# Tackling HIV Stigma: What works?

Using the global evidence base to reduce the impact of HIV stigma
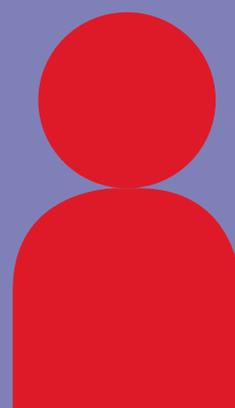
NAT is the UK's leading charity dedicated to transforming society's response to HIV.

We provide fresh thinking, expert advice and practical resources.

We campaign for change.

Our vision

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

Our strategic goals

All our work is focused on achieving five strategic goals:

- effective HIV prevention in order to halt the spread of HIV

- early diagnosis of HIV through ethical, accessible and appropriate testing

- equitable access to treatment, care and support for people living with HIV

- enhanced understanding of the facts about HIV and living with HIV in the UK

- eradication of HIV- related stigma and discrimination

ACKNOWLEDGEMENTS

Contents

1 INTRODUCTION

Stigma and HIV can sometimes seem to be synonymous; but do they have to be? This paper looks briefly at stigma and stigma theory before examining the evidence of what makes an effective stigma intervention and making a series of recommendations.

Stigma has a harmful effect on people living with HIV and the HIV epidemic. The impact on the physical and mental well-being of people living with HIV can be significant; experiences of direct discrimination are common and stigma is linked to poorer adherence to treatment and treatment outcomes.[1] HIV prevention is also dramatically hindered by stigma. Studies have linked stigma to increased risk, non-disclosure and avoidance of health services, including those which may prevent mother to child transmission of HIV.[2] Stigma is also linked to fear and avoidance of HIV testing.[3] Given the preventive benefits of HIV treatment, the part that stigma plays as a barrier to accessing testing and care has an important role in driving the epidemic. Tackling stigma is vital to improving the lives of people living with HIV and is integral to tackling HIV.

The existence of HIV stigma and its impact is widely recognised but concrete strategies for tackling it remain elusive. This is for good reason. Stigma is a complex social phenomenon. It rests on and reinforces societal power structures and in part develops from the way our minds categorise people and behaviours in order to make sense of the world around us. These are difficult things to change.

Stigma associated with HIV is particularly complex. Some HIV transmission routes, for example, sex without condoms and sharing of needles for injecting drug use, are subject to social judgement. In some countries behaviours that carry the highest risk of HIV transmission are against the law. In addition, there are a range of intersecting prejudices experienced by many communities disproportionately affected by HIV. For example in the UK, gay and bisexual men and black African communities are disproportionately affected by the virus and issues of racism and homophobia can interlace with HIV stigma.

1   Chidrawi. C. H., G. M., & Temane M. Q. (2014) Health behaviour change of people living with HIV after a comprehensive community-based HIV stigma reduction intervention in North-West Province in South Africa. Journal of Social Aspects of HIV/AIDS. 11 (1), p222 – p232

2   Mahajan, A. P., Sayles, J. N., Patel, V. A., Remien, R. H., Ortiz, D., Szekeres, G., Coates, T. J. (2008) Stigma in the HIV/AIDS epidemic: A review of the literature and recommendations for the way forward. AIDS. 22 (Suppl 2), p67 – p79

3   ibid

> ❝ **HIV is still intrinsically linked with somehow you having done something wrong, because it's sexually transmitted. I think that we assume that it's our fault that we got it. That's the self-judgement of it. If I didn't have sex, I wouldn't have HIV, fact."**
> **Person living with HIV**
>
> (HIV Stigma Index UK, 2015)
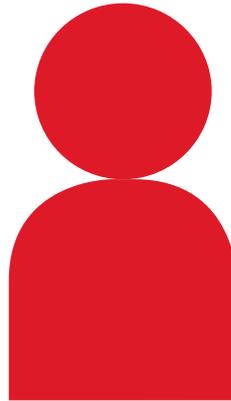
Although the complexity of HIV stigma makes it difficult to address, this is not to say nothing has been done to improve resilience of communities affected by HIV and to tackle stigma at its source. Demonstrable successes have been made. A conceptual framework for HIV stigma has been developed. Several studies have looked at the effectiveness of anti-stigma interventions in a variety of settings within the context of this framework.[4] This body of literature is growing and in 2014 UNAIDS drew on this to develop country-level guidance for policy development on reducing stigma.[5]

> ❝ **Stigma isn't something that's new and it isn't something that's going to go away overnight."**
> **Person living with HIV**
>
> (HIV Stigma Index UK, 2015)

1.1 What NAT did

NAT wanted to gain an overview of what we know about stigma reduction interventions from the academic and non-academic literature, with the aim of finding evidence of effective interventions. In the summer of 2015 NAT issued a call for evidence to the wider HIV sector. This was distributed through NAT's Policy Network of 150 organisations across the UK, and further in Europe through the European Civil Society Forum on HIV. Respondents were asked to provide information on known interventions and available evidence of their effectiveness. This alerted NAT to a number of interventions not otherwise covered in the academic literature.

Academic literature was identified through an internet search, recommendations and use of bibliographies from identified sources. NAT also spoke to individuals who had led on anti-stigma campaigns to gain more detailed information on their design, delivery and evidence of success.

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4   Stangl, A. L., Lloyd, J. K., Brady, L. M., Holland, C. E., Baral, S. (2013), A systematic review of interventions to reduce HIV-related stigmas and discrimination from 2002-2013: how far have we come? *Journal of the International AIDS Society.* 16 (Suppl 2), p1 – p14

5   UNAIDS (2014), 'Reduction of HIV-related stigma and discrimination'. Available at: http://www.unaids.org/sites/default/files/media_asset/2014unaidsguidancenote_stigma_en.pdf

2 | STIGMA: THE WHAT, WHERE AND HOW

UNAIDS describes HIV stigma as 'negative beliefs, feelings and attitudes towards people living with HIV' and as a '"process of devaluation" of people either living with or associated with HIV and AIDS…'[6]

Early stigma theory defined stigma as a 'mark of disgrace'.[7] More recent thinking has developed from this to see stigma as a construct of a range of psychological, social and societal factors, for example, stereotypes, cultural norms, economic circumstances and power structures.[8&9] Stigma holds social structures in place, maintaining boundaries and inequalities between groups of people and between those who have power and those who do not.[10]

2.1 What is stigma made up of?

Figure.1 describes a framework for HIV stigma based on the work of a number of agencies and academics working on stigma reduction. It shows stigma as a cycle, where stigma and discrimination reinforce those things that helped to form it in the first place.

- Drivers
  These are causes of stigma at an individual level. They are the outcomes of our cognitive processes which help us to make sense of the world around us. Things like fear of transmission from casual contact, lack of awareness and our use of stereotypes all fall into this category.

- Facilitators
  These are causes at a societal level that facilitate stigma. They include laws, rights, systems, cultural and gender norms and economic status.

- Power structures
  These are power structures within society that influence stigma – who has power and who does not.

- Intersecting stigmas
  These are the multiple prejudices experienced by people at increased risk of HIV within a society. Prejudices associated with same-sex relationships, race, sex work and drug use, for example, all intersect with HIV stigma.

6   UNAIDS (2014), 'Reduction of HIV-related stigma and discrimination'. Available at: http://www.unaids.org/sites/default/files/media_asset/2014unaidsguidancenote_stigma_en.pdf

7   Goffman E. 'Stigma: notes on the management of spoiled identity'. Englewood Hills, NJ: Prentice Hall; 1963.

8   Link. B. G., & Phelan. J. C. (2001) Conceptualizing stigma. *Annual Review of Sociology*. 27, p363 – p385

9   Parker. R., & Aggleton. P. (2003) HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Social Science and Medicine.* 57, p13 – p24

10 Dodds, C (2015) 'Evidence of HIV-related stigma among African people in the UK', presentation at Croydon University Hospital, 3 June 2015. http://sigmaresearch.org.uk/presentations/item/talk2015g
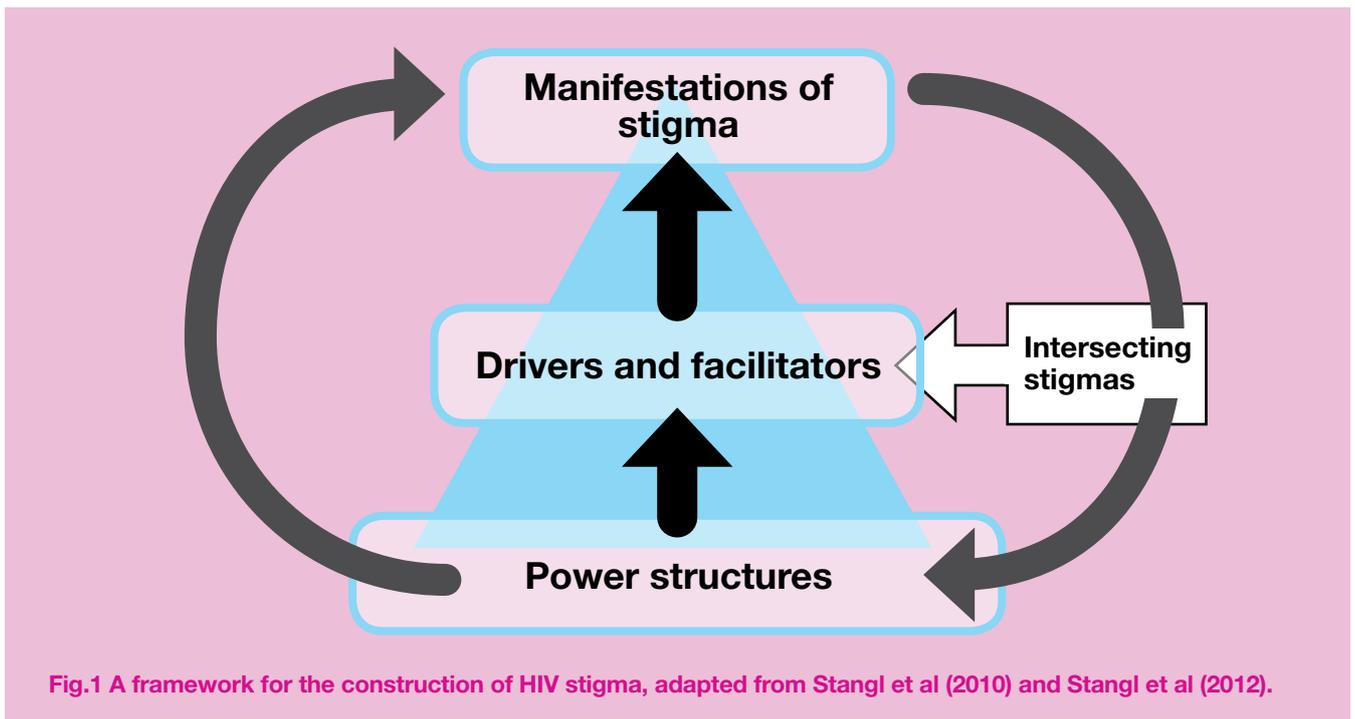
Fig.1 A framework for the construction of HIV stigma, adapted from Stangl et al (2010) and Stangl et al (2012).

- Manifestations
  These are how stigma is exhibited or experienced, for example, direct discrimination, thoughts or feelings about a person living with HIV, anticipated stigma or self-stigma.[11]

2.2 Where do we find stigma?

Stigma can be experienced in a range of social environments. This can be thought of as the level or context at which stigma is experienced and it is helpful in determining where we should target stigma reduction interventions.[12] They can include:

- Individual
  This is how the individual feels about HIV, how they understand and respond to it.

- Interpersonal and community
  Stigma between individuals, including family, friends, social networks and acquaintances.

- Organisational
  Stigma within institutions such as the work-place, schools and hospitals.

- Societal
  Stigma across society as informed by cultural norms and attitudes.

11   These categories and descriptions are derived from the 'domains' of stigma described in Stangl et al (2010) and Stangl et al (2013)
12   Stangl et al (2013)

- Public policy
  Stigma as reflected in national and local laws and policies – these will often be related to cultural values.[13&14]

2.3 How do we reduce stigma?

Many different approaches have been used to address stigma. Programmes designed to reduce stigma might utilise more than one approach. Here are some broad categories of approach which might be part of a campaign or programme. Though not exhaustive, these are useful to consider when comparing interventions.[15]

1. Providing information on HIV, HIV stigma and on key affected populations
Information may be provided to the general public or to targeted groups.

2. Skills-building and participatory learning approaches
This goes further than simply providing information. Often characterised by workshop-based activities, skills can be taught to support a person to recognise and challenge stigma.

13   Ibid
14   Campbell. C., & Deacon. H. (2006) Unravelling the contexts of stigma: From internalisation to resistance to change. *Journal of Community and Applied Social Psychology*. 16 p411 – p417
15   Brown. L., Macintyre. K., & Trujillo. L. (2003) Interventions to reduce HIV/AIDS stigma: What have we learned? *AIDS Education and Prevention*. 15, p49 – p69

3. Counselling and support for people living with or affected by HIV

Support can help people living with or affected by HIV to recognise and deal with self-stigma and to build resilience to experiences of and perceptions of stigma.

4. Contact with affected groups

This involves linking the target group for the intervention with people living with or affected by HIV.

5. Structural change e.g. change in public policy

For example, introducing laws to protect people living with HIV from stigma and discrimination as well as the structural processes to ensure that people can access their rights.

2.4 Using the HIV stigma framework to design a strategy for stigma reduction

The diagram in Fig.2 below shows some of the things to consider when designing an HIV stigma intervention strategy.

There may be more than one answer to each of these questions. The key to the success of a strategy is to ensure that the approach taken is effective in making the desired changes where intended – and the best way to do this is to make use of existing evidence.

Where and with whom are we trying to have an effect? e.g. society; communities; organisations; social networks; families; individuals such as people living with or affected by HIV...

Intervention strategy

What are we trying to affect to achieve change? e.g. stereotypes; knowledge of HIV; knowledge of HIV-related stigma; discrimination; punitive laws; gender norms...

How are we going to achieve this? e.g. providing information; skills-building; increasing empathy through stories; contact with affected groups; counselling...

Fig.2 The where, what and how of an intervention strategy for stigma

3 HIV IN THE UNITED KINGDOM

It is useful to consider the UK context and how it might differ from other places, when considering what interventions might be effective. Context is important in how stigma forms and therefore how it is addressed. Relevant factors include the nature of the HIV epidemic in the UK, the communities most affected, the legal and social policy environment, cultural and religious factors and the influence of the media.

It is also important to bear in mind the contextual differences between countries as well as their sub-populations in the UK. For example, religion is a significant influencing factor in Northern Ireland and may have a different impact there to other parts of the UK. There are also differences between rural and urban areas in the UK and how these contexts influence the lives of affected groups which should be considered.

3.1 Basic facts on the epidemic

Prevalence of HIV in the UK is relatively low in a global context - 2.3 per 1,000 population aged 15-44.[16] In 2014 there were 103,000 people living with HIV in the UK. 41% of those diagnosed are accessing care in London. Prevalence is lower in Scotland, Wales and Northern Ireland.

HIV treatment outcomes in the UK are excellent: 91% of people diagnosed with HIV are on treatment and 95% of those on treatment are virally suppressed.[17] However, one in six people living with HIV do not know they have the virus and over 40% of people are diagnosed late.[18]

HIV disproportionately affects men who have sex with men (MSM) and black African men and women in the UK. One in 20 gay and bisexual men aged 15-44 in the UK is living with HIV (in London this is one in 11).[19] One in 56 black African heterosexual men and one in 23 black African heterosexual women aged 15-44 in the UK is living with HIV.[20]

Although the epidemic varies across Europe, groups in the UK at increased risk are broadly comparable with those across member states of the European Union (EU) and the European Economic Area (EEA), where sex between men is the most common transmission route.[21]

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16   Public Health England (2015), 'HIV in the UK – Situation Report 2015' available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/477702/HIV_in_the_UK_2015_report.pdf

17   Ibid
18   Ibid
19   Ibid
20   Ibid
21   European Centre for Disease Prevention and Control, WHO Regional Office for Europe. HIV/AIDS surveillance in Europe 2014. Stockholm: ECDC; 2015

Diagnoses are fairly consistent at around 6,000 a year, and indications are that incidence is fairly stable and may even be increasing amongst MSM.[22] The rate of diagnosis for the UK is higher than the EU/EEA average at 9.5 per 100,000 compared with 5.9 per 100,000 across the area.[23]

Fewer than 2% of people living with HIV in the UK acquired the virus through injecting drug use.[24] This is in contrast to some other parts of Europe where rates are higher among people who inject drugs. The low level in the UK is attributed to sustained investment in harm reduction programmes.

3.2 The legal context

In the UK HIV is a disability under the Equality Act 2010 and as a result people living with HIV are protected from discrimination.

Since 2001 there have been criminal prosecutions for transmission of HIV in England and Wales under the Offences Against the Persons Act (1861). There have been at least 22 prosecutions to date and many more investigations.[25] This also applies in Northern Ireland although to date there have not been any prosecutions. In Scotland it is also possible to prosecute for exposure to HIV, as well as transmission.

3.3 Experiences of stigma

The HIV Stigma Index UK 2015 shows that stigma continues to affect the lives of people living with HIV in the UK. One in five had experienced verbal harassment or threats. A third reported having their HIV status disclosed without consent by a friend or family member. There is also pressure at work from employers or co-workers to disclose (one in five) and reports of being treated differently by GPs (one in five). The impact of stigma is significant. 18% of respondents reported having had suicidal thoughts within the past 12 months and around half of respondents reported feelings of shame, guilt, low self-esteem, and self-blame in relation to their HIV status.[26]

> ❝ **…to have HIV is also to know one's fair share of isolation and marginalisation within a society that blames us, to begin with, for having it."**
> **Person living with HIV**
>
> (HIVAware website)

3.4 Public knowledge and attitudes

NAT monitored changing public knowledge and attitudes towards HIV through a survey commissioned from Ipsos Mori in 2000, 2005, 2007, 2010 and 2014. Knowledge and attitudes have improved since 2000 but there is still a significant minority of people who report negative attitudes towards HIV and people living with or affected by HIV.[27] Support for people living with HIV is higher among people with greater knowledge of HIV although this does not mean that improving knowledge alone will reduce stigma.[28]

3.5 Policy addressing HIV stigma

There is no clear strategic plan for addressing stigma across the UK, although it is referred to in the various strategies for sexual health. The Framework for Sexual Health Improvement in England says there is a need to: *'continue to tackle the stigma, discrimination and prejudice often associated with sexual health matters'*.[29] Tackling stigma within the black African population and amongst men who have sex with men is therefore a component of the national HIV prevention programme, commissioned by Public Health England (PHE).

> ❝ **It's amazing that despite the advances in treatment, people's attitudes are still exactly the same."**
> **Person living with HIV**
>
> (HIV Stigma Index UK, 2015)

22 PHE situation report, 2015
23 European Centre for Disease Prevention and Control, WHO Regional Office for Europe. HIV/AIDS surveillance in Europe 2014. (Data tables)
24 PHE, 2015
25 For more information see NAT's webpage on criminal prosecutions: http://www.nat.org.uk/HIV-in-the-UK/Key-Issues/Law-stigma-and-discrimination/Criminal-prosecutions.aspx
26 See the initial findings of the Stigma Index UK 2015 here: http://www.fpa.org.uk/news/stigma-index-uk-2015-findings-stigma-and-discrimination-era-undetectable-hiv

27 'HIV public knowledge and attitudes, 2014' NAT (commissioned from Ipsos MORI), 2014
28 Ibid
29 Available at: https://www.gov.uk/government/publications/a-framework-for-sexual-health-improvement-in-england

Box A

Key findings on public knowledge about and attitudes to HIV in 2014:[30]

28% of the public identify one or more incorrect routes of transmission when given a list of options.

Only 45% can correctly identify all correct routes of transmission with none of the incorrect routes when given a list of options.

20% of people know that *'the risk of someone who is taking effective HIV treatment passing on HIV through sex is extremely low'* is true.

23% of people agree with the statement *'I don't have much sympathy for people with HIV if they were infected through unprotected sex'*. A further 20% are neutral.

15% of people report that if a family member informed them that they were HIV positive it would damage their relationship with them.

Recommendation:

1. All UK Governments should develop an evidence-based strategy for reducing HIV stigma which includes a range of approaches to tackle the many different factors contributing to stigma.

The Sexual Health and Wellbeing Action Plan for Wales 2010-2015 tasks the All-Wales Sexual Health Network and the third sector with developing action to tackle HIV stigma in partnership with people living with HIV.[31] The Northern Ireland Sexual Health Promotion Strategy contains a similar action, but the 2013 update to this did not include any information on how or whether this had been addressed or any specific actions for the future beyond suggesting that it should be one of a number of considerations in the development of a sexual health campaign.[32&33]

Tackling stigma was part of the Sexual Health and Blood-Borne Virus Framework 2011-2015 for Scotland.[34] An update to the framework for 2015-2020 continues this and confirms that the Scottish Government will continue to fund the Always Hear campaign, discussed later on in this briefing, along with research into the benefits of further national campaign activity.[35]

There is a need to strengthen the collective response to HIV stigma across the UK. In 2014 NAT recommended that *'all four nations of the UK should as a matter of urgency develop and implement strategies to reduce HIV stigma in society.'*[36] The recommendations made in this paper further develop and build on this recommendation.

30 'HIV public knowledge and attitudes, 2014' NAT (commissioned from Ipsos MORI), 2014

31 'Sexual health and Well-being action plan for Wales 2010-2015', 2010, available at: http://www.shnwales.org.uk/Documents/485/Strategy%20(English).pdf

32 'Sexual Health Promotion Strategy and action plan 2008-2013', Department of Health, Social Services and Public Safety, Northern Ireland, 2008, available at: https://www.dhsspsni.gov.uk/sites/default/files/publications/dhssps/sexual-health-promotion-strategy-and-action-plan-2008-13.pdf

33 'Progress and priorities: Addendum to the sexual health promotion strategy and action plan (2008-2013) to December 2015', DHSSPS, Northern Ireland, 2014, available at: https://www.dhsspsni.gov.uk/sites/default/files/publications/dhssps/sexual-health-promotion-strategy-and-action-plan-addendum-2015_0.pdf

34 'The sexual health and blood borne virus framework 2011-15', The Scottish Government, 2011, Available at: http://www.gov.scot/Resource/Doc/356286/0120395.pdf

35 'Sexual health and blood borne virus framework 2015-2020 update', The Scottish Government, 2015, Available at: http://www.gov.scot/Resource/0048/00484414.pdf

36 Recommendation made in 'HIV public knowledge and attitudes, 2014,' NAT, 2014

4 | WHAT THE EVIDENCE TELLS US ABOUT THE EFFECTIVENESS OF HIV STIGMA INTERVENTIONS

Although there are many examples of creative stigma reduction initiatives from across the world, evidence of intervention outcomes can be difficult to find. This is often because when money is limited the work itself is prioritised over funding for evaluation. It is also very difficult to evidence a direct causal link between some of the social interventions we discuss below, such as changes in public policy, and changes in stigma. In a recent review of the evidence, Stangl et al (2013) found: *'…critical challenges and gaps remain which are impeding the identification of effective stigma and discrimination reduction strategies that can be implemented by national governments on a larger scale'*.[37]

This gap is evident in the UK and the rest of Europe where there is a deficit in evaluated programmes that can contribute to the evidence base. While there are barriers in translating programmes from one context to another, this does not wholly explain the lack of investment in expanding some of the proven work on stigma from outside Europe to a European audience. The programmes for addressing stigma which do exist often do not draw upon international learning.

The framework for stigma in fig.1 is helpful in identifying how interventions could be effectively adapted to new contexts. This section looks at different types of stigma interventions and the evidence, where it is available, for how effective they have been.

Recommendations:

2. Funders in the UK and wider EEA should invest in developing the evidence base for effective stigma interventions by funding stigma reduction programmes that incorporate evaluation.

3. The European Centre for Disease Control (ECDC) should work with governments to support roll-out of existing proven stigma interventions in Europe.

37   Stangl et al (2013) pp.9
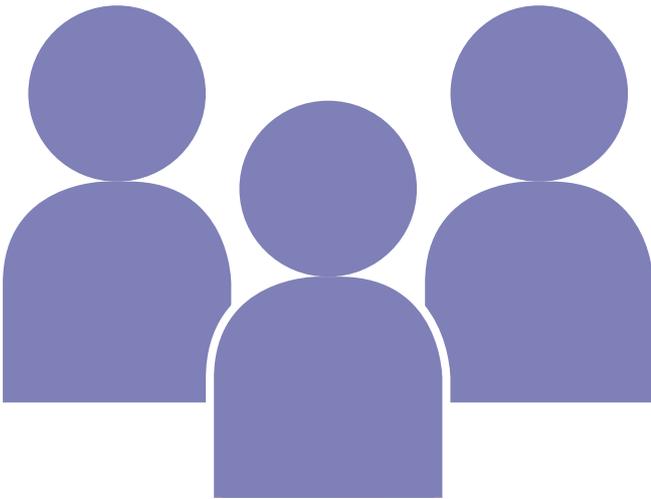
Box B

Measuring stigma

If we are to measure and compare the effectiveness of programmes in reducing stigma, we must first have a consistent and reliable way to measure stigma.[38&39] Various methods have been used. One approach is a single item scale, focussing on one indicator of stigma, such as fear of infection or feelings towards people living with HIV. Other scales use more than one indicator to provide a more detailed picture.

Some scales measure 'perceived' stigma and will use hypothetical scenarios to test this. NAT's Public Knowledge and Attitudes Survey uses some hypothetical scenarios.[40] Respondents are asked to state their level of agreement with statements, for example, 'If someone in my family told me that they were HIV positive it would not damage my relationship with them'. The way a person perceives they would respond reveals their attitudes and is therefore indicative of the level of stigma. The survey also asks about feelings of support or sympathy which are often found in stigma scales.

This study itself is not linked to the evaluation of a programme, but has been repeated over several years and is used to show changes in attitudes over time. However, similar questionnaires have been used pre and post-intervention to evaluate stigma programmes.

Other measures look at experiences of stigma such as discrimination and feelings of self-stigma. The HIV Stigma Index, a survey of people living with HIV which has been repeated in a number of different countries, is probably the best example of a large study using questions about personal feelings and experiences. Another approach is to ask people what they have done in a given situation; some studies have even attempted to monitor behaviours which could be regarded as discriminatory through observation.

For a more detailed look at how stigma can be measured in line with the framework for stigma see the STRIVE and ICRW (2012) Technical Brief on 'Measuring HIV stigma and discrimination'.[41]

38 Sengupta.S., Banks. B., Jonas. D., & Corbie Smith. G. (2011) HIV interventions to reduce HIV/AIDS stigma: A systematic review. *AIDS Behaviour*. 15, p1075 – p1087

39 Mahajan et al 2008

40 NAT (2014) 'HIV Public Knowledge and Attitudes'. Available at: http://www.nat.org.uk/media/Files/PDF%20documents/Mori_2014_report_FINAL.pdf

41 Available at: http://strive.lshtm.ac.uk/system/files/attachments/STRIVE_stigma%20brief-A4.pdf

Box C

Don't die of ignorance

The mass media campaign of the 1980s, whose tagline 'don't die of ignorance' accompanied the falling tombstones image, was undoubtedly very influential in forming public perception of HIV in the UK. In many ways it was a success in public information dissemination, in that it did increase awareness of HIV and AIDS amongst the general population; many people still remember the campaign today.[42] Lord Fowler, Health Secretary at the time of the campaign, noted that the TV adverts were the key to the campaign's success in reaching a mass audience.[43]

The campaign did have shock value which may also contribute to the salience it has in people's minds. This, however, could have inadvertently led to some of the stigma that surrounds HIV in the UK today, in that it relied at the time on generating fear and some of this remains associated with HIV. It has never been followed up by a campaign on the same scale that updates people on the huge advances that have been made in HIV in the last 30 years.[44]

4.1 Mass media campaigns

Use of mass media is a way of conveying information or a message to a wide population audience. The largest HIV campaign in the UK was 'Don't die of ignorance' in the 1980s (see box C). This was a prevention campaign, but could such a campaign targeting stigma be effective today?

Although no recent comparable HIV campaign exists to consider, there has been large scale targeted action on mental health stigma through the Time to Change programme. This campaign used television adverts alongside a range of other social marketing methods. Rather than being a one-off short term effort, it consists of a changing programme of activity since 2009 and has used a range of taglines and messages.

This has had some success, with the most recent evaluation showing that 6% of the population reported improved attitudes towards mental illness – a modest but significant change.[45] Researchers found that greater awareness of the campaign was linked to greater improvements in knowledge and attitudes.[46]

The social marketing, or media, elements of Time to Change have been particularly successful in reducing feelings of 'prejudice' and 'exclusion' towards mental illness and people affected by it. Whilst greater levels of 'tolerance' and 'support' have also been identified, the overall link between the campaign and these outcomes was not as significant. The researchers evaluating the programme concluded that *'the campaign might have been better at disconfirming negative ideas around prejudice rather than enhancing positive attitudes and support'*.[47] This was further backed up by less significant changes in intended behaviour, signalling that further activities may be needed to make a step from changing attitudes to changing behaviour. The Time to Change evaluation suggests that mass media campaigns can have a role influencing some of the drivers of stigma but are not sufficient alone.

42 Fowler, N, 2014. AIDS: Don't Die of Prejudice. 1st ed. London: Biteback Publishing

43 HIV/Aids: Why were the campaigns successful in the West? Jon Kelly; *BBC News Magazine*; 28 November 2011 Available at: http://www.bbc.co.uk/news/magazine-15886670

44 '"AIDS: Don't Die of Prejudice", by Norman Fowler'; Andrew Jack; *Financial Times*; July 11, 2014; Available at: http://www.ft.com/cms/s/2/1a601c7e-010e-11e4-a938-00144feab7de.html
History of advertising: No 109: The government's Aids campaign; *Campaign*; August 21, 2014; Available at: http://www.campaignlive.co.uk/article/history-advertising-no-109-governments-aids-campaign/1308298

45 Time to Change 'Our Impact' webpage and info-graphic on website http://www.time-to-change.org.uk/about-us/our-impact

46 Evans-Lacko. S., Corker. E., Williams. P., Hendrson. C, & Thornicroft. G. (2014) Effect of the Time to Change anti-stigma campaign on trends in mental-illness-related public stigma among the English population in 2003-2013: an analysis of survey data. *Lancet Psychiatry*; 1, p121 – p128

47 Evans-Lacko et al 2014, pp.125

This limitation was recognised in the early design of the campaign; local events and personal contact, on top of media activity, were seen as critical to achieving sustained impact. As well as providing grants for grass-roots activity, Time to Change developed a network of campaign champions to support local events that would reinforce campaign messages. Social contact between people with and without personal experience of mental ill health was shown to increase engagement with the campaign. Positive changes in intended behaviour were more likely among those engaged in this contact than in those only exposed to the media campaign.[48]

Box D

Mixing media to strengthen engagement with a campaign

New communications channels present greater opportunities to reach people, but also challenges for campaigners as people engage with media in varied ways.

Time to Change has targeted both mass and community audiences. A range of messages and taglines have been distributed via a mix of media channels. When asked to identify how they had been exposed to the campaign, a broad range of media channels were identified by survey respondents, not only the television adverts.

In Scotland the Always Hear campaign on HIV stigma used several channels to reach people including social media platforms and news media.[49] Resources, designed to help **people to engage with online video case studies, were targeted at schools and churches. These were distributed through existing networks – giving the campaign the potential to reach approximately half of the Scottish population.[50] Similarly a campaign in Italy used networks of employers to promote equality for people living with HIV in the labour market. For this campaign an online video was again backed up by explanatory resources and training sessions for businesses.[51] Print media was also used in some major cities, including posters and placemats for restaurants.[52] Unfortunately there has not been formal evaluation of these campaigns to assess their effectiveness or the relative reach of the different media channels used. However, both show the varied communication options available.**

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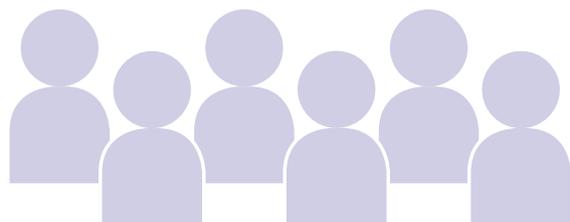
48   Evans-Lacko et al 201
49   Always Hear was run by Waverley Care with the support of the Scottish Government. More information available at http://www.hivalwayshear.org/

50   Information provided to NAT by Waverley Care in 2015
51   Video available at: http://www.lila.it/it/component/allvideoshare/video/featured/qualsiasi-sia-il-lavoro-l-hiv-non-conta
52   Information on the campaign provided by to NAT Fondazione LILA Milano ONLUS in 2015
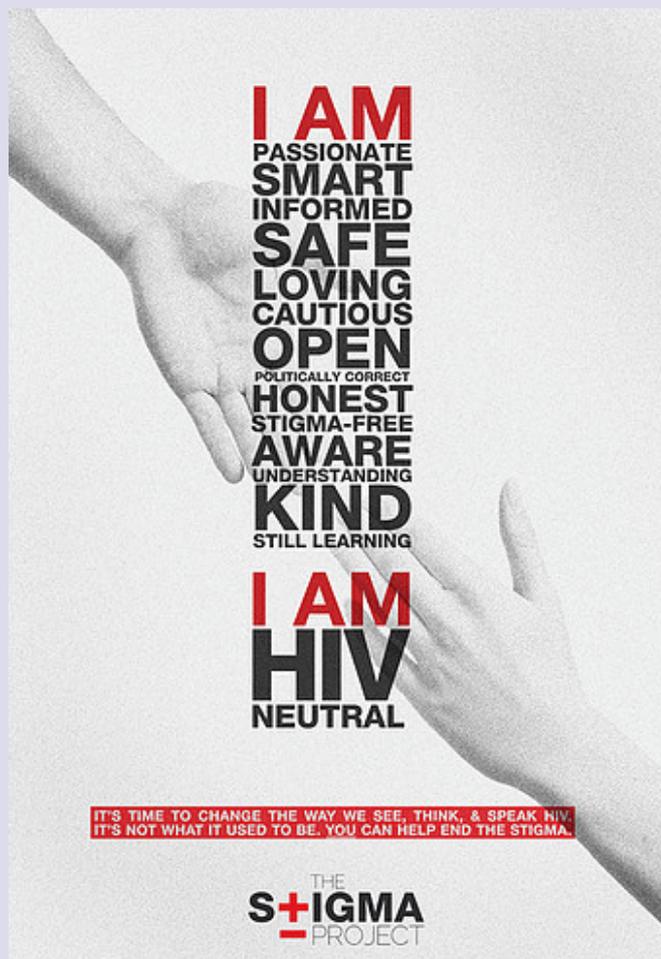
Media campaigns from elsewhere in the world

All over the world organisations have used different forms of media and imagery to communicate messages challenging stigma. Below are a few examples. Although these campaigns are not evaluated, they provide useful insight into some of the approaches used in the past.

Live HIV Neutral from United States of America

The Stigma Project in the USA has produced a range of eye-catching images for the Live HIV Neutral campaign. The images challenge pre-conceptions about HIV and people living with HIV.

'"HIV Neutral" is a state of mind, regardless of your status, in which you are informed and aware of the constantly evolving state of HIV/AIDS.' (Stigma Project website)

Some of the images look at the language used to describe HIV and people living with HIV. As well as providing basic information, this highlights some of the unintended stigma people may display through the language they use and supports people to alter their behaviour.

Working with celebrities in France and Belgium

Between 2006 and 2009 campaigns were run by Aides in France and Sensoa in Brussels which used well-known celebrities and asked people:

'Would you still…., if I was HIV positive?'

Below is French chef Cyril Lignac and to the right is Nicolas Sarkozy, one of several politicians in France who participated.

VOTEREZ-VOUS POUR MOI MÊME SI J'EN AI RIEN À CIRER DU SIDA ?

C'EST LE SIDA QU'IL FAUT EXCLURE, PAS LES SÉROPOSITIFS.

AIDES
www.aides.org

EST-CE QUE JE SERAIS TRAITÉ COMME UN CHEF SI J'ÉTAIS SÉROPOSITIF ?

C'EST LE SIDA QU'IL FAUT EXCLURE, PAS LES SÉROPOSITIFS.

Participez vous aussi à la campagne sur www.sijetaisseropositif.com

AIDES
www.aides.org

Below are pictures of the model Ann Van Elsen and boxer Sugar Jackson, both well known in Flanders in Belgium. She asks, 'would you still fantasise about me if I was HIV positive?' and he, 'would you dodge me if I was HIV positive?'

Well-known figures were used as a reference for the audience with the intention that it would provoke them to think again about their own opinions and responses.
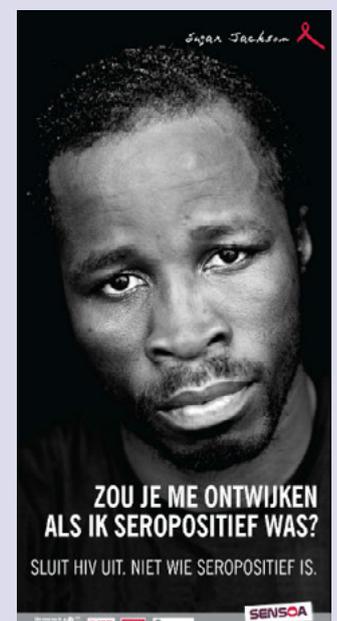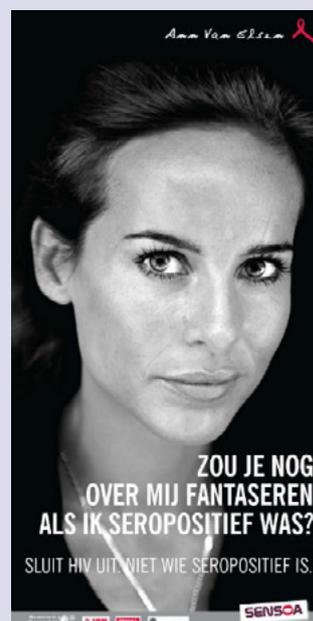

Ann Van Elsen

ZOU JE NOG OVER MIJ FANTASEREN ALS IK SEROPOSITIEF WAS?

SLUIT HIV UIT. NIET WIE SEROPOSITIEF IS.

SENSOA

Sugar Jackson

ZOU JE ME ONTWIJKEN ALS IK SEROPOSITIEF WAS?

SLUIT HIV UIT. NIET WIE SEROPOSITIEF IS.

SENSOA

LILA – Employment is a fundamental right, 2013/14 campaign in Italy

The Italian organisation LILA created colourful and whimsical images and captions of people working in a range of recognisable occupations, stating 'HIV positive or not…'

The people included a cook, a medical professional, a sailor, a reporter, a nanny and a plumber. Some of the materials contained additional information about HIV, how HIV is and isn't transmitted and the law. Here a translated version is shown. These images featured on posters, flyers and on placemats at restaurants.


G. Duck
62
chef

exquisite
experienced
genuine
imaginative
HIV positive

HIV positive or not
she's a fabulous Cook!

employment is a fundamental right
let's stop HIV and not the people living with HIV

www.lila.it

LEGA ITALIANA
PER LA LOTTA
CONTRO L'AIDS

HIV is transmitted in only one of three ways, and proximity at the workplace is not one of them:

- unprotected sex
- childbirth and breastfeeding
- contact with contaminated blood

People living with HIV and AIDS can live long and healthy lives and work normally.

The Italian Constitution, national laws and international norms equally protect the workplace from any forms of discrimination, also in relation to health issues and HIV.

And yet, ignorance and prejudices still infringe these rights: unlawful requests for HIV-testing to access public examinations or prior to signing working contracts, dismissals due to HIV, workplace transfers and unjustified changes in working assignments, or data protection breaches.

Employment is a fundamental right of all women and men
Let's fight ignorance and prejudice
Let's stop HIV and not the people living with HIV

www.lila.it

Art director **Giorgia Di Pasquale** | Photo **Viola Damiani** | Graphics **Cliccaquì**

4.2 Altering the media narrative

Negative media portrayal of HIV is a major concern as it can influence perceptions of HIV and the associations people make between HIV and negative stereotypes and behaviours. Viewed in the context of the HIV stigma framework (fig.1), negative media will increase drivers of stigma such as labelling, stereotypes, separation and status loss of people living with HIV. This is particularly the case when the general public is only exposed to negative stories and therefore these are seen as the norm, not the exception. For this reason, the Scottish Always Hear campaign promoted news articles which presented a new narrative around HIV that was more positive and encouraged empathy with individuals affected.

NAT has also found that it is possible to change media representations of HIV but that this requires a level of sustained activity. Working with Press Gang, a group of people living with or affected by HIV who take action on misleading media portrayals, NAT has successfully challenged negative and/or inaccurate news articles, securing amendments to articles online and in print. Where necessary, complaints have been made to the Press Complaints Commission (now the Independent Press Standards Organisation) to challenge direct inaccuracies or discriminatory content. In 2010 NAT and the National Union of Journalists (NUJ) jointly updated their reporting guidelines for the media.[53] Monitoring of the media in the year following the initiation of Press Gang and the guide revealed some real success from this multi-faceted approach – with a substantial decrease in inaccurate or stigmatising coverage of HIV.[54] However, analysis of the UK media coverage in late 2015 showed that there is still a considerable issue with negative portrayals of HIV, much of this is related to coverage of criminal prosecutions for HIV transmission which will be discussed below.[55]

What works?

- Increase access to accurate information on HIV and HIV transmission using a range of media tools

- Expose people to a range of messages addressing different aspects of stigma

- Challenge negative media messaging around HIV and use relationships with the media to maintain more accurate reporting

- Link to opportunities for people to further engage with campaigns at a local or community level.

Recommendation:

4. Social marketing and a mix of media channels should be used as part of a strategy to address HIV stigma as a way of increasing public exposure to information and messages.

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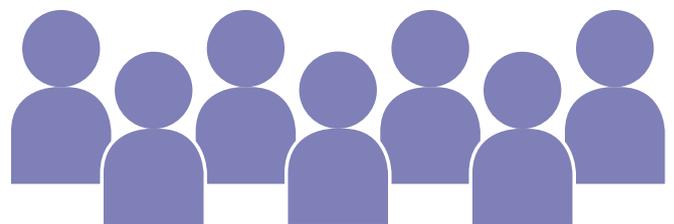
53 NAT; June 2010; 'Guidelines for reporting HIV'; available at: http://www.nat.org.uk/media/Files/Publications/June-2010-Guidelines-for-reporting-HIV.pdf
54 'Improving the media reporting of HIV: using guidance and complaints to bring about change', poster at International AIDS Conference Mexico 2008
55 'HIV in the Media', NAT, 2015

4.3 Involving people living with HIV

The literature on stigma reduction has long made the case for involving people living with HIV in interventions.[56&57] Evidence shows that people are more likely to hold stigmatising attitudes when they don't perceive that they know anyone living with HIV or that HIV affects their community.[58&59] Interventions which involve people living with HIV try to overcome this by making HIV more relatable. Increasing empathy and reducing the separation which forms part of the framework for stigma (see fig.1) disrupts the stigma process.[60]

Contact with people living with HIV in the delivery of workshops and other face-to-face interventions has been shown to be a promising strategy across different countries.[61] When hospital staff in India and Vietnam attended HIV stigma workshops led by people living with HIV, this helped them to relate to these individuals in a different way to if they were a patient.[62] There is also a power shift here – in this dynamic the person living with HIV is made equal to, or is put in a position of greater knowledge than, the person being trained.

4.3.1 Using the media to connect people to the experiences of people living with HIV

While not the same as actual contact with people living with HIV, use of media to put across real-life stories can provide a viable alternative where this is not possible.[63] In Scotland the Always Hear campaign made use of real-life stories. The campaign used videos of negative experiences such as rejection by friends following disclosure to invoke a response from the viewer.

Interventions have also incorporated similar ideas through use of narrative – allowing the exploration of the personal experience through a story. In the US faith leaders have used sermons to convey stigma-reduction messages which are compatible with the faith-based setting. Examples have included adaptations of existing stories, such as 'the good Samaritan', as well as sermons with stories which relate to the impact of HIV on that community or individuals within it.[64]

Narratives can be developed based on real-life experiences and familiar situations. A film used by the Life in my Shoes campaign relayed a fictional story written by young people living with HIV. This video was shown to other young people and provided the basis for discussion of key themes which came out of the narrative, it *'created a chance for [the] audience to create an emotional connection to the issue, rather than just be told not to hate…'*[65] The Canadian website HIVstigma.com (see Box E) made use of narrative to encourage gay and bisexual men to consider how they would behave if they were in a situation involving disclosure of HIV status. Both of these examples in different ways use relatable situations and empathy to initiate a conversation about stigma.

Recommendation:

5. Interventions designed to reduce HIV stigma should be developed and delivered in partnership with people living with HIV.

4.4 Discussing stigma itself

Increasing awareness of stigma as a concept has been shown to be an important aspect of stigma reduction initiatives. The Time to Change programme aimed to create discourse around people's attitudes to mental health, introducing them to the concept of stigma and prompting them to think about whether they hold stigmatising beliefs. Similar things have been done in the context of HIV.

56   Parker & Aggleton 2003
57   'The Greater Involvement of People Living with HIV'; UNAIDS policy brief (2007)
58   Li et al 2014
59   Bekalu. M. A., Eggermont. S., Ramanadhan. S., & Viswanath. K. (2014) Effect of media use on HIV-related stigma in sub-saharan Africa: A cross-sectional study. *PLoS ONE* 9(6): e100467. doi:10.1371/journal.pone.0100467
60   Link & Phelan 2001
61   Pulerwitz et al 2010 refer to studies in hospitals in Vietnam and India as well as a community intervention in Zambia
62   Mahendra VS, Gilborn L, George B, Samson L, Mudoi R, Jadav S, et al. Reducing AIDS-related stigma and discrimination in Indian hospitals. Horizons Final Report. New Delhi: Population Council; (2006). & Oanh et al (2008) – in Pulerwitz et al (2010)
63   Derose et al 2014

64   Ibid
65   Information provided to NAT by Body & Soul in 2015

In Tanzania training was designed to enhance understanding and recognition of stigma and discrimination within the routine work of community leaders. Programme evaluation found that not only did this lead to greater recognition of HIV-related stigma, but it was also linked to reduced stigmatising attitudes in follow-up surveys. Although this effect was not community-wide, the reduction in stigma was also seen for people who were not exposed to the original training intervention.[66&67]

Discussion of HIV stigma was a common feature in many of the successful interventions delivered in organisational settings referred to above. In the UK, Body & Soul commented that when delivering their stigma reduction workshops in schools, talking about stigma as a concept improved the overall discussion.[68]

Box E

HIVstigma.com[69]

The HIVstigma.com campaign was developed by the Gay Men's Sexual Health Alliance (GMSH), a consortium of community groups working in frontline HIV prevention in Canada. The campaign aimed to develop ideas of 'community mobilisation' – the empowerment of a community of people to create collective action against the inequalities and prejudices which lead to stigma (see Box G). The inclusion of HIV positive men in the GMSH was integral. The campaign aimed to address the issue of stigma directly, with the word 'stigma' featuring in the title of the campaign and the main campaign website (HIVstigma.com).

Perhaps the most important element of this campaign was the reliance on discourse. Reflecting on stigma as part of a conversation has been a key element of effective workshop-based interventions. With HIVstigma.com the conversation was online, potentially opening the intervention to a broader range of people and allowing varying degrees of participation and anonymity.

The campaign asked the question *'if you were rejected every time you disclosed, would you?'*. The question aimed to draw men to the website where the implications of HIV stigma could be discussed in more detail. The website was promoted via media advertising along with print materials distributed by outreach workers.

The programme was evaluated using a pre (September 2008) and post-intervention (April 2009) online questionnaire which was sent by email to members of a separate popular gay contact website. The demographics of the two samples were similar but the evaluation was limited to those engaged through this website. 42% of respondents reported awareness of the campaign, with 25% reporting that they had visited HIVstigma.com. There was an improvement in overall attitudes post-intervention. Those who were aware of the campaign were significantly more likely to recognise the existence of stigma and significantly less likely to report attitudes and intended behaviour which may be considered as stigmatising such as *I use terms like "clean" or "disease-free" when I cruise for sex online'*. While this cannot tell us about longer term impact, this was an encouraging finding.

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66 Nyblade L, MacQuarrie K, Kwesigabo G, Jain A, Kajula L, Philip F. Moving forward: tackling stigma in a Tanzanian community. Horizons Final Report. Washington: Population Council; (2008)

67 Pulerwitz et al (2010)

68 Comment made in information provided by Body & Soul re. the Life in My Shoes campaign

69 Adam. B. D., Murray. J., Ross. S. , Oliver. J., Lincoln. S. G., & Rynard. V.(2011) HIVstigma.com, an innovative web-supported stigma reduction intervention for gay and bisexual men. *Health Education Research*. 26 (5) p796 – p807

What works?

- Involve people living with HIV in the delivery/facilitation of interventions

- Provide information on HIV stigma and its effects within interventions

- Provide opportunities to discuss stigma and the factors contributing to it with peers

- Use mixed media to deliver a relatable narrative to encourage empathy with people living with or groups affected by HIV.

4.5 Reducing structural inequalities through changes in the law and policy

The law can be seen as a reflection of public attitudes and an influencing factor in societal concepts of right and wrong.[70] It is a structural component of stigma. Altering laws that contribute to stigma can be an effective part of a stigma reduction strategy. For example, a key milestone for Time to Change was the passing of the Mental Health (Discrimination) Act in 2013. This brought the legal framework up to date with our understanding of mental health and repealed laws which allowed discrimination on the basis of mental health. Structural changes can have an impact on changing social norms and values. This has been seen through history with major movements such as in gay rights. However, changes take time and are not linear in that there are a wide range of structural and policy influences which have an impact, making them difficult to evaluate.

Structural components of HIV stigma are complex and vary between countries given the wide variations in legal and policy frameworks. UNAIDS advocates for laws to protect people living with HIV from discrimination and has published guidance calling for countries to remove punitive legislation.[71] There are a range of structural influences on stigma in the UK

which could be influenced by public policy change. For example, migrant rights, including access to healthcare, housing and other types of support, are crucial to reducing inequalities that contribute to and maintain stigma affecting those within the migrant community affected by HIV. Changes reducing LGBT inequalities are another important example. Below we look at some areas of law and policy in more detail.

4.5.1 Criminalisation

Criminalisation of activities that can lead to HIV transmission, whether related to sexual behaviour, sex work or drug use, reinforces ideas of right and wrong and further legitimises stigmatising attitudes and discriminatory behaviour. It can also limit the access an individual has to HIV prevention and support. HIV disproportionately affects gay and bisexual men; legislation prohibiting men from having sex with men has been particularly noted in relation to further stigmatisation of gay men and of HIV.[72]

The criminalisation of HIV transmission is also widely recognised as contributing to the stigmatisation of the virus. NAT opposes the criminalisation of HIV transmission and has joined others, including UNAIDS, in calling for the end of such prosecutions that increase stigma and have harmful public health consequences.[73] In the UK, reporting of HIV transmission prosecutions represents a high proportion of HIV coverage in the news.[74] This can lead to an association of HIV with criminality and of HIV transmission with criminal prosecution, when in reality these are a relative rarity.

As well as the overall negative connotations these cases can contribute further to damaging stereotypes of people living with HIV and misunderstanding of HIV. For example, closing statements by judges, reported in the news, have often included reference to the imposition of a 'life-threatening' condition.[75] Although there is no legal requirement to disclose HIV status to one's partner in the UK, coverage of criminal transmission cases can imply that non-disclosure is a criminal

70 Bilz. K., & Nadler. J. 2014. Chapter 10: Law, moral attitudes and behavioural change. In: Zamir. E., & Teichman. D (Eds). *The Oxford Handbook of Behavioural Economics and the Law*.: Publisher, chapter page numbers

71 'Reduction of HIV related stigma and discrimination', UNAIDS 2014, and 'Key programmes to reduce stigma and discrimination and to increase access to justice in national HIV responses', UNAIDS 2012

72 'Key programmes to reduce stigma and discrimination and increase access to justice in national HIV responses', UNAIDS guidance note, 2012

73 'Criminalisation of HIV transmission: Policy brief', UNAIDS, UNDP, 2008 http://www.unaids.org/sites/default/files/en/media/unaids/contentassets/dataimport/pub/basedocument/2008/20080731_jc1513_policy_criminalization_en.pdf

74 'HIV in the Media' NAT, 2015

75 'A fair cop', NAT poster at the International AIDS Conference Mexico 2008

act.[76] This also has wider implications for how we think about responsibility for sexual health in consenting sexual relationships and on the public's perception of risk of HIV transmission.

4.5.2 Equality law and HIV

More encouragingly, in the UK HIV is recognised as a disability under the Equality Act 2010 and people living with HIV are protected from discrimination from the point of diagnosis. This provides important legal rights, reinforces anti-stigma and discrimination messaging, and provides an accountability framework. However, it does not ensure protection – this relies on awareness of the Act amongst potential perpetrators and victims of discrimination. It also relies on adequate access to justice and enforcement of the Act.

A 2013 evaluation of the Equality Act 2010 demonstrated that awareness of the Act among employers was low.[77] One third of those surveyed had never heard of the Act and a further third had heard of it but did not know any details about it. Prior to this, in a 2009 survey, NAT found that a third of HIV positive gay men were not aware of the legal protection they had (at that time under the Disability Discrimination Act 2005).[78] Of those who were aware of their legal protection, 30% did not know of their right to reasonable adjustments at work. Lack of awareness amongst people living with HIV limits their ability to exercise their rights and to challenge stigma and discrimination.

The above point is illustrated by the fact that in the same survey, only a third of those who experienced stigma and discrimination sought redress. When people did seek support they preferred to approach HIV specific organisations rather than generic advice services. This may be because of concerns about generic providers' knowledge and understanding of HIV and consequent stigma. People's ability to challenge discrimination is becoming more difficult with reductions in funding for the advice sector, legal aid and specialised HIV services across the UK.

4.5.3 Education policy and HIV

There is alarming evidence that essential facts about HIV are not being taught in school despite the obvious opportunity schools present for increasing knowledge of HIV. Currently HIV is taught as part of the science curriculum and schools in the UK have to provide information on STIs. However, Sex and Relationships Education (SRE) as a subject is not compulsory in all schools. There is a statutory requirement to teach SRE in Wales and Northern Ireland (referred to as Relationships and Sexuality Education in Northern Ireland), but in England the growing number of free schools and academies can choose not to teach this. In Scotland there is no statutory requirement for any school to teach SRE (in Scotland it is referred to as Relationships, Sexual Health and Parenthood). Providing young people with high quality information on HIV and relationships has the potential not only to improve public health, but to reduce HIV stigma related to poor knowledge, fear and misunderstanding.

What works?

- End the criminalisation of reckless transmission of HIV and other laws criminalising people at increased risk of HIV

- Remove policies that reinforce negative attitudes towards people living with HIV or people at increased risk

- Provide information on rights to people living with HIV

- Increase access to justice for people living with HIV

- Implement policy to ensure that high quality information on HIV is provided through the school curriculum.

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76   A story reported from a police statement demonstrates this issue:
     http://www.bbc.co.uk/news/uk-england-birmingham-33298191
     http://www.expressandstar.com/news/crime/2015/06/27/
     stourbridge-woman-charged-with-gbh-after-men-infected-with-hiv/
     http://www.stourbridgenews.co.uk/news/13357535.Stourbridge_
     woman_charged_with_GBH_after_men_infected_with_HIV/
77   Government Equalities Office, 2013 'Evaluation of the implementation
     of the Equality Act 2010: Report 2 – Awareness and impact of the
     Equality Act'
78   NAT, 2009, 'Working with HIV'

Recommendations:

6. Criminal prosecutions for transmission of or exposure to HIV should be ended across the UK so that it is only prosecutable in cases of intentional transmission.

7. The Government and the Equality and Human Rights Commission should increase awareness of the Equality Act 2010 and what this means for employers, service providers, public bodies and people living with HIV in Britain. The Equality Commission for Northern Ireland should work with the Government to increase awareness of corresponding laws in Northern Ireland.

8. Governments should review the impact of their laws and policies on people at increased risk of HIV, including gay and bisexual men, black and minority ethnic (BME) groups, migrants, trans* people, sex workers and people who inject drugs, and take steps to reduce structural inequalities for these groups.

9. Local authorities in the UK must recognise the value of HIV-specific services in providing advice and support to people living with HIV and should ensure that the needs of people living with HIV are considered in the shaping of the local advice sector.

10. All young people living in the UK should have access to accurate information on HIV as part of a comprehensive curriculum for PSHE and SRE in schools. This should provide the opportunity to discuss same-sex relationships, prevention of HIV and the issue of stigma.

4.6 Working in organisations to reduce stigma

Strategies to reduce stigma within organisations are important. Institutionalised stigma can serve to legitimise discriminatory views and feed into wider social stigma and discrimination. People living with HIV continue to experience stigma in schools, hospitals and from private service providers and businesses but this is one area where there is more evidence about effective interventions.

4.6.1 Healthcare settings

The importance of addressing stigma in healthcare settings has been recognised across the world and there are several initiatives which have been tested within hospitals. This is perhaps unsurprising – in the UK as elsewhere, stigma in healthcare exists and directly impacts on people's ability to access necessary care. In a 2007-08 survey of people living with HIV in the UK, nearly one in five (19%) reported discrimination from healthcare staff in the previous 12 months,[79] and in 2009 17% reported having been denied healthcare due to their HIV status in the previous 12 months.[80] More recently in 2015, 14% of people living with HIV reported being treated differently by their GP due to their HIV status, 6% felt that they had been refused treatment or that treatment had been delayed.[81]

> " **[The] liver biopsy doctor wore two pairs of latex gloves. GP nurse said I was lucky to have free HIV treatment considering I contracted HIV through my own behaviour.”**
> **Person living with HIV**

79 Weatherburn. P., Keogh. P., Reid. D., Dodds. C., Bourne. A., Owuor. J., Hammond. G., & Jessup. K. (2009) 'What Do You Need? 2007-08 Findings from a national survey of people living with HIV'. London. Sigma Research. Available at: http://www.sigmaresearch.org.uk/files/report2009b.pdf
80 'Give Stigma the Index Finger' Initial Findings from The People Living with HIV Stigma Index UK. (2009) Available at: http://www.stigmaindexuk.org/reports/give_stigma_the_index_finger.pdf
81 UK Stigma Index 2015 survey; results reported at the European AIDS Conference, Barcelona, 2015

> **Come the day of the operation, I was informed that my slot had been pushed to the end of the day. When I asked why I was told that because I was HIV positive. I asked why that would affect my time slot and was told that because I was HIV positive the operating theatre and the equipment had to be 'sterilised' after my operation to 'minimise the risk of cross infection'. I argued that the operating theatre and the equipment should be sterilised REGARDLESS of the fact that a patient was HIV positive or negative."**
> **Person living with HIV**

The International Centre for Research on Women (ICRW) has developed the "Understanding and challenging HIV stigma: Toolkit for action". The initial toolkit was designed for use in Africa but it has been adapted and implemented in a range of countries, including India, Cambodia and the USA. It is based on the framework for stigma outlined in the introduction to this paper. It takes a workshop approach to provide information and skills-building. The toolkit has been used in hospitals in Vietnam and India with evaluations showing promising results.[82,83&84] In these examples the project coordinators worked with representatives from within all levels of the hospitals to design the programme to ensure it would engage participants. Staff ownership also supported the sustainability of the programme and the evaluation process. In Vietnam participants were interviewed to report outcomes and researchers returned to monitor behaviours.[85] As a

Box F

A hospital based intervention in China[86]

In China a hospital based intervention was designed to make the most of the influence that clinicians have on colleagues and organisational culture. A key finding of the study was that identifying people of influence and targeting the intervention at them led to a bigger impact across the organisation.

This programme was implemented in 20 hospitals across two different provinces in China and the results in these hospitals were compared with another 20 control group hospitals.

A key component of this project was provision of information. The aim was to increase knowledge of HIV and of the impact of stigma using information workshops. Researchers had noted the evidence that interventions which combine information with skills-building approaches are generally more effective than those that provide information alone.[87] And so the programme used skills-based workshops that supported attendees to meaningfully challenge stigma. This appears to have been key to the success of this intervention. Researchers found that the stigma reduction effect was maintained in a 12 month follow-up assessment.

result this is one of the few studies which have been able to demonstrate a change in attitudes translated into behaviour. The intervention has led to improved care of people living with HIV and has reduced practices that compound stigma such as labelling of beds and the use of unnecessary protective measures.

Activities to tackle the structural elements of stigma should also be considered a key component of successful interventions within organisational

82 Pulerwitz. J., Michaelis. A., Weiss. E., Brown. L., & Mahendra. V. (2010). Reducing HIV-related stigma: Lessons learned from Horizons research and programs. *Public Health Report*s. 125, p272 – p281

83 Oanh. K., Ashburn. K., Pulerwitz. J., Ogden. J., Nyblade. L. (2008) 'Improving Hospital-based Quality of Care inVietnam by Reducing HIV-related Stigma and Discrimination'. Institute for Social Development Studies; International Center for Research on Women; Horizons Program. Available at: http://www.icrw.org/files/publications/Improving-hospital-based-quality-of-care-in-Vietnam-by-reducing-HIV-related-stigma-and-discrimination.pdf

84 ICRW & STRIVE (2013) 'A global HIV stigma reduction framework adapted and implemented in five settings in India: Summary report'. Available at: http://www.icrw.org/files/images/web_ICRW_STRIVE_India%20stigma%20framework_0.pdf

85 Oanh et al 2008

86 Li, Li, Liang, Li-Jung, Wu, Zunyou Wu, Lin, Chunqing Lin, & Guan, Jihui. 2014. Assessing Outcomes of a Stigma-Reduction Intervention with Venue-based Analysis. *Social Psychiatry and Psychiatric Epidemiology,* 49(6): p991 – p999

87 Brown et al 2003

settings. Policy and procedures, or lack thereof, in a clinical setting are particularly important in framing how staff view the risk of HIV. Inappropriate policies on protective measures, for example, can be taken for granted by staff as necessary to avoid transmission. A lack of clear or consistent policy, or limited access to universal precautions, may lead to staff determining their own practices based on their level of knowledge and perceptions. This can further reinforce stereotypes that lead to stigma. For example, a surgeon in Vietnam described being 'more careful' when, *'We see some tattoos on their body or if they are too thin. Or for those women we suspect to be sex workers when looking at their clothing…'*

Changing the environment to one which is always safe and where good practice is reinforced has been identified as important in initiating cultural change in medical settings.[88&89] In many of the hospitals where the ICRW toolkit has been implemented, significant gaps in safe practice were identified such as low provision of sharps bins or of gloves. While these specific concerns are less relevant in UK hospitals, it is important to consider other structural components which may influence stigma. Despite good coverage of universal precautions in the UK, people living with HIV still report changes in practice such as double-gloving among healthcare workers demonstrating that there is still a role in awareness raising and improved knowledge.

The example in China also shows that there is a role for champions who can show leadership in challenging stigma. Identifying similar individuals in UK health and social care settings who can challenge inappropriate practices could be beneficial.

4.6.2 The police force

Much like hospitals, the internal policies and procedures for the police force are relevant to their responses to HIV. In the UK in 2013 NAT found that police forces' occupational health policies often had inaccurate and inappropriate information about HIV transmission, testing and confidentiality, as well as language that was sometimes offensive or

sensationalist.[90] In response to the findings of the review, NAT gave recommendations for how to improve each policy and published a guide for police forces in the UK which supports them to better understand HIV with the aim of reducing stigma.[91] Although no formal evaluation of this initiative took place, follow-up with the relevant police forces did reveal that improvements were made to occupational health policies. Initiatives such as this can open up further opportunities for face-to-face interventions such as training that can have a further impact on levels of stigma amongst individuals within a police force.

4.6.3 Schools

Section 4.5.3 outlined the need for national-level policy change to ensure universal access to high quality SRE in schools which includes up to date and accurate information on HIV. High quality SRE that considers some of the drivers of stigma and utilises some of the approaches discussed in this section would also help to counter stigma and discrimination experienced by pupils living with or affected by HIV. As with the police force, internal policies and procedures are also likely to be important in ensuring that schools provide a safe and non-stigmatising environment.[92]

4.6.4 Faith settings

Faith settings have frequently been identified as key environments for stigma reduction interventions. This is due to the influence faith leaders and some doctrines can have on communities.

A study in the US is currently evaluating the impact of a multi-faceted intervention in predominantly African American and Latino churches. Early indications from the pilot show that an approach combining information on HIV with skills-building sessions, using role-play and motivational interviewing, has reduced reported negative attitudes amongst participants.[93] There are also examples of work with faith congregations in the UK. These

88   Nyblade. L., Stangl. A., Weiss. E., & Ashburn. K. (2009) Combating HIV stigma in health care settings: What works? *Journal of the International AIDS Societ*y. 12 (15)

89   Stangl et al 2013

90   'Police occupational health policies and blood borne virus training: protecting health?', NAT, 2012

91   'HIV: A guide for police forces', NAT, updated 2014

92   Guidance for schools on supporting pupils living with or affected by HIV was published in 2015 and is available at: http://www.chiva.org.uk/files/9114/4976/8872/HIV_in_Schools.pdf

93   Derose. K.P., Bogart. L.M., Kanouse. D.E., Felton. A, Collins. D.O., Mata. M.A., Oden. C.W., Domínguez. B.X., Flórez. K.R., Hawes-Dawson. J., Williams. M.V. (2014) 'An intervention to reduce HIV-related stigma in partnership with African American and Latino churches'. *AIDS Education and Prevention*. 26, (1), p28 – p42

What works?

- Develop and deliver group-based workshops/programmes where information is combined with skills-building activities

- Involve people living with HIV in the delivery of these programmes, e.g. train people living with HIV as facilitators

- Involve staff across the organisation in the programme design and implementation, not only senior staff

- Identify individuals who hold influence to provide leadership and championing of the anti-stigma message

- Develop strong organisational policies that promote safe working and zero-tolerance to discrimination

- Talk about HIV not only in the context of prevention but in the context of the well-being of individuals living with HIV.

Recommendations:

11. NHS commissioning bodies and relevant health education bodies in the UK should invest in a programme to reduce HIV stigma in healthcare settings building on the existing international evidence base.

12. UK governments should consider the role of the police force, the criminal justice system and schools in a strategy for reducing stigma. Learning from other institutional contexts should be considered in the development of a plan for tackling stigma in these organisations.

13. Governments and other funders should work with community organisations to implement and evaluate a pilot for an HIV stigma reduction programme within UK faith-based settings drawing on existing evidence.

> **" I have to admit that I did sleep around and didn't always use condoms. Now that I have HIV I regret it. I hate myself so much for having it. I sometimes wish I wasn't born gay."**
> **Person living with HIV**
>
> (HIVAware website)

largely focussed on HIV testing.[94] Although no formal evaluation exists, the normalisation of HIV testing in these settings is said to also support more open discussion of HIV among the community, reducing stigma.

4.7 Addressing self-stigma

Much of what we have considered looks at individuals within their wider social context. However, there is one area where the individual needs to be the primary focus of the intervention; this is in the case of self-stigma.

Self-stigma affects the way an individual feels about themselves as well as how they perceive and manage external manifestations of stigma and discrimination. Feelings of self-stigma can include

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94 See 'Guide to HIV Prevention in the context of faith', produced by BHA for HIV Prevention England, 2014, and 'Testing Faith' project www.testingfaith.org run by NAZ Project which has worked with 95 faith leaders and delivered 735 HIV tests

blame, internalised shame and a sense that HIV is a punishment for behaviour. For some it can have a significant impact.

The existence of self-stigma demonstrates the complex relationship between social norms, stereotypes and concepts of good or bad behaviour, and the way these translate into how we feel about ourselves. Support for people living with HIV has long been recognised as an important aspect of treatment and care, in part because it reduces self-stigma which is linked to better adherence to ART and health seeking behaviours.[95&96]

There is evidence to show that support groups for people living with HIV can reduce internalised stigma. Abel et al (2013) found that black African American women living with HIV who took part in an Emotional Writing Disclosure (EWD) intervention reported decreased stigma scores on one scale compared with a control group.[97] This was still the case three months later. However, further psychological and physical health benefits were limited, indicating that some of the wider benefits of lower reported stigma were not realised.

> **How could I discuss it with someone and expect them to come to terms with it, when I hadn't? I then realised that I wasn't going to come to terms with it, unless I discussed it with someone else, but I didn't want to, until I'd made some progress."**
> **Person living with HIV**
>
> (HIV Stigma Index UK, 2015)

Project ACCEPT (Adolescents Coping, Connecting, Empowering and Protecting Together), another programme in the US, involved a mixture of individual and group sessions which included a peer facilitator. The workshops were designed to build skills and improve coping mechanisms using a mixture of role play, group discussion and other activities guided by social cognitive theory.[98&99]

Participants reported high levels of satisfaction with the project, with many reporting some form of positive outcome including increased acceptance of their HIV diagnosis.[100] However, although the programme reduced self-stigma amongst men, it did not have the same effect for women.[101] This difference may be explained by the fact that the men had more consistent support networks outside of the group; the existence of an established community of gay and bisexual men living with HIV was noted here and there was no comparable community for the young women.[102] External support networks may therefore be important in enhancing programmes like this.[103]

An adaptation of ICRW's stigma toolkit, the Unity Workshop, conducted again with African American women living with HIV in the US, showed improvements in feelings of self-stigma.[104] Focus groups of people living with HIV in the local community informed the development of the programme. The intervention addressed internal and external stigma through a range of skills-building workshops. This gave the participants tools to take to future situations and was shown to be key to the lasting impact of the intervention.

Evaluation of the CHIVA support camps for young people living with HIV in the UK has shown benefits to participants. Although self-stigma has not been measured in this case, reduction in social isolation amongst the young people has been

98   Hosek SG, Lemos D, Harper GW, Telander K. (2011) 'Evaluating the acceptability and feasibility of Project ACCEPT: an intervention for youth newly diagnosed with HIV'. AIDS Education and Prevention. 23 (2):128

99   Loutfy. M., Tharao. W., Logie.C., AdenM.A., Chambers. L.A., Wu. W., Abdelmaseh.M., & Calzavara. L. (2015) Systematic review of stigma reducing interventions for African/ Black diasporic women. *Journal of the International AIDS Society*. 18

100 Ibid

101 Ibid

102 Ibid

103 Ibid

104 Rao. D., Desmond. M., Andrasik. M., Rasberry. T., Lambert. N., Cohn. S. E., & Simoni. J. (2012). 'Feasibility, Acceptability, and Preliminary Efficacy of the Unity Workshop: An internalized stigma reduction intervention for African American women living with HIV'. AIDS Patient care and STDs, 26 (10)

95   Chidrawi et al 2014

96   Paudel. V., & Baral. K.P., (2015) Women living with HIV/AIDS (WLHA), battling stigma, discrimination and denial and the role of support groups as a coping strategy: a review of the literature. *Reproductive Health*. 12 (53) doi: 10.1186/s12978-015-0032-9

97   Abel E, Rew L, Gortner E-M, Delville CL. (2004) 'Cognitive reorganization and stigmatization among persons with HIV'. J Adv Nurs. 47 (5)

demonstrated.[105] This camp, bringing young people living with HIV together for four days, is intended to build the resilience of the young people and to allow them to feel more comfortable with their HIV status. Those attending the camps reported greater levels of disclosure to friends outside of the camp three months later.[106]

When asked about their impressions of the camp one young person said in 2011:

> **…when I came back home I felt good that I did [go to the camp] because at the camp it was like everyone was just the same as me and basically I had to accept that I have HIV. It actually lifted me up instead of me stay[ing] scared of what was going to happen through my future."**
> **14 year old after attending the CHIVA camp**[107]

What works?

- Programmes for people living with HIV which combine skills-building activities, peer support and opportunities to discuss stigma and its effects

- Promote opportunities for people living with HIV to speak as a community in challenging stigma and discrimination.

Box G

Building resilience and mobilising a community to oppose stigma

Skills-building interventions have been useful in addressing self-stigma, building resilience amongst people living with HIV. At an individual level this might mean being better able to cope with experiences of stigma or discrimination. This has the potential to be scaled up – developing the capacity of a community of people living with HIV to challenge stigma and improve their own circumstances, which may then impact on the drivers of stigma as a whole.[108]

The role of community activism in HIV is well recognised, particularly in driving the roll-out of AZT and HAART in the 1990s and in raising awareness of HIV and the impact it has had on many communities. However, the role of mobilising the community in reducing stigma is more difficult to measure, despite the fact that many believe it to be an important component of tackling stigma.[109] Several interventions have shown the value of involving people living with HIV, and this can only happen with a degree of empowerment. Structural change and the realisation of rights are more likely to occur if people living with HIV and groups disproportionately affected by HIV are empowered and well supported.

Recommendation:

14. Local authorities should maintain investment in HIV support services as these have a vital role in enabling people living with HIV to manage their health and cope with internal and external stigma.

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105 'Freedom To Be (F2B) summer camp evaluation', 2011, Catherine Dodds, Published by Elton John AIDS Foundation, CHIVA, Sigma research. Available at: http://www.chiva.org.uk/files/4114/2902/2506/f2b-evaluationreport.pdf
106 Ibid
107 Ibid

108 Parker & Aggleton 2003
109 Ibid

CONCLUSION: BUILDING A COMBINATION APPROACH TO HIV STIGMA REDUCTION

5

HIV stigma is complex, made up of many different elements, and so it is unlikely that any one dimensional intervention will have a meaningful impact. This is why stigma theorists now advocate combined approaches to address HIV stigma – in much the same way that recommendations have shifted in HIV prevention practice to a combination approach.[110]

Although there is a definite lack of evidence for effective stigma interventions, the evidence that does exist suggests that any anti-stigma strategy should consider the many different causes of stigma and contain interventions that are suitable for different elements.

Each component of a strategy should be considered in terms of what it is trying to achieve. The pyramid structure below is based on that in Section 2 and shows the main components an intervention strategy should include.

Once the setting for an intervention has been identified – the where (e.g. within healthcare services) – and which causes of stigma should be targeted – the what (e.g. unnecessary fear of transmission) – the evidence available discussed above can be used to select an appropriate approach – the how (e.g. skills based workshops involving people living with HIV). Any comprehensive strategy should have several answers in each segment (**What? Where? How?**) – building a multifaceted response which will affect stigma as a whole.

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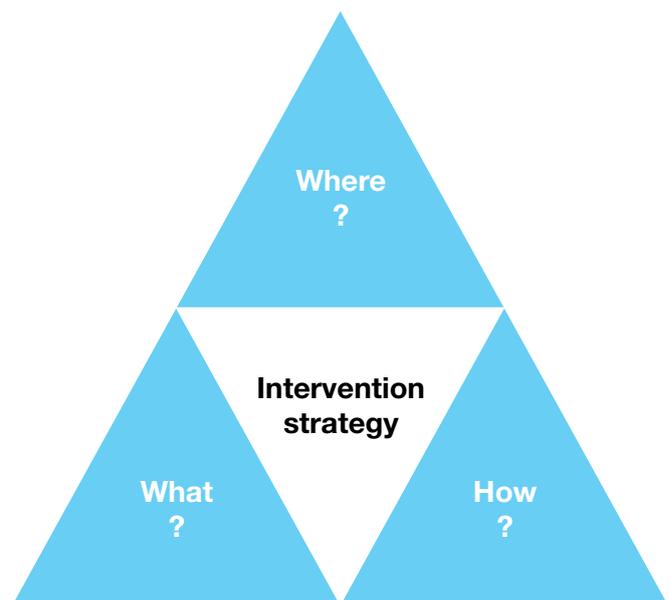
110 'Combination prevention: Tailoring and coordinating biomedical, behavioural and structural strategies to reduce HIV infections', UNAIDS, 2010

Governments should consider stigma at all levels and design evidence-based interventions at each level.

Drawing on the evidence discussed in this report, the table at the end of this section looks at the different contexts of stigma and what works and may be helpful for people designing anti-stigma interventions in the future. However, the process of developing this paper has underlined the lack of evidence about the impact of many stigma interventions. And multi-faceted approaches to stigma reduction are even more complicated to evaluate. There is often a lack of funding and access to research skills. This is particularly the case for the many stigma interventions set up by not for profit organisations reliant on charitable funding. Many grass-roots programmes have no formal evaluation procedures. It is vital that funding and further research capacity building are provided, as

evaluation helps to identify what projects have achieved and how effective the models may be in other settings.

This evidence deficit is particularly notable in Europe, despite the fact that both the 'Dublin Declaration on Partnership to Fight HIV/AIDS in Europe and Central Asia'[111] and the EU Commission's action plan[112] emphasise the importance of taking steps to address stigma. There are now opportunities for Europe to consider the international theoretical and empirical evidence base and how this might apply in new settings.

5.1 A summary of what works

Where?	Reducing stigma between individuals in communities
What?	- Poor knowledge of HIV, HIV transmission and risk - Pre-conceptions, stereotypes and othering of people living with HIV - Low awareness of HIV and HIV stigma and their effect on certain groups and communities - Discriminatory behaviour
How?	- Increase access to accurate information on HIV and HIV transmission using a range of media tools - Expose people to a range of messages addressing different aspects of stigma - Challenge negative media messaging around HIV and use relationships with the media to maintain more accurate reporting - Link to opportunities for people to further engage with campaigns at a local or community level - Involve people living with HIV in the delivery/facilitation of interventions - Provide information on HIV stigma and its effects within interventions - Provide opportunities to discuss stigma and the factors contributing to it with peers - Use mixed media to deliver a relatable narrative to encourage empathy with people living with or groups affected by HIV

111 The 'Dublin Declaration' was first published in 2004 and can be found at: http://www.unicef.org/ceecis/The_Dublin_Declaration.pdf

112 'Action plan on HIV/AIDS in the EU and neighbouring countries 2014-2016', EU Commission staff working document, 2014: http://ec.europa.eu/health/sti_prevention/docs/ec_hiv_actionplan_2014_en.pdf

Where?	Stigma at a public policy/structural level
What?	• Laws which criminalise people living with HIV or communities disproportionately affected by HIV • Lack of legal protection from discrimination for people living with HIV and affected groups • Where rights do exist, lack of awareness amongst people living with HIV, employers and service providers • Limited access to justice for people living with HIV who face discrimination
How?	• End the criminalisation of reckless transmission of HIV and other laws criminalising people at increased risk of HIV • Remove policies that reinforce negative attitudes towards people living with HIV or people at increased risk • Provide information on rights to people living with HIV • Increase access to justice for people living with HIV • Implement policy to ensure that high quality information on HIV is provided through the school curriculum
Where?	Reducing stigma in organisational settings
What?	• Poor knowledge of HIV, HIV transmission routes and risk • Pre-conceptions, stereotypes and othering of people living with HIV • Inappropriate or absent policy and practice • High level tolerance of discriminatory behaviour or attitudes in the organisational culture • Poor understanding of the impact of stigma and discrimination on people living with HIV and their health outcomes
How?	• Develop and deliver group-based workshops/programmes where information is combined with skills-building activities • Involve people living with HIV in the delivery of these programmes, e.g. train people living with HIV as facilitators • Involve staff across the organisation in the programme design and implementation, not only senior staff • Identify individuals who hold influence to provide leadership and championing of the anti-stigma message • Develop strong organisational policies that promote safe working and zero-tolerance to discrimination • Talk about HIV not only in the context of prevention but in the context of the well-being of individuals living with HIV
Where?	Self-stigma
What?	• Feelings of fear, shame and blame or punishment among people living with HIV • Poor self-efficacy and knowledge of rights • Poor health and psychological well-being
How?	• Programmes for people living with HIV which combine skills-building activities, peer support and opportunities to discuss stigma and its effects • Promote opportunities for people living with HIV to speak as a community in challenging stigma and discrimination

5.2 A summary of recommendations for future policy and practice

1. All UK Governments should develop an evidence-based strategy for reducing HIV stigma which includes a range of approaches to tackle the many different factors contributing to stigma.

2. Funders in the UK and wider EEA should invest in developing the evidence base for effective stigma interventions by funding stigma reduction programmes that incorporate evaluation.

3. The European Centre for Disease Control (ECDC) should work with governments to support roll-out of existing proven stigma interventions in Europe.

4. Social marketing and a mix of media channels should be used as part of a strategy to address HIV stigma as a way of increasing public exposure to information and messages.

5. Interventions designed to reduce HIV stigma should be developed and delivered in partnership with people living with HIV.

6. Criminal prosecutions for transmission of or exposure to HIV should be ended across the UK so that it is only prosecutable in cases of intentional transmission.

7. The Government and the Equality and Human Rights Commission should increase awareness of the Equality Act 2010 and what this means for employers, service providers, public bodies and people living with HIV in Britain. The Equality Commission for Northern Ireland should work with the Government to increase awareness of corresponding laws in Northern Ireland.

8. Governments should review the impact of their laws and policies on people at increased risk of HIV, including gay and bisexual men, black and minority ethnic (BME) groups, trans* people, sex workers and people who inject drugs, and take steps to reduce structural inequalities for these groups.

9. Local authorities in the UK must recognise the value of HIV-specific services in providing advice and support to people living with HIV and should ensure that the needs of people living with HIV are considered in the shaping of the local advice sector.

10. All young people should have access to accurate information on HIV as part of a comprehensive curriculum for PSHE and SRE in schools. This should provide the opportunity to discuss same sex relationships, prevention of HIV and the issue of stigma.

11. NHS commissioning bodies and relevant health education bodies in the UK should invest in a programme to reduce HIV stigma in healthcare settings building on the existing international evidence base.

12. UK Governments should consider the role of the police force, the criminal justice system and schools in a strategy for reducing stigma. Learning from other institutional contexts should be considered in the development of a plan for tackling stigma in these organisations.

13. Governments and other funders should work with community organisations to implement and evaluate a pilot for an HIV stigma reduction programme within UK faith-based settings drawing on existing evidence.

14. Local authorities should maintain investment in HIV support services as these have a vital role in enabling people living with HIV to manage their health and cope with internal and external stigma.
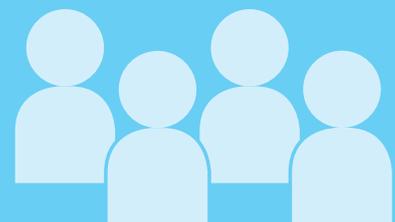
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