TRANSFORMING THE UK'S RESPONSE TO HIV

NAT

HIV&FINANCE

Exploring access to financial services for people living with HIV in the UK

NAT July 2017

Our strategic goals

All our work is focused on achieving five strategic goals:

- effective HIV prevention in order to halt the spread of HIV.
- early diagnosis of HIV through ethical, accessible and appropriate testing.
- equitable access to treatment, care and support for people living with HIV.
- enhanced understanding of the facts about HIV and living with HIV in the UK.
- eradication of HIV-related stigma and discrimination.

Our vision

Our vision is a world in which people living with HIV are treated as equal citizens with respect, dignity and justice, are diagnosed early and receive the highest standards of care, and in which everyone knows how, and is able, to protect themselves and others from HIV infection.

NAT is the UK's policy charity dedicated to transforming society's response to HIV.

We provide fresh thinking, expertise and practical resources.

We champion the rights of people living with HIV and campaign for change.

CONTENTS

1. INTRODUCTION

The issue of financial exclusion of certain groups of people has gained increasing attention in recent years. The term 'financial exclusion' can be used in different ways, but can broadly be defined as "the inability, difficulty or reluctance to access mainstream financial services, which, without intervention, can stimulate social exclusion, poverty and inequality".[1]

Living with a disability or a long-term condition such as HIV can increase the risk of being financially excluded as well as having a significant impact on one's finances. Scope's Extra Costs Commission found that disabled people are subject to additional costs averaging around £550 per month. This can be due to them requiring specialised goods like wheelchairs, greater use of non-specialised goods and services like taxis, and higher costs of non-specialised goods and services, such as insurance.[2]

Compared to other disabilities and long-term conditions, the outlook for someone living with HIV in the UK today is relatively positive. HIV treatment outcomes in the UK are excellent: 96% of people diagnosed with HIV are on treatment and 94% of those on treatment are virally suppressed.[3] Many people living with HIV report that their condition has little impact on their working life,[4] and those diagnosed early and adherent to treatment have a normal life expectancy.[5] Despite this progress, social problems for people living with HIV persist – often as a result of stigma and discrimination at the personal and systemic level.

To address these issues, people living with HIV are now recognised as disabled from the point of diagnosis under the Equality Act 2010, meaning they are protected by law from discrimination when accessing goods and services. However, there is an exclusion within this legislation which allows insurers to legally subject disabled people to proportionate difference in treatment, where reasonable and based on relevant, current and reliable information.[6]

The findings of this report demonstrate that people living with HIV continue to experience barriers to access to some financial products, particularly insurance. The experiences we document here are not unique to those living with HIV, but affect a range of people with pre-existing conditions, as has been highlighted by Scope for disabled people more generally[7] and Macmillan for those living with cancer.[8]

1 Select Committee on Financial Exclusion, *Tackling financial exclusion: A country that works for everyone?*, 25 March 2017, HL 132 2016-17. Available at: https://www.publications.parliament.uk/pa/ld201617/ldselect/ldfinexcl/132/132.pdf

2 Extra Costs Commission, 2015, *Driving down the extra costs disabled people face*. Available at: https://www.scope.org.uk/Get-Involved/Campaigns/Extra-costs/Extra-costs-commission/Full-Report

3 Public Health England, 2016, *HIV in the UK 2016 report.* Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/602942/HIV_in_the_UK_report.pdf

4 NAT, 2009, *Working with HIV.* Available at: http://www.nat.org.uk/sites/default/files/publications/Aug-2009-Working-with-HIV.pdf

5 Tricket, A. et al, 2017, 'Survival of HIV-positive patients starting antiretroviral therapy between 1996 and 2013: a collaborative analysis of cohort studies', *The Lancet HIV*, May 10 2017

6 Monaghan, K., 2013, *Monaghan on Equality Law,* Oxford University Press.

7 Extra Costs Commission, 2015, Driving down the extra costs disabled people face.

8 Macmillan, 2017, *No small change.* Available at: http://www.macmillan.org.uk/documents/policy/money-and-cancer-policy-report.pdf

People living with HIV are part of the 15 million people in the UK living with a long-term condition[9], all of whom require financial products to increase their long-term financial security and resilience to unexpected financial shocks. Financial resilience is crucial for people living with HIV as it supports adherence to treatment[10] and provides security for those who are increasingly living longer lives.

Improving access is not only beneficial to consumers. By improving access to financial products, financial service providers can widen their customer base to include a significant and growing section of the market. The commercial opportunities for providers who are quick to adapt to the changing needs of consumers are substantial.

This report aims to contribute to a fuller understanding of the range of barriers facing people living with HIV when accessing financial products and services. Addressing these barriers will require input and effort from a range of stakeholders. This is reflected in the recommendations of this report, which highlight actions that should be taken by the financial services industry, the financial services regulator, government, and HIV voluntary and community organisations (VCOs). These recommendations have been developed through discussion with members of those stakeholder groups. We hope to work constructively with them to engender change to the benefit of all concerned.

Each of the sections of this report concludes with a list of recommendations but there are some more general themes that have come out of the research process.

The strong parallels between the experiences of people living with HIV and those living with other pre-existing conditions highlight that this is a broad issue requiring a holistic and joined up approach. NAT and other HIV VCOs should engage in such an approach by coordinating with other long-term condition and disability organisations to identify common issues, ensure strategic working and a collective voice on improving access to insurance for people with pre-existing conditions.

There has been increased attention from the regulator on the issue of access for certain groups and this is to be welcomed. For example, the Financial Conduct Authority (FCA) recently launched a consultation on access to travel insurance for people with cancer. The FCA, in line with its business priorities for access and vulnerability,[11] should continue to focus on the needs of marginalised customers, including those with pre-existing conditions such as HIV, in accessing insurance and determine how these needs can be better met.

RECOMMENDATIONS

Recommendation:

NAT and similar HIV VCOs should coordinate with other long-term condition and disability organisations to identify common issues, ensure strategic working and a collective voice on improving access to insurance for people with pre-existing conditions.

Recommendation:

The FCA should continue to focus on the needs of marginalised customers, particularly those with pre-existing conditions including HIV, in accessing insurance and determine how these needs can be better met.

9 Department of Health, 2012, *Long-term conditions compendium of Information: 3rd edition*. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216528/dh_134486.pdf

10 Burch, L. et al, 2014, 'Socio-economic factors and virological suppression among people diagnosed with HIV in the United Kingdom: results from the ASTRA study.', *Journal of the International AIDS Society*, 17(4 Suppl 3):19533.

11 FCA, 2017, *Business Plan 2017/18*. Available at: https://www.fca.org.uk/publications/corporate-documents/our-business-plan-2017-18

2. KEY FINDINGS

SELF-EXCLUSION FROM THE MARKET

There is a lack of awareness amongst people living with HIV of the availability of financial products.

49% of survey respondents thought that life insurance is not available to people living with HIV, despite it being available since 2009.

60% of survey respondents had avoided applying for a financial product because of their HIV status due to fears of high cost, refusal and stigma.

UNSUITABLE PRODUCTS

Products don't always meet the needs of people living with HIV, and policies may exclude HIV-related claims.

DIFFICULTY NAVIGATING THE MARKET

Only **28%** of survey respondents knew where to look for HIV-inclusive financial products.

Mainstream comparison sites often don't work for people living with HIV and specialist insurers can be difficult to find.

BARRIERS THAT CAN EXIST FOR PEOPLE LIVING WITH HIV WHEN ACCESSING FINANCIAL PRODUCTS

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HIGHER PREMIUMS

People living with HIV may be deemed a higher risk by insurers and charged a higher premium, but it's not always clear whether the price fairly reflects the risk.

Some people living with HIV are priced out of the market because they're deemed too risky – often because they don't live well with HIV or they have another health condition.

INELIGIBILITY

25% of survey respondents said they knew or suspected they had been refused a financial product in the last five years because of their HIV status.

Some people living with HIV may find they are ineligible for products because they don't meet the requirements for CD4 count and viral load.*

Some products continue to exclude all people living with HIV, including individual income protection insurance and critical illness cover.

ADDITIONAL BARRIERS

34% of survey respondents thought that another factor apart from HIV may impact their access to financial products.

Factors identified included another health condition, financial status, age and immigration status.




*Viral load tests measure the amount of HIV's genetic material in a blood sample, whilst CD4 count tests indicate the strength of the immune system. A viral load below 50 is classed as undetectable – meaning the virus is at a very low level and cannot be passed on. People living with HIV who have a CD4 count over 500 are usually in good health. For further information see http://www.aidsmap.com/CD4-viral-load-amp-other-tests/page/1327442/

3. METHODOLOGY

Between February and April 2017, NAT ran an online survey and two focus groups to explore how living with HIV impacts upon people's experiences of accessing financial products and services. The aim of the research was to:

- Describe the recent experiences of people living with HIV in the UK of accessing financial products
- Identify how HIV status specifically impacts access to financial products.

The survey was promoted through a broad range of channels (both offline and online) including social media platforms, the LGBT media, and organisations and services working with people living with HIV throughout the UK. The focus groups took place in London and Manchester, and participants were recruited from those who had completed the online survey.

SURVEY ELIGIBILITY

The only criteria for participating in the survey and focus groups was that the individual must be living with HIV in the UK. 215 people responded to the survey, of which 202 were eligible to take part. Of these 202, 16 participants later participated in the focus groups.

SURVEY DEMOGRAPHICS

Whilst the survey sample size was small, the demographics were fairly reflective of the population living with HIV in the UK.

- The majority (96%) of participants were of working age, aged between 18 and 64. The remaining participants were aged 65+.
- Three quarters (75%) of participants identified as male, including two trans men. A quarter (25%) of participants identified as female, including one trans woman.
- Around two thirds (66%) identified as gay whilst just under a third (29%) identified as straight. The remaining participants identified as bisexual (2%), lesbian (1%), or preferred to describe their sexual orientation in a different way (2%).
- Almost three quarters (71%) identified as white, around a fifth (18%) identified as black, and the remaining participants identified as either mixed (6%), another ethnicity (2%), or preferred not to say (3%).
- Participants lived across the UK – 10% in Scotland, 5% in Wales, 2% in Northern Ireland and the remaining 83% in England.

We also asked participants information about their employment status, financial status, and length of diagnosis.

- Just over two thirds (67%) of participants were employed whilst a fifth (20%) were unemployed (including people on long-term sickness benefit). The remaining participants were retired (9%), students (2%) or preferred not to say (2%).
- There was a fairly even spread across income ranges, ranging from under £10,400 to £52,000 and above.
- In terms of length of diagnosis, 33% had been diagnosed 0-5 years ago, 20% 6-10 years, 29% 11-20 years and 18% had been diagnosed for more than 21 years.

4. CURRENT AVAILABILITY OF FINANCIAL PRODUCTS FOR PEOPLE LIVING WITH HIV[12]

Whilst barriers to access remain, a significant range of financial products are available to people living with HIV. Where there are difficulties, these tend to be with products that require medical information within the application process. Of course, there may be additional barriers other than HIV status which create access issues to financial products for people living with HIV – these are discussed in the chapter on 'Additional Barriers'.

People living with HIV should encounter no problems in accessing the following products and services as a result of their HIV status:

- Banking services including credit cards, savings accounts and loans
- Pensions
- Investments in stocks and shares
- General insurance products such as motor insurance, home contents insurance, buildings insurance, pet insurance, etc. which do not require medical information.

The following products have been identified as ones where there may be barriers to access for a variety of reasons:

MORTGAGES

HIV status should not affect access to a mortgage. The mortgage application process determines eligibility on the basis of employment, income and credit history – not medical history. Where problems may arise is when mortgage brokers attempt to sell life insurance, or other types of protection policies, alongside the mortgage. The mortgage applicant is under no obligation to purchase these products or explain why they do not want them. However, mortgages for schemes such as shared ownership may require life insurance to be purchased alongside the mortgage.

PRIVATE MEDICAL INSURANCE

Availability of private medical insurance for people living with HIV varies between providers. Some will not cover people living with HIV at all. Others may offer cover but exclude HIV and any related conditions, and some offer cover for people living with HIV and will include HIV and any related conditions within the cover.

12 Unless otherwise indicated, the information summarised in this section is adapted from NAM Aidsmap, *Social and Legal issues for people living with HIV – Personal Finance.* Available at: http://www.aidsmap.com/Personal-finance/page/1497503/

INDIVIDUAL INCOME PROTECTION INSURANCE

Individual income protection (IIP) insurance is a long-term policy which makes regular payments to the policyholder when they are forced to be absent from work due to illness, accident or disability. These payments will usually be an agreed percentage of the policyholder's income, and will be paid out after an agreed window period of absence has taken place. IIP insurance is currently unavailable to anyone living with HIV. IIP should be differentiated from group income protection (GIP) insurance, which is available through the workplace and is often not medically underwritten.

WORKPLACE BENEFITS

Workplace benefits, including life and protection policies, are mostly available to people living with HIV. These are group policies, with the risk spread across the company, and therefore may not be medically underwritten – particularly in larger companies. NAM Aidsmap advise people living with HIV to request to see the policy and application form before applying – "if there are questions about pre-existing conditions, then it's advisable for the employee to go back to the employer and simply state that they have a pre-existing condition that they know will exclude them from the cover. They are under no obligation to say what the condition is."[13]

CRITICAL ILLNESS COVER

Critical illness cover (CIC) is an insurance product that pays out a one-off lump sum upon diagnosis of one of the critical illnesses listed within the policy. CIC is currently almost entirely unavailable to anyone living with HIV.[14]

LIFE INSURANCE[15]

Life insurance that does not automatically exclude people living with HIV has been available since 2009. Most insurers now offer term life insurance[16] that is inclusive of people living with HIV, though terms and conditions vary considerably. It is generally advised that people living with HIV purchase life insurance through a specialist broker to ensure they are buying a product that meets their needs. Whole-of-life insurance is only available to people living with HIV over the age of 50, as some over 50s life insurance products are not medically underwritten. However, these plans often have restrictions that do not apply to underwritten policies.

TRAVEL INSURANCE

Travel insurance is becoming increasingly accessible for people living with HIV. An application for travel insurance usually involves a medical screening process in which people living with HIV will have to provide the results of recent blood tests and a medical report. Most general travel insurance will usually exclude any pre-existing conditions from cover or offer cover for pre-existing conditions at a higher price, whilst specialist providers will often sell policies that are inclusive of HIV and any related conditions.

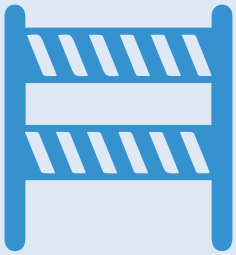
13 ibid.

14 We have been informed that there is one product on the market which can offer up to £50,000 limited cover (covering eight critical illnesses) with pre-existing conditions excluded. For further information see http://www.specialrisksbureau.co.uk/health-conditions/hiv

15 Unusual Risks, 2017, *HIV Life Assurance Fact Sheet.*

16 Term life insurance is insurance which runs for a fixed period – such as 5, 10 or 25 years. These kinds of policies only pay out if you die during the term of the policy. For further information see https://www.moneyadviceservice.org.uk/en/articles/do-you-need-life-insurance

5. ACCESS ISSUE ONE: SELF-EXCLUSION DUE TO FEARS OF HIGH COST, REFUSAL AND STIGMA



5.1 THE NATURE OF THE PROBLEM

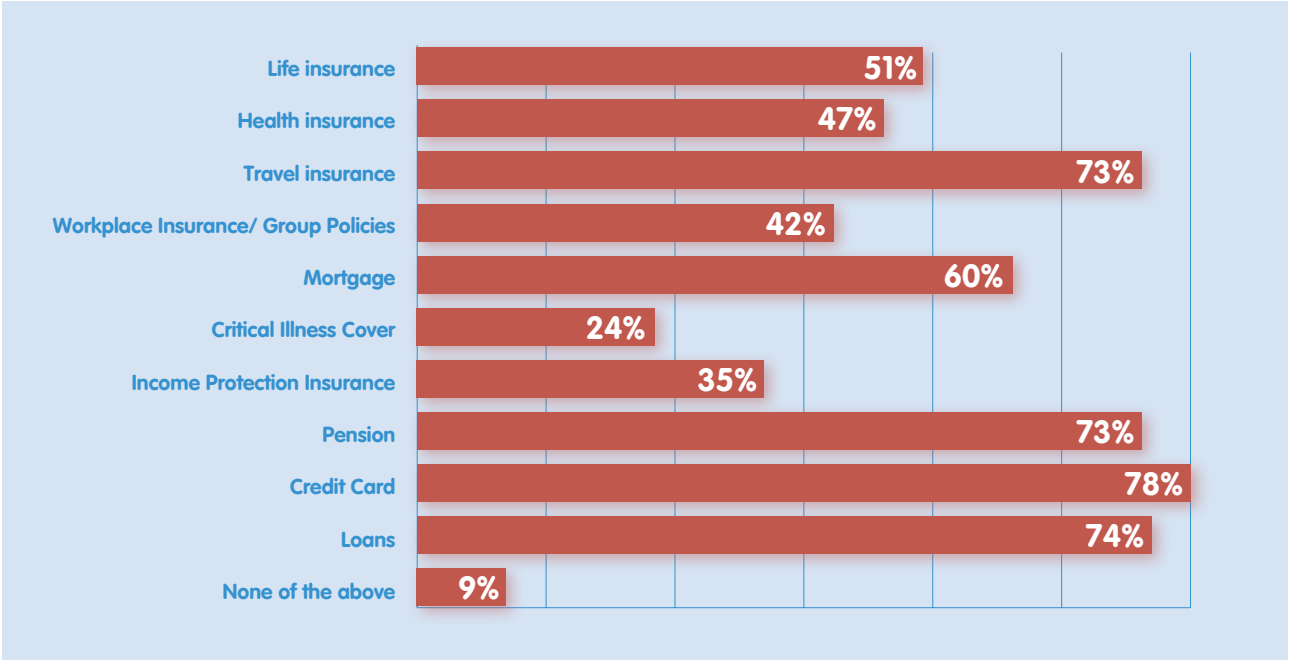
A significant barrier to access to financial services for people living with HIV is the widespread perception that many financial products are not available to them. This perception has led to relatively significant self-exclusion from the financial services market, and has negative implications for the ability of people living with HIV to increase their financial resilience.

When asked "As far as you are aware, which of the following are available to people living with HIV?" the range of responses demonstrated that there is still considerable work to do in improving people's knowledge of what is available to them. It is concerning that nearly half of participants did not think that life assurance is available to people living with HIV, despite it being available since 2009. Around a fifth did not think that travel insurance and credit cards are available to people living with HIV, and around a quarter did not think that pensions and loans are available. Significantly, only 42% think that workplace insurance/group policies are available to people living with HIV, indicating that many people might be missing out on protection policies that are only available to them through the workplace, such as critical illness cover and income protection.

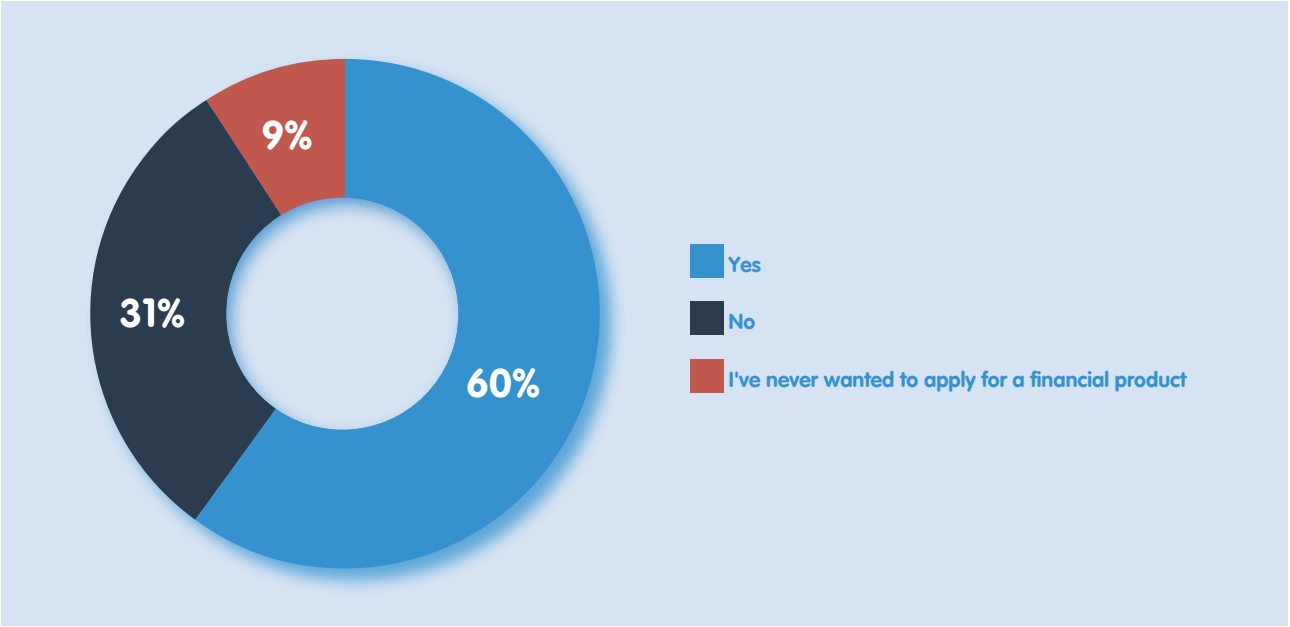
The perception that certain financial products are not available to them leads to people living with HIV excluding themselves from the financial market. When asked whether they had ever wanted to apply for a financial product, but didn't because of their HIV status, 60% replied 'Yes'.

Of those who self-excluded, three-quarters said they had avoided applying for life insurance, approximately a third had avoided applying for travel insurance, and just over a quarter had avoided applying for a mortgage. When asked why they thought accessing these products would be more difficult, the majority of responses can be allocated into three categories, with some sharing elements of all three: fear of disclosure, including concerns about stigma, confidentiality, and data protection; fear of higher costs; and fear of refusal.

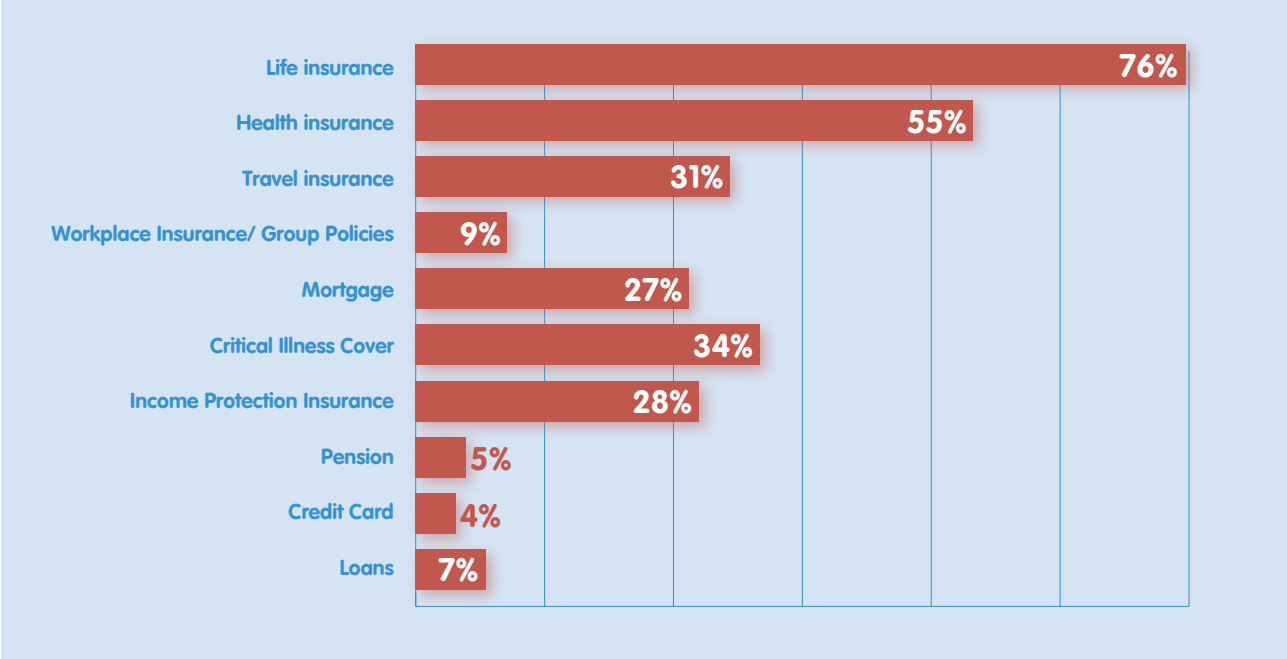
Whilst these fears can be linked to a lack of awareness of availability, they also need to be understood within two contextual factors – past experiences and the current levels of stigma facing people living with HIV.



GRAPH 1. AS FAR AS YOU ARE AWARE, WHICH OF THE FOLLOWING ARE AVAILABLE TO PEOPLE LIVING WITH HIV?



GRAPH 2. PERCENTAGE OF THOSE WHO AVOIDED APPLYING FOR A FINANCIAL PRODUCT DUE TO THEIR HIV STATUS



GRAPH 3. THE TYPES OF PRODUCTS AVOIDED

FEAR DUE TO PAST EXPERIENCES

The perception that insurance and other financial products are not available to people living with HIV has its roots in the historical treatment of people living with HIV by financial services. The fear and stigma that arose in the beginnings of the AIDS epidemic in the 1980s strongly influenced how financial services reacted to people living with HIV, and the resulting panic led to discriminatory treatment underlined by homophobic and ill-informed assumptions.

For many gay and bisexual men, invasive "lifestyle" questionnaires, mandatory HIV testing, heavily-loaded premiums and a refusal to accept the validity of long-term relationships, were a common experience when seeking life and protection insurance[17], until strict guidelines on what questions could be asked of applicants to assess the risks to their health were introduced by the Association of British Insurers (ABI) in 2005.[18] Although there was evidence that some of these practices persisted following the introduction of

> **"Prior to being positive my partner and I changed from individual life policies to a joint policy. Our sexual orientation meant that our premiums went from £11-£15 per month to over £30 each. We were told we were listed on an 'impaired life' register. This was in 2002 and prior to my diagnosis - but as a result of that I am fearful of 'coming clean' with insurers."**
>
> SURVEY PARTICIPANT

17 Collinson, P. "Much pride but a lot of prejudice", *The Guardian*, July 26 2003. Available at: https://www.theguardian.com/money/2003/jul/26/gayfinance.discriminationatwork

18 ABI, 2005, *Statement of Best Practice on HIV and Insurance.*

the guidelines[19], it appears that they have now mostly been eliminated.

Yet whilst discrimination on the basis of sexual orientation no longer occurs and insurance providers have made considerable improvements in their treatment of people living with HIV, firms could still make the consumer journey of those living with HIV a more positive experience. Whilst the majority of survey respondents said they had not experienced stigmatising behaviour when accessing financial products in the last five years, around a quarter of participants said they had. Amongst other examples, these participants highlighted insensitive reactions to disclosure, insensitively phrased questions during the medical screening process, and selling practices that made them feel pressured to disclose when they had already declined to purchase a product.

"Just the attitude of the "customer services" representative I dealt with: they seemed bemused that someone with HIV would be daft enough to apply for cover." **Survey participant**

"The advisor seemed shocked that I had HIV. It was as if oh you don't look like you have HIV. The look on their face was one of horror. It was so uncomfortable." **Survey participant**

"Yeah I had a slightly similar experience with life insurance. [After completing an online quotation tool], the next day I get a phone call, and once they grabbed hold of me they would not take no for an answer. They wanted to contact my doctor, they wanted to do this and that, and in the end, I got the refusal letter as well, and it just hit me like a ton of bricks. I just wish they'd stopped when I asked them to." **Focus group participant, London**

The consequence of these experiences is low levels of trust in financial services, particularly the insurance industry, as well as fears about refusal, high costs, and experiencing stigmatising behaviour. It has also meant that some people living with HIV would rather not disclose their status when applying for insurance, not realising that this will make their policy invalid.

FEAR DUE TO CURRENT LEVELS OF SOCIETAL STIGMA

In addition to this legacy, the level of stigma that people living with HIV still face in today's society makes many of them wary of disclosing their status. The apprehension about accessing financial products where medical information is required must be understood in this context.

A 2014 NAT report found that a significant minority of the British public continue to hold stigmatising beliefs and attitudes towards those living with HIV.[20] The impact of this on people living with HIV is substantial. The Stigma Survey UK 2015 found that 18% of respondents reported having had suicidal thoughts within the past 12 months and around half of respondents reported feelings of shame, guilt, low self-esteem, and self-blame in relation to their HIV status.[21]

People living with HIV can also experience stigma in settings such as healthcare services and the workplace, which can make them nervous about disclosure.[22] This can be especially difficult for people living with HIV in rural areas with services embedded within smaller communities.

> **"Stigma. Non-disclosure = Invalid. Disclosure = Revealing HIV status to people in my community like the bank/building society."**
>
> SURVEY PARTICIPANT

19 See for example, Hughes, K. "Insurers criticised for attitude to gay men", *The Independent,* April 18 2008. Available at http://www.independent.co.uk/money/insurance/insurers-criticised-for-attitude-to-gay-men-811634.html

20 NAT, 2014, *HIV Public knowledge and attitudes 2014.* Available at: http://www.nat.org.uk/sites/default/files/publications/Mori_2014_report_FINAL_0.pdf

21 Stigma Survey UK, 2015, *HIV in the UK: Changes and Challenges; Actions and Answers – National Findings.* Available at: http://www.stigmaindexuk.org/reports/2016/NationalReport.pdf

22 ibid

5.2 ANALYSING THE DATA

INCREASE LEVELS OF AWARENESS

Because of the stigma attached to HIV, many people living with HIV tend to have less trust in mainstream services and more trust in HIV specialist services where they feel they can be open and comfortable about their HIV positive status. When we asked focus group participants where they would like to get information about HIV-inclusive financial services, many participants said they would like to get this from their HIV clinics or HIV VCOs. A number of gay men also suggested that HIV-inclusive insurers could advertise in gay dating apps and the LGBT media as places where they might access and trust this information.

"I think it would be good to have a few more leaflets, also places like THT or Positively UK maybe having a link to some of these insurance companies, maybe in Boys, QX Magazine." **Focus group participant, London**

"Also, adverts in dating apps could be useful… And also the clinic at 56 Dean Street, on the HIV treatment floor – I think leaflets there would be useful."
Focus group participant, London

Some information on personal finance already exists within the HIV sector. NAM Aidsmap and Terrence Higgins Trust (THT) include sections on their websites on personal finances and accessing different types of financial products.[23] The Association of British Insurers also recently published a consumer guide on HIV and Life Insurance which was written in collaboration with NAT and other organisations with specialist knowledge of HIV.[24] Yet it was evident from our research that only a limited number of people are accessing this information.

> **"I think when it comes to HIV and this kind of thing you kind of want your local service provider to be able to relay that information to you because it's like a space where you can…you feel like confident in talking about your status as well as everything else."**
>
> FOCUS GROUP PARTICIPANT, MANCHESTER

HIV VCOs, including NAT, should work together with financial service providers to ensure that accurate and up-to-date information on availability of financial products is more widely disseminated, both online and offline. It is particularly important that HIV VCOs ensure that people aren't excluding themselves from financial products that are easily accessible and do not require medical information, such as banking services and mortgages.

PROVIDE REASSURANCE ON CONFIDENTIALITY AND DATA PROTECTION

Insurers need to reassure consumers that information they provide on their health will remain confidential and is protected under data protection legislation. This is important for all consumers disclosing details of their health, but will be particularly pertinent for people living with HIV due to the unfortunate levels of social stigma attached to this condition. Accordingly, insurers should provide up-front clear information on confidentiality and how data on medical conditions is stored and shared in any promotional material and throughout the application process.

23 See http://www.aidsmap.com/Personal-finance/page/1497503/ and http://www.tht.org.uk/myhiv/Your-rights/Travel/Travel-insurance

24 ABI, 2016, *HIV and Life Insurance*. Available at: https://www.abi.org.uk/globalassets/sitecore/files/documents/publications/public/2016/hiv-and-insurance/hiv-and-insurance-guide.pdf

COMBAT STIGMA

Crucial to combatting self-exclusion is a joint effort from all stakeholders to combat the stigma faced by people living with HIV. People living with HIV and HIV VCOs have been leading on this work for decades, but it also requires effort from those outside the sector.

Within financial services, providers can play an important role in addressing stigma by reviewing their practices. As highlighted above, whilst significant progress has been made in improving the treatment of people living with HIV, a significant minority of people living with HIV have recently experienced stigmatising behaviour when accessing financial products. These experiences have taken place across the consumer journey, including at the point of access, during the medical screening process, and when their claim is being handled. To address this, insurance providers should test products and processes with focus groups of people living with HIV to ensure they are accessible, non-stigmatising and meet their needs. Financial service providers also need to be aware that sales practices can put pressure on people living with HIV to disclose their status when there is no need, and must explore how this can be addressed.

Stigma must also be addressed at a societal level, with clear leadership required from all governments of the UK. In 2016, NAT recommended that "*All UK governments should develop an evidence-based strategy for reducing HIV stigma which includes a range of approaches to tackle the many different factors contributing to stigma.*" Building on this recommendation, it is crucial that any strategy considers how stigma affects access to financial services and how this can be addressed.

5.3 RECOMMENDATIONS

Recommendation:
HIV VCOs should work together with financial service providers to more widely disseminate information to improve understanding of the availability of financial products to people living with HIV.

Recommendation:
Insurance providers should provide up-front clear information on confidentiality, data privacy and data sharing, particularly in regard to information about medical conditions.

Recommendation:
Insurance providers, including those that deal with medical screening and claims handling, should explore how they can improve the customer journey for people living with HIV. This should include testing products and processes with focus groups of people living with HIV to ensure they are accessible, non-stigmatising and meet their needs.

Recommendation:
Financial service providers giving financial advice and guidance, including those for mortgage-related sales, should be aware that selling practices can put pressure on people living with HIV to disclose their status, and explore how this can be addressed.

Recommendation:
All UK governments should develop an evidence-based strategy for reducing HIV stigma including consideration of how stigma may influence access to financial services.

6. ACCESS ISSUE TWO: DIFFICULTY NAVIGATING THE MARKET

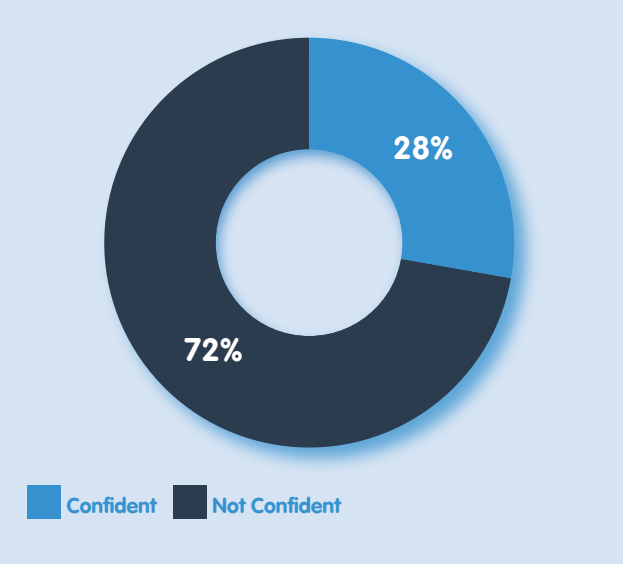
6.1 THE NATURE OF THE PROBLEM

When asked about their knowledge of HIV-friendly services and products, 72% responded that they were not confident in knowing where to look for such specialist services. This corroborates the findings that people living with HIV are not fully aware of which financial products are available to them.

Comparison websites provide one of the most accessible tools to search and compare insurance companies, but these sites tend to cater for the mainstream rather than 'non-standard' customers.[25]

Participants in the survey and focus groups highlighted that they often find themselves automatically excluded when they complete online quotation tools as soon as they state that they have HIV.

"There was a question in these applications 'Have you ever been diagnosed with HIV or Hepatitis C.'



GRAPH 4. PERCENTAGE OF THOSE CONFIDENT IN KNOWING WHERE TO LOOK FOR HIV-INCLUSIVE FINANCIAL PRODUCTS

25 FCA, 2016, *Access to Financial Services in the UK*. Available at: https://www.fca.org.uk/publication/occasional-papers/occasional-paper-17.pdf

As soon as you select yes, sorry we are unable to offer you this product." **Survey participant**

Specialist insurers also highlighted to us that they are often not featured on mainstream comparison sites and do not have the resources to promote their services more widely. Many people living with HIV are left to sift through individual companies, which can be time consuming, exhausting and dispiriting. The combination of repeat disclosure to multiple companies with repeat refusals can be doubly traumatic for people living with HIV.

ONEROUS APPLICATION PROCESSES

Even when people aren't automatically refused initially, participants complained about onerous application processes which involved providing considerable levels of medical information and may still result in refusal. Research participants highlighted that the process was made more difficult by the length of time it took for medical reports to be compiled – sometimes taking up to 3 months. These delays are often due to multiple reports being required from different medical professionals (such as GPs and specialists) and as these reports are not subject to timeframes and most medical professionals have a high number of competing demands on their time, they can often take months to be returned.

"I have already encountered problems accessing the above – I waited 3 months while medical reports from my consultant and GP were compiled. The policy had by then changed and I withdrew my application." **Survey participant**

"Have also approached [specialist broker] for travel insurance and was expected to jump through hoops in giving so much detail about my personal situation there was not enough time to get all the info to them before leaving." **Survey participant**

There was also a perception amongst participants that an excessive amount of information is often required for insurers to make their decisions. The number of questions asked appears to vary depending on the product and the product design.

> **"The thing that really sticks in my throat is the amount of disclosure you've got to do… then you disclose and they're like 'ok no we can still work with this you know but I just need to send this to the underwriters and have a discussion' and you think ok that's a disclosure to one team ok let me hear what comes back. Underwriters come back and they tell you that they can't actually cover you so they refer you to another insurance company. And you think ok so I've disclosed to them, now I'm having to contact somebody else and disclose it to them, these are people who have all of my details and these are people that you know are sitting in an environment where all of your information is there on a screen which is accessed by other people… Then they got back in touch with me having chased them, this was probably the fourth group that I was dealing with, and they quoted me just over fifteen hundred pounds to cover me [for a life insurance policy]."**
>
> FOCUS GROUP PARTICIPANT, MANCHESTER

6.2 HOW ACCESS CAN BE IMPROVED

IMPLEMENT EFFECTIVE SIGNPOSTING

When approaching insurers directly, people living with HIV could benefit from being signposted to insurance providers who can provide cover or to an appropriate signposting service, such as the British Insurance Brokers Association's (BIBA) Find-A-Broker service. The ABI and BIBA currently have a voluntary agreement with the Government to provide this type of signposting for older people who have been refused motor or travel insurance on the basis of their age. BIBA reports that 200,000 older people were referred to their Find-A-Broker service over the first three years of this agreement.[26]

Unfortunately it is difficult to know how effective this has been as the outcomes of signposting are not monitored. It is particularly important that signposting is effective, as being referred to a broker or provider that does not appropriately cater for people living with HIV could serve to exacerbate disillusionment with the industry and contribute to further self-exclusion. NAT believes that an appropriate signposting agreement should also be adopted for people with pre-existing conditions, including people living with HIV. Effective monitoring should be in place to ensure that this service is helping people locate appropriate specialist providers, and leading to successful outcomes.

Insurance intermediaries, such as price comparison sites, can also support people with pre-existing conditions to locate appropriate cover through signposting. From our research it is evident that people living with HIV are often using price comparison sites to try and find cover, even if these sites are not appropriate for their needs. It is important therefore that people living with HIV can locate a more suitable service via these sites, either by being directed to a specialist comparison site or an appropriate signposting service. Such measures will contribute to a more holistic, joined-up approach to signposting that should make navigating the market easier for people living with HIV.

HIV VCOs may also be able to provide some information on specialist companies for their service users. Some organisations already do this; for example, Terrence Higgins Trust has a list of HIV-inclusive travel insurance providers on its website.[27] However, the burden of responsibility should lie with firms and their representative bodies to enable people to be able to access appropriate services. Charities often don't have the capacity to keep information on services up to date, as well as having valid concerns around reputational risk if a service user has a negative experience. For example, Macmillan no longer signposts service users to specialist firms and brokers as feedback on companies varied substantially. They received a number of complaints about pricing, problems with getting cover and the level of customer service.[28]

IMPROVE THE EFFICIENCY AND QUALITY OF THE UNDERWRITING PROCESS

As per the previous chapter, HIV VCOs can play a role in improving financial capability through the dissemination of information about financial services, including how long application processes are likely to take and what medical information is

26 ABI & BIBA, 2016, *Voluntary agreement on age and insurance continues ensuring older people can access insurance.* [online]. Available at: https://www.abi.org.uk/news/news-articles/2016/01/voluntary-agreement-on-age-and-insurance-continues-ensuring-older-people-can-access-insurance/

27 See http://www.tht.org.uk/myhiv/Your-rights/Travel/Travel-insurance

28 Macmillan, 2014, *Getting travel insurance*. Available at: https://be.macmillan.org.uk/Downloads/CancerInformation/LivingWithAndAfterCancer/MAC4056GettingtravelinsuranceE820142912.pdf

usually required. However, insurance providers should also continue to take steps to improve the quality of the underwriting process. Progress has already been made through the adoption of electronic processes to reduce the time it takes to offer cover, but insurance providers could also work more closely with medical professionals to resolve the issue of delays in medical reports being returned. Insurance providers could also reduce the number of questions asked, or ask more individually tailored questions during the medical screening process.

SHARE POSITIVE EXPERIENCES

The above recommendations can facilitate the conditions in which people living with HIV can better access affordable insurance products that meet their needs. These structural changes are crucial to improving access, but individuals living with HIV can also support each other by sharing positive experiences of accessing financial products, where they have had them, on community forums and message boards. As well as combating the perception that financial products are not available to people living with HIV, this can also help people identify companies that are HIV-inclusive and provide a good service. HIV VCOs should help facilitate this by initiating discussions on any forums or message boards that they moderate.

6.3 RECOMMENDATIONS

Recommendation:
Insurance providers and intermediaries, including comparison sites, should implement a joined-up and holistic approach to signposting for people with pre-existing conditions to appropriate specialist providers, ensuring that it is effective by monitoring outcomes and sharing findings.

Recommendation:
Insurance providers should innovate to improve the quality and efficiency of the underwriting process. For example, by working with clinicians to reduce the time taken to compile medical reports, and by reducing or individually tailoring the number of questions asked.

Recommendation:
Where they have had them, people living with HIV should share positive experiences of accessing financial products on community forums and message boards.

7. ACCESS ISSUE THREE: HIGHER PREMIUMS

7.1 THE NATURE OF THE PROBLEM

Where someone has a pre-existing condition, insurers generally use information about that person and their condition alongside claims data and medical studies to estimate the risk of them making a claim, and tailor the premium accordingly. This approach is known as 'individualised risk pricing', and is in contrast to the traditional model of mutuality (where risk is pooled and premiums were the same or similar for everyone). Running through much of the feedback from people living with HIV was the complaint that premiums are often higher than expected, to the point that some find them unaffordable.

> **"Having to declare you have HIV puts the price up for most financial services."**
>
> SURVEY PARTICIPANT

> **"I tried contacting providers that were supposed to cover my condition but the prices quoted were sufficiently prohibitive that it acted as a refusal from my perspective."**
>
> SURVEY PARTICIPANT

LACK OF TRANSPARENCY ON PRICING

There was a strong sense amongst research participants that it was unclear why they were being charged so much, leading them to feel that they were being discriminated against. This feeling was often reinforced by the significant variance in price between providers, particularly between mainstream insurers versus specialist providers. Amongst other reasons,

29 FCA, 2016, *Access to Financial Services in the UK*.

> I'm with [a specialist provider] because I've got [a current account that offers travel insurance] I phoned up, gave them all my information, and they wanted over eight hundred pounds extra as a supplement for the fact that mainly the two of us are HIV positive. Without the HIV it would have been two hundred pounds for anxiety, asthma. You're like well that's still ridiculous when I've got cover for less than a tenth of that. That is blatantly them trying to not cover you.
>
> FOCUS GROUP PARTICIPANT, MANCHESTER

this can be due to mainstream insurers using lower-cost, automated and standardised underwriting processes which do not have the level of detail required to cater for 'non-standard' risks.[29]

Whilst this underlines the need for better signposting to specialist insurers, it also highlights the need for all insurers to improve the consumer experience of people living with HIV. For the insurer, higher premiums may well be justified by the higher risk involved, the expected higher value of claims, and/or a more costly and lengthy underwriting process. However, it is not always clear to the consumer why they have been charged the premium and whether it accurately reflects the risk they represent. As highlighted by the quotes above, this lack of transparency fuels distrust of insurers and can lead to self-exclusion.
At the market level, determining whether the premiums for people living with HIV are fair, and based on accurate, reliable, and relevant data, is also difficult. Insurers treat the algorithms they use and the statistics on which they base decisions as commercially sensitive because they are fundamental to their business model. For consumers and consumer organisations, such as NAT, it is therefore challenging to hold insurers to account over their obligations under the Equality Act.

BEING PRICED OUT OF THE MARKET

As the wealth and quality of information available to insurers increases, the individualised risk pricing approach is taking on a new, more precise meaning. This emerging trend creates a mixed picture for people living with HIV. For those who are adherent to treatment, diagnosed early and otherwise healthy, this approach will probably reduce their premiums. For example, there is evidence that the travel insurance market is dramatically improving for people living with HIV as more specific questions on HIV are incorporated into automated underwriting processes. There were a number of positive comments to our survey and in our focus groups about travel insurance, with some people stating that they had found that they were not charged a higher premium at all, that screening processes were sensitively handled and they had quality cover that covered HIV and related conditions.

> I found that I was able to obtain very good annual travel insurance for no higher cost after giving information about my HIV status and accepted my answers without question."
>
> SURVEY PARTICIPANT

> I mainly use travel insurance but then I make a point of using an HIV friendly insurer. So far in all the years I have used them I have been completely satisfied with their service. They are professional and approachable, efficient and friendly."
>
> SURVEY PARTICIPANT

7.2 HOW ACCESS CAN BE IMPROVED

INCREASE TRANSPARENCY

As highlighted above, the approach used by the insurance industry of individualised risk pricing means that some people will inevitably be charged higher premiums. Yet the lack of transparency around pricing means consumers living with HIV are being asked to take on trust that insurers' premiums are fair and accurately reflect their risk profile. The lack of transparency only serves to exacerbate mistrust of insurers. It is imperative that insurers are more transparent with consumers about the main factors that have influenced the price they have been quoted, as well as the data used in the assessment of risk. For example, citing recent medical studies as well as proving that they have taken individual circumstances into account could demonstrate to a person living with HIV that the insurer has taken into consideration all the information available when reviewing their application.

NAT believe it is important for insurance providers to be more transparent in the public domain about how they determine risk and what other factors influence the price and availability of cover. In doing so, they will make it easier to identify solutions to improve access. The current lack of transparency means it is difficult for consumer organisations to determine whether firms are adhering to their obligations under the Equality Act 2010. We believe this is an area that should be explored by the Equality and Human Rights Commission (EHRC), with the support of the FCA, to determine whether the difference in treatment applied to disabled people is always based on reliable, relevant and up-to-date data.

UTILISE COLLECTIVE PURCHASING POWER

Innovation in insurance through technology and design can also present an opportunity to lower costs for people living with HIV. In their final report, the Extra Costs Commission highlighted the work of Bought By Many, a free members only service that forms groups of consumers with similar needs. This enables them to more easily find insurance that meets their needs whilst negotiating discounts with insurers in order to reduce costs. HIV VCOs should consider the role we can play in facilitating the development and promotion of such schemes.

DETERMINE WHETHER A SOCIAL POLICY INTERVENTION IS REQUIRED

The pricing out of people who have complications with their HIV and/or another health condition, along with a substantial number of people with other pre-existing conditions, raises questions over who is responsible for ensuring their financial inclusion. Insurers are first and foremost profit-making private companies, and they are not obligated to provide cover to those they deem too great a risk. Safeguarding access to a financial market is instead usually characterised as a social policy issue, and therefore the responsibility lies with government.[30] A high-profile example of government intervening in the insurance market is that of the Flood Re scheme, a not-for-profit flood reinsurance fund, owned and managed by the insurance industry, and established to ensure that people living in properties in the UK at the highest risk of flooding are able to obtain affordable cover.[31]

30 FCA, 2016, *Access to Financial Services in the UK*

31 Department for Environment, Food and Rural Affairs (DEFRA), 2014, *A short guide to Flood Re.* Available at: https://consult.defra.gov.uk/flooding/floodreinsurancescheme/supporting_documents/A%20short%20guide%20to%20Flood%20Re.pdf

We welcome the recent government decision to create a ministerial post for financial inclusion, and hope this reflects a desire to show leadership on this important issue. In particular, we believe the Minister for Financial Inclusion should lead a debate on suitable and affordable protection for consumers unable to obtain personal insurance through the market in order to determine how best this can be addressed.

7.3 RECOMMENDATIONS

Recommendation:
Insurance providers should be more transparent with consumers about the main factors that have influenced the price they have been quoted.

Recommendation:
Insurance companies should be more transparent in the public domain about how they determine risk and what other factors influence the price and availability of cover.

Recommendation:
The EHRC, with the support of the FCA, should explore whether insurance providers are meeting their obligations towards disabled people, including those living with HIV, under the Equality Act 2010 in basing their decisions on reliable, relevant and up-to-date data.

Recommendation:
HIV VCOs should consider how we can facilitate the development and promotion of high-quality group purchasing schemes which meet the needs of people living with HIV and help to increase availability and reduce the costs of insurance.

Recommendation:
The new Minister for Financial Inclusion should lead a debate on suitable and affordable protection for consumers unable to obtain personal insurance through the market.

8. ACCESS ISSUE FOUR: UNSUITABLE PRODUCTS

8.1 THE NATURE OF THE PROBLEM

PRODUCTS THAT DON'T PROVIDE THE COVER PEOPLE NEED

There were also numerous examples cited within our research of people living with HIV purchasing insurance products that failed to meet their needs. In particular this would usually manifest itself as exclusions within policies so that the policyholder cannot claim if the claim is due to HIV or any related conditions. Whilst this may offer a solution for some consumers in terms of lowering costs, it does mean that they are paying for a product that only partially provides the cover they need to protect against unexpected financial shocks.

These exclusions appeared to apply particularly when a person living with HIV had purchased a mainstream product, or had been offered free travel insurance as a benefit of a current account. Products purchased via specialists were usually designed to cover HIV, indicating that how consumers living with HIV access the market can substantially affect the quality of cover they are purchasing.

> "I was told that they only cover for delays and missed flights but not my health." SURVEY PARTICIPANT

> "I was told I was eligible for a bank account which came with free travel insurance. When I enquired if it covered HIV it did not."
>
> SURVEY PARTICIPANT

LACK OF CLARITY ON EXCLUSIONS

Some participants felt that there was a lack of clarity around what exactly was excluded from cover, particularly in terms of whether something could be directly or indirectly related to HIV. A thematic review by the FCA in 2014 found that consumers do not always understand exclusions,

with the result that the claims they make are declined.[32] Confusion about the process and the inevitable disappointment that follows leads to a further breakdown in trust between consumers and insurers.

RESTRICTIONS ON COVER

People living with HIV may also find there are other kinds of restrictions placed upon the products they purchase. Insurers use these restrictions to mitigate uncertainty over the potential for increased claims. For life insurance policies, for example, there are usually limits upon the term assured. However, whilst life insurance terms were usually capped at 10 years when policies were first introduced in 2009, the length of terms has increased considerably. Recent research by specialist broker Unusual Risks showed that the average length of term insured is now 19 years, with the longest term at 25 years.[33] These findings are promising as they indicate that as insurers have built up an evidence base of claims data, they are offering better terms to people living with HIV. However, there is some variation across insurers and it is key that insurers continue to review their terms regularly.

> **"It's a bit of a grey area though, if you had a heart attack and you had high cholesterol, they could say that is a result of your HIV or medication."**
>
> FOCUS GROUP PARTICIPANT, LONDON

8.2 HOW ACCESS CAN BE IMPROVED

INCREASE CLARITY ON EXCLUSIONS

In the short-term, we acknowledge that the result of standard underwriting and medical screening processes may be that exclusions relating to long-term health conditions such as HIV apply. However, insurers should ensure that they use simple, easy to read language so people living with HIV know what the product involves, including increased clarity on what is excluded from cover.

TREAT THE 'NON-STANDARD' AS STANDARD

Yet as the proportion of people living with long-term conditions increases, we also believe that firms should be adapting their products to ensure they are meeting the changing needs of the population. As well as adopting the recommendations made in the previous sections of this report, firms should consider how the design of their products can better meet the needs of people with pre-existing conditions, including people living with HIV. Adapting to this growing market is an opportunity for both consumers and insurers. To enable these adaptations, HIV VCOs can support firms to develop a better understanding of the consumer needs and expectations of people living with HIV.

32 FCA, 2014, *TR14/8 Insurers' management of claims, household and retail travel thematic review.* Available at: https://www.fca.org.uk/publication/thematic-reviews/tr14-08.pdf

33 Unusual Risks, 2017, *Average HIV Life Assurance Term & Sum Assured* [Press Release]. Available at: http://unusual-risks.co.uk/?p=764

8.3 RECOMMENDATIONS

Recommendation:
Insurance providers should use simple, easy to read language so people living with HIV know what the product involves, including increased clarity on what exactly is excluded from cover.

Recommendation:
Insurance providers should adapt their product design to better meet the needs of people with pre-existing conditions, including those living with HIV.

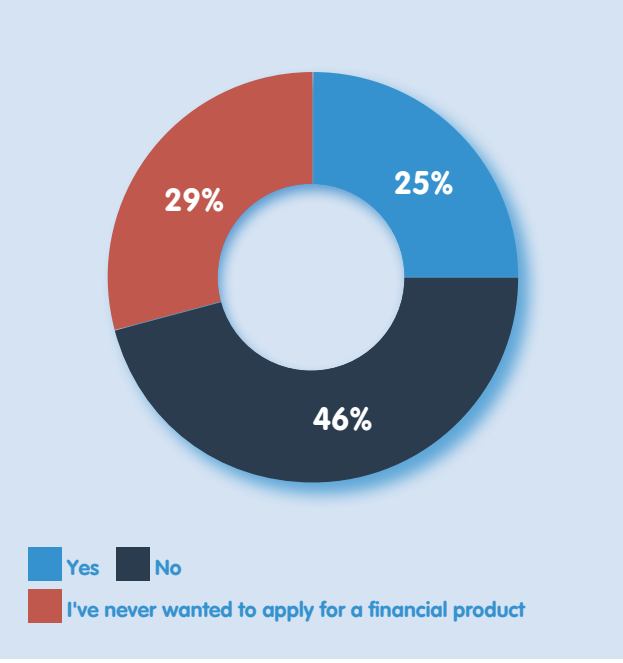
Recommendation:
HIV VCOs should support firms to develop a better understanding of the consumer needs and expectations of people living with HIV.

9. ACCESS ISSUE FIVE: INELIGIBILITY

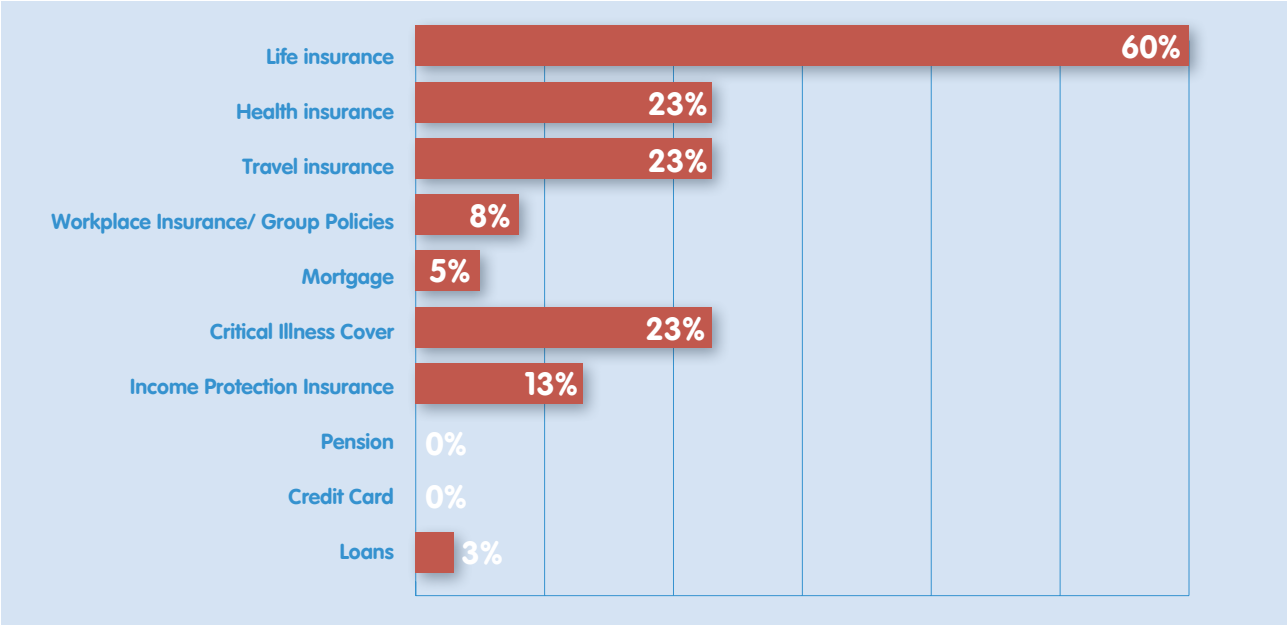
9.1 THE NATURE OF THE PROBLEM

The fears of refusal that lead people to self-exclude themselves from the market are not entirely based on misunderstanding. Despite a range of financial products becoming increasingly available, many people living with HIV remain ineligible for them. When asked if they knew or suspected they had been refused a financial product due to their HIV status in the last five years, around a quarter of survey participants said they had. The majority of those who had experienced refusal had been refused an insurance product.

From the survey responses and focus group discussions we identified the following reasons for refusal: not meeting HIV-related eligibility requirements (usually linked to CD4 count and viral load); the provider does not sell HIV-inclusive insurance products; or the product is not available to people living with HIV, i.e. individual income protection insurance or critical illness cover.



GRAPH 5. PERCENTAGE OF THOSE WHO KNEW OR SUSPECTED THAT THEY HAD BEEN REFUSED A FINANCIAL PRODUCT IN THE LAST FIVE YEARS DUE TO THEIR HIV STATUS



GRAPH 6. THE TYPES OF PRODUCTS REFUSED

NOT MEETING HIV ELIGIBILITY REQUIREMENTS

For most insurance products that do cover people living with HIV, there tend to be eligibility criteria which the applicant must meet. Usually applicants will need to submit records of their most recent CD4 count and viral load tests[34], and confirm that they haven't recently changed medication.

Limits of eligibility vary – people with CD4 counts of under 400 are likely to be able to get cover for travel insurance, albeit at a higher price, but may struggle to purchase affordable life insurance. Where it is available, this would usually be arranged through a specialist broker or insurer.

> **"I don't live well with HIV. My CD4 count hasn't been above 50 in seven or eight years. I think it's something to do with the spleen and the processing and whatever else but I've been undetectable the whole time. So you know it's controlled but it's not controlled and it now makes me totally uninsurable. But at the same time I can still walk around and do the same. I still have the same ambitions to travel but can't."**
>
> FOCUS GROUP PARTICIPANT, MANCHESTER

PROVIDER DOES NOT SELL HIV-INCLUSIVE PRODUCTS

As highlighted in previous sections of this report, there are also providers who do not sell HIV-inclusive products as their underwriting processes do not cater for 'non-standard' consumers. On the whole it does appear that exclusion on the basis of HIV status alone is less common today for travel and life insurance products, but people living with HIV are likely to face much higher premiums from mainstream insurers.

34 Viral load tests measure the amount of HIV's genetic material in a blood sample, whilst CD4 count tests indicate the strength of the immune system. A viral load below 50 is classed as undetectable – meaning the virus is at a very low level and cannot be passed on. People living with HIV who have a CD4 count over 500 are usually in good health. For further information see http://www.aidsmap.com/CD4-viral-load-amp-other-tests/page/1327442/

FINANCIAL PRODUCTS THAT REMAIN UNAVAILABLE TO PEOPLE LIVING WITH HIV

There are certain types of insurance products which remain completely unavailable to people living with HIV. The principal products are individual income protection insurance and critical illness cover.

> **"Received a call back from the provider after making an online application - the rather tactless individual just stated that being HIV positive meant that I was not a suitable applicant for the cover."**
>
> SURVEY PARTICIPANT

INDIVIDUAL INCOME PROTECTION (IIP)

Whilst people living with HIV may be able to access income protection through workplace group schemes, which often do not require medical information, those who are self-employed or whose workplace does not offer such schemes will be unable to purchase individual income protection policies. There are a range of potential benefits to IIP, such as providing financial support for those who aren't entitled to statutory sick-pay, such as the self-employed, and those whose outgoings would not be sufficiently covered by social security provision. In addition to the financial benefit, income protection schemes can also offer rehabilitation services to enable people to get back to work more quickly.[35]

The justification for individual income protection being unavailable to people living with HIV is that there are no data on how HIV affects sickness-related absence from work. There are no medical studies looking at how HIV affects employment specifically, and whilst claims data exist from group protection schemes it will not be clear to insurers if the claim is related to HIV or an HIV-related condition. As a result, it is claimed the risk of those living with HIV in making a claim on an income protection policy is unknown, and therefore they cannot be covered.

> **"In both instances I have been told point blank that as a self-employed person I cannot get IIP or CIC due to my HIV status."**
>
> SURVEY PARTICIPANT

CRITICAL ILLNESS COVER (CIC)

Critical illness cover (CIC) also automatically excludes anyone living with HIV.[36] Based on conversations we've had with brokers and insurers, the justification for this is that HIV is a complex condition which can be associated with a range of other health conditions. Whilst these related conditions could be excluded from the cover, this would potentially lead to the cover being so limited it wouldn't be worth paying for. Furthermore, given that people living with HIV are at an increased likelihood of acquiring heart disease or certain types of cancer[37], a policy would offer them much better value if they can claim on it should they acquire these conditions.

There are also difficulties of access within the claims process for those with existing policies who want to claim on the basis of acquiring HIV. Current industry best practice guidelines advise that a CIC policyholder who acquires HIV can only make a claim if it was "caught [in the UK] from a blood transfusion, a physical assault or at work in an eligible occupation".[38]

35 ABI, 2014, *Welfare Reform for the 21st Century: The role of income protection insurance.* Available at: https://www.abi.org.uk/globalassets/sitecore/files/documents/publications/public/2014/protection/welfare-reform-for-the-21st-century.pdf

36 As highlighted in section 4, one product does currently exist that offers cover to people living with HIV, but it is very limited in terms of cover (only eight critical illnesses covered and any pre-existing conditions are excluded) and sum assured (up to £50,000).

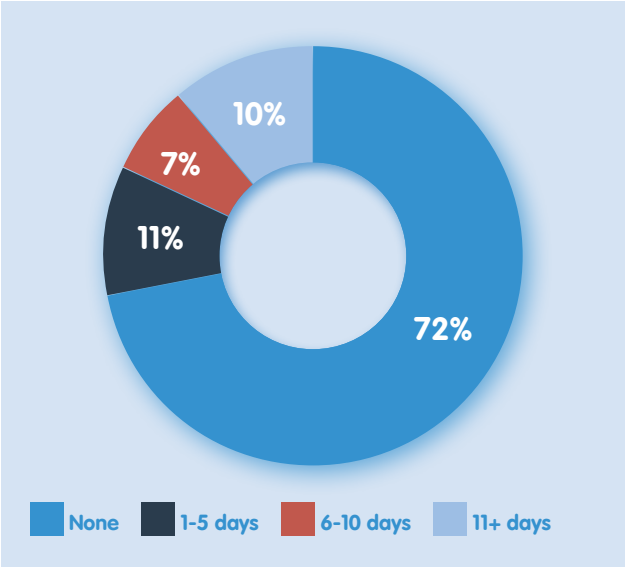
37 See for example Losina E et al. 'Projecting 10-yr, 20-yr and lifetime risks of cardiovascular disease in persons living with HIV in the US'. *Clin Infect Dis,* advance online publication, 12 June 2017 and Silverberg MJ et al. 'Cumulative incidence of cancer among persons with HIV in North America: a cohort study'. *Annals of Internal Medicine* 163, 215.

38 ABI, 2014, *Statement of Best Practice for Critical Illness Cover.* Available at: https://www.abi.org.uk/globalassets/sitecore/files/documents/publications/public/2014/protection/abi-code-practice-on-misrepresentation-and-claims.pdf

9.2 HOW ACCESS CAN BE IMPROVED

PROVIDE MAIN REASONS FOR REFUSAL

Insurers should make sure they are clear on the main reasons for refusal, giving details on why a person hasn't met the eligibility criteria. In some cases, the insurer could provide advice on how the applicant may increase their chance of success – for example, if someone has recently changed their medication, that they can reapply in 6 months. We acknowledge that many insurers may already provide this information on request, but it is better to provide this information upfront with the refusal. The social stigma attached to HIV means some people may not question the decision and simply believe that HIV is not covered at all.



GRAPH 7. PERCENTAGE OF THOSE WHO HAD TAKEN TIME OFF WORK IN THE LAST 12 MONTHS DUE TO HIV-RELATED ILLNESS (EXCLUDING ROUTINE MEDICAL APPOINTMENTS)

EXTENDING IIP AND CIC TO PEOPLE LIVING WITH HIV

Despite the lack of data on HIV-related employment absence, we believe the blanket exclusion of people living with HIV from individual income protection is unjustified. In our survey, we asked participants how much time they had taken off work in the last 12 months due to illness associated with HIV. Almost three-quarters reported that they had taken no time off work.

These findings are corroborated by a survey conducted by NAT in 2009, which found that 70% of the 1830 HIV positive gay men who responded to the survey had taken no HIV-related sickness days in the last 12 months.[39] The survey also found that there was little difference between the average number of days sick leave of HIV positive and HIV negative gay men. A 2015 survey carried out by specialist broker Unusual Risks found that 89% of the 100 participants had taken less than 7 days off work in the last year due to sickness, with 74% reporting they had taken less than the national average of 4 days or less.[40]

It should also be noted that people living with HIV are likely to keep a much closer eye on their health than the general population. People living with HIV are required to attend regular medical appointments to monitor their condition, meaning any ill-health is likely to be picked up on and treated earlier. The potential customer base for HIV-inclusive IIP will be managing their condition well enough to be in employment and their jobs are better protected than the general population due to the protections outlined in the Equality Act.[41]

39 NAT, 2009, *Working with HIV.*

40 Unusual Risks, 2015, '*Could IPP & CIC be possible for HIV Positive People?'* [Press release]. Retrieved from http://www.unusualrisks.co.uk/assets/Press_Release_May_2015.pdf

41 Monaghan, K., 2013, *Monaghan on Equality Law*, Oxford University Press.

As prognoses for people living with HIV have dramatically improved over the past three decades, we also question whether a complete exclusion of people living with HIV from critical illness cover is justified. Whilst there may be evidence of elevated risk of certain conditions, a blanket exclusion of those living with HIV takes no account of the difference in outcomes for those diagnosed early and adherent to treatment compared to those who are not.

It is important that insurance providers recognise the benefits to extending cover, as well as the potential risks. Insurance providers are increasingly aware of the advantages of being seen to be more inclusive of people with pre-existing conditions, as evidenced by recently launched products specifically designed for people with diabetes. Given that people living with a long-term condition make up a quarter of the population and rising[42], it is to insurers' advantage to start recognising these customers as the 'new normal'.

REVISE GUIDANCE ON CIC

Of the 23 conditions listed as critical illnesses in the guidance, HIV is the only condition where mode of transmission is relevant to whether a claim will be paid. This special treatment of HIV seems unfair, and we suspect this is a leftover from the insurance sector's historical approach to HIV. We strongly recommend the Association of British Insurers (ABI) remove the wording that makes mode of transmission relevant to whether a claim related to the acquisition of HIV will be paid.

9.3 RECOMMENDATIONS

Recommendation:
Insurance providers should provide upfront their main reasons for refusal, including information on how applicants can improve their chances of applying successfully in the future if relevant.

Recommendation:
Insurance providers should review their underwriting approach towards people living with HIV for individual income protection policies and critical illness cover to ensure that they fully reflect the latest improvements in life expectancy and morbidity.

Recommendation:
The ABI should review guidance on critical illness cover and remove wording that makes mode of transmission relevant to whether a claim related to the acquisition of HIV will be paid.

42 Approximately 15 million people in the UK are living with a long-term condition. Department of Health, 2012, *Long-term conditions compendium of Information: 3rd edition.*

10. ADDITIONAL BARRIERS

In the course of our research, we also identified a range of additional factors which may act as barriers to people living with HIV from accessing financial services, and particularly insurance. When asked whether there were other factors apart from HIV that might affect access, around a third of participants said that there were.

From the responses we received, we identified financial status, having an additional health condition, age and immigration status as being the major factors that may also impede access to financial products. [43]

FINANCIAL STATUS

Almost half of participants highlighted financial status as a barrier to access to financial products. There was some indication that those with lower financial status were preoccupied with more immediate financial concerns, rather than being interested in long-term financial products such as life insurance.

> "On long term sick, my biggest problem with finances comes from the DWP. I make sure that both credit cards end the month with a credit balance – only use them because credit card purchases have a greater degree of protection than debit card or cash."
>
> SURVEY PARTICIPANT

> "Bad credit history after being diagnosed 20yrs ago."
>
> SURVEY PARTICIPANT

Whilst poorer financial status isn't always directly linked to living with HIV, for some participants who have been diagnosed longer it is. In 2017, Terrence Higgins Trust found that individuals diagnosed prior to the introduction of effective anti-retroviral treatment in 1996 were more likely to be dependent on benefits as their sole or main source of income and were less likely to be in employment.[44] This was reflected in the responses to our research, with a number of people who had been diagnosed longer stating that they had got into debt following their diagnosis, and the impact this has had on their credit score is now affecting their ability to access financial products.

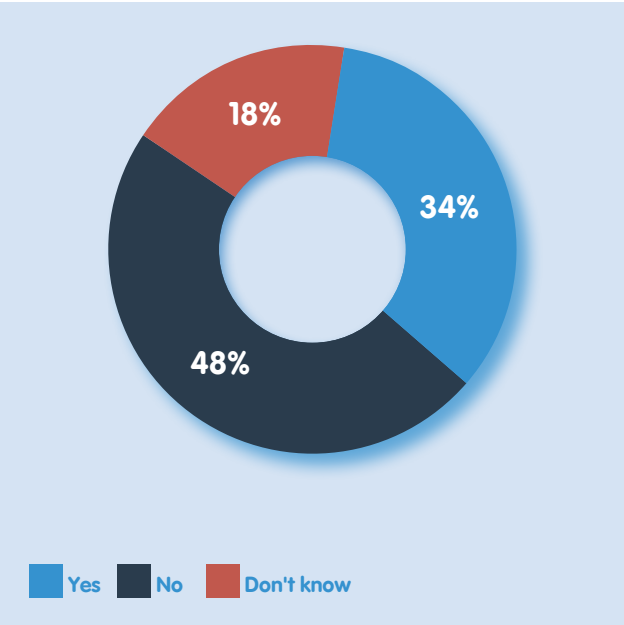
ADDITIONAL HEALTH CONDITION

Exactly half of those who said there were other factors that might affect their access stated that they had another health condition, with around a tenth citing Hepatitis C co-infection – a condition that is known to interact negatively with HIV.[45] When asked to specify their other health conditions there was a range of responses, including high blood pressure, kidney failure, respiratory illnesses, heart problems, arthritis, mobility problems, cancer, diabetes, mental health conditions and neurological problems.

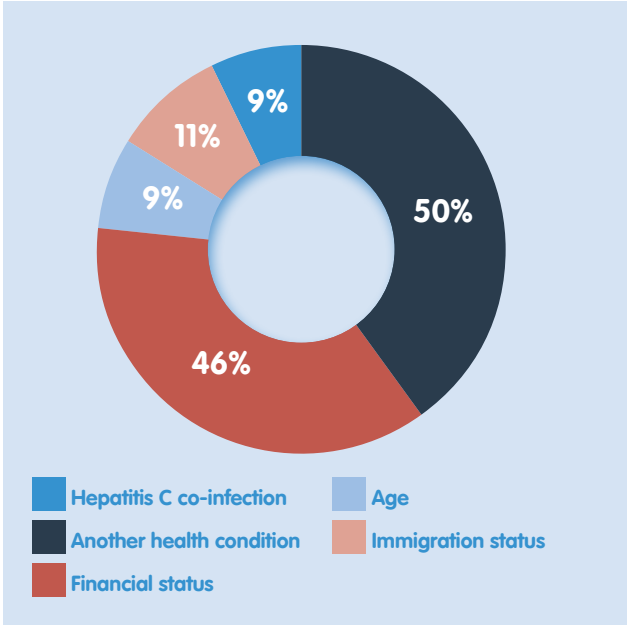
43 Percentages add up to more than 100% because respondents could select more than one answer.

44 Terrence Higgins Trust, 2017, *Uncharted Territory: A report into the first generation growing older with HIV*. Available at: http://www.tht.org.uk/~/media/Files/Publications/Policy/uncharted_territory_final_low-res.pdf

45 NAT, 2012, *Hepatitis C and HIV Co-infection*. Available at: http://www.nat.org.uk/sites/default/files/publications/Jan-2012-Hepatitis-C-and-HIV-co-infection.pdf



GRAPH 8. PERCENTAGE OF THOSE WHO THOUGHT THERE WERE ADDITIONAL BARRIERS (APART FROM HIV) THAT IMPACT THEIR ABILITY TO ACCESS FINANCIAL PRODUCTS



GRAPH 9. TYPES OF ADDITIONAL BARRIERS[43]

> Anxiety and depression. Even though I'm not in therapy or taking any medication for it. The fact that I have a history of it meant I was also turned down for Life insurance cover recently. As well as with the HIV. Double the stigma." SURVEY PARTICIPANT

Whilst it is not impossible for people living with HIV with additional health conditions to get certain financial products such as travel insurance or life insurance, it is considerably more difficult. As people living with HIV live longer, the proportion of those with co-morbidities is likely to increase.[46]

AGE

Around a tenth of participants described their age as a barrier to access to financial products. Along with disability, age is the other protected characteristic in which insurers can apply proportionate differential treatment when selling their products.

> Age. I am nearly 50!"
> SURVEY PARTICIPANT

46 Vance, DE., et al., 2011, 'Ageing with HIV: a cross sectional study of comorbidity prevalence and clinical characteristics across decades of life'. *J Assoc Nurses AIDS Care* 22:17-25

IMMIGRATION STATUS

Another tenth of participants stated that their immigration status is a barrier to access to financial products. Nearly all of these participants said they were asylum seekers – who are not entitled to insurance, and often struggle to access banking services due to ID requirements.[47]

> "I am an asylum seeker so not sure if I'd qualify."
>
> SURVEY PARTICIPANT

47 FCA, 2016, *Access to Financial Services in the UK.*

11. CONCLUSION

The findings of this report highlight that whilst there have been dramatic improvements in access to financial services for people living with HIV over the last decade, they continue to experience barriers to certain financial products, particularly insurance.

The access issues that people living with HIV face can be broadly categorised as: self-exclusion due to fears of refusal, higher costs, and stigma; difficulty navigating the market; higher premiums; unsuitable products; and ineligibility. People living with HIV can also face additional barriers not directly linked to their HIV status, such as having other health conditions, their financial status, age and immigration status.

The issue of access to financial products is one that requires input and effort from a range of stakeholders. This report highlights actions for the financial services industry, government, and voluntary and community organisations, that can be taken to improve access to financial services for people living with HIV.

People living with HIV are also not alone in experiencing barriers to access. There are strong parallels with those living with other long-term conditions and disabilities, highlighting that this is a much broader issue affecting a group that makes up a quarter of the UK's population.[48] A holistic and joined up approach is required to address the shared barriers to access within this group.

Ultimately, this report raises as many questions as it answers. How can we determine whether pricing is fair? How do we define 'fair'? How necessary is it for insurance to be universally accessible? Further work is needed in order to resolve these complex issues. However, we hope that by contributing to a fuller understanding of the barriers to access, we have helped create a foundation upon which greater financial inclusion and security can be achieved for the over 100,000 people living with HIV in the UK.

48 Department of Health, 2012, *Long-term conditions compendium of Information: 3rd edition.*

12. RECOMMENDATIONS

12.1 RECOMMENDATIONS FOR HIV VOLUNTARY AND COMMUNITY ORGANISATIONS (VCOS):

Recommendation: NAT and similar HIV VCOs should coordinate with other long-term condition and disability organisations to identify common issues, ensure strategic working and a collective voice on improving access to insurance for people with pre-existing conditions.

Recommendation: HIV VCOs should work together with financial service providers to more widely disseminate information to improve understanding of the availability of financial products to people living with HIV.

Recommendation: HIV VCOs should consider how we can facilitate the development and promotion of high-quality group purchasing schemes which meet the needs of people living with HIV and help to increase availability and reduce the costs of insurance.

Recommendation: HIV VCOs should support firms to develop a better understanding of the consumer needs and expectations of people living with HIV.

12.2 RECOMMENDATIONS FOR FINANCIAL SERVICE PROVIDERS AND THEIR REPRESENTATIVE BODIES:

Recommendation: Insurance providers should provide up-front clear information on confidentiality, data privacy and data sharing, particularly in regard to information about medical conditions.

Recommendation: Insurance providers, including those that deal with medical screening and claims handling, should explore how they can improve the customer journey for people living with HIV. This should include testing products and processes with focus groups of people living with HIV to ensure they are accessible, non-stigmatising and meet their needs.

Recommendation: Financial service providers giving financial advice and guidance, including those for mortgage-related sales, should be aware that selling practices can put pressure on people living with HIV to disclose their status, and explore how this can be addressed.

Recommendation: Insurance providers and intermediaries, including comparison sites, should implement a joined-up and holistic approach to signposting for people with pre-existing conditions to appropriate specialist providers, ensuring that it is

effective by monitoring outcomes and sharing findings.

Recommendation: Insurance providers should innovate to improve the quality and efficiency of the underwriting process. For example, by working with clinicians to reduce the time taken to compile medical reports, and by reducing or individually tailoring the number of questions asked.

Recommendation: Insurance providers should be more transparent with consumers about the main factors that have influenced the price they have been quoted.

Recommendation: Insurance companies should be more transparent in the public domain about how they determine risk and what other factors influence the price and availability of cover.

Recommendation: Insurance providers should use simple, easy to read language so people living with HIV know what the product involves, including increased clarity on what exactly is excluded from cover.

Recommendation: Insurance providers should adapt their product design to better meet the needs of people with pre-existing conditions, including those living with HIV.

Recommendation: Insurance providers should provide upfront their main reasons for refusal, including information on how applicants can improve their chances of applying successfully in the future if relevant.

Recommendation: Insurance providers should review their underwriting approach towards people living with HIV for individual income protection policies and critical illness cover to ensure that they fully reflect the latest improvements in life expectancy and morbidity.

Recommendation: The ABI should review guidance on critical illness cover and remove wording that makes mode of transmission relevant to whether a claim related to the acquisition of HIV will be paid.

12.3 RECOMMENDATIONS FOR REGULATORS AND GOVERNMENT:

Recommendation: The FCA should continue to focus on the needs of marginalised customers, particularly those with pre-existing conditions including HIV, in accessing insurance and determine how these needs can be better met.

Recommendation: All UK governments should develop an evidence-based strategy for reducing HIV stigma including consideration of how stigma may influence access to financial services.

Recommendation: The EHRC, with the support of the FCA, should explore whether insurance providers are meeting their obligations towards disabled people, including those living with HIV, under the Equality Act 2010 in basing their decisions on reliable, relevant and up-to-date data.

Recommendation: The new Minister for Financial Inclusion should lead a debate on suitable and affordable protection for consumers unable to obtain personal insurance through the market.

12.4 RECOMMENDATIONS FOR PEOPLE LIVING WITH HIV:

Recommendation: Where they have had them, people living with HIV should share positive experiences of accessing financial products on community forums and message boards.

13. ACKNOWLEDGEMENTS

We would like to thank all the people living with HIV and professionals who generously contributed their time to support the completion of this project.

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NAT would like to thank the following for providing further information for this report:

Julie Hopkins (Julie Hopkins Consulting), Professor Margaret May (University of Bristol), Karin Lloyd (Karin Lloyd Consulting), Minesh Patel (Scope), Léonora Miles (Macmillan), Alex Sparrowhawk (Terrence Higgins Trust), Colin Armstead (George House Trust), and all those who supported us by publicising and completing our online and telephone surveys, and participating in our focus groups and roundtable.

We are grateful to Barrow Cadbury Trust for supporting and funding this project.

Barrow Cadbury Trust

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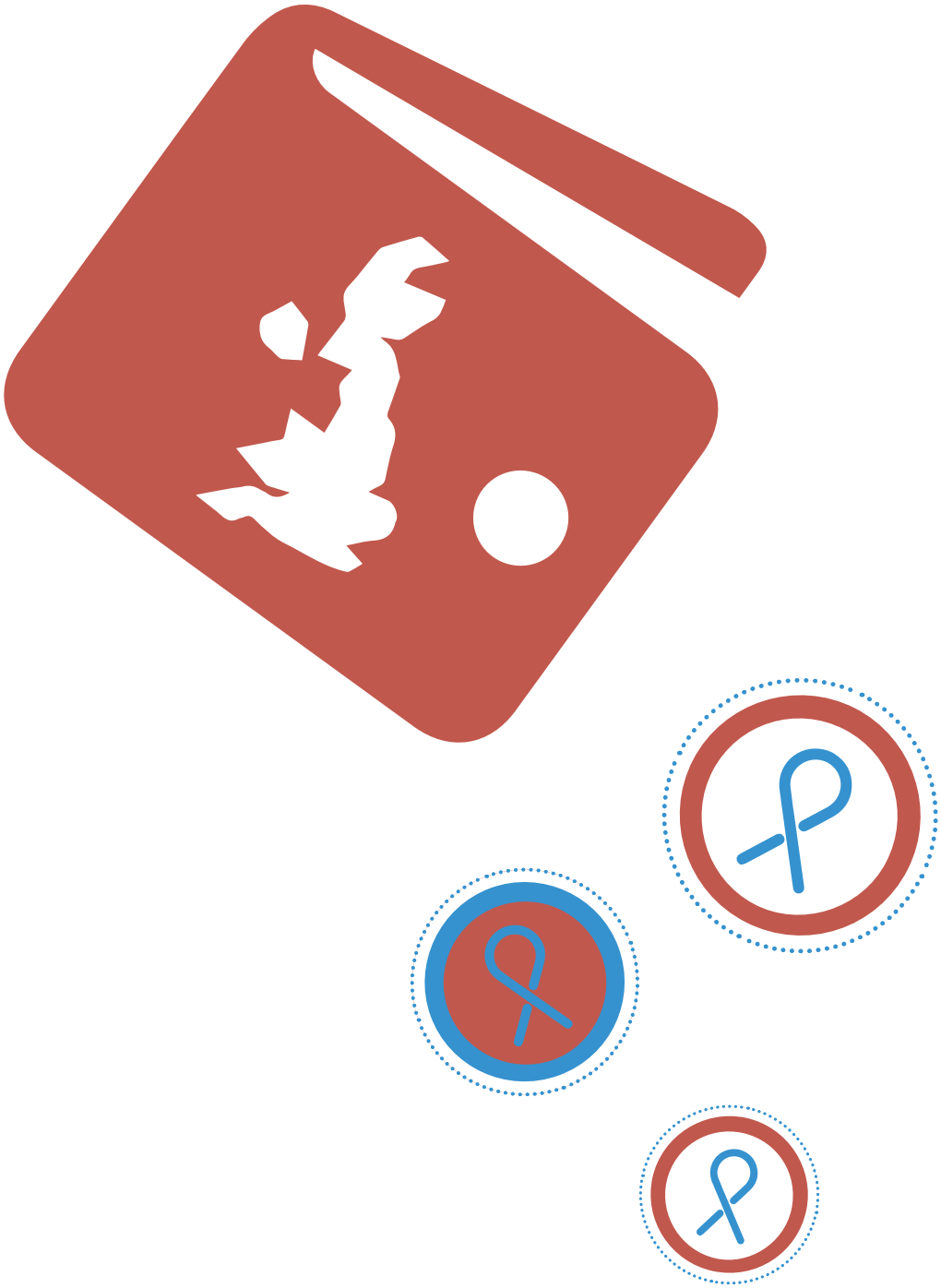

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