussions between participants: facilitators encouraged the participants to contribute their own perspectives and respond to the perspectives of others. The discussions were based, broadly, around the following three topics:

- the changing needs of people affected by HIV;
- the resilience of voluntary and community sector organisations that support people affected by HIV;
- the challenges facing HIV voluntary and community sector organisations.

DSC's researchers recorded and then transcribed the focus group discussions so as to ensure accuracy in reporting. The transcripts were analysed through an initial process of open coding, whereby tags were allocated to segments of text to capture their meaning.[3] The transcripts were then revisited, and the tags were organised in a spreadsheet into areas (for example, 'challenges'), themes (for example, 'staff and volunteers') and subthemes (for example, 'difficulties recruiting into the sector because of changing perceptions about its importance').

Quotes from the focus group participants appear throughout the report to supplement and complement the findings from DSC's two surveys. These quotes generally appear as they were spoken. However, where necessary, minor alterations have been made to improve the readability. Where changes have been made, care has been taken not to alter the original meaning – and all focus group participants had the opportunity to review the quotes that had been used within the report itself.

[3] The description of the coding process as 'open' denotes that the labels were generated based on DSC's researchers' interpretation of the data, as opposed to applying a set of pre-specified labels to the data.

CHAPTER ONE

The changing needs of people affected by HIV

1.1 Introduction

This chapter explores the needs of people affected by HIV and the extent to which these have changed since the onset of the COVID-19 pandemic. It aims to answer the following questions:

- How has demand for support changed overall?
- Which areas of support have become more or less important because of the COVID-19 pandemic?
- Which specific issues are important to people affected by HIV, and how has demand changed around specific issues or topics of support? This question is explored covering the following topics:
    - Mental health and well-being
    - Finances, poverty and social issues
    - Migration and immigration

- Living with HIV
- Prevention and testing

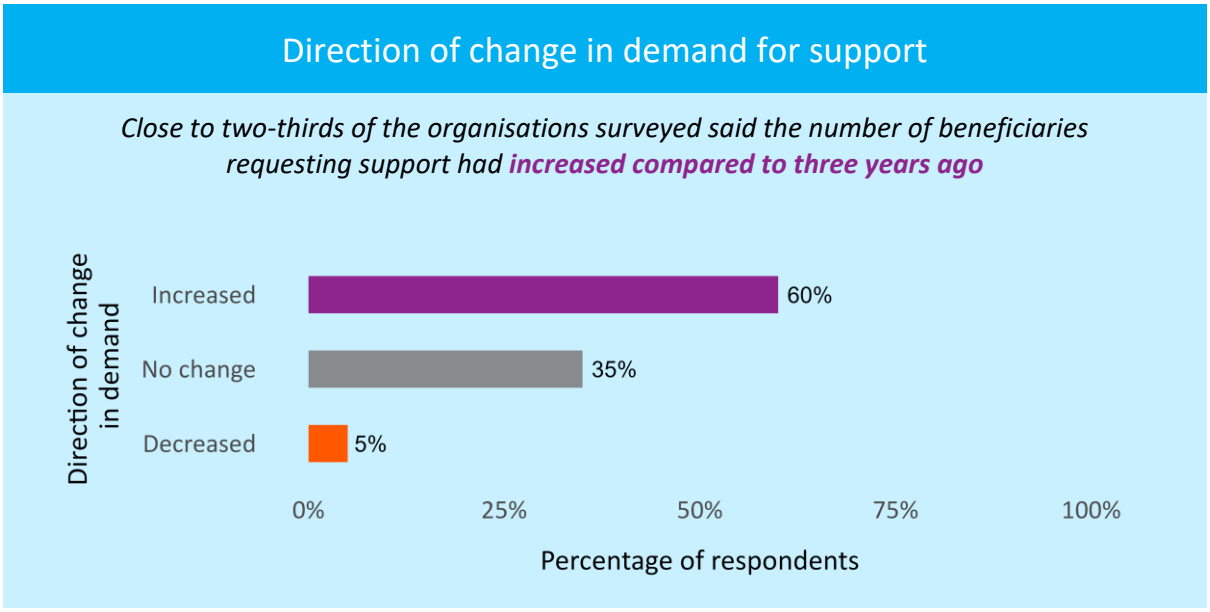
This chapter draws mostly on data from DSC's survey of people affected by HIV in London, which can be found in the green boxes. It also draws on the insights gained from DSC's survey of voluntary and community sector organisations, which can be found in the blue boxes. Finally, quotes from DSC's focus groups with voluntary and community sector organisations can be found in the purple boxes.

1.2 How has demand for support changed overall?

The respondents to DSC's survey of voluntary and community sector organisations were asked to indicate whether their current overall number of beneficiaries affected by HIV in London requesting (or referred for) support differed from the equivalent number three years ago (i.e. from the number in January 2020).

The respondents could state that their number of beneficiaries affected by HIV in London had 'increased', 'decreased' or shown 'no change'. As shown in figure 1.1, close to two-thirds (60%) of the organisations surveyed said the number of beneficiaries requesting support had increased compared to three years ago. Just over one-third (35%) said there had been no change in the number of beneficiaries requesting support. Meanwhile, only 5% said the number of beneficiaries requesting support had decreased.

Figure 1.1



Note: There were 40 responses to this question.

The respondents who said that their current overall number of beneficiaries affected by HIV in London differed from three years ago (i.e. those who said it had 'increased' or 'decreased') were invited to indicate, in percentage terms, the size of this change.

Among the respondents who said that their organisation had experienced an overall increase in demand relative to three years ago, the (median) average increase in the number of beneficiaries accessing or referred for support was 25% (the minimum was 10% and the maximum was 1,000%).[4]

Despite being very uncommon, the theme of decreasing participation was discussed by the voluntary and community sector organisations in DSC's focus groups. As can be seen from the extracts reproduced in box 1.1, participants described how there had been recent decreases among particular groups, such as African men, and for particular support mechanisms, such as peer support groups. The participants observed that this raises questions and concerns around how to respond because a lack of participation does not necessarily mean there is a lack of need.

Box 1.1

Focus group discussions on changing uptake of support and services

In the African communities it looks like things may be a bit different. But after COVID we've noticed that … our numbers have gone low – they've really gone down. Why? As a service provider, I'd say I'd take it positively that they are now empowered … [but] maybe this silence means something is wrong somewhere … It takes service providers like all of us on the ground to discern what that quietness means.

Medium charity – Focus Group 1

I would run newly diagnosed groups when I was at [another organisation] with 10, 15 people. I ran a gay men's group with 20 or 30 men. By the time I was ending those in 2018 and 2019, the numbers had fallen off a cliff … Coming back in this year and trying to run support groups again [I notice] really low uptake among gay men for support groups and peer support and coaching workshops. So, I think that the pandemic definitely exacerbated all of those things, but I don't think we got to March 2020 and all of a sudden life changed.

CIC – Focus Group 1

It's really clear that there's some great strategies of engaging people and things through building spaces for connection … but that's clearly not going to work for everybody … I think the worst thing we should do is assume that because those people aren't engaging it's because they don't need to or because there's nothing to be gained. So, how do you continue to identify those people's needs and make sure that they are met? It's a challenge, but I was just thinking about strategies for different people.

Medium charity – Focus Group 1*

Note: Quotes are for illustrative purposes only and the views expressed by respondents are not endorsed by DSC. An asterisk (*) denotes that the organisation represented was part of the steering group for this project. CIC: community interest company.

[4] The mean average increase was 126%. The median is the preferred average here due to the small number of very large values. There were too few data points to calculate the average among the organisations that said demand had decreased.

1.3 Which areas of support have become more or less important because of the COVID-19 pandemic?

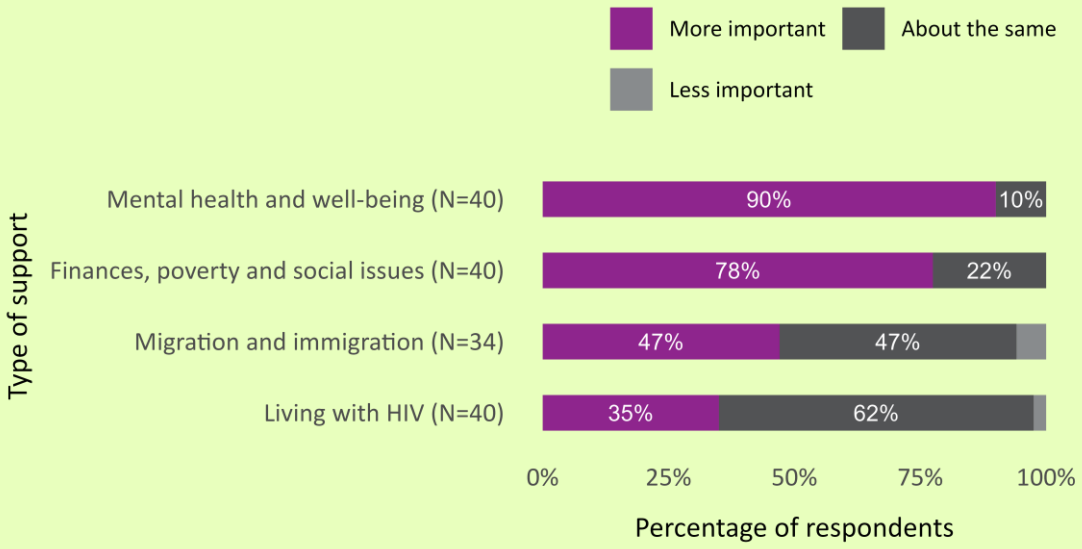
The respondents to DSC's survey of people affected by HIV were asked to indicate whether issues around four areas of support had become 'more important', become 'less important' or 'stayed about the same' because of the COVID-19 pandemic. These four areas of support were: living with HIV; mental health and well-being; finances, poverty and social issues; and migration and immigration.[5]

As shown in figure 1.2, the people who responded to this survey overwhelmingly (90%) said that mental health and well-being had become more important because of the COVID-19 pandemic. This was followed by finances, poverty and social issues, which just over three-quarters (78%) of the respondents felt had become more important because of the COVID-19 pandemic. The remaining areas of support were comparatively more likely to have stayed about the same (it was rare for the respondents to state that an area of support had become less important).

Figure 1.2

Changes in the importance of areas of support because of the COVID-19 pandemic

*Mental health and well-being was the area of support that respondents overwhelming said had become **more important** to them because of the COVID-19 pandemic*



Note: The numbers of respondents to each sub-question are shown in brackets. Percentages below ten are not shown for reasons of space.

In addition, as described in further detail in the following sections (1.4 to 1.8), DSC's survey of voluntary and community sector organisations also asked about specific issues or topics of support within each of the four areas outlined above, and it additionally asked about one further area, which was prevention and testing. To provide a complementary independent perspective on which areas of

[5] These four areas of support were developed by DSC's researchers in close consultation with the project's steering group. Migration and immigration were included in DSC's survey to reflect both impermanent and permanent movement, respectively.

support had become more or less important, DSC's researchers also analysed how demand had changed in these five areas.

Table 1.1 shows the average percentage of respondents reporting an increase in demand for each area of support.[6] To a large extent, these results align with the findings from the survey of people affected by HIV described above (see figure 1.2). Mental health and well-being support was the area for which demand had increased the most, with an average of over two-thirds (72%) reporting demand had increased compared to before the COVID-19 pandemic.

Mental health and well-being was followed by migration and immigration support, which had an average of around two-thirds (68%) reporting increased demand, although this finding is based on a smaller number of respondents. Next was finances, poverty and social issues, which showed an average of just under two-thirds (65%) reporting higher demand than before the pandemic. Of the areas included in both of DSC's surveys, living with HIV was the one where demand had increased the least, with an average prevalence of 52% reporting increased demand, and prevention and testing had a similar level of change in demand overall (56%).

Table 1.1

Area of support	Average prevalence of increased demand
Mental health and well-being	72%
Migration and immigration	68%
Finances, poverty and social issues	65%
Prevention and testing	56%
Living with HIV	52%

Note: For robustness, DSC's researchers undertook further analysis that additionally accounted for reports of decreased demand (increased demand was assigned a value of one, no change in demand a value of zero, and decreased demand a value of negative one). This showed the same rankings as above except for prevention and testing being ranked very marginally last, which reflects the relatively more widespread reports of decreased demand for this area of support, as shown in figure 1.11 (on page 26). Therefore, for each area, the average prevalence of increased demand is shown for ease of interpretation.

The participants in DSC's first focus group discussed the changing importance of various areas of support and the relationships between these different areas. The extracts in box 1.2 illustrate how some participants felt that issues related to living with HIV could be overtaken by other issues, such as those relating to mental health or financial difficulties. They also show how these issues may in turn then exacerbate or compound issues around living with HIV. Insights about the nature of the changing needs of people affected by HIV are discussed in more detail in the following sections (1.4 to 1.8).

[6] The averages are weighted within each area of support to account for the different numbers of respondents who provided a response in relation to each of the specific issues or topics of support within each area. The numbers of respondents (used to determine the weightings) can be found in parentheses within figures 1.4, 1.6, 1.8, 1.10 and 1.11.

Box 1.2

Focus group discussions on the changing importance of issues around living with HIV

I've always been aware of the issues around people being able to take treatment long term, but I wasn't quite prepared for the extent of that … With mental health you've got layers of things that people are concerned about and often taking their treatment could be right at the bottom.

Small charity, Focus Group 1

I guess what you've got really obviously here is … demonstrating how … in times of sort of crisis, HIV kind of ends up at the back of the queue. I think it's really important to acknowledge that although it looks almost like HIV is the least important thing out of all of these, actually that doesn't mean it doesn't compound all of the other things … There's a really significant issue post-COVID with loss-to-follow-up [patients disengaging from health services], so people who have previously engaged with their HIV clinic services … are no longer engaged through those services … but it's interesting to me seeing all of these other things that people are dealing with – it's not really surprising that that's happening.

Medium charity, Focus Group 1*

At the moment in relation to all those intersecting issues – the challenges we're seeing around mental health, substance abuse as a result of poor mental health, homelessness, immigration challenges – all of those key issues … are more likely to mean that people don't engage in care, don't engage in treatment, drop out.

Medium charity, Focus Group 2

Note: Quotes are for illustrative purposes only and the views expressed by respondents are not endorsed by DSC. An asterisk (*) denotes that the organisation represented was part of the steering group for this project.

1.4 Support around mental health and well-being

As shown in figure 1.2, the overwhelming majority (90%) of the respondents indicated that issues around mental health and well-being had become more important because of the COVID-19 pandemic. This section aims to enhance understanding of which issues or types of support around mental health and well-being are important to people affected by HIV and the nature of changes in demand for support.

What issues or types of support related to mental health and well-being are important?

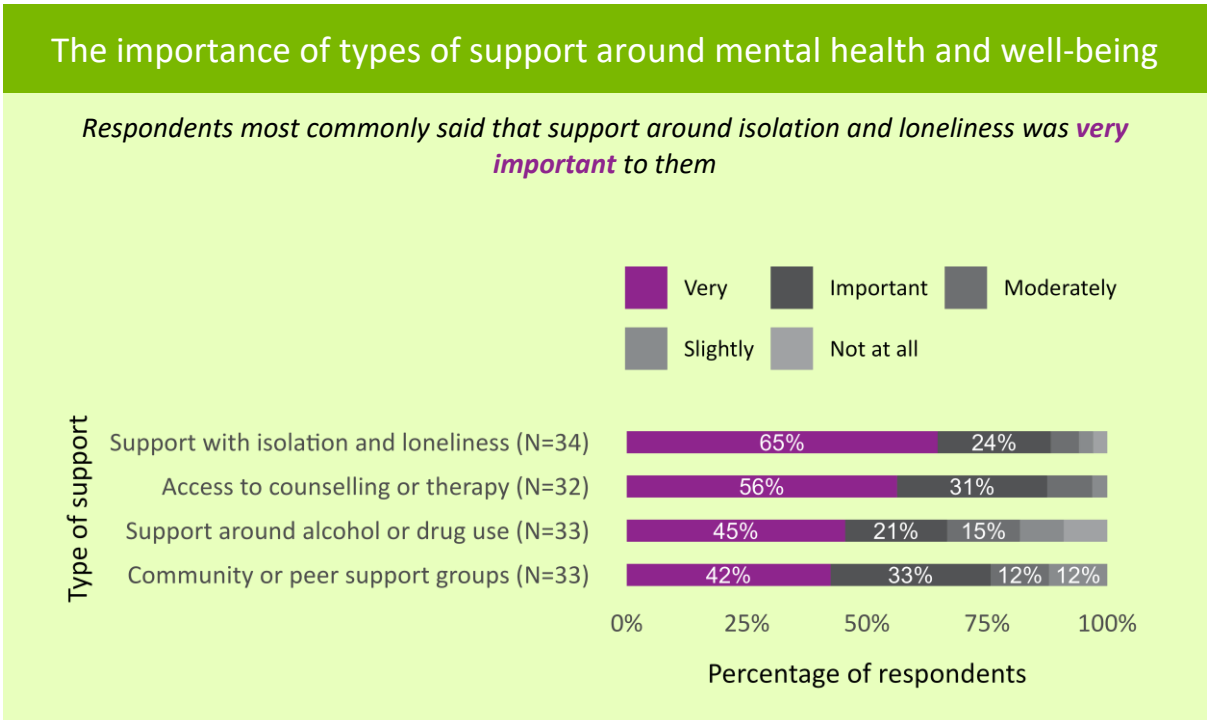
The people DSC surveyed were asked about specific issues or types of support related to mental health and well-being, and how important each one was to them as individuals. The respondents could indicate the importance of each issue on a scale which ranged from 'not at all important' to 'very important'.

Figure 1.3 shows the results for each issue or type of support related to mental health and well-being. The issues and types of support that were most commonly reported to be very important appear first, and those that were least commonly reported to be very important appear last.

As shown in figure 1.3, approximately two-thirds (65%) of the respondents stated that support around isolation and loneliness was very important to them as individuals. A further one-quarter (24%) of the

respondents felt that this was important and less than 10% each of the respondents said that support around isolation and loneliness was moderately (6%), slightly (3%) or not at all important (3%) to them.

Figure 1.3



Note: The numbers of respondents to each sub-question are shown in brackets. Percentages below ten are not shown for reasons of space. The percentages may not sum to 100% due to rounding.

In the space provided for additional comments, the respondents drew attention to the importance of support in relation to and pervasiveness of isolation and loneliness, its interconnection with other aspects of health, and the intersection between ageing and isolation or loneliness. An illustrative selection of responses is reproduced in box 1.3.

Box 1.3

Respondents' comments on support around isolation and loneliness

This should be more of a priority than it appears to be at the moment. It's one of the imperatives to having good mental health and well-being: not feeling isolated or lonely.

Male, 55–64

It's more difficult as I get older.

Non-binary, 55–64

Isolation and loneliness are so prevalent within our community.

Male, 55–64

Isolation and loneliness can lead to all kinds of mental health issues and experiences with addiction, including getting absorbed in 'chemsex' [drug use specifically in relation to sex] culture.

Male, 45–54

Note: Quotes are for illustrative purposes only and the views expressed by respondents are not endorsed by DSC.

Social isolation and loneliness was a key theme in discussions between the participants in DSC's focus groups. The discussions drew attention to how a diagnosis of HIV can be inherently isolating and how this was compounded by physical isolation during the COVID-19 pandemic. The impacts of the pandemic included the inability to socialise in the usual ways and a disconnection from health and support networks as services reduced or changed form. Some of these changes were, however, described as part of longer-term changes to the availability of social and service-based spaces to connect, particularly for older people living with HIV (see box 1.4).

Box 1.4

Focus group discussions around social isolation and loneliness among people affected by HIV

The isolation that an HIV diagnosis often enforces [is] because of the issues around anxiety of telling other people, potential stigma and discrimination. And so, I think it's no surprise that mental health and well-being were significantly increased needs throughout COVID-19 because you add physical isolation onto the already pre-existing isolation and so it's a real challenge.

Medium charity, Focus Group 2

We went online more or less for everything and one of the things that came out was that often people experienced what I call communication poverty … and I think then from a wider perspective … people that were linked into say community mental health services, they weren't being seen face to face either so there was this real lack of connection, personal connection I think, [and] that then developed into loneliness and isolation … I think a lot of people found that their health networks and their community networks were much more difficult to access.

Small charity, Focus Group 1

A lot of people felt like something was taken away from them that nobody else had. It was based around community – [LGBTQ+] communities are very much based around attending events, attending venues, going to spaces where you actually have to physically get up and go and do something, and when that was taken away, a lot of people felt that part of them was taken away as well … For a lot of gay men, the only time they interact with other gay men is when they go to these venues, and that was taken away from them and suddenly their identity was taken away from them. They might be living in situations where they have to hide who they are, have to hide their [HIV] status … That's in a sense what was evidenced to us as to why a lot of people felt isolated and lonely.

Medium charity, Focus Group 1

Pre-lockdown in 2020, we had already seen a huge loss of spaces for us to go to, particularly those of us who are ageing … so the bars if we're thinking about men who have sex with men and [about] queer communities, the bars, the venues, the social spaces, yes some saunas existed but the older you get the less likely you may be to go to those places. Your local pub may be closing down where you had your positive community … many of us [were] already feeling isolated from community before the pandemic, and that exacerbated that. I think the second thing to recognise: a lot of our HIV services were also cut and were not running in the same way from 2010 onwards – we started to see the closure of organisations, the shutdown of weekly or monthly support groups. But, also, with the success of U=U [the Undetectable = Untransmissible campaign] [and] the success of PrEP [pre-exposure prophylaxis medicine], we were seeing less people diagnosed so therefore less people taking up those services as well.

CIC, Focus Group 1

Note: Quotes are for illustrative purposes only and the views expressed by respondents are not endorsed by DSC. CIC: community interest company.

Returning to the importance of various issues around mental health and well-being (see figure 1.3), more than half (56%) of the respondents to DSC's survey of people affected by HIV said that support with access to counselling or therapy was very important to them, and close to an additional one-third

(31%) of the respondents reported that this was important. Less than 10% of the respondents each said that access to counselling or therapy was moderately (9%) or slightly (3%) important to them.

Additional comments provided by the people who responded to this survey suggested that it can be important for counselling or therapy to be provided by those with lived experience and sufficient training (see box 1.5). While one respondent was able to access support through an HIV clinic, others paid for private services because of waiting times, how long support was available for or the perceived quality of the support. The challenges presented by the lack of access to support services, particularly around mental health support services delivered by the statutory sector, are discussed in more detail in section 3.2.3 (see page 62).

Box 1.5

Respondents' comments on access to counselling or therapy

[It is important that these are] given by people with an understanding of life with HIV.

Male, 55–64

[It is important that these are] with a trained professional.

Non-binary, 55–64

I was fortunate to [receive] psychiatric and psychologist support through my HIV clinic.

Male, 55–64

I have benefitted immensely from access to counselling and therapy (and continue to do so). I have been on a waiting list for NHS psychiatric support for six months, so I have paid privately for counselling and benefitted from charitable services.

Male, 45–54

[Support was] rarely available for more than a limited number of sessions and [was of] variable quality. I paid privately for a therapist I could work with.

Male, 55–64

Note: Quotes are for illustrative purposes only and the views expressed by respondents are not endorsed by DSC.

As shown in figure 1.3, while the respondents were slightly less likely to consider this topic important, almost half (45%) said that support around alcohol or drug use was very important to them, with a further one-fifth (21%) indicating that this was important and 15% stating that it was moderately important.

Box 1.6 provides an illustrative selection of the additional comments left by the respondents to this question. These comments draw attention to particular needs around 'chemsex' (drug use specifically in relation to sex), the importance of drug and alcohol support for young people, and the importance of having support services that understand the relationship between drug and alcohol use and other elements of mental health.

Box 1.6

Respondents' comments on support around alcohol or drug use

In particular the challenges of chemsex [drug use specifically in relation to sex].

Male, 55–64

Especially for young people.

Trans man, 16–24

Alcohol and drug use are closely linked to isolation, loneliness, trauma and toxic shame. We need more healthcare and counselling services that understand the links between these things and who can engage in culturally competent ways.

Male, 45–54

Note: Quotes are for illustrative purposes only and the views expressed by respondents are not endorsed by DSC.

Despite being the least widely endorsed as very important among other types of support, community or peer support groups were deemed very important by approximately two-fifths (42%) of the respondents. Moreover, one-third (33%) of the respondents stated that community or peer support groups were important. The remaining respondents said they were moderately important (12%) or slightly important (12%).

Box 1.7 reproduces an illustrative range of the comments left by the respondents. The respondents' comments draw attention to the importance of community or peer support groups and highlight a range of further factors, such as the importance of good group management and sustainable funding, and the role of these groups in countering stigma and isolation.

Box 1.7

Respondents' comments on community or peer support groups

These need to be supported and properly managed.

Male, 55–64

This is a crucial area, as isolation through COVID-19 has really caused problems for many.

Male, 55–64

Peer support and sharing lived experiences [are] so important to raise awareness and combat stigma, including self-stigma.

Male, 55–64

Very important. Helping us to get a free space without the fear of stigma and discrimination.

Female, 55–64

Critical, but fragile due to precarious funding.

Male, 45–54

———

Although I go rarely, [an organisation] does a brilliant weekly email about what happened at the group, often catching issues before they become widespread information.

Male, 55–64

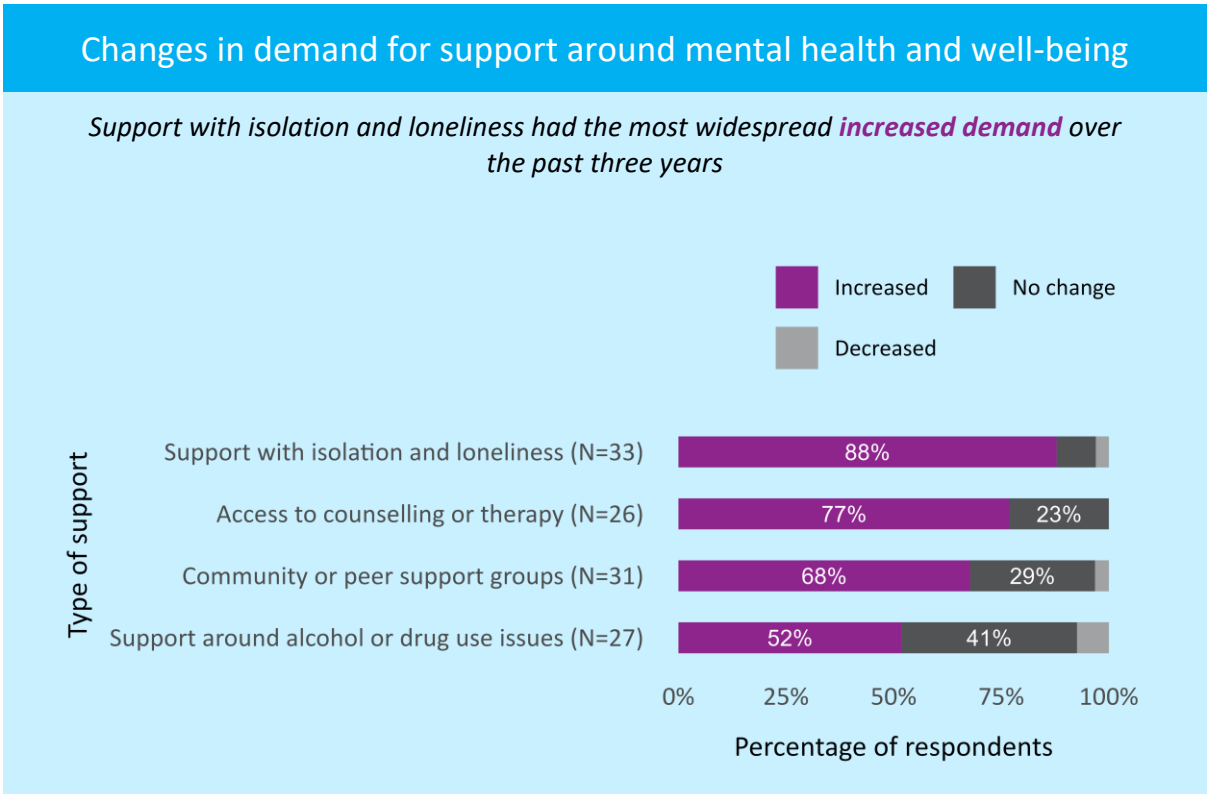
Note: Quotes are for illustrative purposes only and the views expressed by respondents are not endorsed by DSC.

How has demand changed for support around mental health and well-being?

For each of the four topics of support within mental health and well-being, the voluntary and community organisations that responded to DSC's survey were asked to indicate whether demand for support had 'increased', 'decreased' or shown 'no change' relative to three years ago (i.e. January 2020). These four topics of support were the same as the topics included in DSC's survey of people affected by HIV but were worded slightly differently.

As shown in figure 1.4, for each of the four topics of support, more than half of the respondents said that their organisation had experienced increased demand. However, demand for support with social isolation and loneliness was where increased demand had been most widespread: the overwhelming majority (88%) of organisations said that demand had increased in this area. As discussed above, this was also the type of need that people affected by HIV most commonly said was very important to them. Some of the challenges in meeting needs around social isolation and loneliness are discussed later, in section 3.2.3 (see page 56).

Figure 1.4



Note: The numbers of respondents to each sub-question are shown in brackets. Percentages below ten are not shown for reasons of space.

1.5 Support around finances, poverty and social issues

As shown in figure 1.2, just over three-quarters (78%) of the people who responded to DSC's survey of people affected by HIV said that issues around finances, poverty and social issues had become more important because of the COVID-19 pandemic. This section aims to enhance understanding of which issues or types of support around finances, poverty and social issues are important to people affected by HIV and the nature of changes in demand for support.

What issues or types of support related to poverty, finances and social issues are important?

The respondents to DSC's survey of people affected by HIV were also asked about specific issues or types of support related to finances, poverty and social issues, and how important each one was to them as individuals. The respondents could indicate the importance of each issue on a scale which ranged from 'not at all important' to 'very important'.

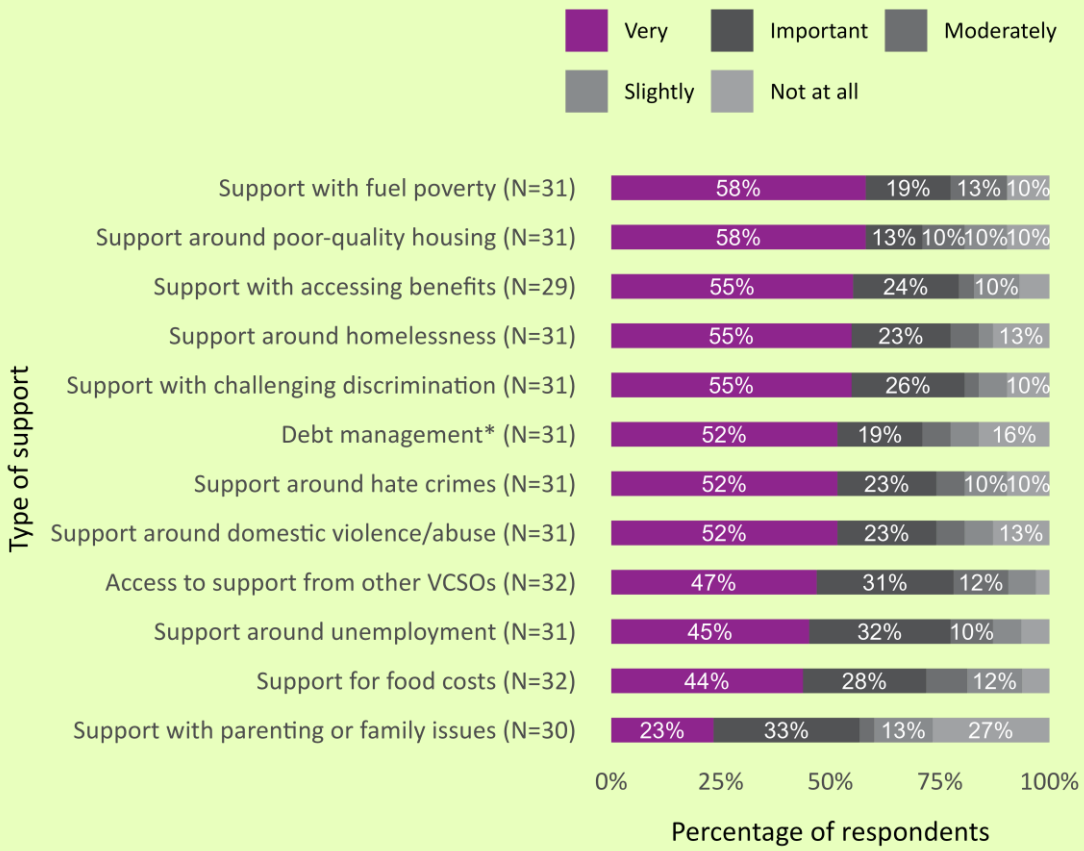
Figure 1.5 shows the results for each issue or type of support related to poverty, finances and social issues. The issues and types of support that were most commonly reported to be very important appear first, and those that were least commonly reported to be very important appear last.

As shown in figure 1.5, more than half (58%) of the respondents said that support with fuel poverty was very important. In addition, around a further one-fifth (19%) of the respondents said that support with fuel poverty was important to them, 13% said it was moderately important and 10% said that this was not at all important.

Figure 1.5

The importance of types of support around poverty, finances and social issues

*Respondents most commonly said that support with fuel poverty and around poor-quality housing were **very important** to them*



Note: VCSOs: voluntary and community sector organisations. The asterisk (*) denotes 'and support with finances'. The numbers of respondents to each sub-question are shown in brackets. Percentages below ten are not shown for reasons of space. The percentages may not sum to 100% due to rounding. Where appropriate, minor changes – which do not alter the meaning – have been made to the wording for continuity with DSC's survey of voluntary and community sector organisations.

The same percentage of respondents (58%) said that support around poor-quality housing was very important to them. A significant minority (13%) said support around poor-quality housing was important to them, 13% said it was important, and 10% each said that it was moderately, slightly or not at all important to them. Relatedly, support around homelessness was perceived as very important by more than half (55%) of the people who responded to this survey. In the space provided for additional comments, two of the respondents drew attention to the relationship between health and housing, as shown in box 1.8.

Box 1.8

Respondents' comments on support around poor-quality housing and homelessness

No housing is the most important, but poor quality does need to be addressed.

Male, 55–64

———

We have never been given a choice in the process – we end up taking anything without anyone considering our health issues.

Female, 55–64

———

We can't expect people to effectively engage in treatment and care if they don't have a home.

Male, 55–64

Note: Quotes are for illustrative purposes only and the views expressed by respondents are not endorsed by DSC.

Despite being comparatively less common, many of the other issues or types of support related to finances, poverty and social issues were rated as very important by more than or close to half of the people who responded to this survey. To provide some further insights in relation to these, a selection of quotes is reproduced in box 1.9.

Box 1.9

Respondents' other comments on support around finances, poverty and social issues

Many will have lost jobs in the service industries through COVID-19.

Male, 55–64

———

[Unemployment support is] especially [important] for young people.

Trans man, 16–24

———

Most of us are ageing with HIV and we are migrants, [and] we are technically challenged [in relation to accessing benefits].

Female, 55–64

———

[Access to support from voluntary and community sector organisations] that will not stigmatise me [is important].

Non-binary, 55–64

———

Having a strong voluntary sector network with easy referral pathways is essential.

Male, 55–64

Organisations [providing support with food costs] are already over-stretched, but provide an essential service.

Male, 55–64

[Support around hate crimes is] especially [important] for those who experience other inequalities beyond their HIV status [such as] racism [or] transphobia.

Trans man, 16–24

People living with HIV need to either be able to confront and challenge [discrimination], or at the very least have an easy way to report this so that advocates can address it.

Male, 55–64

Note: Quotes are for illustrative purposes only and the views expressed by respondents are not endorsed by DSC.

How has demand changed for support around finances, poverty and social issues?

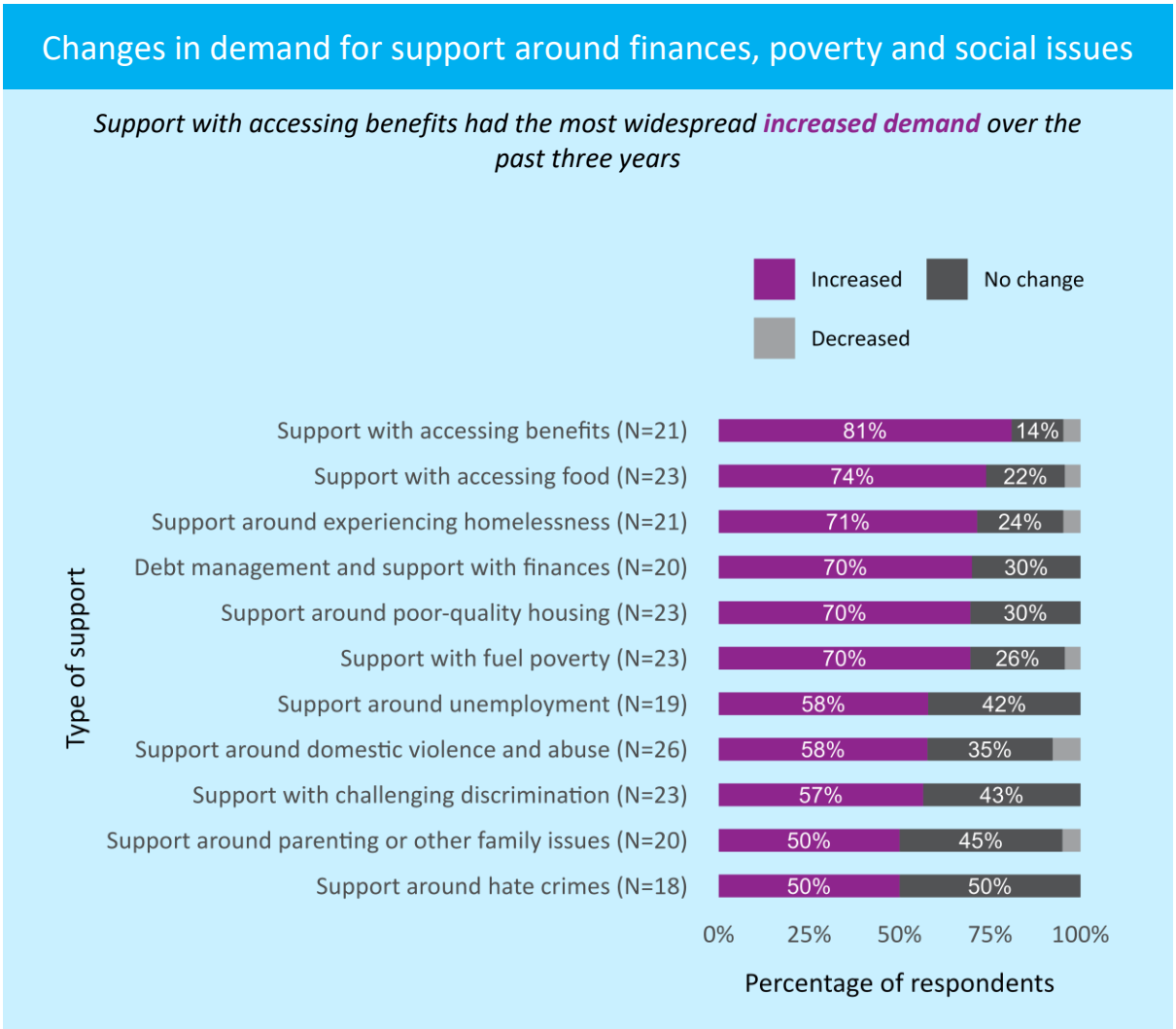
The voluntary and community sector organisations that responded to DSC's survey were asked about 11 topics of support around finances, poverty and social issues. For each topic, the respondents were asked to indicate whether demand for support had 'increased', 'decreased' or shown 'no change' relative to three years ago (i.e. January 2020). These 11 topics of support were very similar to, but not exactly the same as, the topics included in DSC's survey of people affected by HIV.

As shown in figure 1.6, the topic of support for which the organisations that responded to DSC's survey had most commonly experienced increased demand was support with accessing benefits: approximately four-fifths (81%) of the organisations surveyed said that demand for support with accessing benefits had increased, a further 14% said demand had not changed, and 5% said demand had decreased.

Around three-quarters (74%) of the organisations surveyed said that demand had increased for support with accessing food. In addition, around seven in every ten organisations surveyed reported increased demand for support around experiencing homelessness (71%), debt management and support with finances (70%), poor-quality housing (70%) and food poverty (70%).

It was relatively less common for the organisations that responded to DSC's survey to report increased demand for support around parenting or other family issues (50%) or support around hate crimes (50%).

Figure 1.6



Note: The numbers of respondents to each sub-question are shown in brackets. Percentages below ten are not shown for reasons of space.

1.6 Support around migration and immigration

As shown in figure 1.2, equal proportions (47%) of respondents to DSC's survey of people affected by HIV said issues around migration and immigration had become more important or stayed about the same because of the COVID-19 pandemic. This section aims to enhance understanding of which issues or types of support around migration and immigration are important to people affected by HIV and the nature of changes in demand for support.

What issues or types of support related to migration and immigration are important?

The respondents were asked about specific issues or types of support related to migration and immigration, and how important each one was to them as individuals. The respondents could indicate the importance of each issue on a scale which ranged from 'not at all important' to 'very important'.

Figure 1.7 shows the results for each issue or type of support related to migration and immigration. The issues and types of support that were most commonly reported to be very important appear first, and those that were least commonly reported to be very important appear last.

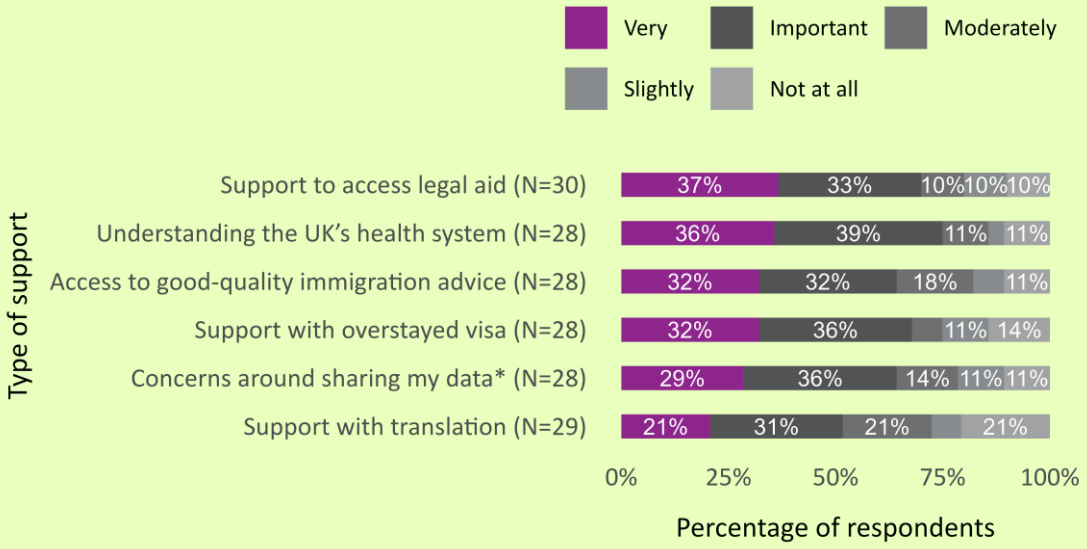
Support to access immigration-related legal aid was the issue or type of support that the largest percentage (37%) of the respondents said was very important. A further one-third (33%) of the respondents said that this was important, and the remaining respondents said that this was moderately important, slightly important or not at all important to them (10% each).

Support around understanding the UK's health system was rated as very important by a similar percentage (36%) of the respondents. Moreover, around a further two-fifths (39%) said that support around understanding the UK's health system was important to them.

Figure 1.7

The importance of types of support around migration and immigration

*Respondents most commonly said that support to access immigration-related legal aid and understanding the UK's health system were **very important** to them*



Note: The numbers of respondents to each sub-question are shown in brackets. Percentages below ten are not shown for reasons of space. The percentages may not sum to 100% due to rounding. The asterisk (*) denotes 'with government departments'. Where appropriate, minor changes – which do not alter the meaning – have been made to the wording for continuity with DSC's survey of voluntary and community sector organisations.

In the spaces made available for the people who responded to this survey to leave additional comments, some of the respondents provided further insights in relation to issues or types of support around migration and immigration. An illustrative selection of the additional comments is reproduced in box 1.10.

Box 1.10

Respondents' comments on issues or types of support around migration and immigration

Where [concerns around sharing data with government departments] is a disincentive to people in accessing healthcare, there need to be reassurances.

Male, 55–64

The challenges for migrants are higher than [for] those born in [the] UK and reducing barriers [through translation] is important.

Male, 55–64

Some of those who have not tested for HIV may not be aware that ARVs [antiretroviral medicines] are free, and that they have a right to healthcare.

Male, 55–64

This is a terrible time for migrants and refugees, so any and all help would be beneficial, since many organisations have closed.

Male, 55–64

Understanding the UK immigration system [is also a relevant issue].

Male, 35–44

Note: Quotes are for illustrative purposes only and the views expressed by respondents are not endorsed by DSC.

DSC's focus groups with voluntary and community sector organisations that support people affected by HIV provided further insights into the types of need that can be related to migration and immigration. As shown in box 1.11, voluntary and community sector organisations highlighted how some of the needs around living with HIV, such as taking medication and accessing care, can intersect with individuals' migration statuses and policies around seeking asylum.

Box 1.11

Focus group discussions on needs related to migration and immigration

> [There is an issue with] people living with HIV who arrive here without their medication, or without sufficient medication, thinking that if they bring their medication it will somehow interfere with their entry to the country because of our hostile immigration policies, who then aren't aware of the way the NHS actually works and need … a bit of hand-holding to be able to enrol clinically.
>
> **Small charity, Focus Group 2**

> The biggest isolated group I work with that we're seeing … is the migrant group … which is isolated and also very easily lost in care. So, we have lots of people who are coming to us and they are trying to stay in London but they are pushed out to certain Home Office hotels or refugee centres, and then they tell us they won't be able to access the HIV care as well because they're in a small village and they don't have any public funds, any access to any money, so then we're trying to work with them on the case with the Home Office to prove that they're with us and we help them to stay in London, so there's a big need around that.
>
> **Large charity, Focus Group 2**

Note: Quotes are for illustrative purposes only and the views expressed by respondents are not endorsed by DSC.

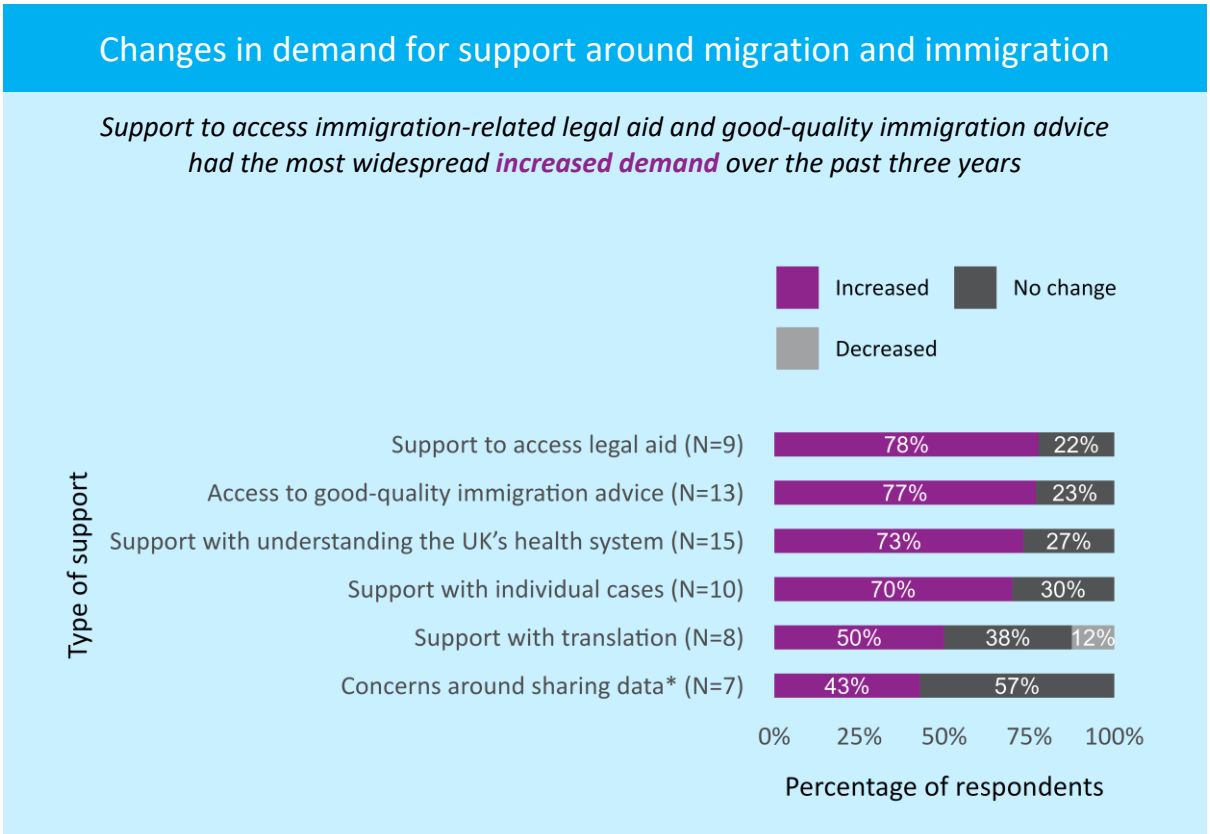
How has demand changed for support around migration and immigration?

The voluntary and community sector organisations that responded to DSC's survey were asked about six topics of support around migration and immigration, and for each topic the respondents were asked to indicate whether demand for support had 'increased', 'decreased' or shown 'no change' relative to three years ago (i.e. January 2020). These six topics of support were very similar to, but not exactly the same as, the topics included in DSC's survey of people affected by HIV. It is also important to note that, relative to the other key areas of support, fewer organisations completed this section overall (see numbers in parentheses in figure 1.8).

The topic of support for which the organisations that responded to DSC's survey experienced the most widespread increased demand was support to access immigration-related legal aid, which was reported to have increased by just over three-quarters (78%) of the respondents. Additionally, approximately two in every ten respondents (22%) said that demand had not changed for support to access immigration-related legal aid – and none of the respondents said that demand had decreased. The results were very similar for access to good-quality immigration advice, the topic of support second most likely to have been reported as having increased demand.

It was relatively less common for the organisations surveyed to report increased demand for support with translation (50%) or for concerns around sharing data with government departments (43%).

Figure 1.8



Note: The numbers of respondents to each sub-question are shown in brackets. The asterisk (*) denotes 'with government departments'.

1.7 Support around living with HIV

As shown in figure 1.2, most (62%) of the respondents indicated that issues around living with HIV had stayed about the same because of the COVID-19 pandemic, but around one-third (35%) felt these issues had become more important. This section aims to enhance understanding of which issues or types of support around living with HIV are important to people affected by HIV and the nature of changes in demand for support.

What issues or types of support related to living with HIV are important?

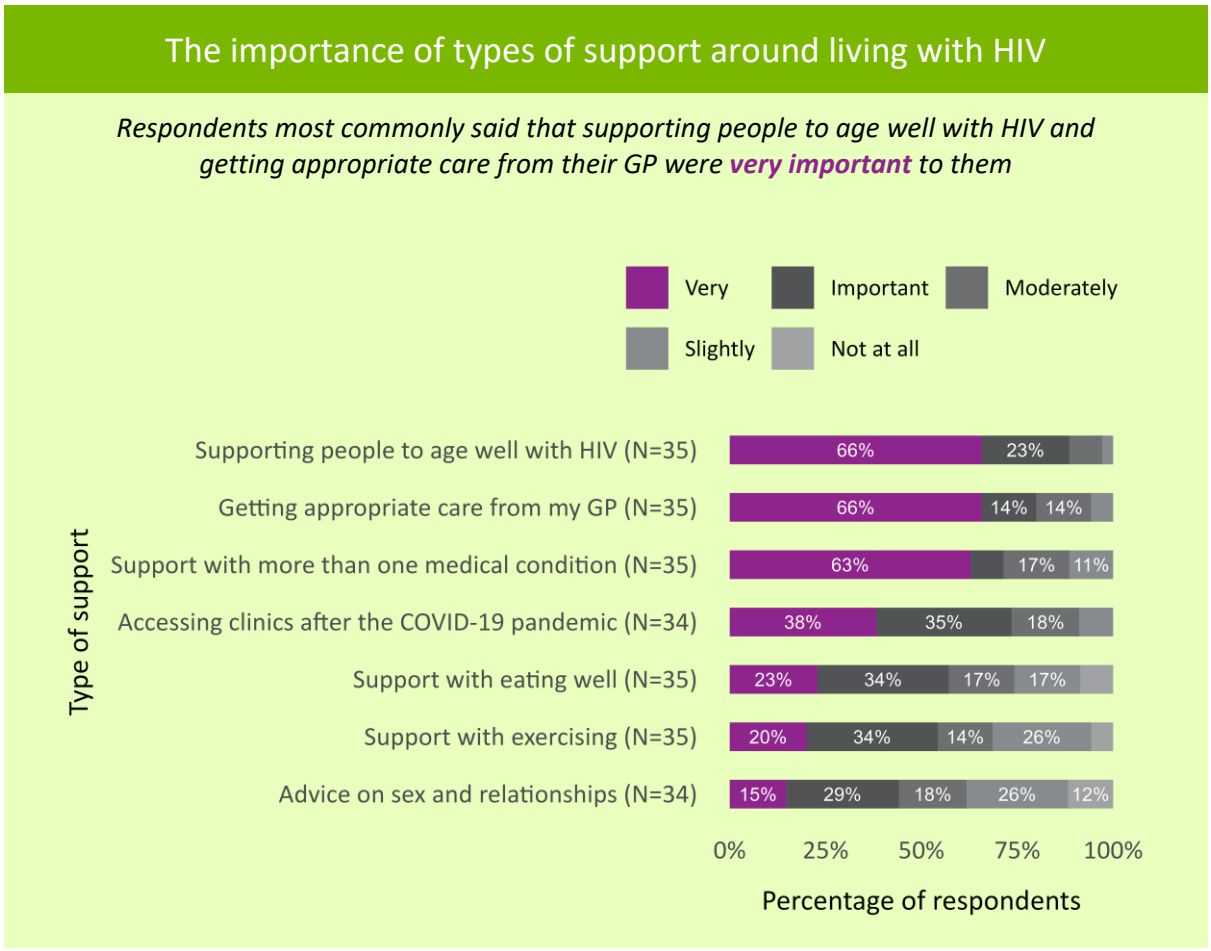
The people who responded to DSC's survey were asked about specific issues or types of support related to living with HIV, and how important each one was to them as individuals. The respondents could indicate the importance of each issue on a scale which ranged from 'not at all important' to 'very important'.

Figure 1.9 shows the results for each issue or type of support related to living with HIV. The issues and types of support that were most commonly reported to be very important appear first, and those that were least commonly reported to be very important appear last.

Supporting people to age well with HIV and getting appropriate care from a GP were the types of support that were most widely reported to be very important to the respondents. In terms of supporting people to age well with HIV, two-thirds (66%) of the respondents said this was very important, just under one-quarter (23%) said this was important, and the remaining respondents said this was moderately (9%) or slightly (3%) important.

Looking at getting appropriate care from a GP, two-thirds (66%) of the respondents said this was very important, significant minorities said this was important or moderately important (14% for each), and the remaining respondents (6%) said this was slightly important. Getting appropriate care from a GP was closely followed by support with more than one medical condition, which was very important to almost two-thirds (63%) of the respondents.

Figure 1.9



Note: The numbers of respondents to each sub-question are shown in brackets. Percentages below ten are not shown for reasons of space. The percentages may not sum to 100% due to rounding. Where appropriate, minor changes – which do not alter the meaning – have been made to the wording for continuity with DSC's survey of voluntary and community sector organisations.

In the space provided for additional comments, some of the respondents drew attention to the increasing importance of supporting people to age well with HIV due to demographic changes among those living with HIV, the importance of the links between physical and mental health, and the importance of preventative measures. These comments are shown in box 1.12.

Box 1.12

Respondents' comments on supporting people to age well with HIV

As the population of people living with HIV ages, this is increasingly important.

Male, 45–54

Particularly preventative measures to maintain good health [are important].

Male, 55–64

Ageing involves those who have grown up with HIV, such as those born with or diagnosed at a very young age.

Trans man, 16–24

It is important to understand the links between HIV and mental health, particularly childhood trauma, addiction, substance use and loneliness/isolation.

Male, 45–54

Note: Quotes are for illustrative purposes only and the views expressed by respondents are not endorsed by DSC.

Some of the respondents also provided additional comments in relation to getting appropriate care from their GP. These comments, shown in box 1.13, draw attention to the importance of HIV-related knowledge and an HIV-sensitive approach among GPs, difficulties accessing appointments, and concerns around the extent to which healthcare services work together to support people living with HIV.

Box 1.13

Respondents' comments on getting appropriate care from their GP

After 40 years there is less understanding about HIV than there is about other long-term health conditions. Patients are still going back and forth between their GP and HIV clinics to get issues resolved.

Male, 55–64

Is it possible to have stronger linkages between HIV clinic and GP? For example, why can't I have routine HIV blood tests at my GP?

Male, 55–64

Ensuring GPs are equipped to deal with people with HIV knowledgably and sensitively is vital.

Male, 45–54

Since the pandemic, it is harder to get a GP appointment.

Male, 55–64

Not all GPs are aware of their patient's HIV status. Not all GPs have the cultural competence to provide holistic care to people living with HIV.

Male, 45–54

Accessing GP appointments has become extremely difficult, even though I should rely on my GP to manage my COPD [chronic obstructive pulmonary disease].

Male, 65+

Note: Quotes are for illustrative purposes only and the views expressed by respondents are not endorsed by DSC.

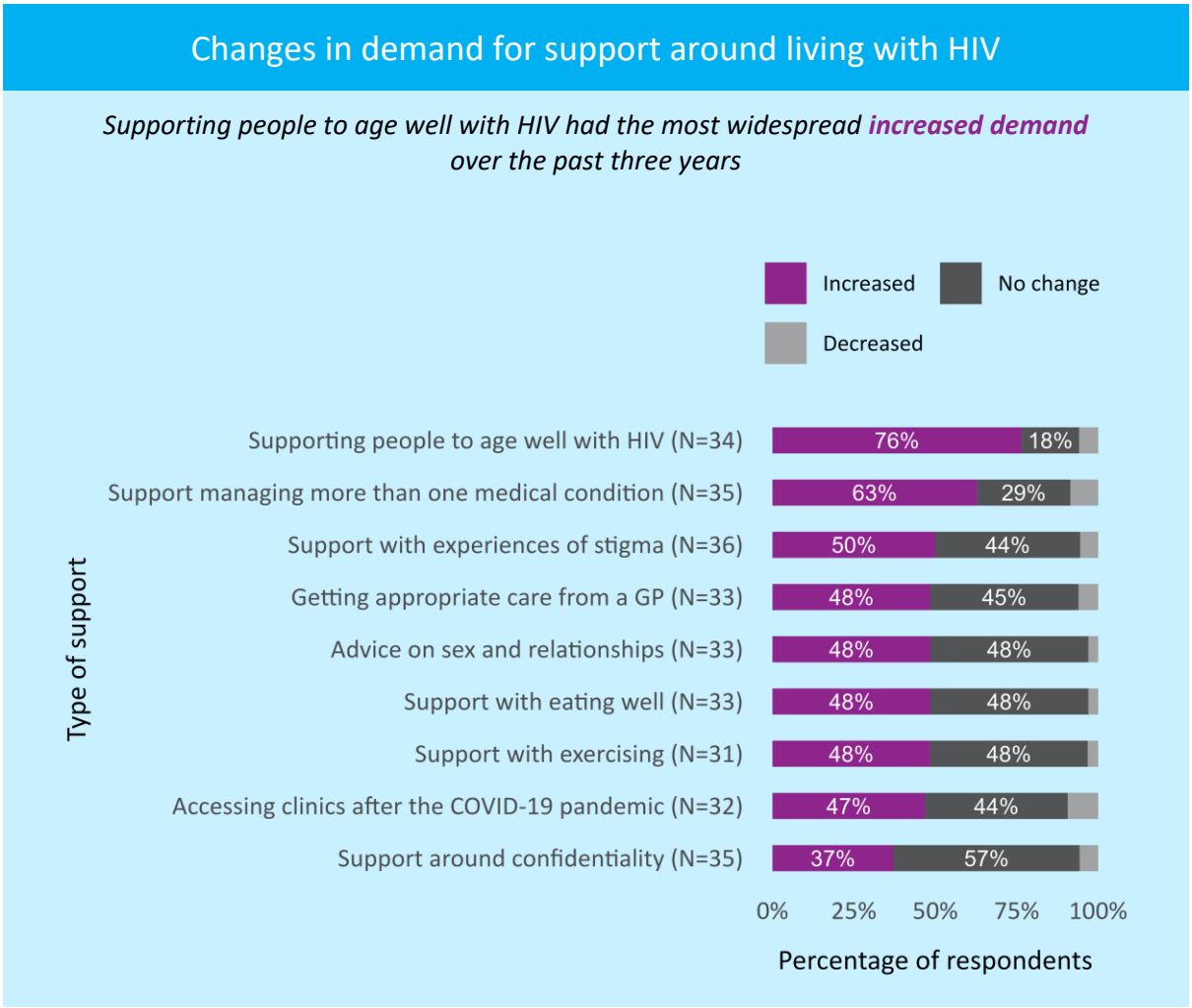
How has demand changed for support around living with HIV?

DSC's survey of voluntary and community sector organisations asked the respondents how demand had changed for specific types of support around living with HIV. The respondents were asked to indicate, for each topic, whether demand for support had 'increased', 'decreased' or shown 'no change' relative to three years ago (i.e. January 2020).

Figure 1.10 shows the topics of support around living with HIV ordered by the percentages of the organisations that said they had seen increased demand. The topic of support for which there was most widespread increased demand was supporting people to age well with HIV: approximately three-quarters (76%) of the organisations surveyed said that demand had increased. This was followed by support with managing more than one medical condition, for which almost two-thirds (63%) of the organisations surveyed said that demand had increased. Widespread increased demand in these two areas reflects what people affected by HIV said was very important to them (as discussed above).

Figure 1.10 also shows, on the other hand, that support around accessing clinics after the onset of the COVID-19 pandemic and support around confidentially were the topics of support for which the organisations surveyed reported the least widespread increased demand (47% and 37%, respectively).

Figure 1.10



Note: The numbers of respondents to each sub-question are shown in brackets. Percentages below ten are not shown for reasons of space.

1.8 Support around prevention and testing

Support related to prevention and testing was not one of the areas included in DSC's survey of the people affected by HIV, based on discussions with the project's steering group. However, the voluntary and community sector organisations surveyed were asked about this. This section therefore aims to enhance understanding of how demand has changed for support around prevention and testing.

How has demand changed for support around prevention and testing?

The final key area of support in DSC's survey of organisations was support around prevention and testing. For this key area, the respondents were asked about six topics of support, and for each topic the respondents were asked to indicate whether demand for support had 'increased', 'decreased' or shown 'no change' relative to three years ago (i.e. January 2020).

As shown in figure 1.11, there was a notable divide between three topics of support for which there had been more widespread increases in demand and three topics of support for which there had been less widespread increases in demand (or, conversely, more widespread reports of demand staying about the same).

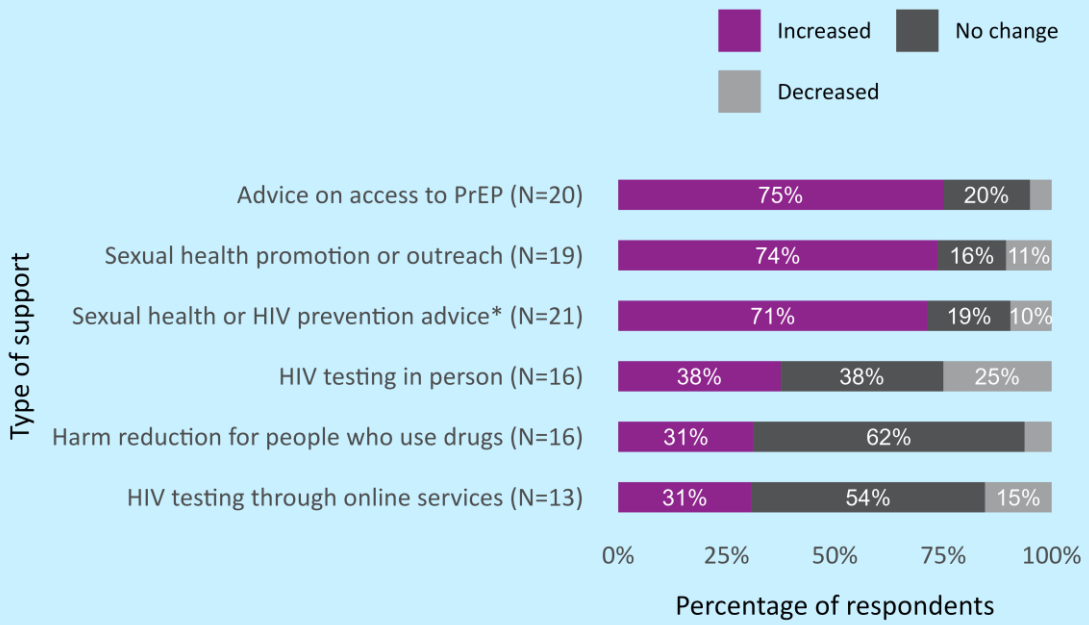
More than seven in every ten of the organisations surveyed said demand had increased around advice on access to PrEP (pre-exposure prophylaxis) medicine (75%), sexual health promotion or outreach (74%), and sexual health or HIV prevention advice and support (71%).

On the other hand, for the other three topics of support, it was relatively less common for the organisations surveyed to report increased demand. For HIV testing in person, approximately two-fifths (38%) said demand had increased, with the same percentage saying it had not changed. However, one-quarter (25%) said that demand for HIV testing in person had decreased. Meanwhile, approximately one-third (31%) of the organisations surveyed said that demand had increased concerning both harm reduction for people who use drugs and HIV testing through online services. For HIV testing through online services – for example, through using a self-test at home or ordering a test to post to a laboratory (Terence Higgins Trust, 2023) – 15% of the respondents said that demand had decreased.

Figure 1.11

Changes in demand for support around prevention and testing

*Advice on access to PrEP (pre-exposure prophylaxis) medicine and sexual health promotion or outreach had the most widespread **increased demand** over the past three years*



Note: The numbers of respondents to each sub-question are shown in brackets. Percentages below ten are not shown for reasons of space. The percentages may not sum to 100% due to rounding. The asterisk (*) denotes 'and support'.

CHAPTER TWO

Resilience and readiness

2.1 Introduction

This chapter intends to foster a more comprehensive understanding of the resilience of voluntary and community sector organisations, providing important context around their readiness to respond to the challenges which are discussed in the next chapter. It aims to answer the following questions:

- What has been the capacity of voluntary and community sector organisations to deliver support?
- How is the financial security of voluntary and community sector organisations changing?
- How have income and expenditure changed since before the COVID-19 pandemic?
- Which sources of income are typically important for voluntary and community sector organisations?
- What is the current level and use of reserves?

This chapter draws mostly on data from DSC's survey of voluntary and community sector organisations, which can be found in the blue boxes. It also draws on the insights gained from DSC's

focus groups with voluntary and community sector organisations, quotes from which can be found in the purple boxes.

2.2 What has been the capacity of voluntary and community sector organisations to deliver support?

The previous chapter showed that more than half of the voluntary and community organisations that responded to DSC's survey had experienced an increased level of demand compared to before the onset of the COVID-19 pandemic (see figure 1.1). DSC's survey of these organisations also sought to better understand whether demand for support is being met and the level of capacity to meet demand around five key areas of support: living with HIV; mental health and well-being; finances, poverty and social issues; migration and immigration; and prevention and testing.

The respondents were asked to choose from five statements about their capacity to meet the demand for support over the past three years. These statements ranged from 'We met demand with significant spare capacity' to 'We fell significantly short of meeting demand'.

To help provide an understanding of where the voluntary and community sector organisations are most commonly struggling to meet demand from people affected by HIV, figure 2.1 shows the five key areas of support ordered by the percentages of respondents who said that their organisation fell significantly short of meeting demand over the past three years.

Finances, poverty and social issues was the area of support for which organisations were most commonly struggling to meet demand: approximately one in every four (27%) organisations surveyed said that they had fallen significantly short of meeting demand. As discussed in section 1.5, support in this area includes, for example, support to access benefits and food, around experiencing homelessness, and around debt management and finances. Despite being less widespread, still around one in every five voluntary and community sector organisations (20%) said they fell significantly short of meeting demand in relation to support around mental health and well-being, prevention and testing, and living with HIV.

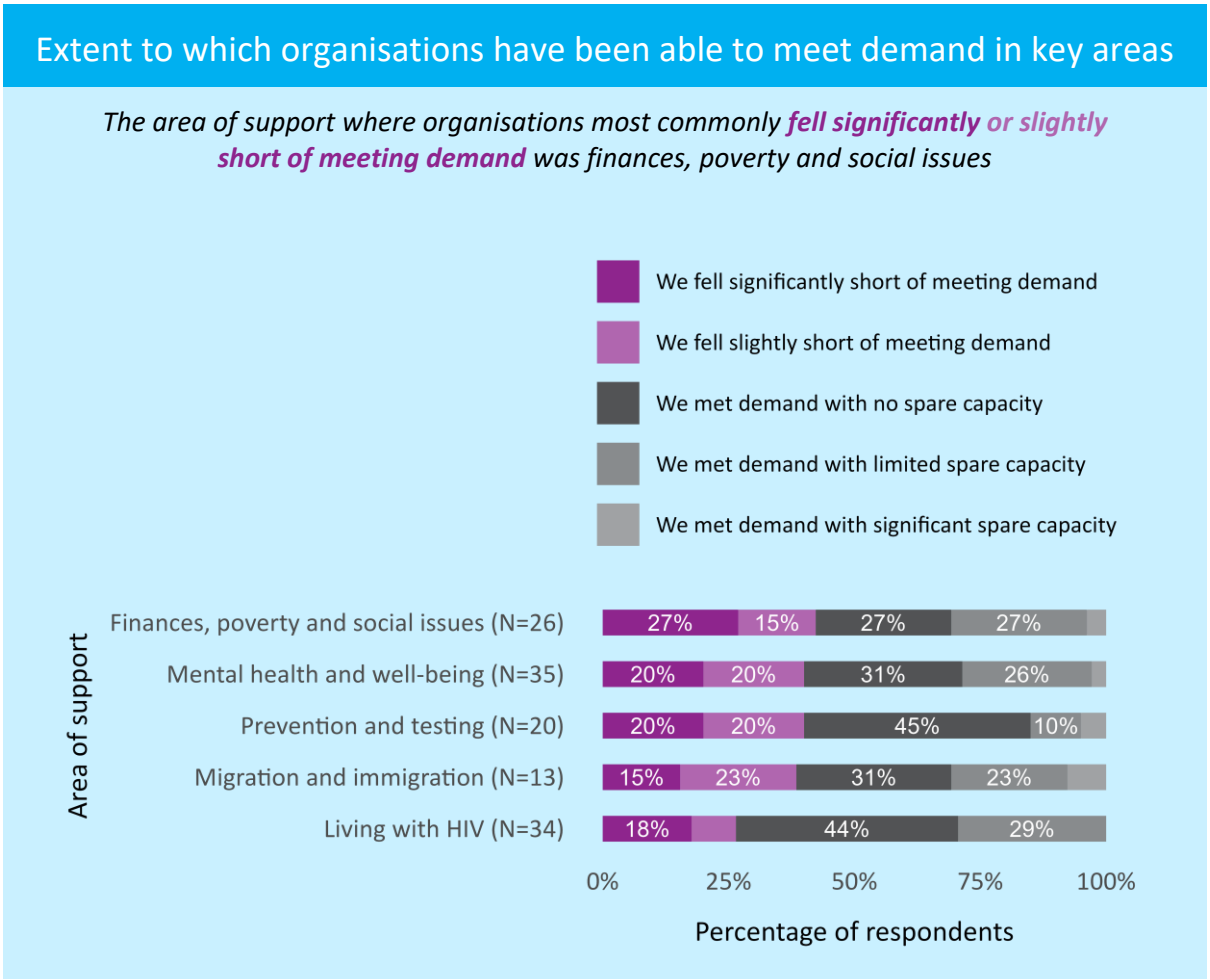
Further analysis was undertaken to better understand whether the ability to meet demand differed between charities of different sizes. Charities that responded to this question were categorised based on their most recent annual income as small (income below £100,000; N=14), medium (income between £100,000 and £1 million; N=9) and large (income above £1 million; N=6).[7] This showed that small charities and medium charities were more likely than large charities to be falling significantly short of meeting demand.[8]

Looking at figure 2.1 more broadly, for each of the five key areas, it was more common for organisations to say that they had met demand (with any or no spare capacity) than to have fallen short of meeting demand (whether significantly or slightly). However, where demand has been met, this was typically with no spare capacity: voluntary and community sector organisations are, overall, typically just about managing to meet demand for support.

[7] Based on the available data from the Charity Commission for England and Wales.

[8] Similar analyses appearing in sections 2.3.1 and 2.4 related to charities' incomes from 2019, as the data was about changes since the start of the COVID-19 pandemic. Here, DSC's researchers used the most recent annual income, as this is more closely aligned with recent capacities to deliver support.

Figure 2.1



Note: The numbers of respondents to each sub-question are shown in brackets. Percentages below ten are not shown for reasons of space.

2.3 How is the financial security of voluntary and community sector organisations changing?

2.3.1 How does financial security differ from before the COVID-19 pandemic?

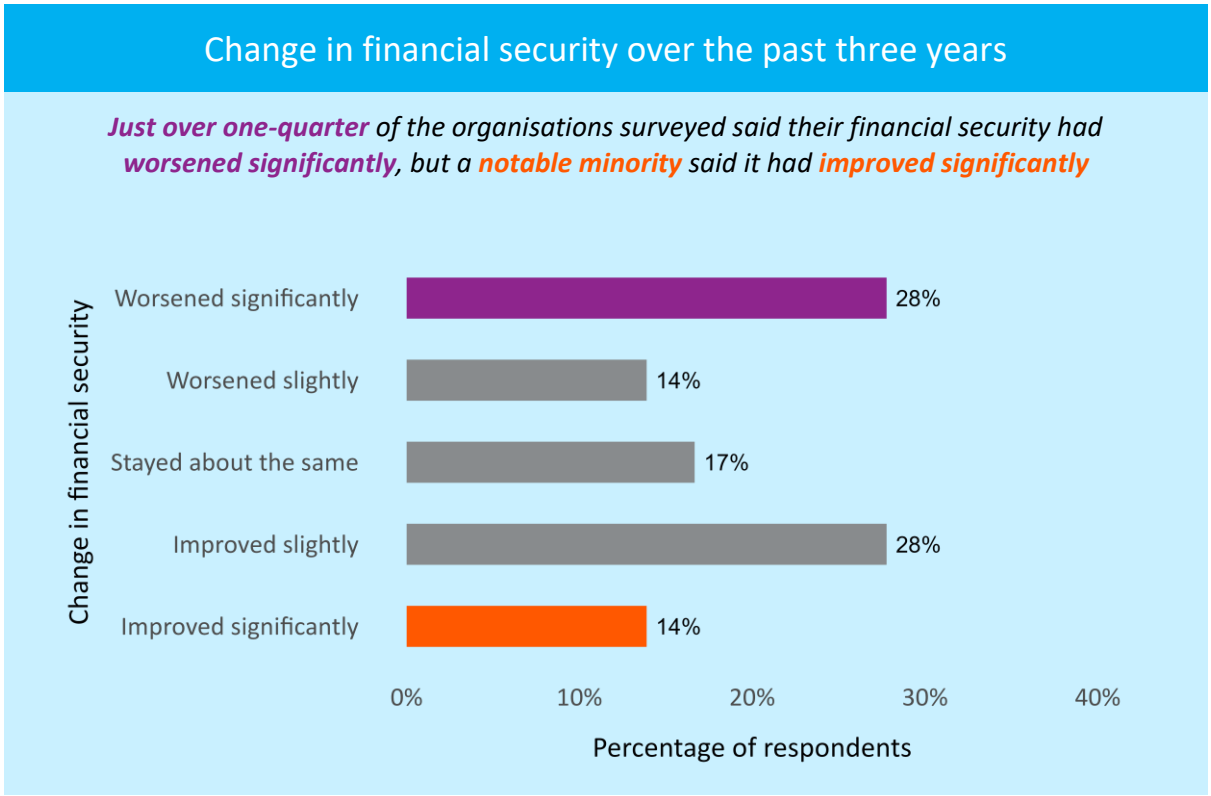
In order to gain a high-level overview of the financial situation facing voluntary and community sector organisations supporting people affected by HIV in London, DSC's survey asked the respondents about the extent to which their overall financial security differed from three years ago (i.e. January 2020). The respondents could choose from statements about their financial security ranging from 'Improved significantly' to 'Worsened significantly'.

As shown in figure 2.2, just over one-quarter (28%) of the organisations surveyed said that their financial security had worsened significantly compared to three years ago, and an additional 14% said that their financial security had worsened slightly compared to three years ago. In contrast, 14% of the respondents said that their organisation's financial security had improved significantly, and just over one-quarter (28%) said that their financial security had improved slightly. Around 17% of respondents' financial security had stayed about the same.

Overall, these findings show that experiencing worsened financial security was approximately as common as experiencing improved financial security. However, the typical magnitude or severity of change among those experiencing worsened financial security was greater (i.e. more likely to be at an extreme end of the scale) than among those reporting improved financial security.

Further analysis was undertaken to better understand whether the reported changes in financial security differed between charities of different sizes. Charities that responded to this question were categorised based on their 2019 annual income as small (annual income below £100,000; N=10), medium (annual income between £100,000 and £1 million; N=9) or large (annual income above £1 million; N=6).[9] This analysis showed no substantial differences between the groups, but charities that were larger (in 2019) were slightly more likely to have maintained a similar level of financial security.

Figure 2.2



Note: There were 36 responses to this question (not including those reporting an 'other' answer). The percentages do not sum to 100% due to rounding.

The organisations that responded to DSC's survey could provide additional information in relation to their responses. Some of these additional comments drew attention to the reasons for changes in financial security. Among those that said their financial security had improved, reasons included the availability of COVID-19-related funding streams and investment performance. Among those that said their financial security had worsened, reasons included having to stretch existing funding to cover increased costs and a lack of funding opportunities. A selection of quotes is reproduced in box 2.1.

[9] Based on the available data from the Charity Commission for England and Wales.

Box 2.1

Respondents' comments on changes in financial security

Comments from those who reported improved security

2022/23 has seen an increase of income from other non-HIV-related sources.

Medium charity – London and outside London

The increase was due to COVID-19 trust funding. We fear that this will decrease.

Small charity – London and outside London

We have a strong balance sheet due mainly to growth in investments amounting to around £20 million.

Large charity – London and outside London

Comments from those who reported worsened security

With the recent increase in cost of living and being on a five-year contract from the local government, need to try and give more for less in real terms.

CIC – London only

Note: Quotes are for illustrative purposes only and the views expressed by respondents are not endorsed by DSC. CIC: community interest company.

2.3.2 How is financial security expected to change over the coming year?

As well as investigating what had already happened to financial security, DSC's survey sought to better understand the respondents' expectations about their organisation's financial security over the coming year. The respondents could choose from five statements – ranging from 'Improve significantly' to 'Worsen significantly' – to indicate whether and by how much they expected their organisation's financial security to change by January 2024.

Overall, the organisations that responded to DSC's survey had a more positive outlook on their future financial security than their historical performance over the past three years might have been expected to indicate had it continued unchanged. As shown in figure 2.3, just under one-quarter (22%) of the organisations surveyed expected their financial security to improve significantly. Additionally, one-quarter (25%) expected their financial security to improve slightly. However, a notable minority (17%) of the respondents expected their financial security to worsen significantly and approximately one-fifth (19%) expected their financial security to worsen slightly over the coming year. Another notable minority (17%) expected there to be no change.

Further analysis was undertaken to better understand whether the expected changes in financial security differed between charities of different sizes. Charities that responded to this question were categorised based on their most recent annual income as small (annual income below £100,000; N=14), medium (annual income between £100,000 and £1 million; N=10) or large (annual income

above £1 million; N=6).[10] This analysis showed that medium and small charities were less likely to expect their financial security to stay about the same and more likely to expect their financial security to improve.[11]

Figure 2.3

Note: There were 36 responses to this question (not including those reporting an 'other' answer).

The additional comments provided by the voluntary and community organisations that responded to DSC's survey largely drew attention to the drivers behind the expected changes in financial security. For example, among organisations that expected their financial situation to worsen, reasons included having to use reserves to cover spending related to the cost of living, a lack of (sustainable) funding for certain areas of work (such as supporting women), a lack of funding for smaller organisations and the end of current funding streams.

Meanwhile, among those that expected their financial situation to improve, reasons included cutting costs, making new applications for core or project funding, diversifying income, and getting external professional support (e.g. a professional fundraiser or other consultant) to increase income. An illustrative selection of responses is reproduced in box 2.2.

[10] Based on the available data from the Charity Commission for England and Wales.

[11] Similar analyses appearing in sections 2.3.1 and 2.4 related to charities' incomes from 2019, as the data was about changes since the start of the COVID-19 pandemic. Here, DSC's researchers used the most recent annual income, as this is more intuitively related to expectations about future financial security than previous income.

Box 2.2

Respondents' comments on expected changes in financial security

Comments from those who expected financial security to worsen

Upcoming change to long-standing leader is likely to impact regular donations that have been a centre of sustainable funding, in addition to … long-standing trust fund support coming to an end.

Small charity – London only

Money from reserves is being used on cost-of-living expenses.

Large charity – London and outside London

We sincerely hope it will improve but cannot say at this point due to no current long-term funding [being] secured.

Small charity – London and outside London

Securing funding for HIV work is difficult because the health authorities are no longer giving HIV funding.

Small charity – London only

We are strategically investing reserves into meeting our new strategy.

Large charity – London and outside London

Comments from those who expected financial security to improve

We hope to source longer-term core funding.

CIC – London and outside London

We have recently engaged a consultant to develop our income generation function. We believe our income will rise … with the plans we have in place.

Small charity – London and outside London

We plan to diversify sources of income.

Small charity – London and outside London

We have not had the opportunity of getting a professional fundraising team to write proposals and tender for bids on our behalf and so this will be one of [the] main strategies we will apply. We shall also do a fundraising campaign.

Small charity – London and outside London

We are cutting significant costs.

Medium charity – London and outside London

_____

We are hopeful that with new project funding secured and more expected we will have a more successful year, expanding both income and staffing.

Medium charity – London and outside London

Note: Quotes are for illustrative purposes only and the views expressed by respondents are not endorsed by DSC. CIC: community interest company.

2.4 How have income and expenditure changed since before the COVID-19 pandemic?

DSC's survey sought to understand how the income and expenditure of voluntary and community sector organisations had changed over the past three years. The respondents were asked to indicate whether their organisation's latest total income had 'increased', 'decreased' or shown 'no change' relative to three years ago (i.e. January 2020), and to provide the same information about their expenditure.

Figure 2.4 shows that the organisations that responded to DSC's survey overwhelmingly (88%) reported increased expenditure compared to three years ago. It was relatively rare for the respondents to report no change in expenditure or a decrease in expenditure (less than 10% for each category). Meanwhile, there was a relatively equal split between organisations reporting increased income (50%) and decreased income (44%), with the remaining respondents (6%) reporting no change in income.

More in-depth analysis showed that every organisation that reported increased income also reported increased expenditure: that is, no organisations had seen their income rise while their spending fell. Meanwhile, the vast majority (79%) of the organisations that reported decreased income had still experienced increased expenditure – and had used reserves for operating costs (discussed in section 2.6).

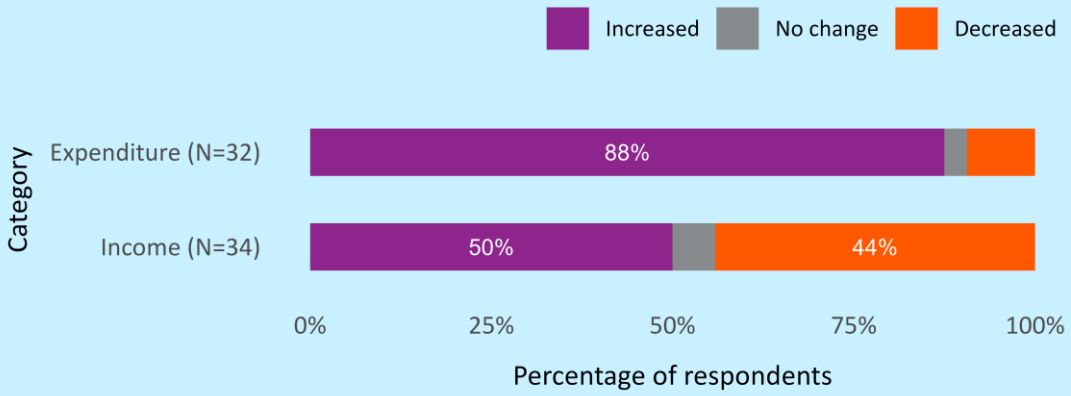
Further analysis was undertaken to better understand whether the changes in income and expenditure differed between charities of different sizes. Charities that responded to this question were categorised based on their 2019 annual income as small (annual income below £100,000; N=7), medium (annual income between £100,000 and £1 million; N=9) or large (annual income above £1 million; N=6).[12] This analysis showed no substantial differences between the groups, but charities that were small (in 2019) were less likely to have seen their income decrease.

[12] Based on the available data from the Charity Commission for England and Wales.

Figure 2.4

Changes in organisations' income and expenditure

*Most respondents reported **increased** expenditure compared with three years ago, and more than two-fifths reported **decreased** income compared with three years ago*



Note: The numbers of respondents to each sub-question are shown in brackets. Percentages below ten are not shown for reasons of space.

The organisations that responded to DSC's survey had the option to provide additional details or explanations relating to their responses. Some of these responses described the changes or the timing of the changes in the respondent's organisation's income in more detail. Meanwhile, others provided a reason for the change in income, such as changes to fixed project funding or contracts to deliver services. An illustrative selection of responses is reproduced in box 2.3.

Box 2.3

Respondents' comments on changes in income

Income has been stable for many years due to regular donors. The upcoming year end will see a decrease for the first time.

Small charity – London only

We put more effort into fundraising and worked in partnership with other organisations to supplement our capacity to fundraise and implement projects.

CIC – London and outside London

Our income increased primarily due to FTC [Fast-Track Cities London] three-year funding, along with project-based funding (which has now ended) from [two other funders].

Small charity – London and outside London

We have new subcontracted arrangements with drug and alcohol services to provide specialist LGBTQ+ support.

Medium charity – London only

Note: Quotes are for illustrative purposes only and the views expressed by respondents are not endorsed by DSC. CIC: community interest company.

As shown in box 2.4, the discussions between participants in DSC's focus groups also provided insights around the temporary improvements in income that were experienced during the COVID-19 pandemic.

Box 2.4

Focus group discussions on temporary improvements in income during the COVID-19 pandemic

It was kind of weird having people asking if you want money [during the pandemic], which is not what I'm used to. [Now, we're back to] a constant cycle of fundraising from as many non-statutory sources as we can find … You didn't have to jump through many hoops which was amazing, and you didn't have to do endless monitoring reports which was kind of amazing as well – but that's all stopped, obviously.

Medium charity – Focus Group 2

Like [the participant above] is saying, during that COVID-19 time, it was a time which was like a bit of relief because we had quite a lot of well-wishers who would just, you know, throw in £200 or £1,000 as we went.

Medium charity – Focus Group 2

Note: Quotes are for illustrative purposes only and the views expressed by respondents are not endorsed by DSC.

The respondents could also provide additional details or explanations related to their expenditure. One of the themes in these responses was around the drivers of changes in expenditure (which, as shown in figure 2.4, almost always increased). These drivers included changes in the level of activity and the cost of providing support, such as staffing and energy. The respondents also described some of the actions their organisation had taken to mitigate against increases in expenditure and some of the limitations on the ability to spend on core costs. An illustrative selection of responses is reproduced in box 2.5.

Box 2.5

Respondents' comments on changes in expenditure

Cost of activities and food is going up in terms of direct activity cost. Cost of staffing [is] going up.

Small charity – London only

Reduced activity including fundraising.

Small charity – London and outside London

We are putting less into reserves these years as we focus on staff.

Large charity – London and outside London

Mostly staff costs related to increased income/subcontracts, and latterly energy and cost-of-living increases.

Medium charity – London only

Note: Quotes are for illustrative purposes only and the views expressed by respondents are not endorsed by DSC.

2.5 Which sources of income are typically important for voluntary and community sector organisations?

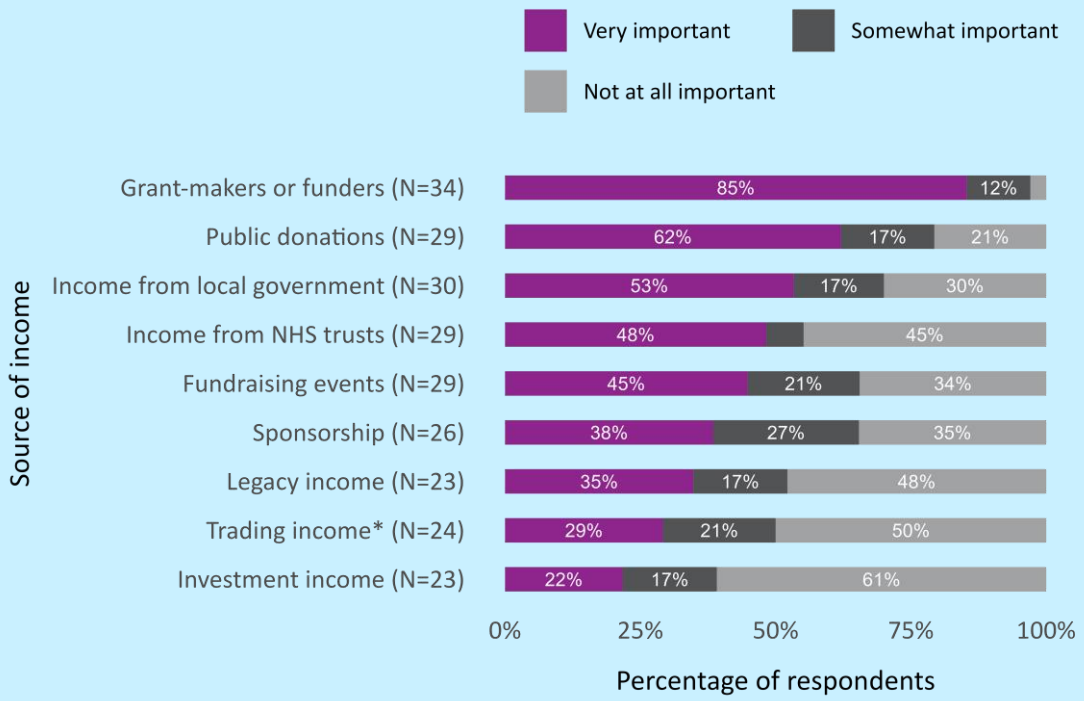
DSC's survey of voluntary and community sector organisations asked the respondents about nine different sources of income. For each income source, the respondents were invited to indicate how important this was to their organisation in a typical financial year, with the options ranging from 'not at all important', to 'somewhat important' and 'very important'.

Figure 2.5 shows the nine income sources ordered by the percentages of the respondents who said that each source of income was very important to their organisation in a typical financial year. The source of income that was, by a notable margin, most commonly (85%) deemed very important was income from grant-makers (charities or other organisations set up specifically to make grants) or other funders (organisations that make grants as part of their wider work or that provide non-grant funding). Income from grant-makers or funders was somewhat important to just over one-tenth (12%) of the respondents, and it was not at all important to only a very small minority (3%) of the respondents.

Figure 2.5

Sources of income ordered according to those that are very important to organisations

*Income from grant-makers or funders was the source of income that was most commonly stated to be **very important** in a typical financial year*



Note: The numbers of respondents to each sub-question are shown in brackets. Percentages below ten are not shown for reasons of space. The asterisk (*) denotes 'from shops and online sales'.

Next, close to two-thirds (62%) of the organisations that responded to DSC's survey said that public donations were very important to their organisation in a typical financial year, and a further 17% said public donations were somewhat important. However, approximately one-fifth (21%) said that public donations were not at all important. Despite commonly being deemed very important, public donations may be affected – at present and in the future – by changing public interest in HIV, because of a perception that issues around HIV are no longer as important, as highlighted in the focus group discussions (see box 2.6).

Box 2.6

Focus group discussions on perceptions of HIV and their relationship with public donations

I'd say what's changed … is that as the public messages around HIV are 'you can live a completely normal life, it doesn't impact your life expectancy, your health, you should get tested', I've found there's been a direct correlation [with] churches saying 'this is no longer an issue, why would we give you air time in our communities because actually the issue's gone away, it's solved' … I think that's my understanding [and it's] having quite a direct impact on us … getting new people to believe it's an issue that's worth us kind of fighting, tackling, giving energy, time and care and money to, is what I'm struggling [with].

Small charity – Focus Group 2

I agree with [the participant above] – the narrative of 'it's over and sorted' is very strong.

Large charity – Focus Group 2*

[Reduced public interest has been] an unintended side effect of the brilliance of the reduction in stigma campaigns over the past years, for good reason I understand it, but an unintended side effect is that a lot of people think it's [i.e. HIV as an issue] done and dusted.

Small charity – Focus Group 2

Note: Quotes are for illustrative purposes only and the views expressed by respondents are not endorsed by DSC. An asterisk (*) denotes that the organisation represented was part of the steering group for this project.

Turning to the sources of income from statutory bodies, just over half (53%) of the organisations surveyed said that income from local government was very important to their organisation in a typical financial year. However, close to one-third (30%) of the respondents said that income from local government was not at all important to their organisation in a typical financial year. Meanwhile, just under half (48%) of the respondents said that income from NHS trusts was very important to their organisation in a typical financial year, but close to half (45%) said that income from NHS trusts was not at all important to their organisation.

In contrast, the sources of income that appear towards the bottom of figure 2.5 were more commonly not at all important. These included investment income (61% of the respondents said that investment income was not at all important to their organisation), trading income from shops and online sales (50% of the respondents said that trading income was not at all important to their organisation) and legacy income (48% of the respondents said that legacy income was not at all important to their organisation).

2.6 What is the current level and use of reserves?

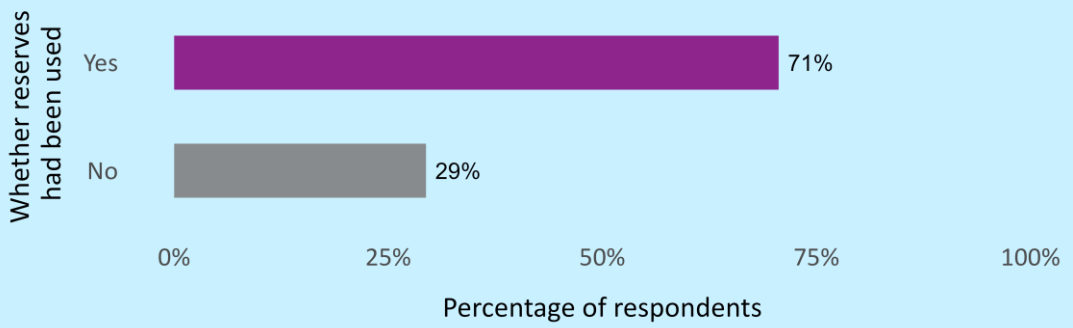
The voluntary and community organisations that responded to DSC's survey were asked to report whether their organisation had needed to use reserves in order to meet its operating costs during the past three years (i.e. since January 2020). Reserves are defined by the Charity Commission for England and Wales as the 'part of a charity's unrestricted funds that is freely available to spend on any of the charity's purposes' (CCEW, 2016). This can include funds that are more easily accessed, such as cash, but also assets that are less easily accessed but could be monetised.

As shown in figure 2.6, almost three-quarters (71%) of the organisations surveyed had used reserves to meet operating costs in the past three years. This included all of the organisations (N=11) that previously said that their expenditure had increased while their income had decreased over the past three years. Less than one-third (29%) of the respondents said that their organisation had not had to use reserves to meet operating costs.

Figure 2.6

Use of reserves to meet operating costs

*Over the past three years, almost three-quarters of the organisations said they **had used reserves** to meet operating costs*



Note: There were 34 responses to this question.

That the use of reserves for operating costs was widespread among the voluntary and community sector organisations surveyed by DSC may reflect a difficult operating environment. One of the focus group participants described how organisations of different sizes may be affected differently by different pressures but suggested that the cumulative impact of these pressures is affecting the sector as a whole (see box 2.7).

Box 2.7

Focus group discussions on financial pressures facing voluntary and community sector organisations

The other end of 14 years of austerity is the inflation that has happened as well, and I just think that really has compounded the two things ... Often I think the bigger organisations can probably withstand austerity for longer but the smaller organisations can withstand inflation for longer, but actually the two are hitting us as a sector together and it really is catching up with us in lots of ways and I think that those two things together are really, really challenging for anybody who has to look at the numbers.

Large charity – Focus Group 2*

Note: Quotes are for illustrative purposes only and the views expressed by respondents are not endorsed by DSC. An asterisk (*) denotes that the organisation represented was part of the steering group for this project.

DSC's survey also asked approximately how many months of expenditure each organisation's current cash reserves could cover. As shown in table 2.1, the lowest number of months of expenditure that could be covered by cash reserves was zero months. The (median) average number of months of

expenditure that cash reserves could cover was four months. Meanwhile, the highest number of months of expenditure that cash reserves could cover was 40 months, which was far above the next highest answer (12 months).

Table 2.1

Number of months of expenditure cash reserves could cover	Percentage of the respondents	Cumulative percentage
0	7% (N=2)	7%
1	7% (N=2)	14%
3	21% (N=6)	35%
4	17% (N=5)	52%
5	7% (N=2)	59%
6	21% (N=6)	80%
7	3% (N=1)	83%
8	7% (N=2)	90%
12	7% (N=2)	97%
40	3% (N=1)	100%

Note: There were 29 responses to this question. For each row, the cumulative percentage shows the percentage of respondents that had that many or fewer months' worth of expenditure.

Further analysis was undertaken to better explain whether the number of months of expenditure that could be covered by the organisations' current cash reserves differed between organisations of different sizes. Charities that responded to this question were categorised based on their most recent annual income as small (annual income below £100,000; N=11), medium (annual income between £100,000 and £1 million; N=8) or large (annual income above £1 million; N=6).[13] This analysis showed that small charities could cover, on average, one month less of expenditure than large charities; meanwhile, medium charities could cover, on average, 1.5 months less of expenditure than large charities. Moreover, the only organisations to report having zero months of reserves were small charities.

[13] Based on the available data from the Charity Commission for England and Wales.

CHAPTER THREE

Challenges and opportunities

3.1 Introduction

This chapter intends to provide insights into the risks and challenges that are currently threatening – or may, in the future, threaten – the ability of voluntary and community sector organisations supporting people affected by HIV to meet the needs of their beneficiaries. It aims to answer the following questions:

- What risks and challenges do voluntary and community sector organisations face?
- What are voluntary and community sector organisations' greatest concerns?
- What are voluntary and community sector organisations' greatest opportunities?
- What support measures are needed for voluntary and community sector organisations?
- What could voluntary and community sector organisations do better?

This chapter draws on data from DSC's survey of voluntary and community sector organisations, which can be found in the blue boxes. It also draws extensively on the insights gained from DSC's focus

groups with voluntary and community sector organisations, quotes from which can be found in the purple boxes. Section 3.6 uses qualitative data from DSC's survey of people affected by HIV, presented in a green box.

3.2 What risks and challenges do voluntary and community sector organisations face?

3.2.1 Risks around beneficiary need and numbers

To build a picture of which risks or challenges may stand in the way of voluntary and community sector organisations meeting the needs of their beneficiaries, DSC's survey asked about eight different risks. The respondents could indicate whether they foresaw each risk reducing their ability to meet needs – and in what time frame. Of these eight risks, figure 3.1 shows the two that were specifically related to beneficiary needs. These are ordered first by the percentage of respondents who said they were already a reality for their organisation and second by the percentage of respondents who said they might become a reality in the medium to longer term.

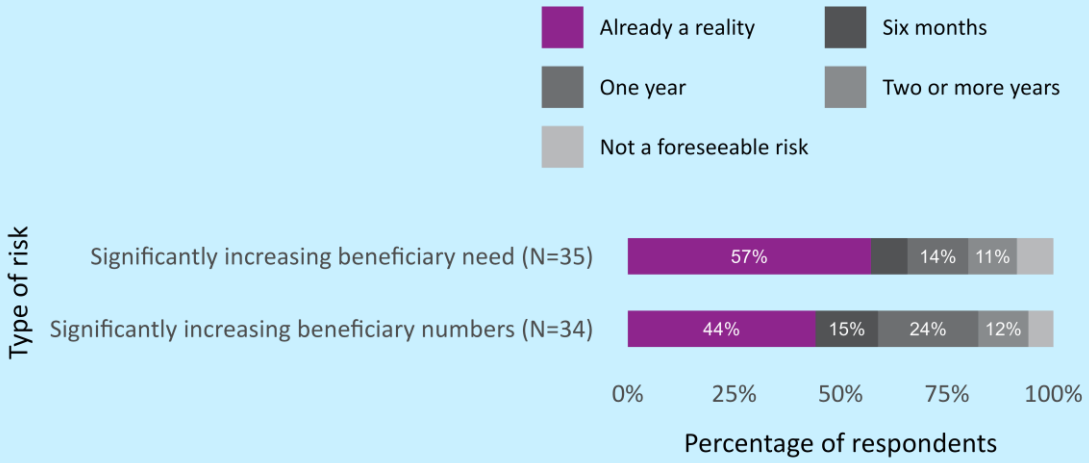
As shown in figure 3.1, more than half (57%) of the respondents said significantly increasing beneficiary need was already a reality for their organisation. Meanwhile, more than two-fifths (44%) of the respondents said that significantly increasing beneficiary numbers was already a reality for their organisation. In other words, changes to the needs and numbers of beneficiaries were already reducing the ability to meet needs for around half of the voluntary and community sector organisations surveyed.

Meanwhile, as shown in the second part of figure 3.1, in the medium to longer term, the more widespread risk around beneficiary needs was significantly increasing beneficiary numbers: around half (51%) of the organisations surveyed said significantly increasing beneficiary numbers might reduce their ability to meet needs within six months, one year, or two or more years. Furthermore, around one-third (34%) of the voluntary and community sector organisations surveyed said that significantly increasing beneficiary need could become a risk to their ability to meet needs.

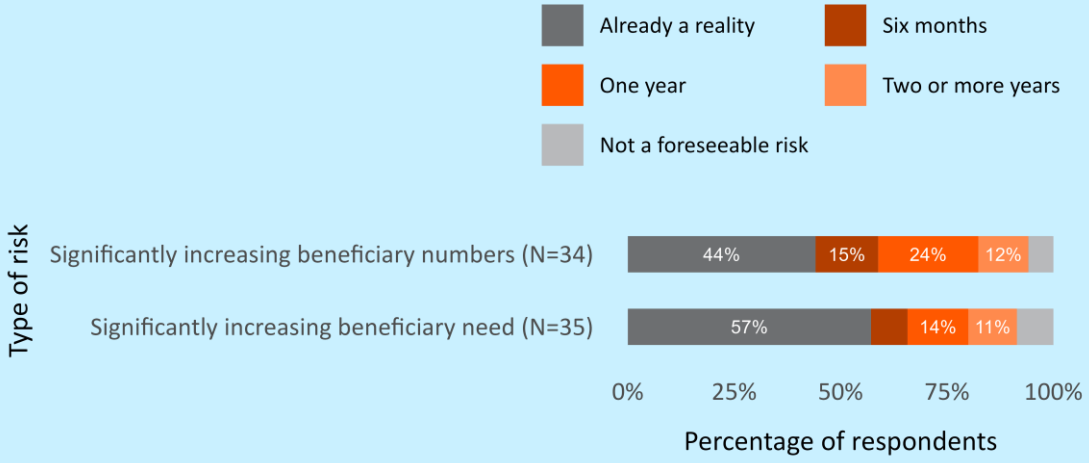
Figure 3.1

Risks around beneficiary needs and numbers

*More than half of the organisations surveyed said that significantly increasing beneficiary need was **already a reality** in terms of reducing their ability to meet needs*



*The risk that was more commonly expected to arise within **six months**, **one year**, or **two or more years** was significantly increasing beneficiary numbers*



Note: The numbers of respondents to each sub-question are shown in brackets. Percentages below ten are not shown for reasons of space.

The nature of challenges around beneficiary need and numbers

As discussed in section 1.4, support around social isolation and loneliness was a very important issue for the people affected by HIV whom DSC surveyed. It was also the issue or topic of support (out of all 36 included in DSC's survey of voluntary and community sector organisations) in which the organisations DSC surveyed were most commonly experiencing increased demand. The importance of support with social isolation and loneliness was also an important theme in the discussions between focus group participants.

Relatedly, one of the challenges raised during the discussions between focus group participants was around how best to meet this need. The series of extracts shown in box 3.1 illustrates how participants felt that face-to-face support and contact were important to their organisations' beneficiaries, and that this need may not be met with the move to a digital model of online support. The discussions also raised questions about how to meet the need for social connection without necessarily viewing this need through a medical lens, and how to make social connection an integral component of support more broadly.

Box 3.1

Focus group discussions on meeting needs around social isolation and loneliness

The whole move to online work obviously was largely down to COVID-19 … It's obviously had a lot of positive things, [and] quite a lot of organisations have continued doing things online [but for] many of our clients, it is that face-to-face work that they really want. We do some online sessions, and some people do prefer that, but the majority of people we ask, they say, 'This is the only opportunity I get to go out, it's something to look forward to – to come into central London and see somebody actually face to face.' So, there's a danger of taking advantage of technology, getting rid of premises and that sort of thing, and doing everything online: we are also losing something at the same time.

Medium charity – Focus Group 1

Certainly, there's this heightened sense of anxiety around HIV services because they have been reconfigured over COVID-19 but we haven't gone back. [A London clinic] used to be a really bustling, busy clinic. You'd be lucky now to see two or three people at any one time in there; it looks desolate and awful. And that's because of the way they've structured the clinics; it's still very busy but you don't have that feel of community … that's something that's really struck me.

Small charity – Focus Group 1

I'm looking over a lot [of] old notes and [a] lot of feedback from people … When people filled out the feedback forms from when they came to our group work in the 1990s or 2000s, [at] the top or [nearly] always at the top of 'Why did you come to this course?' was 'To meet other people – I want to meet new people.' The need for support came in less than the need to meet other people … Sometimes we are probably medicalising what people are looking for a lot more than actually what they want … We kind of need to go back to the reason why people access support groups, the reason why people want to get involved with volunteering. You need human connection first and foremost, and that nearly outweighs the actual support that you're offering.

Medium charity – Focus Group 1

We've just conducted a project at [our organisation] over the past year, working with over 80 queer men, migrant men and men of colour … every single workshop the key outcome was the need for social connection. Even around sexual health, when we've done events … we've never done something as simple as 'come along and learn about HIV testing', but when we've done something which is much more creative and fun – just come for lunch, or come and speed date – we're overrun. So, again, there is that absolute desire for people to connect in a physical way again now.

CIC – Focus Group 1

As soon as we were allowed to, we were face to face again, even doing meals in our garden when it was freezing, but they came along in hats and scarves and gloves and things. We ditched almost everything online. The only thing that survived has been WhatsApp groups – some of them liked those … Everything else has completely gone because they craved that face-to-face human contact, human interaction – and they didn't see Zoom as interaction at all, particularly for our older guys.

Medium charity – Focus Group 1

Note: Quotes are for illustrative purposes only and the views expressed by respondents are not endorsed by DSC. CIC: community interest company.

Other challenges included meeting the needs of the diverse groups of people who are affected by HIV. People affected by HIV are not a homogenous group, with differences across various dimensions such as the length of time diagnosed; demographic factors such as age, ethnicity and language spoken; and other important dimensions such as faith. Because of these different dimensions of diversity, some of which overlap and intersect, specialist support may be needed or wanted by some people affected by HIV – but it can be difficult to find organisations where they can be supported (for example, in terms of language) or feel represented and understood (for example, in terms of gender identity and culture). Effectively reaching – and then meeting the needs of – diverse groups can therefore be a challenge, as reflected in the extracts in box 3.2.

Box 3.2

Focus group discussions on meeting the needs of particular groups of people affected by HIV

Given the fact that we're looking at preventing onward transmission, preventing preventable deaths and addressing stigma, the challenges we've got for those people who are not yet diagnosed and are now being diagnosed – often [through] testing in emergency departments – is the fact that they are the people that are least likely to have considered themselves at risk of HIV. And, therefore, they're probably going to have the least amount of knowledge about HIV … I think it's [also] those challenges around what would have … used to be called 'hard to reach' … for the people that wouldn't go and access a sexual health clinic or wouldn't think about doing home testing, or those people who will end up in A&E, ill … How do you as quickly as possible provide the right information, support and holistic wrap-around care [and] how do we support people as soon as they're diagnosed?

Medium charity – Focus Group 2

With each intersecting challenge for access or stigma – or whether it's age, ethnicity, gender, migration status, sexuality, sexual identity, all of those things – if you have a person that had intersecting challenges there, that makes it less likely that they'll go and engage somewhere else [beyond the clinical setting] because of the fact that they're already feeling marginalised by some of those services. So, it's about being much smarter I think about how we ensure that services are welcoming to everybody that might be diagnosed with HIV.

Medium charity – Focus Group 2

Lots of clients would come to us and tell us there is loads of peer support groups in London … but there is not many of them [that are] language specific … If someone doesn't speak much English, they tell us they're not going to go to this group because they're not going to understand anything … so we're trying to work with that group – it's impossible to speak every language but we try to get enough volunteers.

Large charity – Focus Group 2*

Now, of course … to make [a support group] stronger and accessible, it still has to be unique for that person, it needs to be holistic … so someone might say, 'I want to be able to talk to someone who is Black, gay and maybe a Christian who is HIV positive', and that's becoming increasingly challenging.

CIC – Focus Group 2

It's very, very difficult to find a counsellor for [people living with HIV] who speaks, for example, Portuguese or Spanish … We've looked everywhere, and it's very difficult to find those counsellors that speak the languages.

Large charity – Focus Group 2*

I'm just listening to how men would love to interact, how they want to meet. But this is totally different with the African community, the heterosexual group. To be honest with you, right now, it just looks like they've just vanished. If we do some Zoom sessions, they are not even there. I can have [up to] 40 women, and there's only one man in the group – one participant. And that person, that man, he doesn't want to talk, because he feels like he is not meant to be there.

Medium charity – Focus Group 1

Since 2010, 2011, [healthcare has] been fragmented and many of the people we support have real difficulties with navigating the healthcare system. HIV services are really under the cosh in terms of what they can and can't do, and a lot of older people who've been living with HIV for much longer [than younger people], they're finding this a real struggle and it causes them a lot of anxiety because they're not quite sure who they should be seeing. These are age-old problems, but they just seem to have been exacerbated.

Small charity – Focus Group 1

Note: Quotes are for illustrative purposes only and the views expressed by respondents are not endorsed by DSC. An asterisk (*) denotes that the organisation represented was part of the steering group for this project. CIC: community interest company.

The participants in DSC's focus groups also discussed challenges around the increasing complexity of beneficiaries' needs. In the discussions (see box 3.3), the complexity of the issues facing people affected by HIV were underpinned by broader health inequalities, intersecting issues such as gender and migration status, and changes over time in the types of people that voluntary and community sector organisations focus on.

It was suggested that supporting beneficiaries with complex needs can make it more difficult for organisations to meet those needs – a topic also raised by some of the respondents to DSC's survey of voluntary and community sector organisations (see box 3.4). A related theme was the knock-on

effects of a perceived inability to meet demand in the statutory sector, discussed in section 3.2.3 (see page 62).

Box 3.3

Focus group discussions on increasing complexity of need

What we are seeing is a huge increase in the complexity of beneficiary need, so our caseworkers have to manage and address the initial presenting issues while signposting to additional specialist support services and considering longer-term solutions and support … Basically, health inequalities are widening and worsening for a significant proportion of the people coming to us for support.

Medium charity – Focus Group 2

These [intersecting] issues include domestic violence, care-giving responsibilities, working through COVID-19, … irregular migration issues, [and] women who have got no recourse to public funds … so they go underground – it creates vulnerability, which increases the chances of domestic violence as well. But it's also ageing – we're tending to live with more comorbidities so it's having to manage those comorbidities. And, also, for women who are young and are at the age of childbirth, it's access to sexual and reproductive health facilities. So, for example, IVF and HIV [support] … All of these sorts of little issues pile up and become quite complex.

CIC – Focus Group 2

Over the course of the pandemic, what the HIV sector – and by that, I mean the totality of the HIV sector, the funders, the health sector and agencies, and the larger community sector organisations and agencies – we concentrated on those things that were most apparent and most urgent … [now] we are going to be dealing with people who are in more complex situations, with more complex needs, and that requires us to be much more flexible and sophisticated in our responses.

Small charity – Focus Group 2

More and more very high-need, complex people are coming to us because they need food [but] we're not equipped to provide the kind of intensive support that's needed for those individuals … [who] don't see themselves in the FTC's [Fast-Track Cities London] goals, they don't see themselves in the U=U [the Undetectable = Untransmissible campaign] message, so what we struggle with is a way to make sure that there's a pathway for them to engage with in terms of seeking support. So, onward referrals are mainly what we do around that … But we also don't want to push them to engage because then we lose that trust that we've built with them … It becomes a community of service users that we often feel we're not meeting the complex needs of.

Medium charity – Focus Group 2*

Note: Quotes are for illustrative purposes only and the views expressed by respondents are not endorsed by DSC. An asterisk (*) denotes that the organisation represented was part of the steering group for this project. CIC: community interest company.

Box 3.4

Respondents' comments on complex needs

Reflective of pressures more widely in society, PLWH [people living with HIV] are facing increased stress and social and actual (poverty) disadvantage. Among all PLWH, those who are most disadvantaged and/or disenfranchised already are also those with least capacity to 'survive' increased social and financial pressures. The disintegration of effective support mechanisms in wider society from NHS services to [local authority] services to voluntary sector advice services, etc., makes accessing support especially for those in crisis or with complex needs incredibly difficult.

Charity – London and outside London

———

The difficulty we are seeing is that both [the] number of people with needs and the complexity of needs are increasing. Much of this is due [to] the financial environment, as well as the multiple impacts of COVID-19.

Medium charity – London and outside London

Note: Quotes are for illustrative purposes only and the views expressed by respondents are not endorsed by DSC.

3.2.2 Risks around staff and volunteers

Out of the eight risks to meeting beneficiary needs that were included in DSC's survey of voluntary and community sector organisations, four were related to staff and volunteers. As in the previous section, the respondents could indicate whether they foresaw each risk reducing their ability to meet needs and in what time frame. Figure 3.2 shows the four risks that were related to staff and volunteers. These are ordered first by the percentage of respondents who said they were already a reality for their organisation and second by the percentage of respondents who said they might become a reality in the medium to longer term.

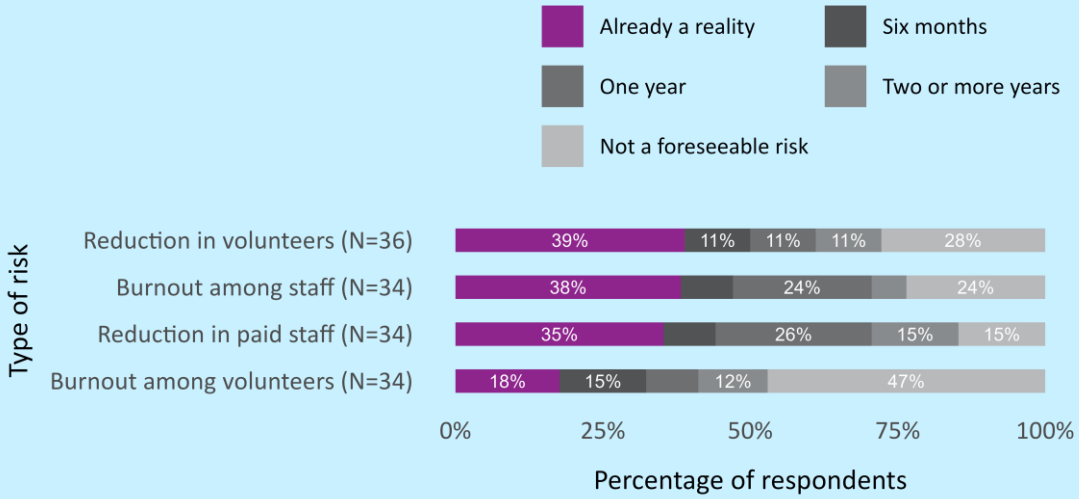
As shown in figure 3.2, the immediate risks around numbers were more widespread in relation to volunteers, while the immediate risks around burnout were more widespread in relation to staff. Specifically, approximately two-fifths (39%) of the respondents said a reduction in volunteers was already a reality for their organisation, while just over one-third (35%) said a reduction in paid staff was already a reality. Turning to burnout, just under two-fifths (38%) of the respondents said burnout among staff was already a reality for their organisation, while just under one-fifth (18%) said burnout among volunteers was already a reality.

In the medium to longer term, as shown in the second part of figure 3.2, the most widespread risk was a reduction in paid staff: half (50%) of the organisations surveyed said a reduction in paid staff might reduce their ability to meet needs within six months, one year, or two or more years. The more widespread medium- to longer-term risks related to staff, while the less widespread medium- to longer-term risks related to volunteers.

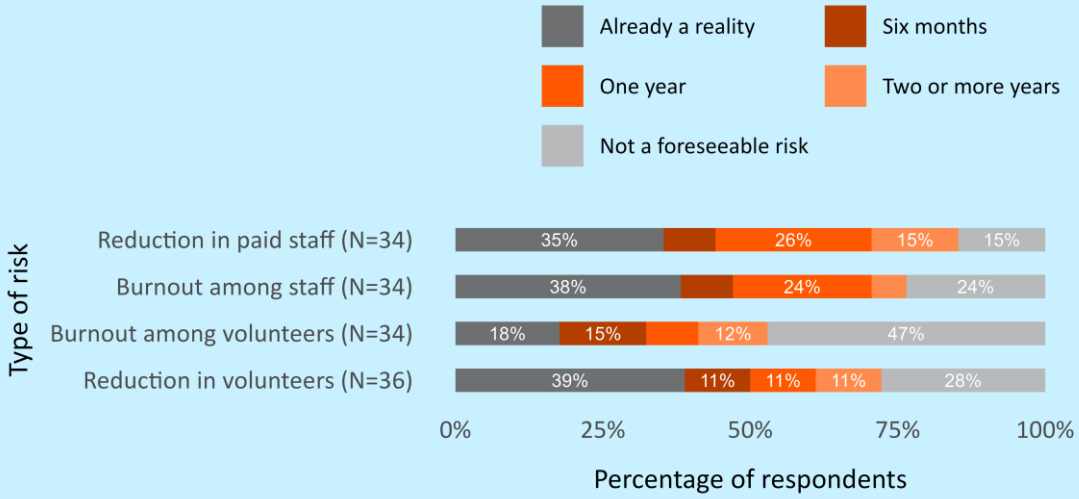
Figure 3.2

Risks around staff and volunteers

*Around two-fifths of the organisations surveyed said a reduction in volunteers and burnout among staff were **already a reality** in terms of reducing the ability to meet needs*



*The risk that was most commonly expected to arise within **six months**, **one year**, or **two or more years** was a reduction in paid staff*



Note: The numbers of respondents to each sub-question are shown in brackets. Percentages below ten are not shown for reasons of space.

The nature of challenges around staff and volunteers

A key theme in DSC's focus group discussions was around challenges relating to staff and volunteers. As shown in box 3.5, the participants talked about a drop in the number of volunteers – which was often related to the COVID-19 pandemic – but also difficulties recruiting new staff and volunteers,

which were linked to the current socio-economic context, changing priorities around people's time and where they volunteer, and longer-term trends around interest in HIV as an issue. One participant also described how the ways in which services are commissioned (for example, by local authorities or NHS trusts) could present challenges for recruiting and training staff for projects.

Box 3.5

Focus group discussions around recruiting and retaining staff and volunteers

Thinking about this in a wider context as well, it's also about attracting volunteers, particularly for small organisations, attracting volunteers and also advertising for people … We can only offer part-time positions and I think the pool of people who are interested in working in the sector has become smaller and smaller and smaller … And because the cost-of-living crisis has increased, people are doing two or three jobs just to get by.

Small charity – Focus Group 1

The work that we do and the sector that we work in is [seen as] less exciting than it used to be so it's a lot more difficult to pull in new younger people to not only volunteer but to work for organisations. Secondly, as [another participant] has mentioned, the cost of living means that people are prioritising their time and where they volunteer, so they may be volunteering in other places.

CIC – Focus Group 1

Just to add to the thing about volunteers, we recently put an advert on … for a receptionist. Our whole reception is run by volunteers – and three years ago when we put adverts there, there [were] literally scores of people wanting to volunteer, but this time not a single reply. So, it's interesting what you're saying about [a] lack of people willing to volunteer now.

Medium charity – Focus Group 1

We are seeing massive changes in volunteers and the nature of volunteering. I think COVID-19 was a turning point for a lot of people – [it] got them to re-evaluate where they are going in terms of their lives, circumstances changed, and we have seen the volunteer numbers that we used to have in the past [have] decreased, and the types of volunteer have actually changed, and their expectations have changed.

Large charity – Focus Group 2*

We've sustained our existing volunteers, many of whom have volunteered for 10 or 15 years and therefore are very committed – but what we're not any longer able to do is replace [them]. So, we used to train very frequently and have [at most, up to] 70 volunteers – we're a very small organisation so that was a lot proportionally – but now, we're maybe at 16 volunteers and they're all very committed but we're not managing to get the new ones in … Getting new people [potential volunteers but also donors] to believe HIV's an issue that's worth us kind of fighting, tackling, giving energy, time and care and money to, is what I'm struggling [with].

Small charity – Focus Group 2

[We] also had a drop in volunteers as well and we have to keep on recruiting volunteers. It's very difficult to recruit volunteers specifically for the HIV community – it's just so, so difficult.

CIC – Focus Group 2

I agree with what others said – we lost quite a few volunteers during COVID-19, and what I mean is probably half of them moved away from us. The reason for that was … when we moved to doing everything online, obviously we didn't need many volunteers [because of how services changed during the COVID-19 pandemic] ... So, in that time, lots of volunteers moved on. And then after COVID-19 [when] we came back to do things in person, they were busy doing other things – they were working, so we reached out to them and some of them we have [attracted back] but they're old volunteers. We find it difficult to recruit new ones.

Large charity – Focus Group 2*

[Regarding one council, there is a] sort of grey area, I suppose, of what we're being tasked to do, alongside another borough that's being very specific about what we're being tasked to do. It's a challenge with training, a challenge with recruiting [and service delivery]. There's always going to be challenges and that's my current one: the ambiguity of the commissioning.

Multi-charity project – Focus Group 2

Note: Quotes are for illustrative purposes only and the views expressed by respondents are not endorsed by DSC. An asterisk (*) denotes that the organisation represented was part of the steering group for this project. CIC: community interest company.

Meanwhile, as shown in box 3.6, there are other issues impacting staff and volunteers in the HIV voluntary and community sector, such as the sector itself being partly made up of people living with HIV (who are also affected by broader societal issues), burnout among staff and volunteers, and demographic changes such as ageing. Some similar issues were raised by the respondents to DSC's survey of organisations, as shown in box 3.7.

Box 3.6

Focus group discussions on issues affecting staff and volunteers

I think the really important thing around resilience in organisations is that many of our organisations are made up of people who are impacted, are living with HIV, or directly affected in some way … Many of us that work in the field are experiencing those things [like increased needs around mental health], so there's issues around staff burnout, there's issues around people meeting the end of their careers – many of us are in our late forties, fifties and sixties now – so again, as we move forward, our sector is going to shrink and we're not really prepared for that.

CIC – Focus Group 1

We've survived when other organisations have fallen by the wayside. And that's partly because we do run on a shoestring. The issue with that though, of course, is that … it relies on a few individuals putting one hell of a lot of their lives into an organisation to keep it going.

Medium charity – Focus Group 1

We're seeing, like many other organisations that are reliant on volunteers also, burnout appearing in volunteers and staff and having to look at new ways to support both volunteers and staff … The expectations upon us are suddenly ramped up as well, and we're being seen to plug the gaps [in statutory provision]. I think, in doing that, we then see the burnout come in, complex cases coming through.

Large charity – Focus Group 2*

At one stage, for about two months, I was the only person working in the whole organisation. I put everybody else on furlough because it was the only way I could save the organisation, because a lot of the roles would have been covered through community donations [which had fallen during the pandemic].

Medium charity – Focus Group 1

Note: Quotes are for illustrative purposes only and the views expressed by respondents are not endorsed by DSC. An asterisk (*) denotes that the organisation represented was part of the steering group for this project. CIC: community interest company.

Box 3.7

Respondents' comments on risks around staff and volunteers

Because we are reliant on volunteers, with no paid staff, our two key activity leads (our CEO and chair) are currently working for free on an almost full-time basis, and the scale of activity is [now] ramping up to a point where it needs single-minded focus. However, both of them need to find time to undertake their own income-generating work and this challenge is getting harder to balance.

Small charity – London and outside London

[Our organisation's greatest concern is] loss of motivation of volunteers due to burnout from pressing intersectional needs, which will impact on the organisation's ability to meet the huge need we have among our beneficiaries.

CIC – London and outside London

Note: Quotes are for illustrative purposes only and the views expressed by respondents are not endorsed by DSC. CIC: community interest company.

3.2.3 Risks around organisational operations

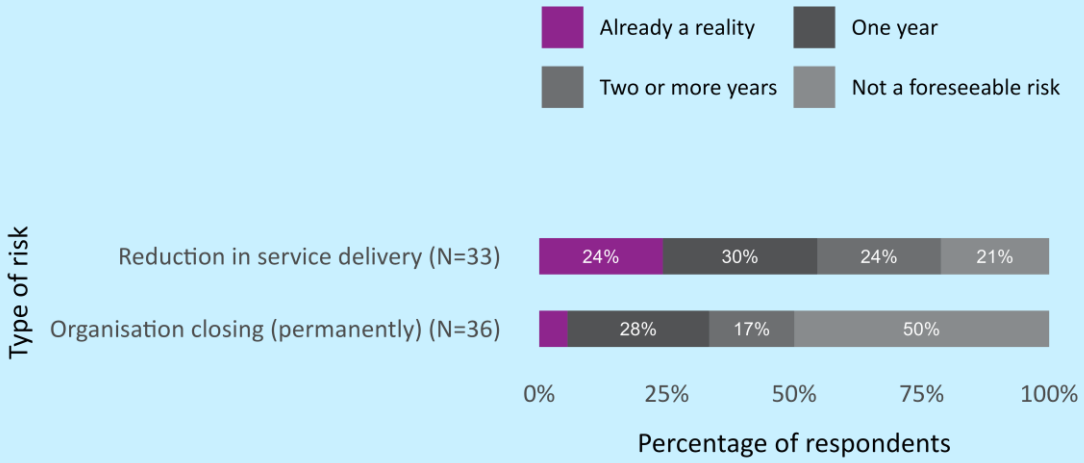
Out of the eight risks to meeting beneficiary needs that were included in DSC's survey of voluntary and community sector organisations, two related to organisational operations. As in the two previous sections, the respondents could indicate whether they foresaw each risk reducing their ability to meet needs and in what time frame. Figure 3.3 shows the two risks that were related to staff and volunteers. These are ordered first by the percentage of respondents who said they were already a reality for their organisation and second by the percentage of respondents who said they might become a reality in the medium to longer term.

As shown in figure 3.3, the most widespread immediate risk to meeting beneficiary needs around organisational operations was a reduction in service delivery. This was already a reality for approximately one-quarter (24%) of the respondents. Moreover, as shown in the second part of figure 3.3, in the medium to longer term, an additional 54% of the respondents expected that a reduction in service delivery would reduce their organisation's ability to meet the needs of people affected by HIV in London. Meanwhile, close to half (45%) of the voluntary and community sector organisations surveyed reported that their organisation closing permanently was a medium- to longer-term risk.

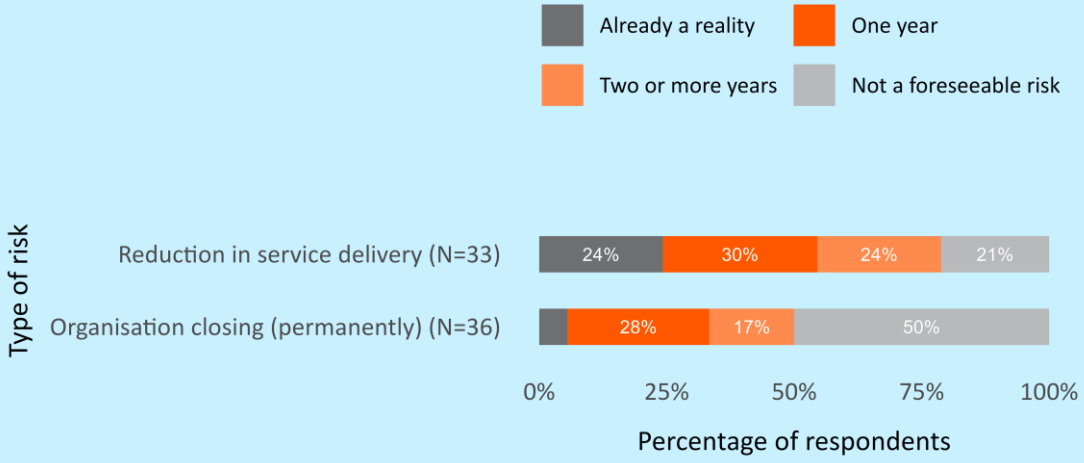
Figure 3.3

Risks around organisational operations

*Around one-quarter of the organisations surveyed said a reduction in service delivery was **already a reality** in terms of reducing their ability to meet needs*



*Close to half of the organisations surveyed said their organisation closing permanently might become a reality within **six months**, **one year**, or **two or more years***



Note: The numbers of respondents to each sub-question are shown in brackets. Percentages below ten are not shown for reasons of space. The percentages may not sum to 100% due to rounding.

The nature of challenges around operations: funding and commissioning

The participants in DSC's focus groups drew attention to several issues surrounding the funding and commissioning environment for HIV voluntary and community sector organisations (see box 3.8). One of these challenges was the extent to which funders and commissioners understand the needs of people affected by HIV. This was particularly highlighted in relation to things that are subjective, such as the social value of providing a lunch or the importance of faith for people who have a religion. One of the participants described how commissioners often use language around evidence and need that

does not align with the vocabulary and approach of voluntary and community sector organisations. Another raised the question of how the impact of smaller organisations, made through more informal contributions, can be measured and recognised.

Box 3.8

Focus group discussions on funding and commissioning to meet the needs of people affected by HIV

The commissioners … like some things that organisations do and don't like others. So, they hate our lunches because it creates dependency apparently. But they don't see that it creates a really nice social space and the cost of a little lunch is by the by – but, they can't get past giving someone a lunch … And [the commissioners don't have] a focus on older people – they're mostly concerned with prevention and peer support, but within very defined parameters that are measurable, SMART, achievable, etc. So, they don't really like some of the other soft fluffy stuff, in particular like we do.

Medium charity – Focus Group 1

The main painful thing is if I look at the people who are [in] this focus group right now, we are the ones that work with the grassroots … But when it comes to commissioners, they talk to other people who don't even know how it feels to be old and … living with HIV – you are facing discrimination from your own family, and you don't have anything, and you actually benefit to have a decent lunch at [an organisation]. They don't feel like that … The thing that brought service users to [another participant's organisation] was that creation of a space, just to sit down for a hot coffee and a croissant and a good lunch. That brought the communities together … But now, [through fenced funding] they cut off the thing that makes me popular with this community … I don't know how we can move away from fenced funding to independent funding – because we know the needs of our community.

Medium charity – Focus Group 1

What we do well, and the reason we exist, is to plug this gap in terms of helping people address issues around their Christian faith – and it might be the most important factor in their lives. To be honest with you, I don't think the charities, or the commissioners, quite understand that.

Small charity – Focus Group 2

I think what worries me is that while we've been collaborative and working within the health and well-being approach, we are probably far ahead of commissioning and the commissioners themselves in terms of their understanding of what's needed, their understanding of how the sector actually works … They're very much caught up in everything being evidence based and needs based – which I fully understand, and we have to show our impact – but it means … the language that they use and that we use is still very different and I don't think they've caught up.

Large charity – Focus Group 2*

We all know what it means to try and fit into the requirements that a funder has decided they want to fund. And I think there's a challenge here for funders and commissioning bodies to really wrestle with: how do we deliver more responsive, flexible services? [For example,] there was a massive reorganisation after the Health and Social Care Act [2012] … [aiming] to normalise … [and] de-stigmatise HIV by making everyone talk about HIV with their GPs. Also, at the same

time, in South London anyway … they de-commissioned all the HIV-specific welfare, benefits and advice services that [another participant's organisation] used to provide down in Waterloo, which were excellent. It gave us, as a small organisation, the confidence to refer people to services where we knew their HIV status would be understood.

Small charity – Focus Group 2

As a small organisation, I want to echo what [another participant] was saying about small organisations and the value that we bring, which may not always be recognised or known about – and may almost certainly be hard to measure sometimes – and is often not funded. But it's based on those organisations that motivate and empower people living with HIV to do stuff for each other in informal ways … That's also a very important driver in terms of addressing internalised stigma. There's perhaps work to do, to try and quantify and measure some of this stuff … how do we measure the contribution that is not usually measured and couldn't be measured because of the burden of doing that, especially in smaller organisations.

Small charity – Focus Group 2

Note: Quotes are for illustrative purposes only and the views expressed by respondents are not endorsed by DSC. An asterisk (*) denotes that the organisation represented was part of the steering group for this project.

Other challenges raised by voluntary and community sector organisations in relation to funding included issues relating to the sustainability of funding. As shown in the groups of extracts reproduced below, these challenges involved difficulties continuing projects for which funding has come to an end (see box 3.9), a lack of funding for core costs (see box 3.10), and difficulties financially sustaining the core cost of premises and/or a presence in London (see box 3.11).

Box 3.9

Focus group discussions on project funding

There's almost an expectation that has built up over the years, so lots of the things that we do at [our organisation] were funded at various points in our history, [but] that funding came to an end and we kind of found ways to make that work and keep that going, but that has happened almost solidly across [a lot of] the series of things that we do … and disproportionately they are now funded by voluntary income, and so that just has a real impact across the board on making [projects] happen.

Large charity – Focus Group 2*

We do our very best to help these people but we're also very tied down because of funding. We operate mainly on project-based funding, and we're a small organisation – we're doing a lot of voluntary work, we are stretched as well, so sometimes it is just hard to meet those needs.

CIC – Focus Group 2

At the moment, with the improvement community [Fast-Track Cities London-funded projects taking place between 2020 and 2023], with that funding coming to an end shortly there will be organisations, my organisation included, [for which] unless that funding is put back in, it's going to make things really, really difficult.

Small charity – Focus Group 1

Box 3.10

Respondents' comments on challenges around core costs

Unless we secure long-term funding, we will have to look at the function of the organisation and [a] realistic projection of what can be achieved.

Small charity – London and outside London

FTC [Fast-Track Cities London] funding enabled our organisation to employ our first two members of staff, our CEO and growth project lead. We have no further funding currently secured to keep them in post.

Small charity – London and outside London

Our expenditure has increased as we have developed programmes of work, but we still haven't managed to secure funding to build our infrastructure as so much of the funding has been focused on COVID-19 emergency front-line needs, not so much core costs, to build organisations internally. Rightly, it has been about responding to the community's needs, but we can't respond to those without building our organisation's infrastructure and sustainability.

Small charity – London and outside London

There is no core funding, so we rely on multiple small project-based funding [streams], which is time-consuming and does not allow sustainability. A lot of the work is unpaid [and] carried out by generous volunteers.

CIC – London and outside London

Because of resources we currently have less capacity. We are also at risk of losing our premises and new premises may cost more or be in a worse location.

Medium charity – London only

We keep stretching the capacity of our team and volunteers working with very little resources in an area of high need. Sustainable core funding will be beneficial.

CIC – London and outside London

Note: Quotes are for illustrative purposes only and the views expressed by respondents are not endorsed by DSC. CIC: community interest company.

Box 3.11

Focus group discussions on premises in London

We've had such a hard time after COVID-19 financially as an organisation – we've had to make some really tough decisions, and it's basically left us homeless because we couldn't afford to be in the café space we were in [and] couldn't afford to be in the office space we were in.

Medium charity – Focus Group 2*

We had challenges with our location. We had to give up our location in London eventually because during COVID-19 we couldn't use it [but] we still had to pay rent.

CIC – Focus Group 2

A lot of organisations have been forced to move out of the centre of London … Our lease has ended and at the moment we're in court fighting to carry on but we might be on the street or looking for other premises … which would probably not be in central London.

Medium charity – Focus Group 1

Having somewhere that people can actually access but also feel safe accessing and getting to is really key … I think maybe the decision to move out of that [central London] area and into other places has been pushed by some of the wrong drivers, because you're being pushed by financial considerations and not necessarily the needs of the people that you're trying to serve and that's something that we really need to think about as well.

Medium charity – Focus Group 1*

Note: Quotes are for illustrative purposes only and the views expressed by respondents are not endorsed by DSC. An asterisk (*) denotes that the organisation represented was part of the steering group for this project. CIC: community interest company.

One cross-cutting theme around funding was the particular challenges faced by smaller organisations, which may also focus on particular demographic groups within the diverse communities affected by HIV, such as Black communities or women (see box 3.12). Concerns around the potential inequities experienced by smaller organisations compared to larger organisations – and how this relates to the communities supported, as smaller and grassroots organisations may focus on particular demographic groups – were also expressed in one of DSC's focus groups, as shown in box 3.13.

Box 3.12

Respondents' comments on financial challenges for smaller voluntary and community sector organisations

We sincerely hope it will improve but cannot say at this point due to no current long-term funding [being] secured … There is also too little funding on women-led, specific women's services and needs for us as a community in the HIV response, both [in terms of] prevention and quality of life.

Small charity – London and outside London

Securing funding for HIV work is difficult because the health authorities are no longer giving HIV funding. Though the council has a budget, bigger organisations … are [its] direct beneficiaries.

Small charity – London only

There is no funding for the voluntary sector, especially Black-led charitable organisations, yet we do more work than the bigger voluntary sector organisations because we are able to reach the grassroots, understand the culture and share [service users'] views due to personal experience.

Small charity – London only

Being a very small charity reliant largely on volunteers puts us at a disadvantage in regard to competitive tendering processes within local authorities. We also think that larger funders often fail to understand the added value and impact delivered by smaller 'grassroots' organisations.

Charity – London and outside London

Note: Quotes are for illustrative purposes only and the views expressed by respondents are not endorsed by DSC.

Box 3.13

Focus group discussions on financial challenges for smaller voluntary and community sector organisations

I would put my money on it being probably some of the larger [voluntary and community sector organisations] that have increased [income] and it's probably the smaller ones – and, usually, the ones that support migrants, or Black and Brown communities – that have lost out [on income], which has always been the way … I think there's a massive bit of inequity.

CIC – Focus Group 2

Then you realise [central government funding is] going to one charity [that's] going to disseminate and decide who gets this work, and it felt very top heavy. And then you have to beg another charity for money – and [it doesn't] know anything about your organisation or what you can do … And the same thing was happening with HIV organisations as well … Yes, you're resilient if you're able to have the right people in place to be able to go and search for this money … The smaller organisations then are resilient in different ways … Resilience for me was putting everybody on furlough and working 70 to 80 hours a week.

Medium charity – Focus Group 2

I think we're actually running off some extra money the lottery gave us as cost-of-living crisis money, but that runs out soon … Because we're running on a shoestring, our work is actually in delivering a service – we've got no professional fundraisers or people in that sort of position who have got time to do all the fundraising.

Medium charity – Focus Group 1

Note: Quotes are for illustrative purposes only and the views expressed by respondents are not endorsed by DSC. CIC: community interest company.

The nature of challenges around operations: the voluntary and statutory sectors

As discussed in section 3.2.1, the focus group discussions in part related the increased pressures facing organisations – around demand and complexity of need – to a lack of statutory provision. A related but distinct theme was the challenges around the relationship between the voluntary sector and the statutory sector. As shown in box 3.14, this centred around difficulties establishing working relationships across these two sectors, such as difficulties for voluntary and community sector organisations needing to make onwards referrals that could meet needs effectively and safely. One of the participants described how this can be a difficult process but, by investing time and effort, these working relationships can be improved.

Box 3.14

Focus group discussions on challenges making onwards referrals to the statutory sector

We did some work alongside [another organisation] looking at IAPT [Improving Access to Psychological Therapies] in relation to mental health and I know there's been some movement on that, but the whole access to these sorts of things made things difficult for people. As a peer support service, we've thought, 'Where do we signpost these people to?' We can [look for organisations to signpost to] within the usual sort of services, but some of them just don't have the capacity any more.

Small charity – Focus Group 1

We're dealing with mental health issues that we shouldn't be [having to deal with] but there's nowhere else for [the people experiencing the issues] to go. So, we're holding people for a long time until they can get into IAPT [Improving Access to Psychological Therapies] services, book into psychology services, even psychiatric services, and that has huge safety implications for both people who use our services and our volunteers and staff, as an example.

Large charity – Focus Group 2*

When we're talking about those people that are dropping out of care, mental health … is one of the most significant problems that we have, and … when you try to get in touch with community mental health services on the ground, they ignore you, they don't get back to you, and the next thing you know is that the person you're working with has been sectioned … I think there's a good point to be made about how we're adapting and working together and becoming more resilient through our unity as a [voluntary and community] sector, but I think the additional challenges that relate to the wider system are some of the key fault lines.

Medium charity – Focus Group 2

So much of this is about accessing other things for people – those with complex needs, but also those with just an immediate crisis, [such as] somebody who needs access to figure out the Universal Credit application who doesn't have the skills to do it – and so that comes back to [another participant's] point: we're in the middle of a structure that's collapsing, in the middle of a society where nothing works, and where people are pushed from pillar to post.

Small charity – Focus Group 2

Building those relationships with community mental health teams, substance misuse [and] housing [can be done] – it's just that it might take a bit longer or it's a different connection that you previously wouldn't have [created] or wouldn't have invested in maybe. [After] a few years of … banging my head against the wall [and] of being frustrated at CMHT [community mental health teams] … I can [now] make a phone call to someone and know there's a little bit more chance that they will work with [the person I'm trying to support] … But it's just down to more relationship-building I suppose. I've had negative experiences of relationships, or attempted relationships, from organisations in this focus group … It's no different when going wider [i.e. approaching organisations outside the voluntary and community sector].

Multi-charity project – Focus Group 2

Note: Quotes are for illustrative purposes only and the views expressed by respondents are not endorsed by DSC. An asterisk (*) denotes that the organisation represented was part of the steering group for this project.

In contrast, there was a perception among the participants in DSC's focus groups that referrals from the statutory sector to the voluntary and community sector, or voluntary and community sector organisations providing services in place of the statutory sector, had become routine and expected, perceived to be filling in for gaps in statutory provision. However, the expectation that an organisation would provide support was not always followed by funding. A selection of extracts is reproduced in box 3.15.

Box 3.15

Focus group discussions on challenges around the expectations of the statutory sector

> We're probably completely off the radar of the commissioners. We're getting loads of referrals from NHS clinics, but the way the NHS is structured means we're not really going to be able to get funding from sources within the NHS. But, also, we're a London-wide organisation so it's problematic getting any local authority money.
>
> **Medium charity – Focus Group 1**

> What strikes me about all of those things – complex cases, burnout, reduction in volunteers, increases in demand – is that what I think has happened recently in the last couple of years is that in many ways the voluntary sector has become the sponge that is mopping up for the local authorities and the NHS, [which] were struggling to cope during COVID-19 and they're still struggling to refocus and rebuild, much like us as well … I often go to meetings, and I hear, 'Well this can't be done but you guys in the voluntary sector you're flexible so we'll pay you to do it – you can do it.' It's almost like we're the victims of our own success … We are good at what we do and we provide great services, but in many ways the expectations upon us are suddenly ramped up as well, and we're being seen to plug the gaps.
>
> **Large charity – Focus Group 2***

Note: Quotes are for illustrative purposes only and the views expressed by respondents are not endorsed by DSC. An asterisk (*) denotes that the organisation represented was part of the steering group for this project.

3.3 What are voluntary and community sector organisations' greatest concerns?

The respondents to DSC's survey of voluntary and community sector organisations were asked to describe what they perceived to be their organisation's greatest concern about providing support to beneficiaries in London affected by HIV over the next year. The respondents were provided with a space to describe their greatest concern in their own words.

One of the key themes that emerged from these responses was concern relating to a lack of funding, including around core costs, longer-term agreements and funding from statutory bodies (such as local authorities and the NHS through commissioning). An illustrative selection of quotes is reproduced in box 3.16.

Box 3.16

Respondents' comments on concerns around a lack of funding

Our main concern is the lack of funding to support beneficiaries to stand on their own in tough times due [to] the rising cost of living. Funding cuts for HIV prevention work have affected us tremendously, so much [so] that we are now minimising the support we provide to keep us functioning.

Medium charity – London and outside London

Loss of funding and lack of funding grants from local authorities.

Large charity – London only

Lack of funding and especially [for] core costs.

Medium charity – London only

Lack of funding to support hugely increased demand, especially for mental health support.

CIC – London and outside London

Receiving sufficient NHS contract funding to continue our services.

Large charity – London only

Not securing any further funding to support our work, which will provide increased staffing to support the delivery of our objectives. The fallout for women living with and at risk of HIV will be impacted as will health-care providers and policymakers who are supported via our expertise, resources, gender-specific approach and policy work.

Small charity – London and outside London

Reduction in funding for the improvement projects [Fast-Track Cities London-funded projects taking place between 2020 and 2023]. Without significant funding we wouldn't be able to continue the service we've developed with our partners.

Small charity – London and outside London

We see real demand, but an ever-smaller pot of money to be divided up to those trying to improve life for the beneficiaries. Alongside this we believe that, as the next generation of young people come along, through not knowing about the story of HIV and its impact on a wide range of communities, the interest in supporting people whose lives continue to be affected will significantly diminish.

Small charity – London and outside London

Sustainable funding for the medium term.

Large charity – London and outside London

However, securing funding for [support around chemsex, which is drug use specifically in relation to sex] from local authorities remains a significant challenge, as substance misuse work tends to be funded by large generic contracts and for local residents only. This requires a small charity like ours to rely on subcontracting arrangements with much larger partners. It also limits where service users can access support, which is in direct contrast to where and how they can access sexual health support – which is often their access point to services.

Medium charity – London only

Note: Quotes are for illustrative purposes only and the views expressed by respondents are not endorsed by DSC. CIC: community interest company.

In addition, the respondents raised concerns around difficulties meeting needs and demand. This could be due to the level or complexity of needs (particularly related to poverty and mental health) or a constrained ability to meet demand (for example, because of finances, issues around human resources or an inability to make referrals to appropriate services). An illustrative selection of responses is reproduced in box 3.17.

Box 3.17

Respondents' comments on concerns around meeting needs and demand

Not being able to meet the financial needs of the users due to [the] cost of living.

Small charity – London only

The need for mental-health-related issues, particularly around isolation and loneliness.

Medium charity – London and outside London

Our greatest concern is the challenge of living well with HIV for those … who are most disadvantaged or in poverty. HIV becomes increasingly 'unmanageable' for those [with the] greatest disadvantage. A 'holistic' approach to support must include addressing issues that intersect with HIV including stigma, faith, poverty, race, immigration status, housing, etc.

Charity – London and outside London

Loss of motivation of volunteers due to burnout from pressing intersectional needs which will impact on the organisation's ability to meet the huge need we have among our beneficiaries.

CIC – London and outside London

We are also experiencing a high level of demand from new arrivals in the UK, impacting on our support for migrants and immigration issues. [We are] concerned [about being] unable to meet these needs with great effectiveness.

CIC – London and outside London

Our greatest concern is that we will not be able to provide the support needed by the ever-increasing number of people being referred to us. We have to 'ration' the service we can provide due to financial circumstances. Our service number is now capped, and our service offer has been reduced.

Medium charity – London and outside London

That the challenges we see require more joined-up support in a charitable sector where services are at breaking point. The issues of poverty, mental health, [and] drug and alcohol use all pose significant difficulties, often at the same time. Being able to make effective referrals to additional specialist support is an ongoing challenge.

Medium charity – London and outside London

The main demand for our support for people affected by HIV relates to chemsex [drug use specifically in relation to sex]. The complexity of need has significantly increased as more [people now have issues relating] to the use of methamphetamine, which is driving a very significant increase in mental health needs.

Medium charity – London only

Note: Quotes are for illustrative purposes only and the views expressed by respondents are not endorsed by DSC. CIC: community interest company.

3.4 What are voluntary and community sector organisations' greatest opportunities?

Similarly, the respondents were asked to describe what they perceived to be their organisation's greatest opportunity to provide support to beneficiaries in London affected by HIV over the next year. The respondents were provided with a space to describe their greatest opportunity in their own words.

The respondents highlighted a range of opportunities, many of which were unique. Themes among the responses included a focus on continuing or developing and expanding new modes of working, such as the opportunities opened up by digital services or the provision of support in new settings. An illustrative selection of responses is reproduced in box 3.18.

Box 3.18

Respondents' comments on opportunities around new modes of working

We can provide cheap and easy-to-access online support groups.

Medium charity – London and outside London

If we can ensure that we are successful in ensuring access to in-clinic peer support, we can provide early support to many of those experiencing the biggest challenges and prevent them falling through gaps between health and social care services.

Medium charity – London and outside London

As an organisation with significant experience in delivering support digitally, we believe our model can be easily expanded … in a cost-effective way, and we're able to provide a completely digital solution whereby peer support participants can self-refer and book appointments online and get to speak to another person living with HIV within days rather than weeks.

Small charity – London and outside London

We believe that by asking those whose lives have been affected by HIV to share their stories, we can help reduce loneliness, anxiety and stigma. We believe [that by] creating communities (through [our] conference, story-telling groups, taking part in our educational activities and our more social events), we can help people who feel they have lost connection to their peers. Sadly, to do this we need support and funding. Of all these activities, we see establishing a one-day yearly conference to bring people together as a key activity and important first step.

Small charity – London and outside London

Note: Quotes are for illustrative purposes only and the views expressed by respondents are not endorsed by DSC.

Several respondents also highlighted the opportunity presented by collaboration – for example, through networking or sharing learning – and the opportunities presented by greater funding. An illustrative selection of responses is reproduced in box 3.19.

Box 3.19

Respondents' comments on opportunities around collaboration

Further collaboration with organisations available through funding.

Small charity – London and outside London

Looking to strengthen partnerships within the sector to ensure our service survives for those who need it.

Medium charity – London and outside London

Collaborative work and sharing of learning.

Medium charity – London only

Networking with other HIV charities and agencies.

Large charity – London only

Reopening of face-to-face meetings to allow networking and increase our profile.

Small charity – London and outside London

Note: Quotes are for illustrative purposes only and the views expressed by respondents are not endorsed by DSC.

The discussions between DSC's focus group participants explored the opportunities available through greater and more effective collaboration in further detail. As can be seen from the extracts in box 3.20, collaboration was perceived as a crucial process in meeting beneficiaries' needs – for example, through referrals from one voluntary and community sector organisation to another. The participants also spoke about collaboration as a way to draw upon the varied expertise and specialisms of different organisations – both within the voluntary and community sector and more broadly in terms of, for example, community mental health trusts in the statutory sector.

The representative of a smaller organisation also spoke about collaboration with larger organisations as having provided a future for their organisation when it faced circumstances where it otherwise may not have been able to continue operating. The potential for larger organisations to collaboratively assist smaller organisations was echoed in other parts of the discussion as one of the ways in which collaboration could be strengthened (see box 3.21).

Box 3.20

Focus group discussions on what is working well with collaboration

[A recent collaborative project] really worked well because it was partnership work starting from the beginning throughout the programme with a number of organisations working together. I feel that moving forward that would be a really good model to use for organisations because then we can tap into the different areas of expertise that you all have – but, also, work together to collect your resources together.

CIC – Focus Group 2

The days of client protectionism – 'These are our people [and] we need them to come to us to tick our boxes in relation to funding' – [are] finally coming to an end and there's a recognition that the needs of the person should be foremost in all of our minds: if there's a specific service group or approach that's used by another organisation, then we want to make that referral and have a better understanding of how we navigate those pathways … It's about getting us to work more collaboratively, getting us to think about what we do together.

Medium charity – Focus Group 2

[In terms of] more collaboration, I totally agree because again collaboration also means that we have the opportunity to make referrals closer to where people might be.

CIC – Focus Group 2

I just wanted to give a good example of collaboration … between us we cover the whole of London nearly and we went to the newly diagnosed workshop last year and this year … [We explained,] 'This is us, this is what we do, and who is in South, North [and] East [London]', so there was a presentation from each of our organisations … and loads of [the people at the event] said because they live, for example, in one part of London, they didn't really know what was happening elsewhere.

Large charity – Focus Group 2*

[We have] basically been saved this year by that – by collaboration, working together. We've been saved by [another charity]. We have office space in [its] building, and our [support activities] are being kindly hosted at [another charity], so we are an example of why and how collaboration is so important and can actually be something that can save a small organisation from literally going under.

Medium organisation – Focus Group 2*

Note: Quotes are for illustrative purposes only and the views expressed by respondents are not endorsed by DSC. An asterisk (*) denotes that the organisation represented was part of the steering group for this project. CIC: community interest company.

Box 3.21

Focus group discussions on how collaboration could be strengthened

[Another participant's] point is key here – there's a lot of discussion and hopes about how ICSs [integrated care systems] might better fund and link health, social care and voluntary sector services, but it is the voluntary sector that often gets left out of the conversation.

Medium charity – Focus Group 2

Those of us who are lucky enough to be in bigger organisations with reserves don't always understand what's going on with some of the smaller organisations, and how we can support capacity and share skills, and support other organisations that might not have some of the resources that we do have. I think that's something that we need to be thinking about as well.

Large charity – Focus Group 2*

How are those larger organisations whose income has increased significantly … how are they then supporting the ecosystem of the smaller organisations?

CIC – Focus Group 1

I think for a significant number of people HIV should be a moment of crisis, where you get the information, [then] you adjust to what actually will be in all likelihood, depending on how late your diagnosis is, a long and healthy life with HIV. But, until you have that kind of reassurance, straight from the horse's mouth in relation to peer support, I think it's a very difficult thing to grapple with. And so, for me, it's about that integrated work across the sector and between the voluntary and clinical sector to bridge those gaps.

Medium charity – Focus Group 2

Note: Quotes are for illustrative purposes only and the views expressed by respondents are not endorsed by DSC. An asterisk (*) denotes that the organisation represented was part of the steering group for this project. CIC: community interest company.

A related theme in the discussions between DSC's focus group participants, illustrated in box 3.22, was that the funding environment is an important contextual factor in fostering collaboration; the participants discussed, for example, that commissioning processes can help or hinder collaboration in the kinds of incentives they produce for voluntary and community sector organisations, and, more broadly, that resources are required to build effective relationships within and beyond the voluntary and community sector. Outside the voluntary and community sector, collaboration between commissioners was discussed as having the potential to alleviate the resource pressures on voluntary and community sector organisations, helping them to build and maintain relationships with these funding providers and further capitalise on the strengths of a wide variety of organisations.

Box 3.22

Focus group discussions on opportunities of funding

I think it's incumbent on all of us to do better at working together and to think about how we also make bids for whole-person care that include partner organisations to bring our individual strengths and unique selling points together so that people don't fall through the cracks.

Medium charity – Focus Group 2

Historically, we've had commissioning processes that put us in competition with each other rather than encourag[ing] us to work collaboratively – something thankfully that's changed with Fast-Track Cities and the funding that's been available there to get us to work together instead of in competition.

Medium charity – Focus Group 2

[I] agree with [another participant] and also agree that there is a need to strengthen relationships within [the] sector and with other agencies, e.g. community mental health. But this takes time and resources too.

Small charity – Focus Group 2

Commissioners have stopped working collaboratively, e.g. in South London, HIV commissioning used to be pan-South London. Now, they work individually or in smaller local authority groupings. This increases [the] demands on HIV sector agencies to attend meetings, develop relationships, etc. In London at [the] very least, as recommended in [the] last Fast-Track Cities report, commissioning should be pan-London, drawing on the strengths [and] expertise in [the] HIV voluntary sector.

Small charity – Focus Group 2

Note: Quotes are for illustrative purposes only and the views expressed by respondents are not endorsed by DSC.

3.5 What support measures are needed for voluntary and community sector organisations?

The voluntary and community sector organisations that participated in DSC's survey were asked what support measures would help them to sustain or improve their organisation's ability to contribute to Fast-Track Cities (FTC) London's 2030 goals, which – as given on FTC London's website – are:

- End new HIV infections in the capital by 2030.
- End HIV-related stigma and discrimination.
- Stop preventable deaths from HIV-related causes.
- Work to improve the health, quality of life and well-being of people living with HIV across the capital. (FTC London, 2023a)

A variety of support measures were raised by the organisations that responded. One of the key themes was funding, and some of the responses drew attention to specific needs or issues which are discussed earlier in this report (see section 3.2.3), such as the sustainability of funding and funding for core costs;

the importance of access to funding for small and grassroots organisations; and the importance of funding for organisations with a particular focus, such as on women. An illustrative selection of responses is reproduced in box 3.23.

Box 3.23

Respondents' comments on support needed around funding

We would need enough resource and finances to attract competent staff and volunteers to do the job.

Small charity – London only

Relax terms and conditions around fenced [i.e. restricted] funding, increase funding opportunities and reach out to grassroot[s] organisations to [ensure] accessibility for all.

Medium charity – London and outside London

Increased and sustained funding … Finding and maintaining reliable sources of funding remains a major challenge for smaller organisations because cultivating relationships takes time and fundraising requires resources which 'take away' from the actual work of delivery of support services.

Charity – London and outside London

Supporting grassroots organisations through continued funding and making partnership[s] with them is crucial. They are the ones reaching the people.

Small charity – London and outside London

Sustainable funding for grassroots community groups to maintain community involvement and health and well-being of people living with HIV.

CIC – London and outside London

Our clear priority is securing sufficient income to sustain and rebuild our service level in the light of increased demand for the most vulnerable and marginalised people living with HIV in London.

Medium charity – London and outside London

Longer-term, pan-London contracts.

Large charity – London only

Increased funding for paid staff [and] training costs for new outreach volunteers.

Small charity – London and outside London

We would hope that FTC recognises the need … for gender-specific funding opportunities for organisations whose work is focused on improving the intersections of women's experiences and risks around sexual health [and] well-being.

Small charity – London and outside London

Note: Quotes are for illustrative purposes only and the views expressed by respondents are not endorsed by DSC. CIC: community interest company.

Other support measures raised by the respondents included fostering collaboration between voluntary and community sector organisations, and between voluntary and community sector organisations and statutory bodies such as the NHS. An illustrative selection of responses is reproduced in box 3.24.

Box 3.24

Respondents' comments on support needed around collaboration

Buy-in from ICSs [integrated care services] and NHS trusts in implementing in-clinic peer support, particularly in relation to the newly diagnosed and those not consistently engaging in care and treatment. Better partnership work across health and social care within ICSs to improve pathways to essential non-HIV support in areas such as mental health, drug and alcohol use, poverty and homelessness. Continued collaborative HIV-sector partnership work to ensure effective support pathways across the capital.

Medium charity – London and outside London

Continue to champion collaborations between the NHS and voluntary and community sector. When these relationships are on an equal footing, we do great things together.

Large charity – London and outside London

Shared resources – particularly in terms of marketing activity.

Small charity – London and outside London

Developing an opt-out testing specialist group with diverse representation that would co-create a clear pathway for people to be able to access peer support via A&E.

Small charity – London and outside London

Note: Quotes are for illustrative purposes only and the views expressed by respondents are not endorsed by DSC.

A further theme among the support measures raised by the respondents was the need for greater awareness-raising about HIV, both among the people affected by or at risk of HIV and among members of the public more broadly (as discussed in section 2.5, the focus groups also mentioned declining public interest in HIV and reduced perception of it as a challenge). An illustrative selection of responses is reproduced in box 3.25.

Box 3.25

Respondents' comments on support needed around awareness-raising and messaging

More awareness campaigns through social media [to] keep HIV prevention on [the] government agenda.

Small charity – London and outside London

Ongoing political commitment, alongside strategic commitment (and funding) to address HIV stigma and … opportunities to highlight the voices of people living with HIV to raise awareness.

Medium charity – London and outside London

[The] reduction in testing among women and increased infections [are primarily being seen among] cisgendered women and men, predominantly BAME [Black, Asian and minority ethnic] groups, but do not forget the minorities within the numbers. We have seen more White women completely missed and present with late diagnosis as they don't fit the box of risk. Consider your messaging around risk as it's not something women relate to.

Small charity – London and outside London

Educating the community to know the importance of HIV testing and to increase the number of Black people who test.

Small charity – London only

Note: Quotes are for illustrative purposes only and the views expressed by respondents are not endorsed by DSC.

3.6 What could voluntary and community sector organisations do better?

The respondents to DSC's survey of people affected by HIV in London were asked what voluntary and community sector organisations could do better, and what they would like to say to voluntary and community sector organisations.

Many of these comments expressed thanks and gratitude, but a number of respondents had suggestions for voluntary and community sector organisations moving forwards. The respondents' comments were wide-ranging and included more social activities, more focus on care for specific communities within the diverse groups of people affected by HIV, and more collaborative working. An illustrative selection of responses is reproduced in box 3.26.

Box 3.26

Recommendations for voluntary and community sector organisations from people affected by HIV

Community consultation and dialogue. Addressing HIV as part of a broader health and rights agenda, demonstrating [the] impact of structural barriers on the ability to live positively.

Male, 55–64

Face-to-face meetings.

Non-binary, 55–64

Bring people together for activities that are physical as well as social, such as walking/hiking groups or dance classes.

Male, 55–64

There needs to be more inclusion, and a greater understanding of the complexity of needs. As a trans person, I struggle to find services that can support but also understand my needs. Also, safe spaces and opportunities for learning and education.

Trans man, 16–24

Learn from the organisations [that] are already providing [an] excellent service – support them to sustain and increase their provision and enable them to teach other/new organisations.

Male, 45–54

Monthly Zoom-type meetings with a theme that anyone who registers can access. I find organisations are not particularly welcoming to those who have been diagnosed a very long time, [and] services seem much more geared to [the] newly diagnosed or those with children.

Female, 45–54

More niche support services – for migrants, trans people and other marginalised communities – around specific topics, and other workshops relevant for all people living with HIV.

Male, 35–44

Looking at issues around social care. Making accessibility a priority and not fudging the issue: access to buildings/toilets/car park is a must for people with mobility, visual, etc. problems.

Male, 55–64

Make connections across health/illness areas and break free from the HIV silo.

Male, 65+

Be more joined up in the strategies and actions, [and] talk more to each other! There is too much competition around money and prestige.

Male, 55–64

Please connect and work with other local and national charities wherever possible, so that there can be a network of support available to help people and reduce the discomfort that people with HIV might feel in accessing mental health and ageing support.

Male, 55–64

There are a lot of people with HIV who received support when they were younger but now lack support at young adult and adult ages. I wish there was something for our age demographic.

Female, 25–34

Please work together to provide specialist services.

Male, 55–64

Equal and open access and support for all, especially as the HIV generation is getting older.

Male, 35–44

Note: Quotes are for illustrative purposes only and the views expressed by respondents are not endorsed by DSC.

CHAPTER FOUR

Conclusions and recommendations

4.1 Introduction

This report has provided new research and evidence relevant to London's HIV voluntary and community sector, with implications for commissioners and policymakers. It has shed light on the changing needs of people affected by HIV and the issues and topics of support that are important to them. It has also provided insights about the circumstances facing London's HIV voluntary and community sector organisations, including changing demand, evolving financial circumstances, and the challenges and opportunities organisations face.

This final chapter revisits the key findings from this research and links them to a set of recommendations for the future, including priorities for further research. It is structured around the following topics:

- the needs of people affected by HIV;
- resilience and readiness;
- challenges and opportunities;
- recommendations.

4.2 The needs of people affected by HIV

4.2.1 Changing, diverse and complex needs

Both of DSC's surveys suggest that mental health and well-being has changed most as an area of need following the onset of the COVID-19 pandemic.

The needs of people living with HIV are not limited to the everyday management of HIV, and they do not stay the same over time (Changing Perceptions Project Team, 2018). Indeed, DSC's surveys suggest that, compared to before the pandemic, some areas of need are now widely perceived to be more important, and demand for support from London's HIV voluntary and community sector has changed.

As shown in table 4.1, mental health and well-being was the area of need which was most commonly (90%) described by the people surveyed as being more important because of the COVID-19 pandemic. Similarly, reports from voluntary and community sector organisations showed mental health and well-being had, on average, the greatest percentage of organisations reporting increased demand compared to before the pandemic. Discussions in DSC's focus groups suggest that some of the key drivers behind the changing perceived importance of mental health have been social isolation and loneliness, and difficulty accessing support services.

More broadly, DSC's two surveys presented a largely consistent picture of changing needs (see table 4.1). Finances, poverty and social issues were second most widely reported (78%) to have become more important because of the COVID-19 pandemic, and the average percentage of voluntary and community sector organisations reporting increased demand was 65% – the third most widely reported increase in demand. Support around migration and immigration was the third most widely reported (47%) area to have become more important because of the pandemic and showed the second most widespread increase in demand, with 68% of voluntary and community sector organisations reporting increased demand. The discrepancy between the two surveys on migration and immigration could be due to an under-representation of people affected by these issues in DSC's survey of people affected by HIV.

Finally, support around living with HIV was least widely reported (35%) to have become more important because of the COVID-19 pandemic and also showed the least widespread increase in demand: across the issues and topics of support included in DSC's survey, the average percentage of voluntary and community sector organisations reporting increased demand around living with HIV was 52%.[14]

[14] DSC's survey of voluntary and community sector organisations also included prevention and testing, which showed a slightly more widespread average increase in demand compared to living with HIV.

Table 4.1

	More important	Higher demand	Issues and areas of support with most widespread increased demand
Mental health and well-being	90%	72%	Isolation and loneliness (88%) Access to counselling or therapy (77%)
Finances, poverty and social issues	78%	65%	Accessing benefits (81%) Accessing food (74%)
Migration and immigration	47%	68%	Access to immigration-related legal aid (78%) Access to good-quality immigration advice (77%)
Living with HIV	35%	52%	Ageing well with HIV (76%) Managing more than one condition (63%)
Prevention and testing	–	56%	Advice on access to PrEP medicine (75%) Sexual health promotion and/or outreach (74%)

Note: The percentages of respondents reporting greater importance because of the COVID-19 pandemic are based on DSC's survey of people affected by HIV. The percentages of respondents reporting higher demand for issues within an area of support are based on DSC's survey of voluntary and community sector organisations. The areas of support with the most widespread reports of increased demand are in some cases closely followed by other areas of support; see figures 1.4, 1.6, 1.8, 1.10 and 1.11 for full details and non-abbreviated issues or types of support. PrEP: pre-exposure prophylaxis.

The needs of people affected by HIV are diverse – and may have become more complex.

Voluntary and community sector organisations reported increased demand for support from people affected by HIV in London, relative to before the COVID-19 pandemic, for a range of topics of support. This reflects how the needs of people affected by HIV are varied and not limited to the everyday management of HIV (Changing Perceptions Project Team, 2018).

While the extent of increases in demand varied across types of support, increases in one area were not, overall, offset by decreases in others. Instead, the data shows that, overall, demand had typically increased or stayed the same: only 4 of the 36 topics of support showed decreased demand among at least 10% of respondents. This could be because additional people are accessing support around specific issues but it may also reflect HIV voluntary and community sector organisations' perception that needs are becoming more complex because of, for example, widening health inequalities, the effects of financial hardship on already disadvantaged individuals, and an inability to refer people to appropriate and timely mental health services.

It is also important to recognise that people affected by HIV are diverse – and their needs may have increased or decreased, or changed in nature, differently between different groups. For example, participants in DSC's focus groups highlighted how LGBTQ+ communities may have experienced a loss of identity differently from other groups when social spaces became unavailable during the COVID-19 pandemic, how older people may have been more adversely impacted by the move to digital support, and how Black African men may have become less engaged with support services.

Voluntary and community sector organisations are well placed to engage marginalised groups (National AIDS Trust, 2017). However, participants in this research raised concerns that groups of people affected by HIV – for example, Black African men, migrants for whom English is a second language and trans people – may not be engaging with support or may not be able to access appropriate support. These groups – in addition to people held in institutions (such as prisons), people experiencing homelessness, sex workers and people who inject drugs – are among those identified as the most marginalised groups with respect to service provision (National AIDS Trust, 2020, p. 4).

4.2.2 Mental health and well-being

Social isolation and loneliness may be a key issue among people affected by HIV in London.

Research prior to the COVID-19 pandemic found that poor mental health is more common among people living with HIV than among the general population (Kall et al., 2020, p. 12). Against this background, as noted in section 4.2.1, DSC's surveys of people affected by HIV and of voluntary and community sector organisations suggest this is the area where needs have risen most widely.

Thinking about the types of support within mental health and well-being, social isolation and loneliness had the largest proportion of people surveyed (65%) stating that this was very important to them. Similarly, social isolation and loneliness was the issue or topic of support for which the voluntary and community sector organisations surveyed reported that increased demand was most widespread (88%).

DSC's surveys therefore suggest that social isolation and loneliness is an important issue and one where needs (interpreted as demand for support) have increased among people living with HIV, compared to before the COVID-19 pandemic. This was further evidenced in DSC's focus groups, where participants said needs around social isolation and loneliness had become a greater consideration because of the social disconnection created and/or exacerbated by the pandemic. However, online service delivery and funding arrangements (discussed in section 4.4) could be challenges to meeting this need, an important finding given that social isolation and loneliness has previously been the issue with 'the greatest unmet need' (Kall et al., 2020, p. 69).

In addition to social isolation and loneliness, more than half of the voluntary and community sector organisations surveyed reported that demand was now higher than prior to the onset of the COVID-19 pandemic in relation to access to counselling or therapy (77%), community or peer support groups (68%), and alcohol or drug use issues (52%).

4.2.3 Finances, poverty and social issues

Demand around support with basic needs has increased compared to before the onset of the COVID-19 pandemic.

Prior to the onset of the pandemic, just over half of people living with HIV did not always have enough money to finance their basic needs – even more so among women and people who are Black African or another minority ethnicity (Kall et al., 2020, p. 63). In addition, unemployment was more common among people living with HIV, despite high levels of education (Kall et al., 2020, p. 14).

As noted above, 78% of the people surveyed said support around finances, poverty and social issues had become more important because of the COVID-19 pandemic. Meanwhile, DSC's survey of voluntary and community sector organisations found widespread increases in demand for various types of support around finances and poverty, including around meeting basic needs. The pattern of increased demand suggests that needs have risen most widely in relation to support around accessing benefits (81%), accessing food (74%), experiencing homelessness (71%), debt management (70%), poor-quality housing (70%) and fuel poverty (70%).

Increased need in these areas is important in terms of negative impacts on the quality of life of people living with HIV – but it may also have health implications. Previous research has linked related socio-economic factors, such as not having enough money to cover basic needs, to irregular or non-attendance at clinics (Howarth et al., 2017) and lower adherence to antiretroviral medication and worse HIV-related health outcomes (Burch et al., 2016). It is, therefore, important to consider the potentially negative consequences of increased demand around finances, poverty and social issues on Fast-Track Cities (FTC) London's 2030 goals around quality of life, transmission and preventable deaths (see section 3.5).

4.2.4 Migration and immigration

Just under half of the people surveyed said that support around migration and immigration had become more important because of the COVID-19 pandemic – and voluntary and community sector organisations described how this intersected with other issues.

As noted above, support around migration and immigration had risen in importance because of the pandemic for just under half (47%) of the people DSC surveyed. It also showed the second-most widespread increase in demand, with 68% of voluntary and community sector organisations reporting increased demand. Meanwhile, among the voluntary and community organisations that delivered such support (a smaller group than those offering support in the other areas), organisations saw widespread increases in demand for forms of support such as immigration-related legal aid (78%) and good-quality immigration advice (77%).

Additionally, the voluntary and community organisations that participated in DSC's focus groups discussed how migration status could intersect with or compound needs – for example, around isolation and loneliness. Migration status can also be compounded by a lack of support services that are able to effectively cater to individuals' needs – for example, in terms of language support.

4.2.5 Living with HIV

Just over one-third of the people surveyed said that support around living with HIV had become more important because of the COVID-19 pandemic – for the majority it had stayed about the same.

The people surveyed by DSC were more likely to say that needs around living with HIV had stayed about the same (62%) than that they had risen in importance (35%). This finding contrasts with those for each of the areas of need described above, especially mental health and well-being, and finances, poverty and social issues.

However, issues or topics of support around living with HIV were still widely considered very important. Two-thirds (66%) of the people surveyed indicated that support around ageing well with HIV was very important to them and another two-thirds said the same of getting appropriate care from a GP.

Meanwhile, the voluntary and community sector organisations that responded to DSC's survey reported widespread increases in demand for several issues or topics of support around living with HIV, such as supporting people to age well with HIV (76%) and supporting people to manage more than one medical condition (63%). Both of these issues have previously been highlighted as important due to the fact that the first (largest) generation of people living with HIV is ageing (Terence Higgins Trust, 2017).

In addition, as described by the focus group participants, it is important to consider how other increasingly important issues – such as those around mental health and well-being, or finances, poverty and social issues – can compound aspects of living with HIV, such as by negatively affecting people's ability to adhere to HIV treatment. Such concerns are supported by previous research (Burch

et al., 2016; Ibrahim et al., 2008). Attending to needs around living with HIV as well as other areas of need therefore has implications for the achievement of FTC London's goals around ending new diagnoses and stopping preventable deaths.

4.2.6 Prevention and testing

There have been widespread increases in demand for advice on access to PrEP (pre-exposure prophylaxis) medicine, sexual health promotion or outreach, and sexual health or HIV prevention advice and support.

The voluntary and community sector organisations that responded to DSC's survey were asked about changes in demand for several topics of support around prevention and testing. Increased demand was widespread in relation to advice on access to PrEP medicine (75%), sexual health promotion or outreach (74%), and sexual health or HIV prevention advice and support (71%). Demand was more likely to have stayed about the same for HIV testing in person (38%), harm reduction for people who use drugs (62%) and HIV testing through online services (54%).

4.3 Resilience and readiness

Most of the voluntary and community sector organisations surveyed said that demand for support was greater than before the onset of the COVID-19 pandemic.

DSC's survey of voluntary and community sector organisations found that, for more than half (60%) of those who responded, the level of demand they were receiving from people affected by HIV in London was higher – by, on average, 25% – than it had been three years ago, prior to the COVID-19 pandemic. The remaining organisations were mostly experiencing the same level of demand (35%) or decreased demand (5%). This suggests that voluntary and community sector organisations are experiencing more widespread and/or more intense levels of need among people affected by HIV than they were before the COVID-19 pandemic.

Voluntary and community sector organisations have typically been meeting demand but with no spare capacity – and a significant minority have not been meeting demand.

Against the backdrop of widespread increases in demand – both overall and for specific issues and topics of support – DSC's survey found that voluntary and community sector organisations were generally meeting demand in each of five key areas. However, the organisations that responded were, in four out of the five areas of need, more likely to be meeting demand with no spare capacity than with limited or significant spare capacity.

Nevertheless, in each area of need, between around one-third and two-fifths of the voluntary and community sector organisations were falling short of meeting demand – and the voluntary and community sector organisations falling significantly or slightly short of meeting demand were generally small and medium charities. Just over one-quarter (27%) of voluntary and community sector organisations were falling significantly short of meeting demand around finances, poverty and social issues, while one-fifth were falling significantly short around mental health and well-being and around prevention and testing (20% for each).

These findings suggest that many voluntary and community sector organisations are managing to keep up with increased demand for support from people affected by HIV in London. However, a large minority are falling short of meeting demand – and a concerning minority consider their organisation to be falling short by a significant margin. These present potential barriers to achieving FTC London's goal around health, quality of life and well-being for people living with HIV – and, because of the

relationship between wider social issues and health outcomes, also to achieving the goals to end preventable deaths and new cases.

Voluntary and community sector organisations were twice as likely to say their financial security had significantly worsened than that it had significantly improved.

The voluntary and community organisations that responded to DSC's survey were asked how their current financial security compared with their financial security three years ago, prior to the onset of the COVID-19 pandemic. Overall, the voluntary and community sector organisations reported both improved financial security and worsened financial security in equal measures (42% each). However, it is important to note that twice as many voluntary and community sector organisations said their financial security had worsened significantly (28%) than said it had improved significantly (14%).

Overwhelmingly, the voluntary and community sector organisations had seen their expenditure increase relative to three years ago – but many had not seen their income increase accordingly.

DSC's survey of voluntary and community sector organisations found that, for the overwhelming majority (88%) of those who responded, expenditure was now at a higher level than prior to the onset of the COVID-19 pandemic. Drivers of increased expenditure reported by voluntary and community sector organisations included increased costs of delivering support, such as staffing and energy costs.

Despite widespread increases in expenditure, only half (50%) of the voluntary and community organisations that responded to DSC's survey said that their income was now greater than it had been prior to the onset of the COVID-19 pandemic. In fact, for close to half (44%) of the organisations surveyed, income was now lower – including for the vast majority (79%) of those that were seeing increased expenditure.

A clear majority of voluntary and community sector organisations said they had used reserves to meet operating costs during the past three years.

DSC's survey further found that more than two-thirds (71%) of the voluntary and community sector organisations surveyed had used reserves to meet operating costs during the past three years (i.e. since January 2020). Linking back to the cash-flow changes described above, this included each of the voluntary and community sector organisations (N=11) that said their expenditure had increased but their income had decreased.

DSC's survey found that around half (52%) of the voluntary and community sector organisations surveyed could use their existing cash reserves to cover up to four months of expenditure; such reserves can provide financial protection in difficult times. However, using reserves (which can involve having to sell off assets) is not a sustainable way to fund operating costs – it can indicate financial deterioration (Jemal et al., 2022, p. 10). DSC's findings therefore suggest a clear majority of voluntary and community sector organisations supporting people affected by HIV in London have during the past three years faced, or are facing, financial deterioration.

Statutory funding is widely considered very important for voluntary and community sector organisations – but it is not at all important to a large minority.

DSC's survey found that statutory funding was among the sources of income that were most widely considered very important (considered very important by up to 53%). However, it was deemed less widely important than income from grant-makers or funders (considered very important by 85%) and income from public donations (considered very important by 62%). Indeed, income from local government and NHS trusts was considered not at all important by almost one-third (30%) and half (45%) of the respondents, respectively.

There may be a perception that the income of London's HIV voluntary and community sector is largely derived from statutory sources such as local government and the NHS. These findings run counter to this perception. Moreover, it is important to consider the widespread importance of public donations

evidenced in this research in light of concerns raised by voluntary and community sector organisations that public interest in HIV as an issue is declining. This is especially relevant given that, more broadly, the percentage of the general public who are donating remains approximately ten percentage points below pre-pandemic levels (DCMS, 2023, fig. 5.7).

4.4 Challenges and opportunities

Increasing beneficiary need and numbers are already reducing the ability of voluntary and community sector organisations to meet the needs of people affected by HIV in London.

In DSC's survey of voluntary and community sector organisations, more than half (57%) of the respondents said that significantly increasing beneficiary need was already a reality in terms of reducing their ability to meet needs. This reflects how needs had increased across a variety of types of support but rarely decreased (discussed in section 4.2.1) and were considered by some to be becoming more complex. In addition, more than two-fifths (44%) of voluntary and community sector organisations said significantly increasing beneficiary numbers were already reducing their ability to meet needs.

Focus group participants noted that face-to-face support and contact is an important part of meeting the need for social connection. While online support can provide benefits in some ways, needs around social connection may not be met, or may be met less effectively, because of the move to a digital model of support catalysed by the COVID-19 pandemic, particularly for older people. In addition, participants described how a social element to support could bolster engagement and in turn help meet other needs. The discussion suggested consideration is needed about how to adapt service delivery following the COVID-19 pandemic to respond to needs around social connection.

Another challenge is how the voluntary and community sector – and, more broadly, the statutory sector – can reach, and meet the diverse and potentially complex needs of, people affected by HIV who have differences across various dimensions, such as length of time since diagnosis, age, gender, ethnicity, sexuality, language spoken or faith. Social and economic issues such as poverty can also make needs more complex and, as seen in section 4.2.3, such issues have widely become seen as more important and more prevalent compared to before the COVID-19 pandemic – and a notable minority of voluntary and community sector organisations are falling significantly short in this area.

Burnout and shrinking numbers of staff and volunteers are reducing the ability of voluntary and community sector organisations to meet the needs of people affected by HIV.

With respect to the numbers of staff and volunteers, around two-fifths (39%) of the voluntary and community sector organisations surveyed said a reduction in volunteers was already a reality, and a further one-third (33%) said this might reduce their ability to meet the needs of people affected by HIV in London in the medium to longer term (within six months, one year, or two or more years). Meanwhile, just over one-third (35%) said a reduction in paid staff was already a reality and an additional half (50%) thought this might become a reality in the medium to longer term.

Thinking about burnout, just under two-fifths (38%) of the respondents said burnout among staff was already a reality, and a similar percentage (39%) said this might reduce their ability to meet the needs of people affected by HIV in London in the medium to longer term. In terms of volunteers, just under one-fifth (18%) said burnout among volunteers was already a reality and more than one-third (36%) expected this to become a reality within the medium to longer term.

Challenges relating to staff and volunteers were also a key theme within DSC's focus groups. The discussions helped to shed further light on the nature of these challenges, which included a loss of volunteers during the COVID-19 pandemic, difficulty recruiting because of declining interest in the HIV voluntary and community sector, and staff and volunteers potentially shifting their attention and

priorities elsewhere (for example, in relation to the cost-of-living crisis). Concerns were also raised about burnout from increased demand and complexity of cases, as well as a lack of resources.

Permanent closure is among the potential challenges that voluntary and community sector organisations foresee in the medium- to long-term future.

In terms of challenges around organisational operations, a reduction in service delivery was already a reality for around one-quarter (24%) of the voluntary and community organisations that responded to DSC's survey. A further 54% of the respondents expected this to become a reality in the medium to longer term. This is a worrying finding in a context where, as discussed in section 4.3, overall demand is higher than before the pandemic and up to around a quarter of voluntary and community sector organisations are already falling significantly short of meeting demand.

Concerningly, close to half (45%) of the respondents said that their organisation closing permanently was a foreseeable risk within one year (28%) or two or more years (17%). In absolute terms, that means 10 (out of 36) of the HIV voluntary and community organisations that responded to DSC's survey question believed they might close within the next year and a further 6 believed they might close in two or more years. These organisations collectively provided support in each of the five key areas included in this report, covering all of the London sub-regions, to people from various demographic backgrounds.

This risk of closure represents a potential loss of the valuable contributions voluntary and community sector organisations make to the health and social outcomes of people affected by HIV (National AIDS Trust, 2017, pp. 38–42). This may disproportionately negatively affect those subgroups that particularly tend to benefit from support services, such as newly diagnosed people, women, Black African people, migrants, older people and young people (National AIDS Trust, 2017, p. 15). The successful outcomes seen in London (Lowbury, 2021, p. 42) have been achieved within an ecosystem of support services which have included the contributions of the HIV voluntary and community sector (National AIDS Trust, 2017, p. 17).

Related challenges brought to DSC's attention by voluntary and community sector organisations included how far funders and commissioners of support for people affected by HIV understood their needs – particularly subjective or less tangible needs, such as the social value of providing a lunch or the importance of faith for people who have a religion. This potential gap in understanding has previously been noted elsewhere (Lowbury, 2021, p. 14). Moreover, insufficient funding for core costs, such as staff and premises, was a challenge, which is especially relevant for voluntary and community sector organisations providing support to people affected by HIV in London because of the high rental costs there.

One cross-cutting theme was that funding challenges can be exacerbated for smaller voluntary and community sector organisations. These smaller organisations can have less capacity to engage professional fundraisers and to develop relationships with commissioners, as previous research has suggested (Backus and Clifford, 2013).

The voluntary and community sector organisations frequently raised collaboration as an opportunity to better meet the needs of people affected by HIV in London.

Collaboration was perceived as a crucial process in meeting beneficiaries' needs – for example, through referrals from one voluntary or community sector organisation to another – in part because it can draw upon the varied expertise and specialisms of different organisations. However, there was recognition that effective collaboration requires resources (for example, in terms of staff time) and appropriate incentives (for example, in terms of funding structures).

Collaboration between the voluntary and community sector and statutory providers (such as the NHS) can lead to positive outcomes – as has been demonstrated through FTC London's improvement

community projects (FTC London, 2023c). Working to resolve the current perceived weaknesses in the relationship between the voluntary and community sector and the statutory sector may help foster more effective collaboration to provide the more holistic support that successive policies have aimed for (NHS England, 2014, 2021).

4.5 Recommendations

DSC makes the following recommendations to stakeholders across FTC London. DSC recognises the variety of organisations and stakeholders that make up FTC London and the following recommendations aim to support a diverse range of organisations to achieve their shared commitment to the FTC London 2030 goals (as outlined in the introduction to this report).

FTC London should facilitate ongoing information-sharing, intelligence-sharing and policy development through collaboration

Delivering together is a fundamental element of FTC London's Roadmap to Zero (FTC London, 2023d). It is also particularly important with the establishment of the integrated care systems (ICSs), which aim to foster collaboration between the voluntary and community sector and statutory bodies (NHS England, 2021). Equality, diversity and inclusion need to be embedded in policy development and collaborative efforts.

1. **Raise awareness of which voluntary and community sector organisations support people affected by HIV in London and what they do.**

As part of this research, DSC combined a systematic search of the Charity Commission for England and Wales's register of charities with a systematic search of data published on HIV Lens to build an initial picture of the scope and composition of London's HIV voluntary and community sector (HIV Lens, 2023). FTC London should continue to develop this picture – in collaboration and consultation with the voluntary and community sector and other users – to generate a comprehensive resource that can be shared with practitioners, policymakers, and funders and commissioners. DSC suggests that responsibility and resources for keeping this up to date should be identified in advance, which will help to ensure it can remain a continually relevant and useful tool for understanding the scope and nature of the sector, connecting organisations and facilitating referrals.

2. **Create working groups around policy and workshops for practitioners to facilitate an inclusive and ongoing dialogue between diverse voluntary and community sector organisations.**

Both the working groups and the workshops would share information and intelligence from the perspective of voluntary and community sector organisations and should include a wide variety of organisations with knowledge of the diverse communities affected. Quarterly meetings, with clear aims and objectives, for working groups comprised of organisations' leaders or policy leads could generate locally and nationally relevant proposals that would help voluntary and community sector organisations and the people they support. Themed practitioner workshops of the same frequency could share particular challenges and issues, opportunities and best practices, and the changing needs of people affected by HIV.

FTC London should influence funders to better meet the needs of people affected by HIV in London

This research found that the financial resilience of many voluntary and community sector organisations is being reduced, and this report has evidenced the threat of organisations closing or reducing services in the aftermath of the COVID-19 pandemic. This is a problem across the voluntary sector and is not limited to London. Decreasing resilience of voluntary and community sector organisations puts their ability to serve the needs of people affected by HIV – and, therefore, the delivery of the FTC London goals – at risk.

3. **Develop guidance to help funders and commissioners understand how to ensure their funding is available to all types of voluntary and community organisation.**

FTC London should support funders and commissioners to make their funding as inclusive as possible. For example, this could include paying attention to how geographical restrictions in contracts may affect which organisations can and cannot apply, how commissioning processes may present barriers for smaller organisations, and how Black- and other minority ethnic-led or women-led organisations may have less equitable access to funding. These are important considerations to ensure that, by 2030, no communities are left behind without their needs being met and that specialist support is available for those who need it.

4. **Help to foster a funding environment which encourages and strengthens collaboration between voluntary and community sector organisations.**

It is important that funders and commissioners understand which elements of their funding processes may create barriers or enablers to collaboration among the organisations they fund – and to make changes where necessary to enable collaboration. This could be informed by consultation with working groups from the voluntary and community sector which are part of FTC London.

5. **Help to reform funding and commissioning practices to repair and prevent further erosion of the financial resilience of voluntary and community sector organisations.**

This research revealed concerns that funders and commissioners do not always understand how voluntary and community sector organisations operate or the needs they are aiming to meet. Funders and commissioners such as ICSs, local authorities and independent funders should work more collaboratively with the voluntary and community sector to understand the needs they are trying to meet and how to best support their financial resilience. This could include, for example, increasing the length of grants or contracts, and providing inflationary increases in funding agreements so organisations do not subsidise the rising costs of service provision from depleted reserves.

6. **Provide guidance and training on creating effective funding applications.**

FTC London should facilitate guidance and training, including peer-led support, for voluntary and community sector organisations to help produce more successful funding bids. Through this support, the limited resources of voluntary and community sector organisations could be maximised, and the total incoming funding could be increased. This is especially relevant for smaller organisations and for organisations led by or serving people for whom English is a second language, both of which may need additional support to write bids and engage with potentially resource-intensive contracting processes.

7. **Undertake dedicated research on the distribution and nature of funding for HIV voluntary and community sector organisations in London.**

FTC London should commission a deep-dive analysis of funders in this sector. This would be an important policy document highlighting which areas of support are being funded and by which funders. In addition, such research would identify which areas are under-funded and where evidence-gathering and policy work should be focused, in order to incentivise funders to address a particular funding priority.

FTC London should support the voluntary and community sector to recruit and retain paid staff and volunteers

Voluntary and community sector organisations involved in this research said a drop in their paid or voluntary workforce was reducing their ability to meet the needs of people affected by HIV in London. This threatens the provision of services for people affected by HIV and the delivery of the FTC London goals.

8. **Create a workforce development fund for training and practical support on the recruitment and retention of paid staff and volunteers.**

FTC London should support voluntary and community sector organisations to access resources and training that can help to improve recruitment processes and bring in volunteers. Given the central importance of having enough adequately trained staff, this could be achieved through the creation of a workforce development fund, financed by statutory bodies (such as the ICSs) and other funders (such as grant-making charities).

9. **Raise the profile of work in the HIV voluntary and community sector among potential staff and volunteers, and support a diverse workforce of staff and volunteers to enter the sector.**

In collaboration with the voluntary and community sector, FTC London should leverage the profiles of various stakeholders (such as the Mayor of London) to create new campaigns. These would aim to raise awareness and increase interest in the HIV sector among potential staff and volunteers and could include a focus on recruiting volunteers through non-voluntary sector sources, such as the other FTC London members. This could be complemented by creating a single point of entry (such as a website portal) for potential volunteers and staff, in collaboration with existing resource providers where appropriate. This work should have an explicit focus on inclusivity to help foster a diverse community of staff and volunteers.

10. **Support voluntary and community sector organisations to improve paid staff and volunteers' well-being.**

The workforce development fund recommended above (Recommendation 8) could be used to provide resources for a programme of training and support to promote well-being in the workplace and prevent burnout in the longer term. However, these outcomes could primarily be achieved through collaboration and peer mentorship within the voluntary and community sector, including through the practitioner workshops recommended above (Recommendation 2).

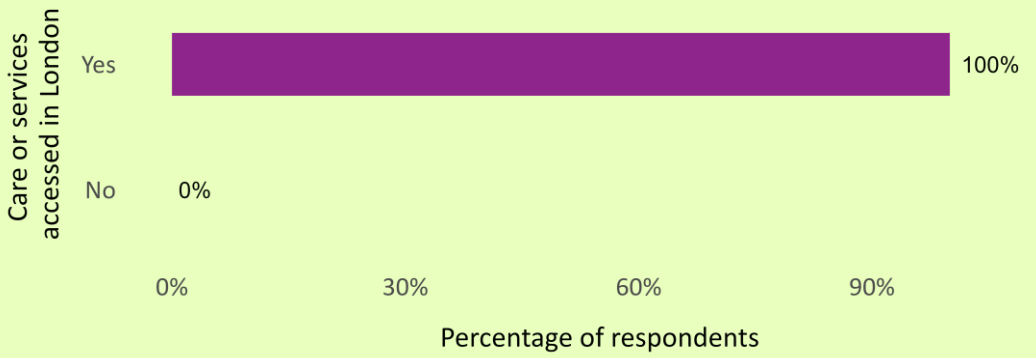
Appendix

Respondent profile: survey of people affected by HIV

Figure A.1

Whether the respondents accessed care or services for HIV in London

All of the respondents said that they accessed care or services for HIV in London

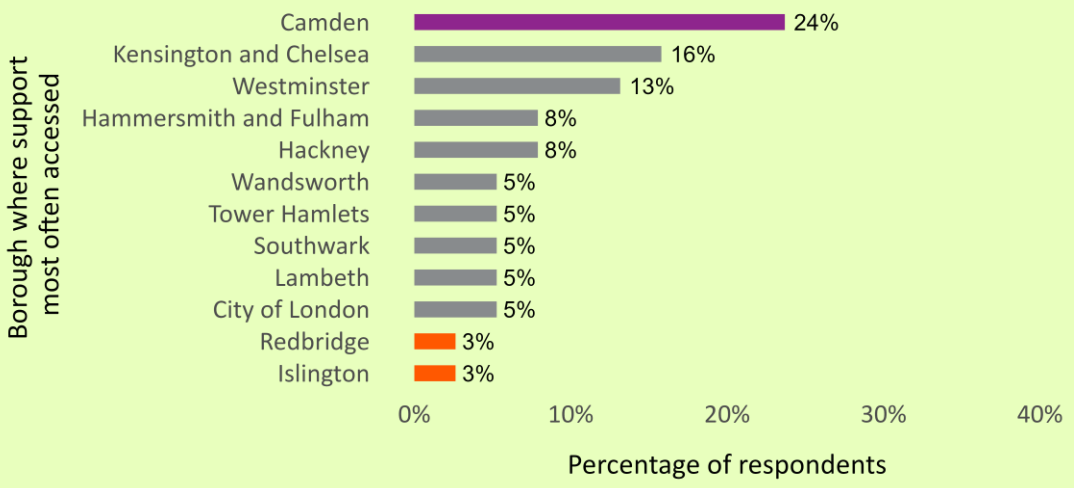


Note: There were 40 responses to this question.

Figure A.2

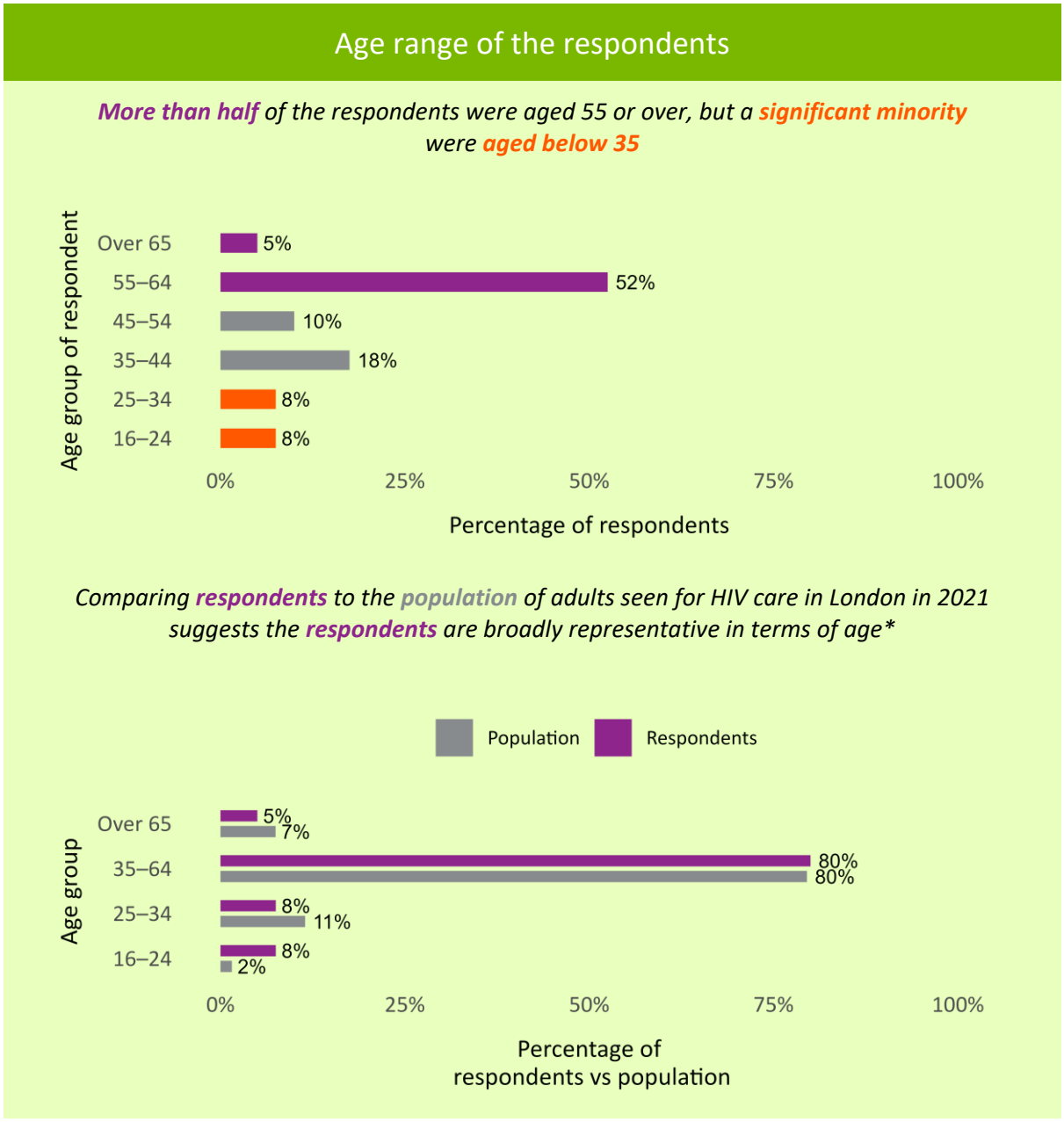
Where the respondents accessed care or services for HIV in London

Respondents most commonly accessed support in Camden and least commonly accessed support in Redbridge or Islington



Note: There were 40 responses to this question.

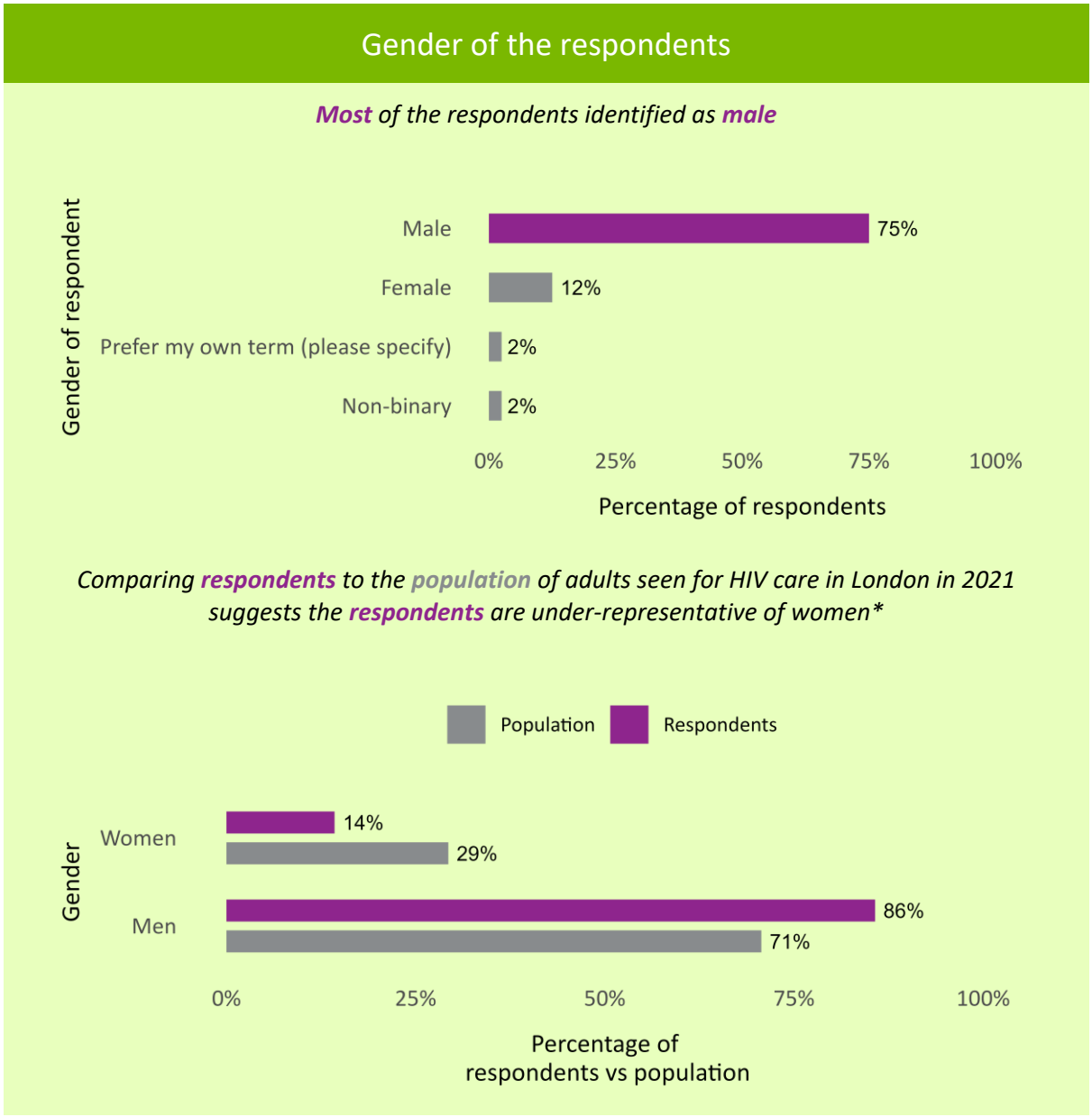
Figure A.3



Note: There were 40 responses to this question (not including those reporting an 'other' answer). The percentages do not sum to 100% due to rounding.

* For comparison, the 35–64 category is based on the overlap between DSC's age categories and the age categories used in official statistics (UK Health Security Agency, 2022b). The groups within the official statistics are 35 to 49 (38%) and 50 to 64 (42%), which suggests an over-representation of individuals towards the older end of the 35-to-64 category.

Figure A.4



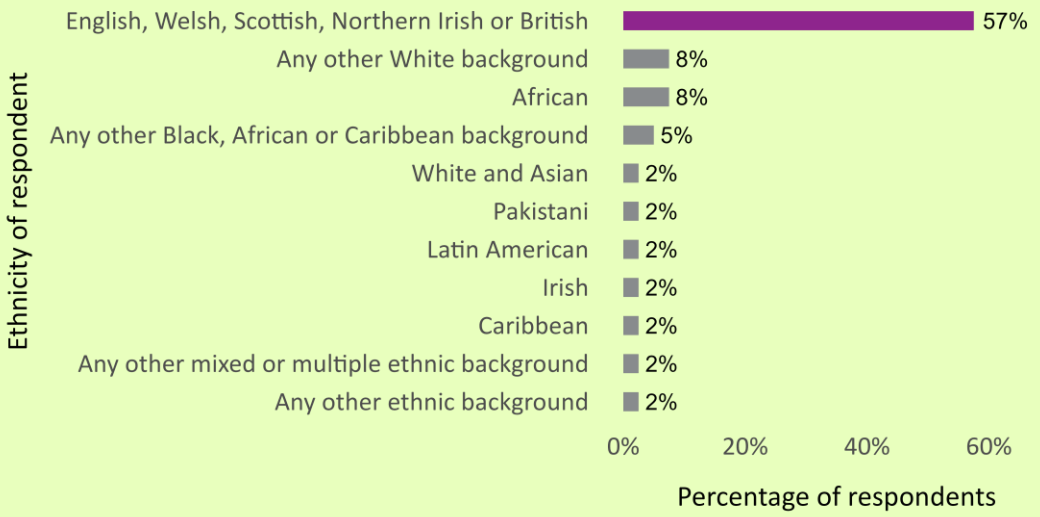
Note: There were 40 responses to this question. The percentages do not sum to 100% as an additional 8% preferred not to answer and due to rounding.

* For comparison, the terms 'male' and 'female' used in DSC's survey have been recategorised as 'men' and 'women' to accord with the terminology used in the official statistics (UK Health Security Agency, 2022b), and this analysis removes all other response options when calculating the percentages.

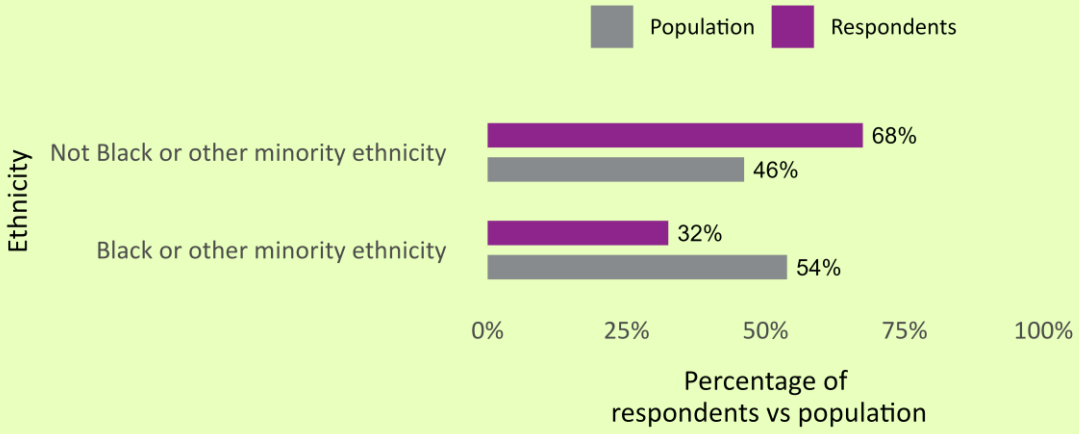
Figure A.5

Ethnicity of the respondents

Most** of the respondents identified as **English, Welsh, Scottish, Northern Irish or British



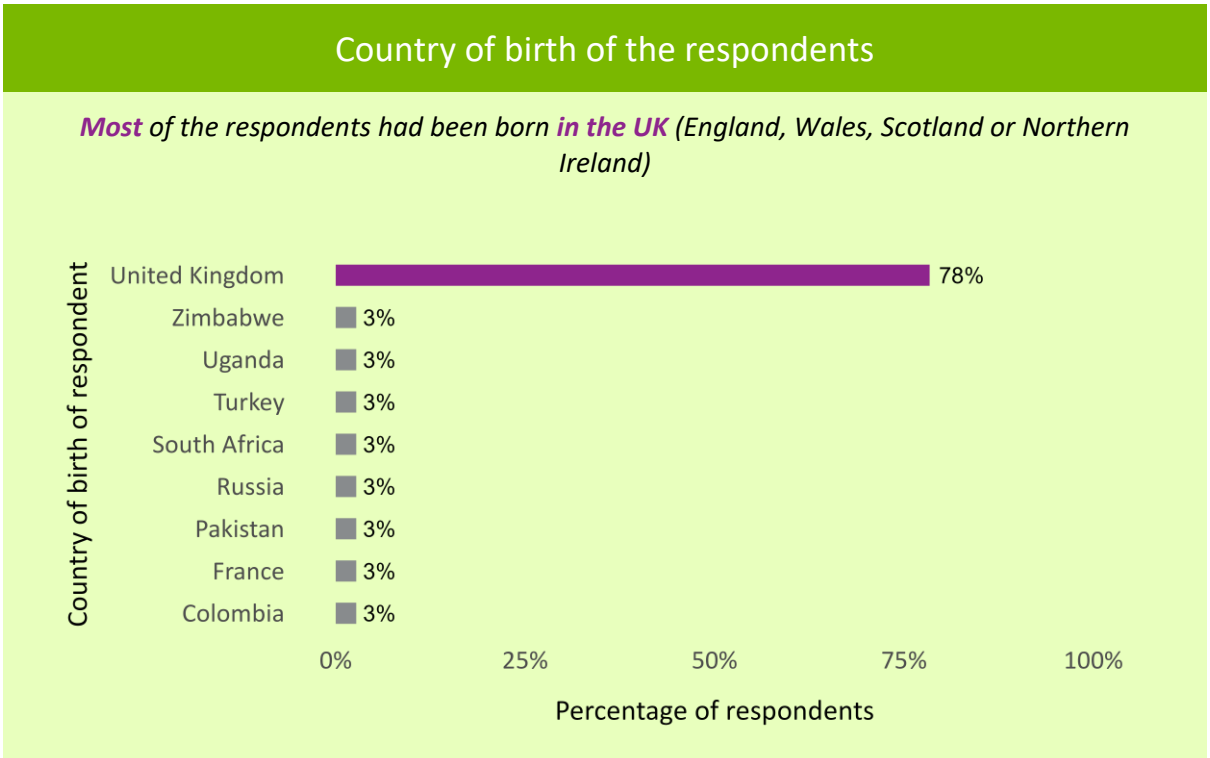
*Comparing **respondents** to the **population** of adults seen for HIV care in London in 2021 suggests the **respondents** are under-representative of people from Black and other minority ethnic groups**



Note: There were 40 responses to this question. The percentages do not add up to 100% as an additional 5% preferred not to answer.

* For comparison, the categories 'English, Welsh, Scottish, Northern Irish or British', 'Any other White background' and 'Irish' in DSC's survey have been recategorised as 'Not Black or other minority ethnicity' and all other responses are categorised as 'Black or other minority ethnicity'. Meanwhile, the category 'White' in the official statistics (UK Health Security Agency, 2022b) has been categorised as 'Not Black or other minority ethnicity' and all other categories have been labelled 'Black or other minority ethnicity'.

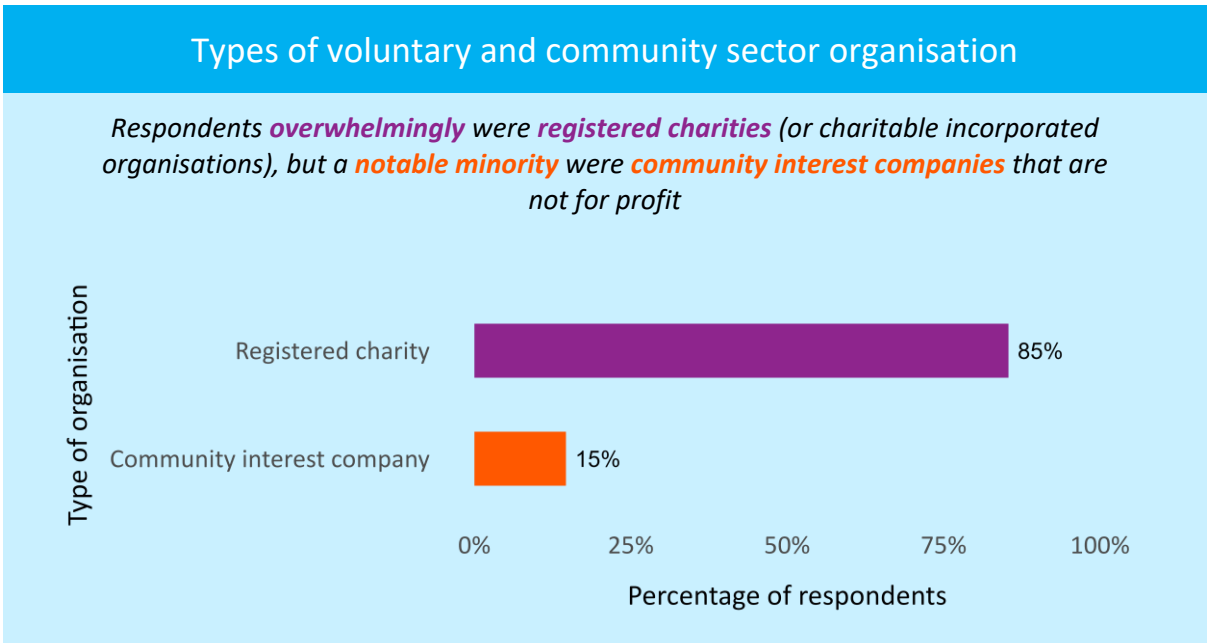
Figure A.6



Note: There were 37 responses to this question. This was an open-answered question and some responses have been grouped by DSC's researchers: responses of 'England', 'UK', 'London' and 'Wales' were categorised under 'United Kingdom'. Percentages do not sum to 100% due to rounding.

Respondent profile: survey of voluntary and community sector organisations

Figure A.7

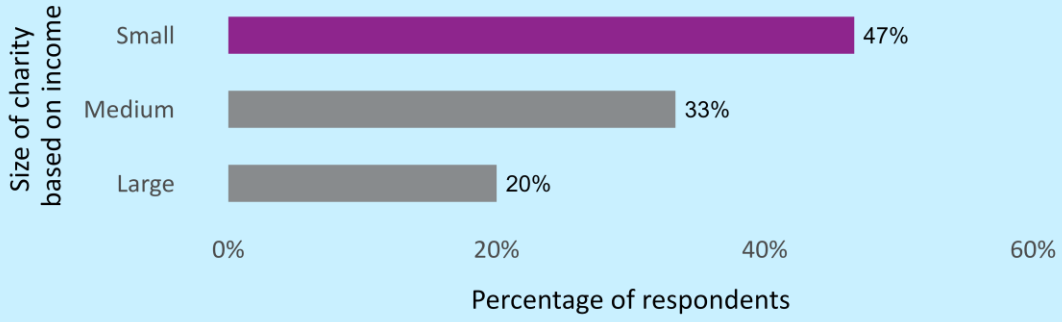


Note: There were 41 responses to this question (not including those reporting an 'other' answer).

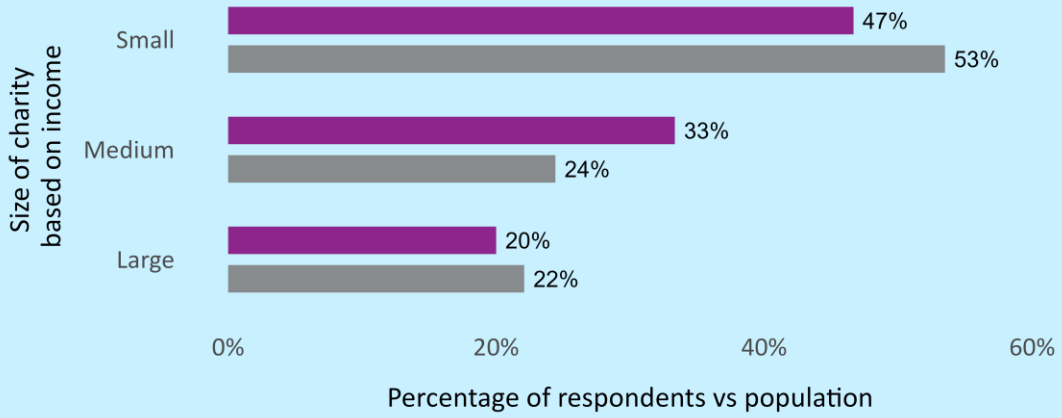
Figure A.8

Financial (income) sizes of voluntary and community sector organisations

*Respondents **most commonly** were **small charities** but one-third were medium charities and one-fifth were large charities*

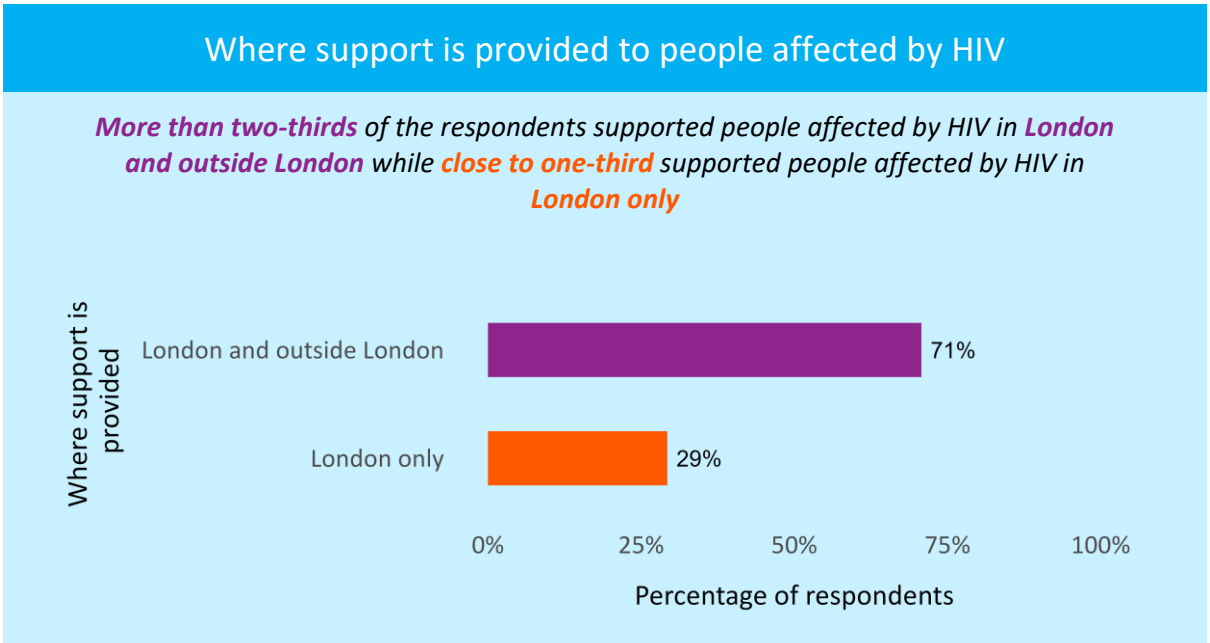


*Comparing **respondents** to the **population** of charities among the voluntary and community sector organisations identified by DSC, small charities were slightly under-represented and medium charities were slightly over-represented*



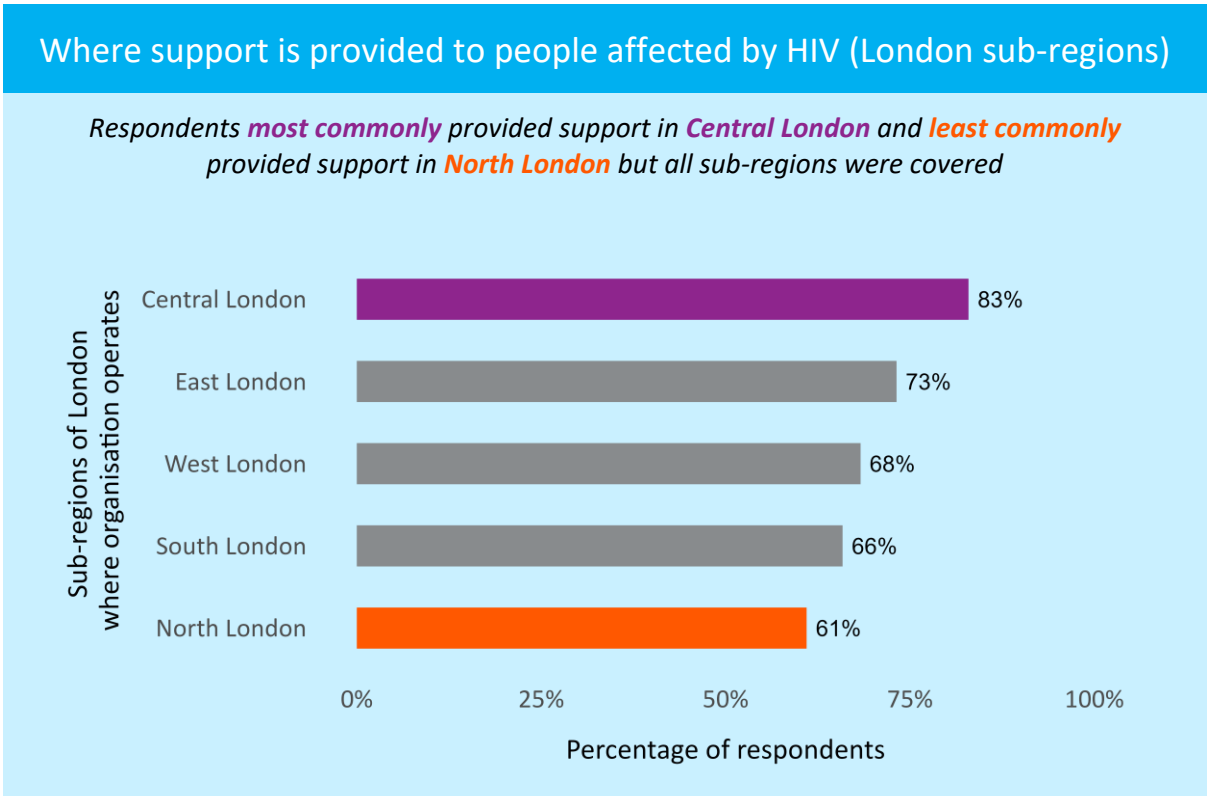
Note: Based on information from 30 respondents that provided a registered charity number and could therefore be linked to the Charity Commission for England and Wales's register of charities. Categories are based on most recent annual income. Small charities have incomes below £100,000; medium charities have incomes between £100,000 and £1 million; and large charities have incomes above £1 million (Jemal et al., 2022). Further analysis showed that the under-representation among small charities is mainly due to an under-representation of those with incomes under £10,000. Population of charities refers to the subset of voluntary and community sector organisations identified by DSC's researchers (see 'Methodology' on page xvii) that are registered charities.

Figure A.9



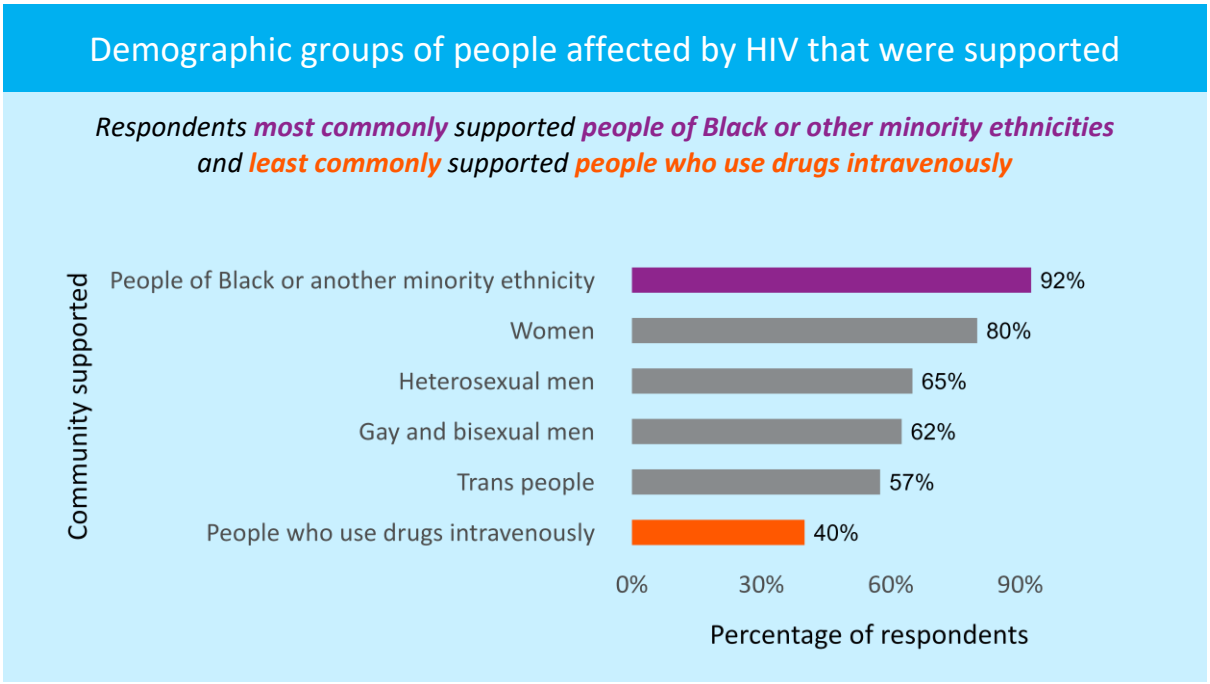
Note: There were 41 responses to this question (not including those reporting an 'other' answer).

Figure A.10



Note: There were 41 responses to this question (not including those reporting an 'other' answer).

Figure A.11



Note: There were 40 responses to this question (not including those reporting an 'other' answer).

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London's HIV Voluntary and Community Sector

Responding and rebuilding after COVID-19

This report presents new research investigating the extent to which the needs of people affected by HIV in London have changed following the onset of the COVID-19 pandemic. It also sheds light on the resilience of voluntary and community organisations and their readiness to respond to these varied and changing needs. This research comes at an important time in the aftermath of the COVID-19 pandemic and with the approaching deadline for the Fast-Track Cities 2030 goals for London in relation to improving lives of people affected by HIV.

The research findings provide a body of evidence and insightful analysis to inform policy, practice and future research. In particular, the report aims to answer the following questions:

- What are the changing needs of people affected by HIV in London after the initial impact of the COVID-19 pandemic?
- How do these changing needs relate to the achievement of Fast-Track Cities London's goals?
- What are the challenges anticipated by voluntary and community organisations serving people affected by HIV in London?
- How resilient are voluntary and community organisations, and how ready are they to respond to these challenges?

This report provides insights that will be useful to those supporting people affected by HIV, within and beyond the voluntary and community sector. DSC hopes that the conclusions and recommendations of this research will help inform policies and strategies that can sustain and strengthen the support provided by voluntary and community organisations to people affected by HIV.

'Fast-Track Cities London Leadership Group welcomes this research and the recommendations within it and will work with the HIV voluntary and community sector to ensure its sustainability in the future.'
Professors Jane Anderson and Kevin Fenton,
Co-Chairs of Fast-Track Cities London [from the foreword]

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