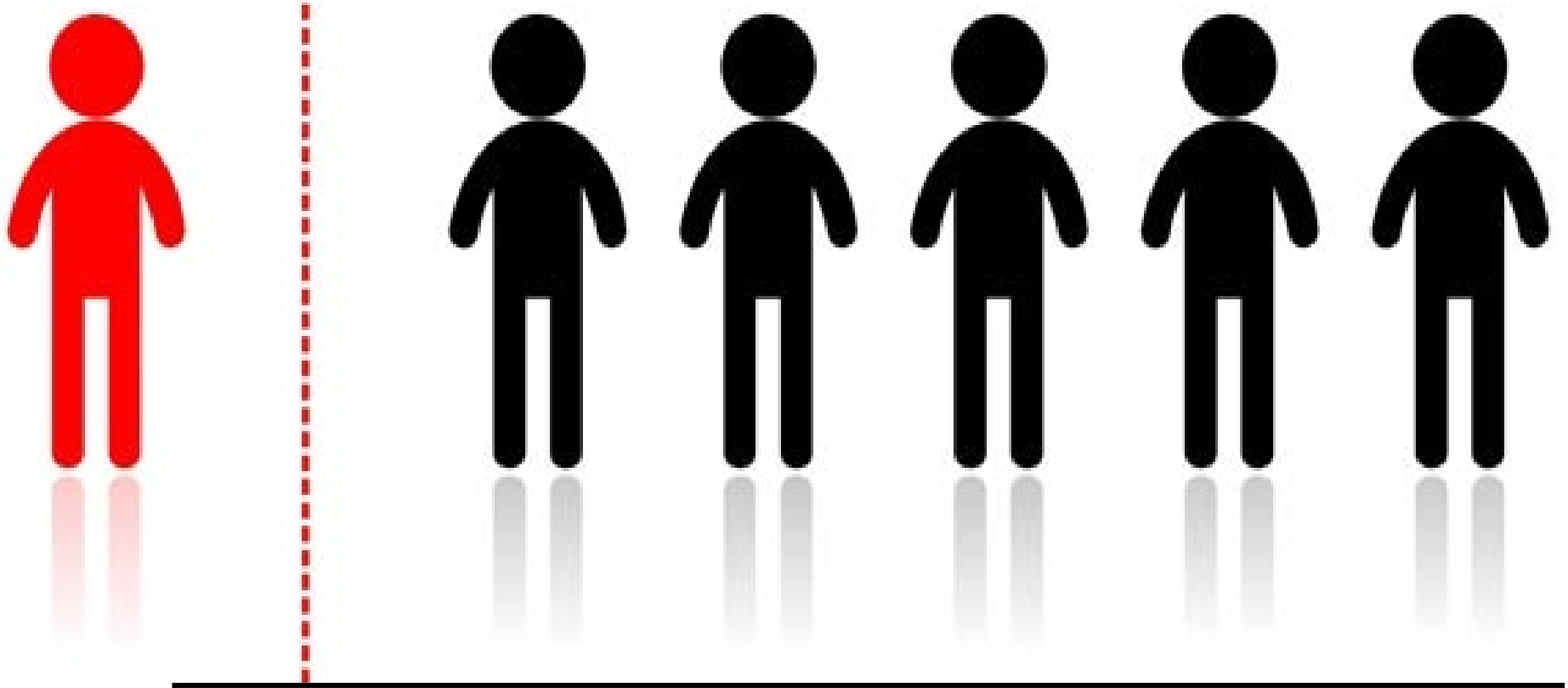
HIV and Employment:
Positive Changes?



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Some context to HIV and social attitudes in the UK…

- UK Nationwide figures: 101,200 – late diagnosis 1 out of 4 over 50 years old (Public Health England, 2017).
- National AIDS Trust (NAT) HIV Social Attitudes Survey (2014):
- 1 in 10 people have 'no sympathy' for those who are living with HIV.
- 1/3 of people 'simply do not know' about the realities of the HIV epidemic.
- 37% of people in employment want their employer to tell them if they are working with an colleague who is living with HIV.
- 51% people have 'no sympathy' for those who are infected with HIV through sex. 95% of transmissions through sexual contact (Public Health England, 2017).
- "Ignorance of how to prevent HIV is still vast and in the absence of public health education campaigns it has increased over the last twenty years" (Fowler, 2013: X).
- No nationwide campaign since 1987 on a national level. Fragmented. Schools and sex education is poor around HIV (NAT, 2014).
- "HIV may have slipped out of the headlines, but we should avoid any false assurances that the battle is almost won or HIV is no longer a problem" (Fowler, 2013: 253). Bio-medical causes have been dominant.

DON'T DIE
OF
IGNORANCE
Government information about AIDS
This leaflet is being sent to every household in the country to inform everyone about AIDS, in order to help stop the spread of this serious disease. It deals with matters of health and sex that may be disturbing.
Please make sure that everyone
household who may
sees this leaf

Employment and HIV in the U.K…

- Research has 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 (Public Health England, 2015)
- This is despite evidence that with the right treatment and support, someone diagnosed with HIV today, should have similar, if not the same, ability to work as someone without HIV (Elzi, et al, 2016).
- 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 (Working with HIV, 2016).
- Wielding and Scott (2016) found high rates of employment (75%) among women attending an NHS HIV clinic in Scotland. However, most (85%) earned below the national average.

- Research 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 job loss, and loss of earnings (Feeley, 2004; Fox, 2004; Kaiser Family Foundation, 2007; Sendi, 2004).
- The U.K. Stigma Survey (2015) found that a significant proportion of respondents felt stigmatised and had experienced HIV-related discrimination at work.
- 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 (Stigma Survey, 2015)

- Despite being a named condition in the Equality Act (2010), a fifth of respondents who had disclosed their HIV positive status at work had experienced discrimination in their current or previous job.
- 12% of participants had decided not to apply for, or turned down, employment or a promotion due to their status.
- Just over half (52%) of working respondents reported they had told no one in their workplace about their HIV status (Stigma Survey, 2015).
- 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 (Working with HIV, 2016).
- 'Internalised' or self-perceived stigma is a persistent theme throughout my own research. It has been suggested that HIV-related discrimination may be anticipated by PLHIV even when experience indicates it is unlikely (Stigma Survey, 2015).

Emerging themes from my research…

1. **Structural/political factors:** school and sexual health; or lack of it. **Stigma from health care** and the HIV education levels of healthcare professionals.
2. **Work:** employment experiences of living with HIV.
3. **Personal, lived and emotional:** coping methods of living with HIV: identities and their complexities in telling others (stigma and mental health).
4. **Campaigns:** invisibility of HIV in long lasting public dialogue.
5. **Education:** as a way of combating HIV stigma **"nobody talks about it anymore."**

- **All of these themes contained HIV-related stigma** and the need to break it down. Expressed by **all respondents powerfully, as well as the 'silencing' of the subject.**

BodyPositive Education

Silent Scream? The Life Histories of People Living with HIV in the North East of England (2015)

Executive Summary

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LOTTERY FUNDED

University of Sunderland

Theoretical background: Ghaziani (2014)

- 'Gaybourhoods' (e.g. Castro, Soho) have gone through three transitions in regards to identity and reactions to that identity. These are also situated within a physical and geographical space which is changing Ghaziani (2014).

1. An insular stage: people not 'out' and public uninformed about LGBT issues – regarded with shock or disgust in limited communities that do exist;
2. A protection/security stage: live together and share experiences within the gaybourhood, campaigns;
3. A post-gay stage: a mixing of straight/LGBT people within the gaybourhood, changing legal landscapes – no need to inhabit gay bars as part of LGBT identity and slow dissolution of strictly LGBT spaces as it becomes more 'accepted.'

- Largely a positive step forward for the LGBT community…

How is this reflected in HIV in the UK?

- In order to tackle HIV related stigma, I modified the three stages of Ghaziani's (2014) model and applied it to how UK society has reacted to HIV 'communities.' It has followed a similar trajectory:

1. An insular stage: only gay/bi men or deviant groups have it. Ignore it or attack the groups. Panic toward those living with HIV. Media fear.
2. A protection/security stage: everyone could get it now, media fear fades a little, transmission campaigns and sexual health, state intervention, medical advances. Growth of HIV activism.
3. A post-HIV stage? It is not a huge thing anymore, you can live your life like anyone else, it is the same as diabetes (WHO), post-PrEP world, media reporting of 'cures.' This is dominated by bio-medical dialogue and takes little into account around the HIV 'communities' affected by HIV-related stigma (Dalton, 2017). Stalled at the third stage.

- Funding cuts under austerity (Dalton, 2015, 2018) have led to funding for HIV organisations being cut or changed…a stagnation of HIV discourse. HIV activism less 'public' now and in siloes now. What now?

POSITIVE ALLIES

"Changing the world of work for people living with HIV"

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@PositiveAllies

positiveallies@sunderland.ac.uk

Positive Allies Level One (Entry Level):

- demonstrate that the organisation has an effective Champion within the workplace who can work as a point of contact for people living with HIV and to drive this award forward
- the organisation has a continuously reviewed policy that explicitly bars discrimination of someone living with HIV
- the organisation has a bullying and harassment policy which clearly indicates zero tolerance around stigma of those living with HIV
- the organisation delivers training to key staff to raise knowledge and awareness of HIV stigma and HIV awareness
- the organisation demonstrates a clear commitment to build on the work they have already done and to strive for more

Positive Allies Level Two (Advanced Level):

- demonstrate continued achievement of all aspects contained in Level One
- demonstrate that the organisation takes active steps to support HIV charities and community groups (this could be through fundraising, volunteer support, partnership working, etc.)
- demonstrate that the organisation has a visible presence of relevant HIV literature and awareness (posters, leaflets, displays, etc.)

Support offered to achieve your application:

Whilst you work on successfully achieving your Positive Allies Charter Mark, we will provide the following support to help your organisation:

- a model HIV Staff/Volunteer Policy for your organisation (this can be amended to suit your organisation's needs and size);
- an online 'HIV Awareness' training course to fit all staff/volunteer levels and abilities. This includes a certificate wh
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