WORKING WITH HIV

By Karen Steadman and Helen Sheldon

The Work Foundation
This report is based on research that was funded by ViiV Healthcare. While ViiV Healthcare has reviewed the content to ensure technical accuracy, The Work Foundation have retained final editorial control and the recommendations do not necessarily reflect the views of ViiV Healthcare.

Please note the people depicted throughout the imagery of this report are models and do not necessarily have HIV.
ABOUT THE WORK FOUNDATION

Through its rigorous research programmes targeting organisations, cities, regions and economies, now and for future trends, the Work Foundation is a leading provider of analysis, evaluation, policy advice and know-how in the UK and beyond.

The Work Foundation addresses the fundamental question of what Good Work means: this is a complex and evolving concept. Good Work for all by necessity encapsulates the importance of productivity and skills needs, the consequences of technological innovation, and of good working practices. The impact of local economic development, of potential disrupters to work from wider-economic governmental and societal pressures, as well as the business-needs of different types of organisations can all influence our understanding of what makes work good. Central to the concept of Good Work is how these and other factors impact on the wellbeing of the individual whether in employment or seeking to enter the workforce.

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FOREWORD:
HIV AND PRODUCTIVITY

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More people than ever before are living with HIV in the UK. Today’s medicines increase life expectancy, reduce risks of health complications and bring down infectiousness. Despite these advances health challenges persist for people with HIV when compared to the general population, in particular other coexisting clinical conditions (co-morbidities) and reduced quality of life.

Work and wellbeing are closely linked. Those employed in “good work” have better health outcomes than those who are either workless or are in poor working environments. Even with improvements in HIV therapy and physical health, rates of worklessness amongst people with HIV remain higher than within the general population.

The Work Foundation’s report is a timely and important contribution to improving HIV related wellbeing. There is a paucity of information on the impact of HIV on productivity and workforce that is applicable in a UK setting. The importance of work and employment for people with HIV is in both commissioning and provider guidance, yet there is no consistency in promoting good work in existing pathways of care. Importantly much of the expertise that facilitates people with HIV to get good work comes from the HIV voluntary sector, which is under severe pressure due to austerity measures and fractured commissioning arrangements.

The report draws attention to factors that compromise the ability of people with HIV to engage in beneficial work, ranging from the personal through to the structural and political. Those of us who work at the front line are well aware that there is no “one size fits all” approach. HIV affects diverse populations with different duration of infection and comorbidity patterns. Symptoms and the ability to work fluctuates, even amongst those with well controlled virus. Communities with a disproportionately heavy burden of HIV are often already vulnerable to worklessness in other ways. Stigma and discrimination within society remain stubbornly high and are key barriers to employment for people with HIV.

What needs to be done? We must have higher ambitions for quality of life for people with HIV. That will require a fair, just and tolerant society that recognises peoples’ skills and strengths, that understand the challenges of living and working with HIV and does not discriminate.

Supporting people with HIV to secure good work when they are able to do so, whilst ensuring proper resources for those unable to work with easy-to-navigate pathways between the two are crucial. There is a need for better recognition that good employment is a health benefit, ensuring appropriate employment support is explicitly commissioned and embedded within pathways of care. We need workplaces to take the needs of people with HIV into proper account. Legislation alone is not enough to make the difference that is needed. Examples of good practice and mechanisms to share learning are all-important.

Success will depend on working cooperatively and collaboratively across organisational and disciplinary boundaries. The Work Foundation report sets out very clearly who needs to do what nationally and locally to make the difference and move us from theory to reality.
INTRODUCTION

According to the World Health Organisation, 36.7 million people are living with human immunodeficiency virus infection (HIV) and acquired immune deficiency syndrome (AIDS).\textsuperscript{1} HIV became widely recognised in the 1980s and since then we have seen dramatic changes in the way the once devastating virus is prevented, treated, and managed. Today, these advances mean that many people living with HIV (PLHIV) will be managing their condition well and will have a similar life expectancy to the rest of the population.\textsuperscript{2} Furthermore, effective medication which can reduce the risk of PLHIV transmitting the virus to others is now widely accessible.\textsuperscript{3}

Access is however not universal, and addressing inequalities in treatment and variation in access is a UN goal. Known as the 90-90-90 goals, the aim is that by 2020: 90% of all people living with HIV will know their HIV status; 90% of all people with diagnosed HIV infection will receive sustained antiretroviral therapy; and, 90% of all people receiving antiretroviral therapy will have viral suppression. The UK is also working towards achieving these goals,\textsuperscript{3} and though the UK is currently falling short of the first UNAIDS target on percentage of people diagnosed, it has met the second two metrics on treatment and viral suppression (see Figure 1). According to Public Health England (PHE) areas of concern include continuing high levels of transmission and high rates of late HIV diagnosis.\textsuperscript{3}

Some experts believe that these goals do not go far enough; there is a call to look beyond viral suppression as an endpoint and incorporate wider measures of health-related quality of life – moving beyond

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**FIGURE 1**

**UK HIV continuum of care: progress against UNAIDS targets**

**PEOPLE LIVING WITH HIV**

- **87%** of which Aware of their HIV status
- **96%** of which On HIV treatment
- **94%** Virally suppressed

direct measures of health to incorporate domains related to physical, mental, emotional and social functioning. In this context, good health-related quality of life for PLHIV is seen as being measured in terms of comorbidities (the experience of having multiple long-term health conditions) and self-perceived quality of life.4

In the UK, around 100,000 people are living with HIV.3 The majority of whom have been diagnosed and are receiving specialist HIV care which minimises symptoms7 (see Figure 2).

FIGURE 2
HIV in the UK in 2015

101,200 PEOPLE WERE LIVING WITH HIV IN THE UK.
HIV prevalence was 1.6 per 1,000 population

![Image](https://example.com/image.png)

The majority, 69% (69,500) were men and 31% (31,600) were women.

An estimated 13% (13,500) of people living with HIV were living with an undiagnosed infection and at risk of passing on their infection if having unprotected sex.

The groups MOST AFFECTED by HIV in the UK

MEN WHO HAVE SEX WITH MEN (MSM)
BLACK AFRICAN HETEROSEXUAL MEN AND WOMEN

A total of 6,095 people (4,551 men and 1,537 women) were diagnosed with HIV in the UK, similar to numbers reported in recent years. This included:

- 65 children
- 5,012 adults aged 15–49 years
- 1,018 adults aged 50 years and over

Nearly all (97%) of those diagnosed with HIV in 2015 were linked to specialist HIV care within three months of diagnosis, similar to previous years.

The numbers diagnosed late remain high. In 2015, among those with CD4 data available, 39% (1,958/4,980) of adults were diagnosed late, a decline from 56% (3,349/5,974) in 2006.

The number of people living with diagnosed HIV and accessing HIV care is up 73% from a decade ago.

The vast majority (94%) of people accessing HIV care were receiving antiretroviral therapy (ART) and, as a result, have undetectable virus in their blood and are very unlikely to pass on their infection to others.

HIV mainly affects working age adults: the median age of people accessing treatment for HIV in the UK is 45, and about 95% are aged 16 to 64. Employment rates for PLHIV in the UK (as in other countries) are consistently found to be below the national average. This is despite evidence that with the right treatment and support, someone diagnosed with HIV in 2016, should have similar, if not the same, ability to work as someone without HIV.

This research sought to explore the impact of HIV on work productivity in the UK. There is a strong rationale for this focus at present; with concerns about UK productivity and the sustainability of welfare, social and health care services and systems. We argue that through identifying the barriers to productivity for PLHIV we can make a valuable contribution to the debates surrounding these issues, and, most importantly, improve the quality of life for individuals living with HIV in the UK.

This research was conducted in the context of a significant body of knowledge that highlights the benefits of work, particularly good quality work, for most people of working age (e.g. Wadell and Burton concluded that there was broad consensus amongst multiple disciplines that if the health condition permits, sick and disabled people should be encouraged and supported to remain in or to (re)-enter work as soon as possible because it has multiple benefits- as summarised in Figure 3). In this sense, we argue that acting to improve employment outcomes for PLHIV is worthwhile in and of itself, and in particular, it can be seen as a factor in improving quality of life.
OVERVIEW OF METHODOLOGY

This project set out to answer three main questions:

1. **WHAT IS THE IMPACT OF HIV ON EMPLOYMENT?**
2. **WHAT INTERVENTIONS SUPPORT PLHIV TO ENTER, RETURN, REMAIN IN, OR PROGRESS IN, EMPLOYMENT?**
3. **WHAT IS THE COST OF WORK PRODUCTIVITY LOSS ASSOCIATED WITH HIV IN THE UK?**

To answer these questions we first undertook a review of the existing evidence in the ‘grey’ and academic literature; second, we conducted a series of interviews with UK-based experts (primarily clinicians and representatives of voluntary sector organisations) to further develop and explore the issues raised by the literature review; and, third, we held an expert roundtable to discuss the implications of the research and what could be done to improve productivity for PLHIV in the UK. This approach allowed us to iteratively build our knowledge, identifying and exploring gaps as the project progressed. Taking this information we identified some key areas which we believe if acted upon, could improve productivity for PLHIV in the UK (See Figure 4).

* Full research questions and methodology is available in the appendix
PART ONE: THE RELATIONSHIP BETWEEN HIV AND EMPLOYMENT

SECTION SUMMARY

- Unemployment and job loss resulting from HIV are seen as major public health and economic concerns.

- Despite advances in treatment, which have potential to minimise health-related barriers to working, employment rates for PLHIV remain lower than average.

- A range of health, attitudinal and social barriers influence employment outcomes for PLHIV, including:
  - Health and functional status, in particular: the fluctuating nature of the condition; the likelihood of having co-occurring conditions; the higher risk of poorer health associated with late diagnosis; and, the impact of medication changes and side effects.
  - Stigma and discrimination, in particular: people’s attitudes towards the condition and those who live with it; the challenges of disclosure; and, self-stigma.
  - The socio-economic status of PLHIV as a population also heightens the risk of poorer employment outcomes within the group. Ethnicity, gender, sexuality, wealth, ex-offender status or migrant status, etc., are all compounding factors which influence employment outcomes, as well as the likelihood of experiencing poorer health (e.g. through late diagnosis) or stigma.
  - Ageing with HIV was also highlighted as a challenge. With changes to pension age and people both with and without HIV living longer, we are now finding more older people with HIV (including long-term survivors and those with a more recent diagnosis) engaged with the labour market or welfare-to-work system.
THE RELATIONSHIP BETWEEN HIV AND EMPLOYMENT

As a condition found predominantly in people of working age, understanding the impact of HIV on employment – in terms of the ability for PLHIV to enter, return to, remain, and progress in work – is important. This includes costs to employers, e.g. in terms of sickness absence, presenteeism (attending work while ill) and job loss/recruitment; costs to government through welfare, health and social support associated with unemployment and economic inactivity; and costs to individuals and their families.

Although HIV is seen as very relevant in terms of total NHS care costs, there are relatively few European studies compared to other diseases on the medical and non-medical costs. This is true also in terms of productivity costs; though recognised as having a likely economic impact in terms of productivity losses, few studies consider this in a western context. Indeed, the “economic impact of HIV/AIDS beyond healthcare including other components of social burden” has been highlighted as an area in which further research is needed.

These findings were echoed in a 2015 Cochrane systematic review of interventions to improve employment outcomes in PLHIV. The review concluded that “unemployment and job loss resulting from HIV infection are major public health and economic concerns” (see Box A), but also recognised that the evidence base on both the impact of HIV on productivity and on interventions to improve employment outcomes is limited. Most of the few existing studies are methodologically weak, and were conducted in low income countries and therefore have limited relevance to the Western European context.

The available UK data supports the view that PLHIV are likely to experience disadvantages in terms of employment. Although there is not currently a national dataset which allows us to clearly see the employment rates for PLHIV in the UK, a number of small scale studies show variation in employment rates depending on the setting and the population; their estimates ranging from 39% to 75%. The best source identified is a recent pilot survey of PLHIV in England conducted by Public Health England (PHE) of 781 PLHIV. The survey identified that despite higher educational attainment than the general population, the employment rate for participants with HIV aged 16-64 was 64%, compared with 73% in the UK population during the same period – a difference of 10 percentage points (see Figure 5). While 17.4% identified as unemployed, a further 9.7% identified as being economically inactive due to their health or care responsibilities, and 5% identified as retired. Furthermore, through

** A larger version of this survey has been commissioned and will report in 2017/18
BOX A

The relationship between HIV and work: findings from a 2015 systematic review (Cochrane collaboration)

A systematic review of interventions to improve employment in PLHIV was conducted in 2015. (Robinson et al., 2015). This paper provided a summary of the evidence on the impact of HIV. They stated:

“The HIV literature suggests that HIV infection in individuals of working age is associated with: loss of employment, particularly in women (Dray-Spira 2006), increased absenteeism from work, reduced productivity, increased financial burden on employers, increased job loss, and loss of earnings (Feeley 2004; Fox 2004; Kaiser Family Foundation 2007; Sendi 2004).”

However, none of the studies reported in this summary were conducted in the UK, and most of the studies included are based on evidence from low income countries with relatively high HIV prevalence compared to the UK. Just two of the studies were conducted in European settings - Dray-Spira et al. (2006) (France) and Sendi et al. (2004) (Switzerland). The latter looked at determinants of productivity, suggesting that up to 40% of PLHIV had some aspect of disability which limited their ability to work.

Source: Robinson et al. (2015)

personal correspondence with the survey coordinators at PHE, it was confirmed that higher unemployment rates were identified for Black, Asian and Minority Ethnic respondents, and for female respondents. A larger survey is currently taking place and will report in 2017/18.

As noted above, work is generally good for people’s health and wellbeing. This is supported by evidence from Canada that reflects the broader consensus that work quality matters for the health of PLHIV. Surveys in 2012 and 2013 found “employment was associated with lower depressive symptoms”, but only for those in ‘good jobs’ (i.e. those providing job security, psychological demands, and decision authority), and better physical function than not being employed. A survey of illicit drug users living with HIV found employment was associated with a lower risk of mortality during the six months research follow up period. Furthermore, the desirability of work for working age PLHIV was not questioned by any of the experts we spoke to during the course of this research.
Given the existence and availability in the UK of effective treatment for HIV which should minimise functional implications of the condition, and the broad consensus that work (in particular ‘good’ work) is positive for PLHIV, why are we seeing worse employment outcomes for PLHIV?
DETERMINANTS OF EMPLOYMENT FOR PLHIV

OVERALL EMPLOYMENT DETERMINANTS FOR PLHIV

Therapeutic advances have substantially changed the impact of HIV on labour participation, which before the mid-1990s was ‘devastating’. Today, for the majority who receive a timely diagnosis and effective treatment, impact on work productivity has potential to be minimal. However, two high quality European longitudinal studies suggest that although the ability to work in those with HIV has improved from earlier decades, there has not been a corresponding increase in employment rates; indicating continuing barriers to employment other than health. This is not universal however with a study in Denmark finding some improvement in employment rates for those entering HIV care after 2000.

Reviewing the published evidence on the determinants of employment for PLHIV we identified two key influencing factors on whether someone is working and working well:

- Health status, i.e. the way the condition affects someone’s health and functioning, and
- People’s attitudes towards the condition and those who live with it, i.e. stigma and discrimination.

The likelihood that these factors will be significant enough to affect the employment outcomes of PLHIV however is strongly influenced by the broader socio-economic context, i.e. someone’s ethnicity, gender, sexuality, wealth, migrant status and so on. Although socio-

“For people living with HIV and their ability to work, things have not changed massively [since effective treatment became available]. Although things are constantly improving, the treatments are getting better and the side effects are getting less... things haven’t changed dramatically [in the work context]”

Expert interviewee (HIV voluntary sector organisation)
economic factors are relevant to most if not all health conditions, they appear particularly relevant to HIV, influencing the likelihood of someone becoming HIV positive, the timing of the diagnosis, and the way it is treated and managed. Socio-economic factors are both a determinant of employment for PLHIV, as well as a determinant for poorer health outcomes and poorer attitudes which compound the work disadvantage. In this sense, the socio-economic context can be seen as acting as a filter, affecting the way health and attitudinal barriers are experienced (see Figure 5).

Another factor that we are increasingly recognising as important, is age. As people are living and working longer including those with HIV, we will also need to reflect on what this means; and particularly for those who were diagnosed before the availability of effective treatment, and are now entering their 50s and 60s.

**HEALTH STATUS OF PLHIV**

PLHIV may experience physical and functional challenges or disabilities associated with their condition or its treatment (i.e. as side effects), which present a barrier to employment. The experts we interviewed...
supported the findings from the literature review that the majority of people who receive a timely diagnosis and adhere to effective treatment, should experience this only minimally and consequently, HIV status on its own should not have an impact on an individual’s ability to work.

A survey conducted with 1,800 gay men living with HIV in the UK saw over half report that being HIV positive had no impact on their working life. However, there is considerable variation in the extent of poor health experienced by someone living with HIV in the severity of the disease – and consequently in the way it effects work outcomes. Indeed, several of the health care professionals we interviewed worked in hospital settings and emphasised that most of the PLHIV they worked with were very unwell and had greater functional impairments than the majority of PLHIV in the UK, and as such were highly unlikely to be in work (see Box B).

**BOX B**

**Functional disability among PLHIV requiring specialist care**

A review of referrals to a specialist HIV outpatient physiotherapy service in the UK over 24 months found that amongst 137 patients (97% of whom had an undetectable viral load), median age 52 (range 29–77):

- 61% unemployed
- 71% lived alone
- 87% did not meet UK physical activity recommendation
- 50% were limited in their ability to undertake paid employment

**Comorbidities were common:**
- Patients lived with median 5 comorbidities and
- 87% meet definition of “complex comorbidity” (≥2 additional chronic conditions in ≥2 different body systems)

**Most common comorbidities were:**

- 21% diseases of the musculoskeletal system and connective tissue
- 13% mental and behavioural disorders
- 11% endocrine, nutritional and metabolic diseases
- 11% diseases of the nervous system

**Most common functional impairments were:**

- 88% pain
- 75% mobility of joint
- 71% emotional function

(Using ICD-10 and ICF criteria)

Source: Brown et al. (2016)
Higher levels of frailty have been associated with unemployment among PLHIV. Other HIV-associated symptoms mentioned in interviews as creating difficulties for work, include: fatigue and low energy levels, memory and cognition problems, peripheral neuropathy, and diarrhoea. Some of these may however be caused by comorbidities – co-occurring health conditions – or medication side effects.

In the section over the page we discuss the main causes of health-related barriers to working for PLHIV. These are: the fluctuating or episodic nature of the disability; having comorbidities (particularly mental health conditions); late diagnosis, and medication and its side effects.

**Fluctuating or episodic nature**

HIV can be described as a ‘fluctuating’ or episodic condition. These are long-term conditions that are characterised by periods of good health interrupted by periods of illness or disability. These periods may vary in severity, length and predictability from one person to another. Other common examples include multiple sclerosis, arthritis, diabetes, hepatitis C, chronic fatigue syndrome, migraines, chronic pain, some forms of cancer and mental illness.

The fluctuating nature of HIV symptoms was consistently described by interviewees as having implications for employment. This was also a dominant theme in the published evidence, where it was identified as an important concern for PLHIV.

Experiencing repeated episodes of physical and cognitive impairment were identified as major concerns for working with HIV. Such episodes were also suggested to alter an individual’s perception of time, which may adversely affect expectations and motivation to work.

"As with any long term condition, some weeks are good and some aren’t.”

Expert interviewee
(HIV voluntary sector organisation)
The lack of predictability of symptom onset and the individual course of the condition was also a major concern in regards to work, presenting challenges for both employees and employers, e.g. making it difficult to plan for sickness absence cover or additional support during periods of poorer work productivity, or making it difficult to accurately assess an individual’s needs to enable helpful workplace adjustments to be made. The invisibility of many fluctuating conditions may also exacerbate any feelings of distrust from employers and even colleagues about the implications of a health condition for work. Such concerns are also reflected in assessments of work capability provided through the welfare system.  

**Comorbidities**

Many PLHIV also have other chronic health conditions or disabilities which may have an impact on their daily lives. Common comorbid physical health conditions seen in PLHIV include: HIV-associated neurocognitive disorder (HAND); cardiovascular disease and stroke; diabetes; bone and joint disorders (including rheumatic diseases such as arthritis); and, hepatitis C (HCV) co-infection. The likelihood of being in work decreases as the number of long-term conditions increases.  The presence of a mental health condition both on its own and as a comorbidity, is associated with worse employment outcomes. The incidence of poor mental health is high amongst PLHIV. Studies in high income countries indicate rates of depression and anxiety for PLHIV are around 20-25%. Living with HIV and a mental health condition is identified as seriously limiting someone’s ability to work and the likelihood that they will be in work.  

The point of diagnosis was identified as a time when someone might be at increased risk of psychological stress and mental illness. The experience of diagnosis, and the way an individual responds and adapts to the diagnosis, is a psychological experience, which may be
unrelated to the experience of physical symptoms. One study found that the impact of the diagnosis itself decreases the chances of finding employment by 25%, with authors describing unemployment in PLHIV as “a consequence of the adaptation of expectations of the person to a health shock that implies a lower life expectancy”. This might be a key point for work-related intervention – in one survey a third of PLHIV reported needing some time off of work to adjust to their diagnosis.

The likelihood of comorbidities, and greater numbers of comorbidities, increases with age; the majority of people aged 65 and over have multiple long-term conditions. There will likely therefore be specific implications as PLHIV grow older.

Late diagnosis

People who are diagnosed ‘late’ have an increased risk of have poorer health outcomes (see Box D). In the UK, late diagnosis is more common among heterosexual men and women and is particularly high among those of black African ethnicity and injecting drug users. Regionally, rates are higher in the Midlands, East and Northern England, and in Wales.

Although the reasons for late diagnosis are complex, and may vary between different socio-economic groups, research indicates a strong link with social disadvantage. Interviewees suggested there were many active programmes focussed on raising awareness and improving testing in higher risk communities, including the introduction of routine testing, offered on an opt-out basis, to patients presenting in A&E.

**BOX D**

Late Diagnosis:

People living with HIV can expect a near-normal life span if they are diagnosed promptly. However, for individuals who receive a late diagnosis there remains a ten-fold increased risk of death in the year following diagnosis compared to those diagnosed promptly.

Public Health England define ‘Late’ HIV diagnosis as a CD4 count under 350 cells/mm$^3$ within three months of HIV diagnosis. They go on to state that “people diagnosed late have been living with an undiagnosed HIV infection for at least three years and are at risk of premature death and of transmitting the virus to their sexual partners”.

In 2015, PHE reported 39% of all those newly diagnosed met the definition of ‘late diagnosis’ (n=2350). The proportion of all new diagnoses defined as ‘late’ has fallen gradually since 2005 when 56% of all diagnoses were defined as ‘late stage’.

Source: PHE (2016) HIV diagnoses, late diagnoses and numbers accessing treatment and care 2016 report

“There is evidence that you are ten times more likely to die if you are diagnosed late.”

Expert interviewee (HIV voluntary sector organisation)
Though the impact on health, functioning and employment can be hugely significant, it should be recognised that this still only affects a minority of those with a late diagnosis. Furthermore, in terms of employment and productivity outcomes the clinical parameters around ‘late’ diagnosis that would indicate difficulties in work are not clearly defined.

**Medication and side effects**

Side effects (also known as adverse events) of medication used to treat HIV, including current antiretroviral therapies (ART), have also been identified as having an effect on employment and productivity. Over half of the participants in a USA study of 953 PLHIV taking medication reported experiencing side effects including fatigue, diarrhoea, insomnia, dizziness, neuropathy, joint pain, nausea, and abdominal pain. Experiencing any of the side effects was associated with worse outcomes; either self-assessed health status, increased health care resource use, and/or increased work productivity loss – such as absenteeism, presenteeism, and overall work impairment. As suggested in interviews, newer medications have less risk of (or more ‘tolerable’) side effects. Consequently, different medications, and individuals’ differing response to side effects, may have an impact on an individual’s ability to work. Furthermore, the literature also suggested that changes to treatment regimens can affect productivity at work in the short-term.

**STIGMA, DISCRIMINATION AND DISCLOSURE**

In the UK we have come a long way in terms of the stigma and discrimination around HIV. This stigma was initially driven by fear as a result of 1980s national public awareness campaigns (before the availability of effective treatment) and moral panic generated by a sexually transmitted disease (largely associated with gay men). Although much improved, understanding of HIV within the general public is still thought to be outdated, and a significant level of stigma around HIV remains in UK society. The 2015 Stigma Survey of PLHIV found that a significant proportion of respondents felt stigmatised and had experienced HIV-related discrimination (see Box E). This had a substantial effect on wellbeing; with around half reporting feelings of shame, guilt or self-blame in relation to their HIV status in the last year, while one in five reported having felt suicidal.

The literature and particularly the interviews indicated that stigma remained a barrier to employment for PLHIV. It was thought to be felt most significantly by those who are unemployed and seeking work,

“A lot of the cases we hear about are misunderstandings about how the virus is passed on: old fashioned stigma, and ideas that you can’t be a health or social care worker, even with controlled viral load”

**Expert interviewee**
(HIV voluntary sector organisation)
but was also a concern for those in work in terms of job retention and progression. A survey of 1800 gay men living with HIV identified just 60% had disclosed their HIV status to someone at work. While the majority had reported a positive response, almost a third either faced or feared a negative reaction to disclosure. Despite being a named condition in the 2010 Equality Act, a fifth of respondents who had disclosed their HIV positive status at work had experienced discrimination in their current or previous job, and many reported being specifically asked about their HIV status on a pre-employment health questionnaire.

For those in work, there is a complex interdependent relationship between stigma and disclosure in the workplace; this was reflected in the literature review and supported in interviews. Almost all interviewees reported at least one example where an individual living with HIV had been affected by workplace discrimination and this was an issue recognised by patient groups. Experiences of HIV-related discrimination were thought to persist across different industries; however, because migrants living with HIV often worked in health and social care, the problems in this industry were considered a particular problem by some interviewees.

This reflected the findings of a French study of Sub-Saharan migrants which looked at social support from migrant organisations and recognised that employment support was highly relevant in care industries where they “anticipate HIV-related discrimination.”

“a lot of people do have a positive experience when they go to work.... You hear people saying they dreaded telling their employer, but it was actually better than they expected.”

Expert interviewee (HIV voluntary sector organisation)
BOX E

Findings from the Stigma Survey 2015

The 2015 Stigma Survey of PLHIV in the UK found that in that year 12% of participants “had decided not to apply for, or turned down, employment or a promotion due to their status”. Of all respondents, “a significant proportion had worried about being stigmatised, had avoided encounters or had experienced discriminatory treatment in the last 12 months”. Many felt this was mainly due to their HIV status (rather than other factors). Although just over half (52%) of working respondents reported they had told no one in their workplace about their HIV status. 63% of the respondents who had told their employer, or a colleague, said they felt supported after disclosure.

Awareness of status and support in the workplace

### In the last 12 months...

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<th>% of all who report experience is due to HIV</th>
<th>% of all who answered yes</th>
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<td>27%</td>
<td>48%</td>
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<td>Sexual Rejection</td>
<td>35%</td>
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<td>Job Security</td>
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<tr>
<td>Excluded - Social Gatherings</td>
<td>14%</td>
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<td>Verbal Harassment</td>
<td>12%</td>
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<td>Excluded - Family Gatherings</td>
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<td>Physical Assault</td>
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<td>Job Change - Consensual</td>
<td>4%</td>
</tr>
<tr>
<td>Excluded - Family Gatherings</td>
<td>5%</td>
</tr>
<tr>
<td>Excluded - Social Gatherings</td>
<td>5%</td>
</tr>
<tr>
<td>Lost Job</td>
<td>3%</td>
</tr>
<tr>
<td>Refused Employment / Promotion</td>
<td>3%</td>
</tr>
<tr>
<td>Physical Assault</td>
<td>2%</td>
</tr>
<tr>
<td>Job Change - Against Wishes</td>
<td>2%</td>
</tr>
</tbody>
</table>

The strongest evidence from high quality systematic reviews indicates that workplace disclosure remains a major dilemma and barrier to work in PLHIV (see Figure 7). These reviews report that most people tend not to disclose their HIV status at work; this is significant because non-disclosure may be detrimental to psychological wellbeing, and prevent access to adjustments and other workplace support.

‘Internalised’ or self-perceived stigma emerged as a persistent theme throughout the interviews. It was suggested that HIV-related discrimination may be anticipated by PLHIV even when experience indicates it is unlikely. One interviewee quoted the Stigma Survey to support the suggestion that fear of workplace discrimination may be greater than the actual extent that it occurs.

**FIGURE 7**
Factors identified as related to disclosure among PLHIV

Source: Robinson et al. (2015); Wagener et al. (2015)
SOCIO-ECONOMIC CHARACTERISTICS: DETERMINANTS OF HEALTH AND EMPLOYMENT

In order to understand the employment disadvantage related to having HIV, caused by the health and attitudinal barriers discussed above, we need to consider the wider health and social context. The likelihood that someone will develop a long-term health condition, such as HIV, is determined by social factors. The WHO describes these ‘Social Determinants of Health’ as being “the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life.”

Although true of many health conditions, the broader socio-economic context of PLHIV was highlighted as highly relevant by experts and in the literature. It is important to recognise that the prevalence of HIV is higher among groups who already experience labour market disadvantage. One clinician spoke explicitly of the “familiar overlap between poverty and HIV”. This reflects evidence from the UK that financial insecurity and poverty is common among PLHIV (a summary of evidence is provided in Box F over the page).

It was suggested that for certain groups the impact that living with HIV has on their daily lives is exacerbated by other factors such as low social capital, isolation and lack of social support. An HIV diagnosis in this context may have a significant compounding negative impact; i.e. having a poor socio-economic situation (e.g. poor housing) at the time of diagnosis reduces the chance of being in work after diagnosis. The importance of level of education (particularly having a university education) and work status prior to diagnosis was identified as important in a number of studies. One expert suggested that being unemployed at the time of diagnosis was a major barrier to future employment. For someone out of work, whose confidence is likely already low, uncertainty about handling HIV in work may be reinforced, while gaps in work history can be seen as problematic by employers. It is important, therefore, to recognise and consider the complex employment support needs of different social groups, and how this relates to PLHIV.
The UK and international published evidence on PLHIV indicates women, Black, Asian and Minority Ethnic (BAME) people, and those of older age (see section over the page) are more likely to experience difficulties with work. Along with those who have a comorbid disability, another significant group of PLHIV (identified both in the literature and by the experts) to experience employment disadvantage and have particularly high employment support needs were migrants. Within this group the risk of HIV infection may be greater than that of British born individuals, as many come from high HIV prevalence regions such as Sub-Saharan Africa. Furthermore, there are multi-faceted difficulties related to immigration status (e.g. refused asylum seekers and other undocumented migrants may be unwilling to access health care for fear of costs or legal implications) and structural racism related to ethnicity. A clinician we interviewed said in their experience, patients of a migrant background were unlikely to be in work and those that were in work were more likely to be on zero hour contracts, insecure, or poor quality work.

**BOX F**

**Summary of UK evidence on socio-economic determinants of employment for PLHIV**

Barnes & Karpf (2016) surveyed 100 adults living with HIV. The majority of respondents self-identified as Black-African ethnicity. The participants cited that their barriers to working included health and immigration status.

- Of the respondents, older people (aged 50+) were more likely to report an employment barrier than adults younger than 40, and younger adults were most likely to be looking for work.

- Only one third reported that it was easy to access support services like benefits advice, counselling, or other advocacy, in their local area.

**AMONGST RESPONDENTS:**

- 34% have been homeless
- 45% regularly do not have enough money for food
- 25% do not feel safe in their neighbourhoods
- 76% report being worried about their future
- 51% feel like people treat them differently because of their HIV status.

Wielding and Scott (2016) found high rates of employment (75%) among 44 women attending an NHS HIV clinic in Scotland. However, most (85%) earned below national average.

The 2015 Stigma Survey of PLHIV found 35% of all participants were in the lowest socio-economic status (SES) group. Those diagnosed less recently were more likely to be in the lowest SES group, as were women (50%) and BAME participants (46%).

Burch et al (2016), in the UK ASTRA study, identified unemployment as one of four measures of lower SES. It was found to be strongly associated with non-adherence to antiretroviral therapy (ART) and virological non-suppression. The other measures were financial hardship, unstable housing, and non-university education.
AGEING WITH HIV

Recent years have seen another important group emerge: people who are ageing with HIV. Improvements in treatment over time have meant that more and more people are living longer with HIV. Those ageing with HIV will include both long-term survivors of HIV, diagnosed before effective treatment was available (See ‘Long-term survivors’ over the page), and those diagnosed more recently but at an older age - 17% of people diagnosed with HIV in 2015 were aged 50 years and over, an increase from 9% in 2006.3 There appears to be greater need of specialist care for people who are ageing with HIV; in 2015 the average age of people accessing care had increased to 45 (compared to 39 in 2006), while one in three people accessing HIV care were aged 50 years or over, compared to one in seven a decade ago.3

The ageing of the PLHIV population is happening at the same time as an ageing of the general population in the UK, and an ageing of the UK workforce, with changes to pension age placing an expectation on people to remain in work for longer. This is recognised as a challenge for UK governments, employers and workers. Given the continuing improvements in treatment and management of HIV, the ageing workforce will include an increasing number of people who are ageing with HIV. As this is a relatively recent phenomenon, the labour market challenges posed by people living to older ages with HIV are only just beginning to emerge (see Figure 8).42

FIGURE 8
People ageing and working with HIV

Two recent surveys of PLHIV aged 50+ provide some insight into employment for this group

PLHIV aged 50-60 reported that their career has been affected by having HIV. In particular citing:

- Broken career pathways or loss of careers due to HIV diagnosis and related ill-health.
- Having to retrain and pursue an alternative career as they are no longer physically able to carry out the job they were doing pre diagnosis.
- Competing in the job market against younger people is more difficult when a fluctuating condition, such as HIV, is added to the mix.
- Concern was also shared about the impact of the ever-rising age of retirement on PLHIV who are physically ageing earlier because of their HIV diagnosis.

A third were in work while another third were reliant on state benefits often as their sole income.

Compared to their peers, PLHIV aged 50+ were less likely to be economically active and far less likely to have a financial ‘cushion’ for their old age.

Almost half of 50-60 year olds were very concerned about retaining or seeking employment in the future.

Half wanted advice around employment and almost two thirds wanted financial advice. Support for work, welfare and financial advice was seen as an important part of long-term condition management, though it was suggested there were few existing services to provide such support.

Many were concerned about of being reassessed for benefits, or the threat of benefits being stopped at any time, with several citing a lack of understanding from assessors.

Source: Source: Power et al., 2010; THT, 201742
A likely area of concern for the near future is the number of PLHIV who have been limited in their ability to earn an income during their core working years, and therefore may have insufficient funds to support themselves in older age. UK research with PLHIV aged over 50 found their provisions for financial security after retirement were less favourable compared to the general population in the same age group. This has led to a call for improvements in financial advice services for PLHIV as part of standard long-term condition management of HIV.

**Long-term survivors**

The impact of living with HIV on long-term survivors, diagnosed before treatment was widely available (i.e. prior to the mid-1990s), is often very different from those diagnosed since the availability of ART. Long-term survivors often have higher levels of functional disability. Furthermore, they often have to deal with a wide range of issues, potentially including: the psychological legacy of the ‘HIV diagnosis death sentence’ of the 1980s; the ongoing side effects of multiple treatment regimens as treatment developed; or be very ill from AIDS. Comorbidities are particularly high in this group, with a recent survey

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**BOX G**

**Long term survivors and the welfare system**

Changes to the Government benefit system having negative impacts on long term survivors was a recurring theme in the interviews with experts. Previously, those diagnosed when no treatment was available did not have to work and were awarded disability benefits without question, but changes mean many are now expected to work. This is despite the fact that long periods out of work have reduced skills and self-confidence in long term survivors, which in turn has hampered their ability to find work.

Furthermore, people are reporting to consultants in HIV clinics that changes to benefit systems, especially Employment and Support Allowance (ESA), are having a dramatic effect on their mental health. Often having been out of the workplace for a very long time, long-term survivors of HIV are at risk of developing mental health problems, including stress and anxiety, relating to returning to work or education.

“It has become more difficult for people to stay on benefits and they are more likely to be pushed back into work. We know people are having real problems with Personal Independence Payment (PIP) and ESA and things like that but those are people who were diagnosed a long time ago. [They] are not going to get back into work very probably.”

_Expert interviewee (voluntary sector organisation)._
suggesting that individuals diagnosed before 1996 are more likely to have three or more additional health conditions. 

Individuals diagnosed before 1996 are less likely to be employed, and more likely to be dependent on benefits as their sole or main source of income. This was reflected in our interviews, with people in this group identified as having particular concerns around recent changes to the welfare system (Box G).

**SUMMARY**

In this section, we have highlighted the clear, yet complex, link between HIV and employment. Important factors include the extent of disability related to HIV, influenced by factors such as later diagnosis, the presence of concurrent health conditions, and stigma (or self-stigma) towards HIV and related discrimination. These factors are compounded by a complex interplay with the broader socio-economic context of individual living with HIV. This context may be a driver of late diagnosis, and consequently have further implications for health status and experiences of stigma and discrimination. As we try to understand these challenges to employment, we must also recognise the emerging challenge of ageing with HIV, whether as a long-term survivor or after a more recent diagnosis.

In Part Two we will look at what is, and could be, done to address these challenges and improve support for PLHIV to enter, return to, remain and progress in employment.
PART TWO: EMPLOYMENT SUPPORT FOR PLHIV

SECTION SUMMARY

- There is a range of support which can help people living with long-term conditions or disabilities to enter, return to, remain in, and progress in, work.

- There are a range of stakeholders who are, or who should be, involved in providing such support. However, in reality, much of the burden falls on the voluntary and community sector.

- Health care professionals can act as gatekeepers to support but this role is not explicitly recognised in clinical guidance. Indeed, some health care professionals may not recognise the important role that work can have in the lives of PLHIV.

- A varied range of employment support for PLHIV exists in the UK, with the voluntary sector and others working in employment and health settings often utilising key support provided by PLHIV themselves, such as peer support systems. Some examples are provided in case studies.

- Although there is a range of employment support available for PLHIV, there are questions over its accessibility; we have a poor understanding of need and there is considerable variation in service provision nationally.

- As well as poor recognition of the issue at commissioning level, challenges to service provision include: getting the balance right between HIV specialist and generic services; fragmentation of health and social support locally; and, cuts to funding driven by the austerity agenda.

- Traditional vocational rehabilitation approaches, and psychological support have been found to be important in effective employment support for PLHIV.

- Although there is limited academic evidence on what works in terms of employment support, good practice tells us that support can be focused on:
  
  - The workplace: through the development of resources and guidance for managers; the implementation of policy and training for managers; the provision of workplace adjustments; and, through taking action to address HIV-related stigma and discrimination in the workplace.
  
  - The health and social care system: through technological improvements which further reduce the impact on accessing treatment on work; a more general shift away from the biomedical model and increasing recognition of social determinants of health; and, the role of social support such as peer support.

  - Key principles for designing person-centred employment support for PLHIV should include consideration of self-management, and take a multi-staged approach, reflecting on where there are increased risks of falling out of work, including at diagnosis.
EMPLOYMENT SUPPORT FOR PLHIV

Most PLHIV in the UK are able to access timely, effective treatment, and support to manage their condition and live fulfilling lives, which often includes work. However, as we have seen above, others will experience greater difficulties in terms of health, attitudinal and social barriers. These challenges are key reasons for poorer labour market outcomes for many PLHIV.

In Part Two we discuss the evidence on what is being done and what could be done to address some of these challenges and inequalities, to improve employment outcomes for PLHIV (See Figure 9).

There are a number of stakeholders who are relevant to employment support for PLHIV. Some of the main stakeholders and their roles are summarised in Box H, including references to key sections of the report where they are discussed in more detail.

FIGURE 9
Overview of Part Two

How do PLHIV get referred into employment support?

What employment support services exist?

What does effective employment support look like?
# The main stakeholders and their roles in employment support for PLHIV

<table>
<thead>
<tr>
<th>STAKEHOLDERS</th>
<th>KEY ROLES</th>
<th>MORE INFORMATION</th>
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</thead>
<tbody>
<tr>
<td>National government</td>
<td>• Setting national policy agenda and priorities;</td>
<td>See Part 2: Challenges to service provision (p40)</td>
</tr>
<tr>
<td></td>
<td>• Provides legal framework, in terms of health care and equal opportunities/discrimination/human rights</td>
<td></td>
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<tr>
<td>Clinical/health bodies (inc. BHIVA, NICE, NHSE, PHE)</td>
<td>• Development of guidelines for practice and commissioning, including those pertaining to broader determinants of health and wellbeing;</td>
<td>See Box I: Clinical guidance on employment for PLHIV (p34)</td>
</tr>
<tr>
<td></td>
<td>• Commission services;</td>
<td></td>
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<td></td>
<td>• Provide and fund treatment.</td>
<td></td>
</tr>
<tr>
<td>Department for Work and Pensions and JobCentre Plus</td>
<td>• Provide employment services and support;</td>
<td>See Part 2: Examples of employment services in the UK (p36-39)</td>
</tr>
<tr>
<td></td>
<td>• Assess work-related support needs and welfare entitlement.</td>
<td></td>
</tr>
<tr>
<td>Local government and public health</td>
<td>• Provision of funding for local health, employment, and social services;</td>
<td>See Case Study A (p36)</td>
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<td></td>
<td>• Encourage local economic growth (e.g. working with local enterprise partnerships)</td>
<td></td>
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<tr>
<td>Voluntary and community sector (inc. patient groups) &amp; trade unions</td>
<td>• Provision of support services to individuals and employers;</td>
<td>See</td>
</tr>
<tr>
<td></td>
<td>• Advocating for change</td>
<td>• Case Study C (p38)</td>
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<td>• Case Study D (p39)</td>
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<td></td>
<td>• Case Study E (p44)</td>
</tr>
<tr>
<td>Employers</td>
<td>• Employ and provide workplace support to PLHIV</td>
<td>See Part 2: In-work support for PLHIV (p43)</td>
</tr>
</tbody>
</table>
ACCESSING EMPLOYMENT SUPPORT FOR PLHIV

There are a range of potential routes to support PLHIV in accessing support (Figure 10), but PLHIV may not be aware of these routes or there is no systematic sign-posting to access this support. Specialist employment support services specifically for PLHIV are not typical across the UK. A 2016 survey of service users of one London HIV voluntary sector organisation found “only a third reported that it was easy to access support services like benefits advice, counselling, or other advocacy, in their local area.”

Employment support (specific to HIV or more generic) may be accessed through a variety of different routes, including: via the health system or other statutory service providers (e.g. housing, social care or JobCentre Plus), patient groups, voluntary and community services, employers or self-referral. In practice the voluntary and community sector are the main providers of support (see following section) and many people access support through them.

Our research highlighted a need to improve access to other services via health care professionals. The role of health care professionals

FIGURE 10
Range of potential routes to employment support for PLHIV
in recognising the importance of work and supporting patient’s employment goals is increasingly recognised as valuable. This is in recognition of the positive health outcomes associated with employment in good quality jobs.

The health care professionals we interviewed were on the whole very positive about employment, telling us they discussed employment with patients and saw it as important to “try to encourage people to continue with their jobs”. One clinician described work as a “crucial outcome of care”. However, health care professionals were clear that the decision to discuss work “depends on the individual”; citing the unique challenges associated with different groups of PLHIV (see Part One). Further, several health care professionals noted that a lack of appropriate local services was a barrier to engagement.

Despite the positive views on work from health care professionals we spoke to, several suggested that work was not always seen by health care professionals as an outcome of care for PLHIV. A determining factor was the type of health care professionals as those in different roles focus on different aspects of care. For example, while doctors will more likely focus on the clinical implications of managing the condition, a nurse will often also focus on social outcomes, while those involved in occupational therapy and vocational rehabilitation (including for example physiotherapists) will explore functional outcomes, including those relating to ability to work.

The lack of clarity here was perhaps reflected by the limited clinical guidance available on improving employment outcomes in PLHIV. The most relevant document in this regard was identified as the British HIV Association (BHIVA) Standards of care for people living with HIV (see Box I). Though employment is referred to, they do not offer any practical guidance on what this means for health care professionals or how access can be achieved given services are not necessarily available in the local area (see following section).
BOX I
Clinical guidance on employment for PLHIV

The clinical guidance identified by health care professionals as most relevant for employment outcomes was the British HIV Association (BHIVA) Standards of care for people living with HIV. Developed in collaboration with a number of other national health bodies, these standards define the quality of service that any provider of services to PLHIV should meet. For this study, Standard 9 is of particular relevance:

Self-management - People living with HIV should be enabled to maximise self-management of their physical and mental health, their social and economic wellbeing, and to optimise peer-support opportunism.

Under this standard, there is a quality statement: “People living with HIV should have access to services which promote self-management of HIV including: provision of support and information to enable people to optimise their entitlement and access to financial and housing support, and to optimise their ability to gain/regain employment.”

The standard further requires HIV services to have referral arrangements in place to enable PLHIV to access a range of services that may be needed. These services should be accessible both via HIV specialist clinical services and by direct access, and include those which might relate to employment, such as: interventions from occupational therapists, physiotherapists, speech and language therapists, and dieticians; and, services delivered by HIV support services. However, despite this attention to employment, there is no specific reference to employment in the ‘measureable and auditable outcomes’ identified.

Other guidance also makes limited reference to employment, see:

- 2013/14 NHS Standard Contract For Specialised Human Immunodeficiency Virus Services (Adults), developed by NHS England
  - Refers to employment for people with long-term conditions under ‘health improvement’

- Making it work: A guide to whole system commissioning for sexual health, reproductive health and HIV (2015), developed by Public Health England (PHE)

However, these do not provide guidance around how employment outcomes could be improved or the role of health care professionals. There is reference to the potential role of the voluntary sector, but no guidance on how support would be funded.

National Institute for Health and Care Excellence (NICE) were developing guidance for employers to support employees with disabilities and long-term conditions, with HIV specifically included in the guidance’s scope. However, work on this ceased in 2016 due to a lack of evidence.
WHAT EMPLOYMENT SUPPORT SERVICES EXIST

Employment support services for PLHIV in the UK are primarily provided by the voluntary and community sector. Published evidence and experts working in the field identified the crucial role that the voluntary sector has in providing employment support for PLHIV, especially those from the most socially disadvantaged groups. Other bodies, such as local government, public health, the NHS and clinical commissioning groups, or the JobCentre Plus may also run employment support services for PLHIV, often in partnership with the voluntary sector.
EXAMPLES OF EMPLOYMENT SERVICES IN THE UK

During this research we came across examples of different types of employment support services for PLHIV. Case studies have been provided below, representing services provided via local government, the NHS, and, most often, the voluntary sector.

Case study A provides an example of a local government run employment support programme for PLHIV. Blackpool City Council began the Positive Steps into Work initiative in 2007, since November 2013 the programme has offered direct support to people living with HIV to find employment. Though the initiative has not been independently evaluated, a 2015 report by PHE found some positive results, concluding: “Initial indicators suggest it is providing valuable support to clients who would not otherwise have accessed specialist employment advice.”

CASE STUDY A

Positive Steps into Work: Blackpool Council employment support for people living with HIV

Since November 2013, in partnership with public health, Blackpool Council’s employment support service has had a dedicated employment adviser for clients from substance misuse and HIV services. The initiative offers personalised employment support and access to the wider service which includes work placements, online job search workshops, access to training, CV writing, application support, and interview skills training. Support with back-to-work costs (e.g. for interview/work clothes, transport, childcare costs and work equipment) is also available.

In 2015 it was reported that the service was supporting clients who would not otherwise have accessed specialist employment advice. From its caseload of 48 clients:

- 2 with complex needs were supported into paid employment with others in the pipeline
- 17 had received additional support from the National Careers Service
- 19 had been referred into the work placement programme (Chance2Shine)
- 3 had been referred to volunteering services, 2 to training and 3 to wider support services.

From the 1st February 2017, as part of the Changing Futures Project, the service provider, Renaissance, will be employing a full time transformational coach who will aim to get 72 PLHIV across Lancashire and Blackpool into training, volunteering and employment. Funding for this project is being supplied by the Big Lottery Fund and European Social Fund ‘Building Better Opportunities Programme’.
Case Study B is an example of a collaboration between a hospital and the voluntary sector. A small number of hospitals (often working with the voluntary sector) were identified as having NHS-funded non-clinical support roles embedded in the HIV multi-disciplinary team, such as benefits advisors and paid peer-navigators (see Case Study B). This model of service delivery was described as being currently unpopular within the NHS due to increasing pressure placed on the provision of care outside of hospitals. Although one interviewee raised concern that hospital-based services could lead to medicalisation of the condition and reinforce stigma, more typically interviewees considered the loss of specialist hospital support services of this nature, particularly social

CASE STUDY B

Positively UK’s and Homerton University Hospital’s Peer Navigators’ Project for people living with HIV

Positively UK has been working in partnership with Homerton University Hospital in East London to provide peer support to people living with HIV in this high prevalence area. Approximately 1,100 adults receive HIV care at the hospital. 75% of those receiving treatment are women and 75% from ethnic minority communities. Significant numbers are within the immigration system, compromising their eligibility for statutory support and increasing their vulnerability. Poverty, housing and food security are also common problems.

Positively UK and Homerton Hospital wanted to increase capacity to meet growing support needs by appointing ‘Peer Navigators’: patients trained and employed to provide peer support. Three patients were trained and accredited, achieving an NVQ Level 2 in Peer Mentoring from the Open College Network. Supervision was provided by the clinic’s Social Care Co-ordinator and Positively UK’s Peer Case Worker. Peer support was provided during all HIV clinics. Peer Navigators worked with patients to identify needs and priorities, set action plans, work towards agreed goals and undertake advocacy with support agencies.

The service was evaluated using an outcome star, with patients self-assessing at the beginning and end of the programme, as well as through regular reviews. Exit interviews with patients assessed to what extent needs had been met. 40 patients with high level needs were supported through 200 hours of one-to-one support and the project evaluation found the outcomes to be positive:

- 76% of patients said they talked to others about HIV more and were more likely to disclose their HIV status
- 53% reported being in a better financial position
- One Peer Navigator has since gained further employment as a result of the project

Overall, the project found that embedding peer support within the clinic is an effective way of skilling up patients and providing essential peer support, information and advocacy. Collaboration with the voluntary sector was crucial to the success of the project.

This case study originally appeared in May 2015 as part of the ‘Wellbeing Our Way Exchange’, available on the National Voices website, reproduced with permission of National Voices, see: http://www.nationalvoices.org.uk/node/262

A copy of the evaluation report can be found at http://positivelyuk.org/publications/
workers, a negative consequence of the 2012 Health and Social Care Act. A 2016 UK study found improved function, health-related quality of life and goal attainment among PLHIV completing an NHS hospital outpatient rehabilitation intervention combining physiotherapy-led group exercise and education.24

Case Study C is an example of a voluntary sector support programme. Most employment support for PLHIV is provided by specialist HIV organisations in the voluntary sector. Provision is highly variable coverage across the UK. The London based health care professionals and service providers we spoke to often mentioned the Terrence Higgins Trust’s Work Positive Programme (see Case Study C), but many other organisations were also mentioned, delivering services in a localised area. For example, Positively East in east London. Body Positive in

CASE STUDY C

Terence Higgins Trust’s Work Positive Programme

In 2010, the Terence Higgins Trust developed a new work programme in response to difficulties associated with welfare reform reported by their service users. It was initially designed to build self-confidence and skills in PLHIV who had been out of work for some time and to enable them to return to the workplace, following changes to disability benefit regulation. However, the programme now accepts applications from any person living with HIV who is out of work and finding it difficult to find work. Fifty applications were received in 2016 and 150 PLHIV have been through the programme since it started in 2010.

The aim is to place people in ‘suitable work’. The programme is advertised via clinics and other providers and offers an 8 month course which includes work experience, workshops, and one-to-one support (mentoring, peer support and coaching). Many of the programme’s placements have been within health and social care organisations, which are likely to have a better understanding of the issues involved in working with HIV.

An internal evaluation of outcomes for 42 participants in 2015/16 found:

- 87% of participants reported making improvements to their CVs as a result of the training and 43% have completed or enrolled onto courses outside of the project; 70% of participants completed their work placement
- All reported improved work-related skills and a high proportion reported improvements in writing applications (96%) and interview skills (74%). The majority indicated they agreed that: ‘I feel I have much to be proud of’ (91%); ‘I feel more optimistic about the future’ (78%); and indicated increased confidence in their career (87%) and in applying for paid employment (83%)
- Feedback from managers of participants who successfully completed their placement was also positive: 88% would employ their volunteer if vacancy/budget was available; 100% would provide a reference following their work experience; and 88% report skills development of their placement volunteer

For further information visit: http://www.tht.org.uk/myhiv/Your-rights/Work/Work-Positive
north east England, Eddy Stone in the south west region, and the West Sussex Education, Training, Volunteering and Employment (ETE) project (described in Case Study D). Some small specialist providers also work with specific sub-groups of PLHIV, such as migrants, men who have sex with men (MSM), or sex workers. In Brighton, the Citizens Advice Bureau, a national voluntary sector organisation, has an advisor who works specifically with PLHIV.

The role of statutory employment support via the Department for Work and Pensions, in the form of JobCentre Plus was rarely raised in interviews. When it was mentioned, discourse focussed on the

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**CASE STUDY D**

**West Sussex Education, Training, Volunteering and Employment (ETE) project for PLHIV**

With funding from the Big Lottery, the ETE project was established in 2014 by St Peter’s House, a voluntary sector organisation providing support to PLHIV in West Sussex, to meet gaps identified by their service users around support to access training and employment.

The overall aim of the project is to increase uptake of volunteering, further education or paid employment by PLHIV in the county, with a secondary goal to increase PLHIVs participation in local peer groups and engagement with community activities. Other stated aims include: developing work-related (e.g. IT) and life skills (e.g. self-confidence) through service user-led workshops and training sessions, peer group meetings and one-to-one support; increasing employability through work placements or relevant volunteering activities; improving CV writing and interview skills; and, increasing knowledge of job, training and volunteering opportunities.

The University of Brighton is currently conducting a formal evaluation of the ETE project. Their initial report indicates feedback from service users and stakeholders has been positive, and provides examples where the project has made a positive impact including: success in gaining job interviews, obtaining employment, participating in volunteering, enrolling on a college course, and learning a range of computer skills. It states:

“A further additional positive contribution of the project, identified by many of the stakeholders interviewed, is the success of the project in addressing social isolation for PLHIV in West Sussex.”

“The Sussex Community Trust’s HIV specialist nursing team have confirmed the need for this type of work across West Sussex. The Sussex Department for Work and Pensions supports the project and is looking at how best to facilitate the HIV education workshops in local Job Centres.”

For more information visit: http://www.stpetershouse.org.uk/index.php?idPage=23
difficulties for PLHIV created by welfare reforms, rather than reflecting on any support provided to find or retain employment. Where this was discussed, there was a general concern that JobCentre Plus staff were unlikely to be equipped to provide HIV-specific support.

**CHALLENGES TO SERVICE PROVISION**

The viability of providing specialist HIV employment and other support services was noted as concern throughout interviews, with funding cuts affecting the voluntary sector, and a general feeling that this was not an issue on the government’s agenda.

The policy and practice challenges around providing support for PLHIV and developing policy around health and employment, must be viewed in the context of the changing status of HIV, which has only recently been viewed as a long-term condition.

Challenges to service provision suggested in interviews are summarised in Figure 11 below:

> **“This government has no appetite for dealing with this; [there is] no policy strategy for people living well with HIV”**

Expert interviewee (Clinician)

---

**FIGURE 11**

**Challenges to Service Provision**

- Lack of knowledge on service coverage and need
- Balancing population size with need for specialist services and advice
- Fragmentation of local health and social support services
- Cuts to existing services due to the ‘austerity agenda’
Lack of knowledge on service coverage and need

Although we were able to identify some examples of employment support for PLHIV, we do not know the coverage of such support, and whether it is sufficient to meet the needs of PLHIV in the UK. Data on availability and use of HIV support services is currently limited. Surveillance data for over 4,000 PLHIV in the North West of England found less than a third (30%) of people had accessed the social support services provided by eight HIV voluntary sector organisations.50 In terms of employment specifically, there does appear to be some need for services, with over half of the respondents to a survey of 246 PLHIV aged 50 or over reporting that they wanted advice around employment.42 In a recent report, NAT highlighted Information, advice and advocacy on employment as an essential service for PLHIV.†

Our interviewees also suggested that demand for employment support or welfare advice might be increasing. This is in response to recent changes to the welfare system seen by some as placing certain groups of PLHIV, particularly migrants or long-term survivors who are less likely to be working, at greater risk of poverty. Further changes to the welfare system can make people more reluctant to seek work, as people can be unwilling to risk trying to return to work out of fear of losing the ‘safety net’ of disability allowance.5

Balancing population size with need for specialist services and advice

The size of the population, and lack of knowledge about need, presents a clear challenge to setting up and sustaining employment or other support services for PLHIV. As we have seen in practice, having specific services for PLHIV is likely only to be feasible in certain high population localities. There was some conflict in interviews about whether the HIV specificity of these services was an enabler or a barrier to provision of support. The specialist knowledge and support for PLHIV in employment was greatly valued. However it was recognised that a reluctance to disclose might be a barrier to accessing HIV specific services. On the other hand there were concerns that staff working in generic services may hold discriminatory attitudes about PLHIV or may simply not have the necessary knowledge to provide appropriate support – this was highlighted as often being the case in the JobCentre Plus. The co-location of services for PLHIV with those for other conditions which often co-occur with HIV (given the high incidence of certain comorbidities) was suggested as possible resolution. Concern about stigma within health services was still raised as a barrier, as well as a concern about people ‘losing control’ of their disclosure.

Fragmentation of local health and social support services

Experts also talked about the increasing fragmentation of health and social support services for PLHIV, driven in part by provisions in the Health and Social Care Act (2012). It was suggested that this has created service silos which prevent joined-up commissioning of

services for PLHIV, and had also created ambiguity over which actor has responsibility for providing HIV support services. New service delivery models were seen by some as threatening well-designed existing hospital-based support services for PLHIV. An important example was the loss of peer support roles from multi-disciplinary teams.

**Cuts to existing services due to the ‘austerity agenda’**

Challenges to the provision of support services for PLHIV were seen as having been exacerbated by cuts to funding in recent years, as part of the ‘austerity agenda’.

Concerns about the negative impact of austerity on support services for PLHIV, mainly provided via the voluntary sector, was a consistent theme throughout the interviews; challenging service sustainability. Peer support services, and support for PLHIV outside of London (and especially in rural areas) were identified as particularly vulnerable. PLHIV are seen as increasingly reliant on generic support services run by local government, which are also under considerable financial pressure.

**WHAT WORKS IN EMPLOYMENT SUPPORT FOR PLHIV**

In order to improve productivity for PLHIV in the UK, we need to understand what works in terms of interventions and activities which employment outcomes for PLHIV, in the UK and comparable countries. However, evidence on the efficacy of UK initiatives to support PLHIV in and into employment is very limited. We did not identify any evaluations of employment support for PLHIV in a European setting, however, a few small studies from the USA were identified. These indicated that there was particular value in:

- **Vocational rehabilitation approaches**, e.g. skills training, case management, job search assistance, in work support, benefits and legal advice; and,
- **Psychological interventions**, such as counselling.

Drawing on our expert interviews, below we discuss what is important in terms of developing appropriate work support for PLHIV. The findings are broken-down into specific areas of interest:

- **In-work support for PLHIV**: Providing employers with resources and guidance, addressing policies and providing training, making helpful workplace adjustments, providing access to occupational health advice, and raising awareness and tackling...
stigma and discrimination in the workplace.

- **Clinical and social care:** Changes in the provision of health care and peer support.

## IN-WORK SUPPORT FOR PLHIV

The following were highlighted in interviews as important in-work intervention to support PLHIV.

### Resources and guidance for employers

HIV specialist information and policy organisations, including National AIDS Map (NAM) and National AIDS Trust (NAT), and trade unions (such as the Public and Commercial Services Union) have developed detailed guidance on working with HIV for employers and employees. However, although experts recognised the value of these resources, concern was expressed about whether employers accessed them.

Our research identified considerable variation in the expectations of employers. For example, **Sunderland University** is developing a charter mark initiative to improve the visibility of employers with good practice around HIV, and encourage others to do more (see Case Study E). Though this would resonate with some organisations, it was suggested that, given the number of PLHIV in the UK, this approach was unlikely to be widely adopted. However, the programme builds on a more general premise about the importance of demonstrating a positive attitude towards HIV.

This has been suggested as important in tackling stigma, including internalised stigma and allaying concerns around disclosure and discrimination.

### Policy and training

In interviews and via the roundtable, it was suggested that as a minimum, all employers should have an HIV policy for staff and provide relevant staff training, to ensure they understand their responsibilities under the Equality Act (in which HIV is explicitly acknowledge as a long-

“There are examples out there but it is down to employers to seek that out and any improvement comes from within organisations themselves”

**Expert interviewee** (HIV voluntary sector organisation)
CASE STUDY E

Sunderland University Employers HIV Charter: ‘POSITIVE+ALLIES’

Sunderland University, in a joint venture with a regional HIV network, are developing a “charter mark” for employers (modelled on the Stonewall Index). The POSITIVE+ALLIES initiative will make Sunderland University’s internal policy and online training available for use by other organisations and enable charter mark accreditation at two levels:

LEVEL 1
- Does the organisation have a policy that explicitly bars discrimination of someone with HIV?
- Does the organisation have a bullying and harassment policy which clearly indicates zero tolerance?
- Does the organisation deliver training to key staff to raise knowledge and awareness of HIV and AIDS?
- Does the organisation demonstrate clear commitment to build on the work they have done and further?

LEVEL 2
- Does the organisation take active steps to support HIV/AIDS charities/community groups?
- Does the organisation have an open ally or role model within the workplace?

The charter mark will enable employers to promote their place of work as HIV friendly. Employers who sign up and become accredited will be able promote their “POSITIVE+ALLIES” status on their websites and other resources.

Further suggestions for training included: ensuring implementation of the Act’s provisions making pre-employment health questions illegal; and, ensuring good understanding of issues around confidentiality, and reasonable adjustments.

This reflects findings of a research report commissioned by NAT, which recommended employers:

- Have a specific policy that addresses HIV and incorporates it into diversity or disability training.
- Take proactive steps to raise awareness of HIV at work (e.g. by marking World AIDS Day).
- Understand their obligations under the Disability Discrimination Act 2005, including the sorts of adjustments that people living with HIV may need in the workplace and the ease with which they can be accommodated.

“One simple step is for organisations that are positive towards HIV, promoting that and making themselves visible.”

Expert interviewee (HIV voluntary sector organisation)
Making workplace adjustments

Only a small minority of PLHIV who are very ill (e.g. due to being diagnosed late) will need physical workplace adaptations to enable them to work. However, psychosocial support may be needed by many more, in particular around mental health wellbeing and managing disclosure.

The importance of flexible workplace practices was frequently mentioned, particularly in terms of supporting people’s self-management. This reflected NATs findings that the “most common kinds of reasonable adjustments people with HIV asked for were time off to go to clinic appointment and flexibility over working hours both of which are relatively simple and inexpensive requests for employers to accommodate.” This was particularly emphasised for newly diagnosed employees. Providing a good occupational health service for staff was also suggested by a number of interviewees to be important.

An occupational health service provides advice and practical support about how to stay healthy in the workplace and how to manage health conditions. This is frequently offered through access to health care professionals, or direct support and advice for making workplace adjustments. Work conducted in Holland to develop a multidisciplinary, evidence-based guideline for HIV and employment identified an explicit role for occupational health practitioners. In the UK, access to occupational health is limited; around half of employees report having access to an occupational health service through their workplace, however the proportion is far lower in smaller businesses and is unlikely to be available for the self-employed.52

Occupational health services were seen as having a particularly strong role in terms of early intervention. It was suggested that an effective early consultation with an occupational health professional should consider “the resilience of the employee, the workload he or she can cope with, and the potential risk factors for absenteeism”.21

Raising awareness and tackling stigma and discrimination in the workplace

Several experts remarked that the workplace provides a valuable setting for addressing and preventing stigma around HIV. In particular, modernising the messages around HIV, so people understood the current context and addressing fears about transmission.

Given many PLHIV work in health and social care, it was suggested that focusing efforts on raising awareness of positive practices around HIV and addressing stigma and discrimination in these work settings would have double benefits; for employees, and for patients.

It was also suggested that public awareness raising in schools could be an effective method to bring about the change needed in perceptions around HIV.
THE STRUCTURE OF HEALTH AND SOCIAL CARE PROVISION

Interviewees also made suggestions about changes within the health and social care context which they felt would have a positive effect on employment outcomes for PLHIV.

Technological developments

It was suggested that technological developments in health care would likely have benefits for PLHIV in terms of employment. For example, using technology to conduct consultations by Skype or phone, especially for PLHIV with suppressed viral load living in rural areas, was suggested to reduce time spent attending appointments.

Shifting away from the bio-medical model

It was suggested that a shift away from the bio-medical model towards a more biopsychosocial approach – which includes biological, psychological, and social aspects of health – would be valuable in some areas of health care for PLHIV. Although experts felt that the BHIVA guidelines still conformed to a traditional bio-medical model, there was discussion that a broader move towards helping people live well with HIV should include access to rehabilitation and allied health services.

Building on this, it was suggested that the ability to identify and quantify HIV associated disability was key in developing appropriate interventions. Although the UK has no existing standardised tool, the ‘HIV episodic disability questionnaire’ (developed by the Canadian working group on HIV- REALIZE) was identified as a good model.53, 54

Peer support

Several experts also mentioned that peer support was an important element in health and social support for PLHIV. Peer support is the help and support that people with lived experience give to support others with similar conditions to manage in their everyday life. Peer support may be part of a multi-disciplinary health care team, or sit outside it. Evidence indicates that peer support is positive in a range of ways: promoting hope and belief in the possibility of recovery; empowering individuals; increasing self-esteem; enabling self-management; and, supporting the development of supportive social networks. Whilst these outcomes have advantages on their own, they are also associated with improved employment outcomes, and there is growing evidence about the value of peer support in supporting people living with health conditions to find, retain and progress in work.55

Peer navigators were highlighted as having a valuable role in terms of providing PLHIV with greater access to social support (as part of a multi-disciplinary team), as well as in itself providing work for PLHIV. A hospital embedded peer support programme is highlighted in Case Study B.

“More discussion is needed on the topic of stigma and discrimination to address widespread fear around transmission. The last nationwide campaign was the ‘tombstone campaign’ in 1987 and attitudes are stuck in the situation then, when HIV was not curable. Whereas now, with anti-retrovirals, the situation is very different.”

Expert interviewee (HIV voluntary sector organisation)

“The way HIV health services are structured– hospital based services causes the condition to be medicalised and doesn’t deal with the problem of stigma”

Expert interviewee (HIV voluntary sector organisation)
PRINCIPLES FOR DESIGNING EFFECTIVE INTERVENTIONS

Along with specific interventions we identified some key principles to guide the development of effective interventions. These were identified reflecting on our interviews, the research literature (in particular Wagener et al 2015[3]), and the BHIVA standards. These two principles are in addition to those we have already confirmed: it is vital to ensure that all interventions recognise the individual health context, the challenges of stigma and discrimination, and the broader socio-economic context.

Self-management

As stated in the BHIVA standards: “People living with HIV should be enabled to maximise self-management of their physical and mental health, their social and economic well-being, and to optimise peer-support opportunities.”44

Improving self-management facilitates independent living, including work, and consequently we believe that any effective intervention to support work outcomes must incorporate and encourage self-management. Facilitating self-management is also important in person-centred approaches to support; recognising the individual as an expert in managing their health and wellbeing and ensuring they are empowered to take control. Allowing PLHIV the time and space at work (and outside) to manage their condition, and in particular to engage with treatment, will likely improve outcomes in the longer term.
Multi-staged approach

Much like interventions to support people with other long-term conditions to remain in work, interventions for PLHIV will need to recognise the different points at which there is a greater risk of difficulties emerging, i.e. when there is greater risk of productivity loss. Three important stages for intervention are:

- **Health and wellbeing support (i.e. prevention) and early intervention** – taking proactive action before there is an issue to prevent risks to work.
- **Sickness absence** – ensuring that the reasons for the absence are understood and appropriate support is provided to identify any work-related issues.
- **Return to work** after longer periods of absence – to help ensure the individual is integrated back into work, and receiving the support they need to work well.

Further, as discussed above, ensuring support is available at the time of diagnosis can be critical in retaining an employee.

### SUMMARY

Although employment is recognised in clinical and commissioning guidance, there is little practical information available and no drivers in terms of outcome measurement. Access to employment support for PLHIV in the UK is limited and highly localised, and we do not know how well current provision responds to current need. What is available is largely provided by the voluntary sector; however, a combination of policy reforms and local challenges (including recent funding cuts) are seen as limiting their ability to continue to provide such support, and there is an increasing shift towards more generalist provision, which comes with some barriers for PLHIV.

The evidence on employment interventions specific to PLHIV is limited, what is available suggests that traditional vocational rehabilitation approaches and psychological support can be effective. Furthermore, experts highlighted examples of ‘in-work’ support, such as workplace adjustments, guidance for employers, and activities to address stigma, as well as suggesting changes in health and social care, which could be positive for employment outcomes; in particular activities to improve recognition of the need for social as well as clinical support, including via peer support.

Experts highlighted a range of ‘in-work’ support examples:

- **Workplace adjustments**
- **Guidance for employers**
- **Activities to address stigma**

As well as suggesting changes in health and social care, which could be positive for employment outcomes

* i.e. early intervention in providing support and making adjustments at work to reduce the risk of absence or additional stress for the employee.
Developing effective employment interventions for PLHIV requires recognition of consider the wider context for PLHIV – their individual health (including comorbidity), the possibility of stigma and discrimination, and their socio-economic context. Along with these, key principles for developing interventions include supporting self-management, and understanding the different stages where people may be of higher risk of falling out of work.

In the following section we look at how productivity loss relating to HIV can be quantified.
PART THREE: QUANTIFYING THE IMPACT OF HIV ON WORK PRODUCTIVITY

SECTION SUMMARY

- The costs of reduced in-work productivity and absence from the workforce due to sickness, or long-term unemployment associated with a health condition are significant. Costs fall on the health, welfare and social care systems, but also more importantly on individuals and their families.

- Although likely to be significant, we do not currently know the specific costs associated with HIV and productivity in the UK; this was last estimated in the late 1990s.

- To calculate costs for PLHIV, we require not only ‘standard’ data on productivity loss for PLHIV – e.g. employment rate average wage, sickness absence, welfare spend – but we would also need to assess the impact of comorbidity, and medication side effects, as well as accounting for the situation of an ageing population.

- Furthermore, the socio-economic context of the population with HIV, and the likelihood of pre-existing work disadvantage must also be taken into account.
QUANTIFYING THE IMPACT OF HIV ON WORK PRODUCTIVITY

In the UK, the combined costs of reduced in-work productivity and absence from the workforce due to sickness, or long-term unemployment associated with a health condition, are estimated to be over £100bn annually.56

Some key drivers of productivity costs include:57

- Sickness absence – long- and short-term
- Lost in-work productivity, primarily due to presenteeism (attending work while ill) and lost working hours to attend medical appointments
- Staff turnover, in terms of job loss and recruitment
- The opportunity cost to the economy of not being in work (including due to premature death)
- Impacts on the productivity of family members and those providing informal care.

There are other indirect economic costs associated with poor health. These include the costs of the welfare needed to support people who are unemployed or economically inactive due to ill health (including those who take early retirement). There are also wider societal costs resulting from exacerbated health inequalities and increased social exclusion.

Productivity costs vary for different conditions. For example, for mental illness, which is estimated to affect around 1 in 6 people of working age,58 the costs to employers of related sickness absence, reduced in-work productivity, and staff turnover is estimated at nearly £26bn each year.59 It is estimated that such indirect costs relating to productivity account for around 40% of the total cost of mental illness to society.60 Mental illness is common in PLHIV; the prevalence of psychological distress is substantially higher than that of the general population with PLHIV twice as likely to be diagnosed with depression.32

Recent research by the Work Foundation estimated the productivity costs associated with five long term health conditions (LTCs) in the UK working age population, reflecting on the above factors. For example, the calculations estimated that heart failure, which affects around 750,000 people in the UK and is more common in PLHIV than those without the infection,61 had an indirect cost of almost £1bn to the UK economy in 2014.57
CALCulating Productivity LosSES Associated WItH HIV

It is recognised that there are productivity losses associated with HIV, but few studies have estimated these costs. A 2014 systematic review (see Box J) found just one study on the productivity costs of HIV in the UK, leading them to call for more studies “to reflect the economic impact of HIV/AIDS beyond health care including other components of social burden.”

Converting the 1997/8 data from this study into 2010 values, the authors estimate the mean annual occupational loss for each PLHIV to be 5,613.33 Euros (equivalent to GBP £4,785.20 in today’s exchange rate). Assuming a figure of 95,000 working-age PLHIV in the UK, this indicates annual productivity losses associated with HIV are around £431m.

Given the great shifts in HIV treatment and management as well as in the labour market since 1998 when Mullins estimated the indirect costs of HIV, up-to-date research is needed to provide an accurate figure for today.

* As at 29th January 2017 1 EUR = 0.852470 GBP

BOX J

Summary of productivity costs data for PLHIV in the UK (converted to 2017 values)

The Trapero-Bertran and Oliva-Moreno (2014) systematic review of evidence on the economic impact of HIV/AIDS in five European countries included meta-analysis of estimates of lost work time reported in Mullins et al. (2000). Mullins analysed 1997/8 HIV cohort study data for England. They identified indirect costs relating to HIV (including the costs of statutory, community, and informal services; disability payments; and lost economic productivity). Data was split into two types of costs: public sector, or societal (i.e., costs paid by patients, their families, or employers), and reflected three different population groups: Asymptomatic PLHIV, symptomatic PLHIV, people with AIDS.

To calculate loss of economic productivity to employers due to HIV, mean disability days were combined with average gross weekly income. The average gross weekly income in 1998 was £421, so the estimated value of lost economic productivity per disability day was £60. The estimated value of lost economic productivity due to disability therefore amounted to £1524 for asymptomatic individuals, £4242 for people with symptomatic non-AIDS, and £10,584 for people with AIDS (converted to 2017 values an estimated £1,291, £4,450 and £18,732 respectively).
In Figure 12 we provide some key data, and an indication of where there might be gaps, required to quantify productivity costs associated with HIV.

**Basic productivity information for PLHIV and all population (data restricted to last 10 years)**

<table>
<thead>
<tr>
<th>DATA FOR HIV POPULATION</th>
<th>DATA FOR UK POPULATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Working age population (16-64)</td>
<td>Approx. 95,000³</td>
</tr>
<tr>
<td>Employment rate³</td>
<td>63.8% employed,</td>
</tr>
<tr>
<td></td>
<td>17.4% unemployed (2014)</td>
</tr>
<tr>
<td>Income</td>
<td>Median hourly wage among PLHIV attending a London hospital clinic was £15 per hour (2013)⁶⁴</td>
</tr>
<tr>
<td></td>
<td>What is the average income for PLHIV?</td>
</tr>
<tr>
<td>Sickness absence</td>
<td>What is the average number of work days lost due to absence for PLHIV?</td>
</tr>
<tr>
<td></td>
<td>Sickness absences cost the economy around £15-29 billion a year, predominantly in lost output. (2013)⁶⁷</td>
</tr>
<tr>
<td></td>
<td>For employers, the financial costs of sick pay and other indirect costs of managing absence are estimated at £9 billion per year. (2011)⁶⁸</td>
</tr>
<tr>
<td>Presenteeism (attending work while ill)</td>
<td>58 per cent of the respondents said being HIV positive had no impact on their working life⁶⁹ (2009)</td>
</tr>
<tr>
<td></td>
<td>What is the average number of work days lost due to presenteeism for PLHIV?</td>
</tr>
<tr>
<td>Other lost work time</td>
<td>Est 36% of PLHIV take time off for appointments. Cost per appointment: Lab testing £7.26, PIMA testing £4.38 per patient per visit (2013)⁶⁴</td>
</tr>
<tr>
<td>Welfare system costs</td>
<td>What percent/number of PLHIV are receiving welfare benefits due to HIV?</td>
</tr>
<tr>
<td></td>
<td>Daily benefit of moving an ESA support group claimant into employment - £35 exchequer, £53 society.⁷⁰</td>
</tr>
</tbody>
</table>
OTHER KEY COSTS TO INCLUDE

Side Effects
A thorough calculation would need to take into consideration the impact of the side effects of different treatment regimens on productivity. One study suggested side effects including fatigue, diarrhoea and insomnia can have a significant impact on absence and presenteeism, finding that the level of work productivity loss was often several times higher for those reporting a given side effect relative to those who did not. 36

Extent of comorbidity
Although we do not know exact levels of comorbidity for PLHIV (rates vary considerably depending on setting of the data collection10) a study of PLIV in one London borough found 29% of PLHIV had at least one comorbidity.34 This study identified the most common comorbidity is hepatitis, followed by cardiovascular disease, diabetes, mental illness, and liver disease.34 A recent systematic review found that in high income countries, rates of depression and anxiety for PLHIV (on ART) are around 20–25%.33 Mental illness has particular implications for productivity, e.g. only 32% of people with mental health conditions are in employment.71

Ageing of the population with HIV
One in three people accessing HIV services are aged 50 or over, and less than half (45%) of PLHIV aged 50 to 64 years old are economically active (full-time, part-time or self-employed).41 The likelihood of comorbidities increases with age. A Brighton study of PLHIV age fifty or older, found 84% reported at least one comorbid condition and 61% reported multi-morbidity (two or more conditions) which was associated with polypharmacy and increased use of non-HIV services.72

Socio-economic context
As discussed above, the nature of HIV indicates that calculations to understand associated productivity costs need to be substantively different from those used in other long-term conditions. In particular, calculations must take account of extreme variations in the economic outcomes associated with different segments of the population most affected by HIV.

For example, unemployment rates for people of Black, Asian and Minority Ethnic background in the UK are consistently higher than those for white people.73 Such disparity is reflected within PLHIV - unpublished evidence from the PHE 2014 Positive Voices pilot survey indicate that whilst 17% of all survey respondents were unemployed, rates were significantly higher in respondents who in the ethnic group ‘Black other’ (53%), in ‘Black Africans’ (29%) and Asians (26%). This is further compounded by the knowledge that 11% and 10% respectively of African heterosexual men and women are unaware of their infection. More data should be available via the expanded version of this survey in 2017.

Based on the available evidence on influences on productivity for PLHIV, we have developed an initial hypothetical model of the productivity costs of HIV (Figure 13) to illustrate the relationship between HIV and
FIGURE 13

A preliminary model for quantifying the impact of HIV on employment related productivity

The following diagram maps the factors which influence work outcomes for PLHIV.

The colour-coding is used to indicate where impact on ability to work is more likely to be high or low, and where we do not know.
productivity loss. A traffic light system is used to indicate the factors which lead to a greater (red) or lesser (green) risk of productivity loss. It seeks to show that productivity loss relating to HIV is not a necessity, but instead, as indicated by the colour green, with timely diagnosis and access to effective treatment (with limited side effects) and care throughout the entire course of an individual’s life with HIV, the impact on productivity could be minimised or even removed.

However, we also see that there are barriers to work productivity, such as HIV associated stigma and discrimination and disability, which convert these potential gains, into productivity losses. To illustrate how the negative impact of stigma on productivity can be compounded, the red arrow here is two way. The evidence tells us that stigma can have a negative impact on mental health and wellbeing, and that stigma can cause discrimination which prevents access to services necessary for health and wellbeing - at diagnosis as well as over the life course. The consequences of this for physical and mental health, as well as social and economic wellbeing, in turn, increase the risk of the HIV health and disability barriers having a negative impact on productivity.
In summary, the model indicates the following features that warrant consideration in attempts to quantify the impact of HIV on productivity:

- Stigma and disability are the two principal barriers to employment in PLHIV.
- HIV associated discrimination prevents access to effective treatment (with minimal side effects) and care – at diagnosis and in on-going care.
- Lack of effective care decreases wellbeing (physical, social and economic); it increases the health barriers to employment, and provides the conditions for a cycle of stigma and discrimination with destructive consequences for productivity.
- Increasing numbers of people are living with HIV into older age, when the impact of comorbidities is further compounding the risks of HIV associated disability. Long-term survivors are a specific group in this category with high needs in terms of maintaining their full potential for economic productivity.

We hope this preliminary model will inform discussion around three key gaps in the data available to calculate productivity costs associated with HIV.

- Firstly, the relatively low prevalence of PLHIV at a national level means that organisations providing generic services, such as JobCentre Plus, do not routinely collect data about the HIV status of their service users.
- Second, the extent of comorbidity, and the stigma associated with HIV may mean that people do not disclose their HIV status at work, in the JobCentre Plus, or in employment and other services. Some services, such as JobCentre Plus only collect primary condition data meaning others get obscured.
- Finally, accurate quantification of productivity loss associated with HIV would have to place a numeric value on the socio-economic factors, shown in this report to be crucial in determining work outcomes for PLHIV. These are included in the model, but we have limited robust data to attempt to accurately calculate a figure for this component.

With these three data gaps in mind, in the final chapter we identify ways in which data may be improved, and in general call for greater investment in and better use of data, to allow us to develop more accurate models and assessment of productivity loss relating to HIV in the UK.
CONCLUSIONS AND IMPLICATIONS

CONCLUSIONS

This research explored the relationship between HIV and productivity in the UK. Although progress has been made in terms of treating and managing HIV, it is not clear that similar progress has been made in terms of employment outcomes. This is concerning given many PLHIV see employment as important to their lives, and that it may confer health and wellbeing benefits. This is particularly relevant in the discourse around quality of life for PLHIV.

In this study we identified certain groups who are at greater risk of experiencing worse employment outcomes. Those who have received late diagnosis are one such group; and we must continue to work on both reducing the incidence of HIV, and improving timely diagnosis, and consequently access to appropriate treatment. This will also have the effect of bringing the UK in line with, and moving beyond, the UN’s 90-90-90 goals. Similarly, we need to ensure that PLHIV are receiving appropriate treatment and support to reduce the likelihood of developing comorbidities or experiencing side-effects, which may provide further barriers to working. Indeed, we must improve recognition of the role of employment in the health system, ensuring that health care professionals are mindful of the broad range of factors that can help and hinder someone’s health and wellbeing, making treatment decisions that reflect people’s aspirations around quality of life, and are positive about the life opportunities available to patients, which will, for many, include employment.
We must ensure there is recognition within welfare and health policy of the challenges of working with HIV. Although in many cases HIV is well controlled and many PLHIV can work and are in work, there remain some PLHIV who cannot, and who should be supported to live fulfilling lives outside of employment. For those who can work, specialised employment support for PLHIV is the ideal, and would allow us to respond to the specific needs and challenges within this group, however it is understood that resources are not always available to provide this. Therefore, we need to find ways to improve access to appropriate employment support. If we want PLHIV to use and to benefit from more generic services, we need to ensure that such services (and those working in them) understand the particular needs and challenges for PLHIV. This includes the socio-economic context of many PLHIV, the history of the condition and how it has affected people's lives (particularly those who were diagnosed many years ago), and the continuing stigma around HIV, which makes disclosure a difficult decision for many. Indeed, despite progress, stigma and discrimination still present considerable barriers to people's employment aspirations. The Equality Act on its own is not enough; we need to develop good practice on addressing stigma and supporting staff with HIV. The workplace is an important setting for tackling this head on; particularly in industries, such as health and social care, where outdated concerns may be heightened. Encouraging and supporting positive and high profile action in such workplaces might help to address this once and for all. We need to improve understanding of the challenges through improving information.

Drawing on the above challenges, below we highlight some areas for actions which we believe, if addressed, will improve employment outcomes and therefore productivity among PLHIV. As discussed in the previous chapter, we are unable to put a cost on this – currently there is not sufficient data to even make a basic assessment – but what information does exist has allowed us to map out what data we need to enable us to do this. HIV and employment is a complex issue. There are
clear limitations in the evidence, but also lots of examples of practice and good experience that we can build on. In order to really address the productivity challenges experienced by this group, we need to take a close look at the support we offer PLHIV and the way we collect and use data to ensure we are recognising the unique status of this health condition.

**IMPLICATIONS AND AREAS FOR ACTION**

We believe that there is capacity to improve work productivity for PLHIV in the UK; allowing more people who can work to work, and to work well, while supporting those who cannot work to live their lives. The following have been identified as areas for action to help us achieve this objective:

**Key Identified Areas for Action**

1. Reducing the incidence of HIV, and improving timely diagnosis
2. Improving recognition of the role of employment in the health system for PLHIV
3. Increasing recognition within welfare and health policy of the challenges of working with HIV
4. Improving access to appropriate employment support
5. Developing good practice on addressing stigma and supporting staff with HIV
6. Understanding the challenges through improving information: identifying areas for future research

Specific recommendations on how to achieve these goals are suggested below. We believe that taking action in these areas would improve the ability for PLHIV in the UK to enter, return to, remain in and progress in employment – with potential benefits for individuals and their families, the health and welfare systems, and the UK economy. This is a complex issue. It is clear that in order to effect real change in this area, we need to have buy-in and see action from a range of stakeholders. As demonstrated by attendance and commitments made at our roundtable event, there is appetite for this; we need to harness this and drive through an agenda for change.

Although beyond the remit of this research, we recognise that the most effective way to reduce the work barriers associated with HIV is to reduce the transmission of the disease itself. The continuation of activities to address this is essential to productivity, as a part of the broader agenda.

“We believe that there is capacity to improve work productivity for PLHIV in the UK; allowing more people who can work to work, and to work well, while supporting those who cannot work to live their lives.”

The Work Foundation, April, 2017
## Areas for Action Detailed Recommendations

### 1. Reducing the Incidence of HIV, and Improving Timely Diagnosis

**Issues**
By minimising the transmission of HIV we will minimise its effects on productivity. Action must continue on HIV prevention activities as well as on activities which improve the likelihood of timely diagnosis and access to effective, safe treatment.

**Recommendations**
- Continue activities to prevent transmission of HIV prevention, and achieving the 90-90-90 goals. We need to:
  - Improve awareness about HIV in at risk groups and of the benefits of accessing and adhering to treatment.
  - Recognise and communicate the impact on productivity as a further driver of this activity.
  - Address stigma around HIV testing and diagnosis.
  - Continue exploring treatment as prevention.

**Stakeholders**
- Led by: Department for Work & Pensions and NHS England
- Other stakeholders: Department of Health

### 2. Improving Recognition of the Role of Employment in the Health System for PLHIV

**Issues**
Health care professionals have a key role in providing treatment and support which helps PLHIV manage their condition, and lead fulfilling lives. Not all however recognise that activities such as work can be an important part of people’s recovery and affect health outcomes, and treatment may not be optimised to support these outcomes. Even for those that do, time, resource and skills may limit what they can do for patients in terms of social support to enhance quality of life, including through work.

**Recommendations**
- Identify ways to encourage recognition of employment in clinical interactions, such as through mechanisms to drive recognition of work as an important health outcome for PLHIV.
- Optimise capacity in medicine use reviews to reflect on broader quality of life goals such as employment.
- Explore ways to improve consistency between HIV specialist services and voluntary and community sector support.
- Improve access to social support in multi-disciplinary teams, for example through enhancing access to and availability of peer navigators (case study B).
- Develop commissioning guidance and ascertain funding sources for employment support provision for PLHIV to support the existing reference in HIV service specification (and others) to employment, and to the voluntary sector.
- Raise awareness within the HIV specialist health professional community by developing a position statement on employment and employment support for PLHIV, and developing resources such as guidance for writing ‘fit notes’.

In support of these points, we join existing voices in calling for an additional target to be added to the UN’s 90-90-90-90 goals around quality of life.74

**Stakeholders**
- Led by: Department for Work & Pensions and Department of Health Joint Unit on Work and Health
- Other stakeholders: BHIVA, NHS England, Public Health England, Voluntary and Community Sector
### 3. Increasing Recognition Within Welfare and Health Policy of the Challenges of Working with HIV

**Issues**

It is important that we raise awareness of the barriers to working for PLHIV, and ensure such issues are on the agenda in deliberations on health, disability and work policy.

**Recommendations**

- Government departments concerned with health and welfare should recognise and strive to understand the challenges associated with living with HIV and their implications for work, and ensure this is reflected in policy.
- The HIV voluntary and community sector already have a voice in this area, this needs to continue - in particular through the current period of change in work, health and disability policy, and through forthcoming changes within the NHS.

**Stakeholders**

Led by:

- Department for Work & Pensions and Department of Health Joint Unit on Work and Health

Other stakeholders:

- Public Health England
- Voluntary and Community Sector
- PLHIV

### 4. Improving Access to Appropriate Employment Support

**Issues**

The relative infrequency of an employer or employment support provider working with someone living with HIV has implications for the nature of effective, practical support. We must ensure that appropriate support is available when people need it, working with the voluntary sector who already lead in this space. This includes ensuring employers and employees have access to advice and support, and ensuring that providers of back to work services (including the JobCentre Plus), understand the needs and the challenges within this population. Similarly we need to improve recognition of those who cannot work, to ensure that financial and other support is available to assist them to also live fulfilling lives.

**Recommendations**

- Improve provision of information to PLHIV about sources of employment support, initially prioritising information provided in GP surgeries and HIV clinics. This could be via peer navigators where available. Advice should relate to job-seeking as well as retention, with time of diagnosis recognised as a high risk period.
- Develop guidance for employers on reasonable adjustments around common HIV symptoms and medication, initially prioritising fatigue (which is also relevant to other long-term conditions).
- Develop guidance for JobCentre Plus work coaches to improve support for claimants with HIV.
- Explicitly include people disabled by their HIV status in the recent government commitment to end repeat ESA assessments for people with severe long-term health conditions.

**Stakeholders**

Led by:

- Department for Work & Pensions and Department of Health Joint Unit on Work and Health
- JobCentre Plus

Other stakeholders:

- Employment and vocational rehabilitation specialists
- ACAS
- Local government and public health services
- BHIVA
- Voluntary and Community Sector
### 6. UNDERSTANDING THE CHALLENGES: AREAS FOR FUTURE RESEARCH

**Issues**

A significant challenge to our understanding of the impact of HIV on work and productivity is the absence of good quality data in the UK on employment outcomes and demand for employment support.

In particular, we are unable to quantify the burden of living with HIV on productivity because there is a lack of empirical evidence on the compounding impact of HIV in population groups already disadvantaged in the labour market.

Furthermore, the relatively small numbers of PLHIV in the UK and the methods of data collection mean that this group is not always identifiable in government data about social and employment-related support.

**Recommendations**

- Include detailed employment questions in the expanded ‘Positive Voices’ survey*, and undertake specific analysis on employment and employment service use.
- Include a basic employment question in HIV and AIDS Reporting (HARS) Data Set
- Change data collection in JobCentre Plus to improve chances of HIV data recording, e.g. in claimant data.
- Encourage studies which include a counterfactual comparison group that are observationally identical except that they are not infected with HIV, e.g. matched by similar socio-economic characteristics.
- Map existing data sources on HIV and productivity, and develop a consortium of interested researchers to share data, and develop proposals to address gaps.
- Consider the implications of ageing with HIV in the context of employment.

**Stakeholders**

- Led by: Public Health England
  - Department for Work & Pensions
- Other stakeholders: Research funding bodies, Academic researchers, Public Health England

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* https://www.ucl.ac.uk/voices
FINAL THOUGHTS

This report shines a light on the implications of having HIV for productivity in the UK. It reflects on the barriers PLHIV may experience to being in work and to progressing in work, and explores the main sources of support. In doing so we identified a range of challenges; in the way that HIV is (and has in the past been) diagnosed, treated and managed, and the opportunities available for work, and for support to work for PLHIV today. Based on this learning we call for action in a number of areas to help improve productivity for PLHIV, for example through: improving access to employment-related support; normalising work as an outcome to be considered in care and treatment decisions; and, learning about what works, and in particular ensuring the unique context of PLHIV is recognised not only in terms of service provision, but also in the data collection that will inform improvements in understanding and support. It is only through these actions that we can address the social and economic disadvantages faced by some people due to their HIV status.
GLOSSARY OF TERMS AND ABBREVIATIONS

AIDS
Acquired Immunodeficiency Syndrome

ART
Antiretroviral therapy

BAME
Black, Asian and Minority Ethnic

CD4 COUNT
A lab test that measures the number of CD4 T lymphocytes (CD4 cells) in a sample of your blood. In people with HIV, it is the most important laboratory indicator of how well your immune system is working and the strongest predictor of HIV progression.

COGNITIVE IMPAIRMENT
A measurable decline in cognitive abilities, including memory and thinking skills.

DISABILITY
Under the Equality Act 2010, you have a disability if you have a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on your ability to do normal daily activities.

EPISODIC DISABILITY
See fluctuating conditions

FLUCTUATING CONDITIONS
Long-term conditions that are characterised by periods of good health interrupted by periods of illness or disability.

FRAILTY
A syndrome characterized by age-related declines in functional reserves across an array of physiologic systems

HAND
HIV-associated neurocognitive disorder

HCV
Hepatitis C

HEALTH-RELATED QUALITY OF LIFE (HRQoL)
A multi-dimensional concept that includes domains related to physical, mental, emotional, and social functioning.

HEALTH STATUS
The way the condition affects someone’s health and functioning

HIV
Human Immunodeficiency Virus

INTERNALISED STIGMA
The product of internalization of shame, blame, hopelessness, guilt, and fear of discrimination associated with being HIV-positive

JOBCENTRE PLUS
A government-funded employment agency and social security office

MSM
Men who have sex with men

NHS
National Health Service

PERIPHERAL NEUROPATHY
Damage to or disease affecting nerves, which may impair sensation, movement, gland or organ function, or other aspects of health, depending on the type of nerve affected.

PLHIV
People living with HIV

PRESENTEEISM
Attending work while ill

SOCIAL DETERMINANTS OF HEALTH
The conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life

SOCIO-ECONOMIC FACTORS
Relating to or concerned with the interaction of social and economic factors:

SES
Socio-economic status

STIGMA
A set of negative and often unfair beliefs that a society or group of people have about something

UN 90-90-90 GOALS
By 2020, 90% of all people living with HIV will know their HIV status. By 2020, 90% of all people with diagnosed HIV infection will receive sustained antiretroviral therapy. By 2020, 90% of all people receiving antiretroviral therapy will have viral suppression. http://www.unaids.org/en/resources/documents/2014/90-90-90
FULL RESEARCH QUESTIONS AND METHOD

FULL RESEARCH QUESTIONS

- What is the impact of HIV on employment? Considering in-work productivity (performance and progression, sickness absence, presenteeism and underemployment), and broader labour market productivity (unemployment and economic inactivity, and associated losses related to social exclusion, human capital and tax revenue)

- What are the quantified costs of this productivity loss?

- What are the causes of the identified productivity loss? What are the barriers to PLHIV being fully productive in the labour market (finding employment, retaining it and progressing)?

- What interventions and support are effective in addressing these barriers, to the end of optimising labour market productivity of PLHIV; including current provision and access (NHS, social care, employers, policy-makers, self-management support)?

METHOD

An initial scoping review of the literature identified two reliable systematic reviews of evidence on work and HIV published in 2015 (Robinson et al.; Wagener et al). Subsequent work focused on reviewing material published in 2015 or 2016 in peer reviewed journals, and current material available on institutional websites, including UK government, research bodies and organisations working with people living with HIV in the public, private or third sectors. The findings of both stages of the review were then mapped against the research themes under four headings derived from the research questions:

- Impact of HIV on employment
- Productivity costs quantified
- Causes/barriers
- Interventions and access
The research team undertook a series of semi-structured interviews with ten individuals with expertise in HIV, work and/or rehabilitation. The majority of the experts were health care professionals or representatives from the voluntary sector. The experts provided descriptions from different perspectives of the impact HIV has on employment based on their practical experience of working with PLHIV. Audio and written records of the interviews were analysed using Grounded Theory (Glaser and Strauss 1967). The findings were then mapped against thematic synthesis of the published evidence (Dixon-Woods et al 2006) presented in four tables as above. The content of the tables was then analysed to identify the key themes for consideration at a roundtable held in November 2016.

Ten experts participated in the roundtable, including representatives from British HIV Association (BHIVA), the Rehabilitation HIV Association (RHIVA), Public Health England, Department for Work and Pensions, ACAS, as well as colleagues from the HIV voluntary sector, and the HIV research and academic community. Discussion of the slides summarising the Work Foundation’s research findings led to the identification of recommendations for policy and actions which will most effectively improve productivity in PLHIV.
REFERENCES


