

HIV-RELATED STIGMA INTERVENTIONS

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INTRODUCTION

This paper has been developed with the intention of providing a framework for people developing HIV-related stigma interventions to consider how to design, implement, and evaluate such activities. The paper first provides a brief explanation of some HIV stigma definitions, followed by an overview of the theory and concepts related to stigma, including its origins and mechanisms. It then describes seven approaches – informed by previous reviews, and specific examples from Australia and elsewhere – used in the development of HIV-related stigma interventions. Finally, it provides an overview of how HIV-related stigma is measured, with an emphasis on how outcome measures need to be calibrated to the approach, the domain, and the level of any specific intervention. The paper is intended as a practical tool for people developing and evaluating interventions.

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Dr Dean Murphy has a long background in the HIV sector, having worked at AFAO for many years. Dean completed his PhD at the University of New South Wales, exploring meanings of parenthood among gay and queer men (from Australia and the USA) pursuing parenthood through commercial surrogacy arrangements. His PhD formed the basis for his book *Gay Men Pursuing Parenthood Through Surrogacy: Reconfiguring Kinship*, which was published in 2015.

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HIV-RELATED STIGMA: DEFINITIONS

EXPRESSED AND EXPERIENCED STIGMA

Given the overwhelming amount of research and writing on stigma, it is worth attempting to categorise some of the concepts used in the literature, with a particular focus on HIV-related stigma. A useful starting point is to make a distinction in terms of the power dynamics i.e. between stigmatising and being stigmatised.

EXPRESSED STIGMA

Expressed stigma (or enacted stigma) refers to the practices through which members of certain groups prejudice, or discriminate against, others, for example on the basis of their positive HIV status.¹ These practices include both overt and covert forms of **avoidance** or **exclusion**, or other forms of marginalisation and social devaluation.² In the case of HIV, this may include rejecting people living with HIV (PLHIV) as (potential) sexual partners. Earlier research has found previously that people expressed more HIV-related stigma if they were more concerned about infection and perceived greater likelihood of acquiring HIV from an HIV-positive partner.³

In recent years, there has also been more attention given to micro-aggressions, which are subtle forms of discrimination that in relation to HIV could include comments or jokes about HIV, assumptions about sexual behaviour, or even rendering the experience of living with HIV as invisible (which is a sub-category of micro-aggressions called micro-invalidations).^{4,5} An example of the latter could be the common question on hook-up apps, 'Are you on PrEP (Pre-Exposure Prophylaxis)?', which assumes all users are HIV negative.

However, expressed or enacted stigma also includes a range of other domains. For example, stigma can be expressed through embodied **emotional responses** e.g. as disgust or anger.^{6,7} Stigma can also be expressed through what are called **attributions of responsibility**, whereby control over acquisition or transmission of HIV (to use this specific example again) is assumed to be a result of the actions of the individuals or groups affected.

When prejudice or discrimination is codified into – and perpetuated by – institutional systems, for example laws, regulations, policies, procedures, and professional practice, it is known as structural stigma. **Structural stigma** is also associated with structural violence (e.g., racism, sexism) and pre-existing stigma (e.g., regarding gay men, sex workers, people who inject drugs), which exacerbates power imbalances and provides the conditions for more intensive stigma and discrimination.^{8,9}

EXPERIENCED STIGMA

Experienced stigma is where individuals or groups experience, discrimination, devaluing, or prejudice. This can be the result of stigma expressed/enacted by others (as described in the section above), and can have real material effects, ranging from denial of opportunities, such as being socially (or sexually) excluded, to being subject to overtly punitive laws. The ways in which stigma is experienced also includes **perceived stigma** or **felt stigma** which refers to awareness of negative social attitudes, and therefore also the extent to which it is expected or pre-empted (i.e. **anticipated stigma**) by those who are subject to it. Fear that disclosure will lead to stigmatisation is an example of perceived stigma.^{1,10} Felt stigma can manifest through fear, self-isolation, or self-blame.²

Finally, experienced stigma also includes the ways in which negative attitudes can be internalised (i.e. **self-stigma**),¹⁰ whereby people hold negative or devaluing core beliefs about themselves as individuals or a group.^{2,11} This occurs when individuals blame and devalue themselves and accept other negative connotations. Such beliefs can cover a range of areas, including self-perception, body image, and sex and sexuality¹² and deviance.¹ These negative core beliefs are embodied for example through emotions such as shame.¹¹ HIV self-stigma is also impacted by perceptions of the risk of onward transmission, and this self-stigma can be reinforced when other people express anxiety about HIV.¹³ Stigma originating from external sources and experienced (i.e. **felt stigma**) are therefore closely interconnected.²

HIV-RELATED STIGMA: THEORY AND CONCEPTS

ORIGINS AND MECHANISMS OF STIGMA

Identifying the mechanisms of HIV stigma can provide important insights into how HIV stigma impacts health and well-being and can also therefore provide a better theoretical basis to inform – and evaluate – interventions.¹⁴ Contemporary understandings of stigma owe a great deal to the writings of Erving Goffman, who theorised the origins and mechanisms of stigma in the 1960s.¹⁵ Goffman described stigma as an attribute that deeply discredits an individual and reduces them from an accepted or acceptable person to one that is spoiled, tainted, or discounted. Goffman (1963) distinguished three broad types of stigma, each of which is associated with HIV: physical imperfections; blemishes of individual character (or character flaws); and tribal stigma of race, nation and religion (or membership of a negatively regarded social group). Fife and Wright note that each of these three broad types of stigma are commonly linked with HIV.¹⁶ Stigmas can taint a person's social identity because socially undesirable attributes become associated with stereotypes.

For Goffman, an attribute “is neither creditable nor discreditable as a thing in itself”,¹⁵ and stigmatisation reflects *social relationships*. And most contemporary views of stigma argue that “stigma is relationship- and context-specific; it does not reside in the person but in a social context”.¹⁷ Stigma is therefore the social construction of a consequential form of difference between individuals and communities.

Goffman also argued that people manage impressions of themselves, mainly through concealment. Stigma is therefore related to the shame a person may feel when they fear of being discredited. Thus, a person may withhold information about themselves for fear of judgment. Therefore, an important concept introduced by Goffman is that of ‘passing’ whereby a person with a potentially stigmatised attribute blends in with others by way of not disclosing it. Building from Goffman's initial work, Jones and colleagues (1984) identified six dimensions of stigma – concealability, course, disruptiveness, peril, origin, and aesthetics.¹⁸

According to Link and Phelan, stigma exists when a set of five interrelated processes converge¹⁹:

1	Social categorisation. <i>People distinguish and label differences.</i>
2	Stereotyping. <i>Dominant cultural beliefs associate labelled persons with undesirable characteristics.</i>
3	In-group–out-group differentiation and prejudice. <i>Labelled persons are seen as different from the dominant group.</i>
4	Status loss and discrimination
5	Reinforcement of social, economic and political power.

This conceptual model emphasises that the stigmatised and the non-stigmatised are social roles, with the former holding less power and fewer resources than the non-stigmatised.¹ Stigma occurs when the non-stigmatised construct a cognitive theory that to them explains the other's inferiority by highlighting potential dangers represented by the stigmatised individual or group; and this construction subsequently justifies prejudice or discrimination.^{1,15}

Phelan and colleagues propose three power-related functions of stigma and prejudice: legitimising exploitation and dominance, enforcing social norms, and avoiding disease.⁷ These functions parallel the stigmas Goffman distinguishes as related to group membership, behaviour, or appearance.^{15,17} The third function – avoiding disease – is particularly relevant for HIV-related stigma and discrimination. It suggests that people should express more HIV-related stigma if they are more concerned about infection and perceive more risk of HIV transmission from sex with a partner who is HIV positive. And indeed, it has been found previously – including among gay men in Australia – that people expressed more HIV-related stigma if they were more concerned about infection.^{3,8}

Stigma may be triggered by fear, as well as lack of information, and lack of contact with HIV and PLHIV.²⁰ HIV-related stigma is also heavily influenced by the history of the epidemic (and its representations) and as already noted in relation to stigma in general, is intensified by power inequalities.²⁰

Stigma can be observed at multiple levels, and its origin and/or dynamics can vary accordingly. For example, discrediting of PLHIV among the broader community may reflect negative social views of already marginalised communities most affected by HIV, such as gay men, people who inject drugs, and sex workers.⁸ However, in gay communities, stigma may be the result of dividing practices *within* these communities, that seek to differentiate PLHIV from others via associations with perceived individual character flaws, which historically have included engagement in practices such as condomless sex.

Contemporary sociological writings on stigma have called for greater attention to stigma's social and political dimensions, including 'questions about *where* stigma is produced, *by whom* and *for what* purposes' (emphasis added).²¹ This shift draws on earlier work, notably by Parker and Aggleton, which theorised the ways in which social inequality is produced and reproduced through the enactment of stigma by individuals, communities, and the state.²² The renewed sociological focus, which seeks to understand how stigma functions as a form of power, marks a departure from the majority of research on stigma over several decades which has sought to describe and measure stigma and its effects at an increasingly micro level (e.g. an individual's mental processes).²¹

Consistent with Goffman's and Brewer's^{6,23} theorisation of intergroup relations, it has been the case historically that higher levels of experienced and internalised HIV-related stigma are reported by people whose *positive* HIV status was a more important aspect of their self-identity.^{8,24} Also, PLHIV who engage more with the HIV-positive community experience more stigma.^{9,25} However, social support does reduce reported internalised stigma.^{24,26}

There has been surprisingly little research on HIV-related stigma in communities of gay, bisexual and queer-identifying (GBQ+) men. Earlier studies found that experiences of HIV-related stigma tended to cluster in the domain of sex and relationships.^{8,27-31} Specifically, in Australia, overall experiences of stigma were low among HIV-positive gay men, with little social distancing and little attribution of responsibility (e.g. blaming and judgment) from HIV-negative people, with somewhat higher self-reports of negative emotional reactions. However, HIV-positive men reported experiencing moderate levels sexual exclusion, and notably the same study found the degree to which these men experienced sexual exclusion was comparable with the degree to which HIV-negative men reported excluding PLHIV as sexual partners.⁹

More recently, Enoksen's (2022) study set in Scandinavia found most participants described the gay community as where they met the most stigmatisation.¹ Similarly, a study in the Netherlands found stigma in the LGBTQ community, including with sexual partners, remained largely unchanged between 2007 and 2019–2020.³² In a UK study, 42% of gay men reported worrying about HIV-related sexual rejection, 37% reported avoiding sex because of their HIV status, and 27% reported specific experiences of HIV-related sexual rejection in the past 12 months.²⁸ There has been some other research among gay men on rejection/rejecting HIV-positive partners³³⁻³⁸ although these have not usually been framed in terms of stigma.

Given the introduction of antiretroviral-based HIV prevention (i.e. TasP [treatment as prevention] and PrEP) it would be reasonable to hypothesise that HIV-related stigma, including sexual exclusion, would decrease among communities with high awareness and uptake. For example, recent research among young Black gay men, reduced sexual and HIV anxiety as a result of taking PrEP is associated with decreased HIV-related stigma.³⁹ However, we don't yet have much information about the situation in Australia. Although PrEP use in this country is similarly associated with reduced anxiety related to HIV,⁴⁰ research among early PrEP users found there was still some discomfort with the idea of sex with known HIV-positive men.⁴¹ Subsequent studies have found PrEP users are somewhat more willing to have sex with an HIV-positive partner than non-users of PrEP,⁴² however, there has not been any detailed investigation into HIV-related stigma among this group.

Instead, since 2016, there has been a great deal of focus on U=U, and in particular:

- 1)** knowledge/awareness; **2)** belief/acceptance; and **3)** willingness to rely on U=U.

While the latter could be seen as a proxy measure of sexual exclusion, it's clearly not the same thing. There is a need to include questions about sexual exclusion in surveys of gay bisexual men, similar to those asked in the past²⁹ as well as to undertake more research on the different factors associated with stigma, such as fear of HIV acquisition, but also some of HIV-related stigma's affective and cognitive dimensions, including blaming, disgust, etc. We know however, that U=U does seem to have reduced internalised HIV stigma for PLHIV.⁴³

There has also been increasing interest in intersectional stigma. Intersectionality is a concept that comes from Black feminist scholarship and social activism. It was developed by Kimberley Crenshaw to highlight how race, class, sexuality, gender, and other social categories are both interconnected and shape access to power, resources, and opportunity.⁴⁴

Intersectional stigma refers to the process by which people are exposed to multiple forms of oppression, prejudice, and discrimination. It emerged from Michele Tracy Berger's study of HIV-positive women who have a history of drug use, sex work, and/or conflict with the law, which explored how these women's experiences of race, class, and gender oppression have an impact

on their experience of living with HIV and their political participation.⁴⁵ Subsequent work has explored how social processes, structures, and power dynamics marginalise people who are historically disadvantaged.⁴⁶ Intersectional stigma has increasingly been used to explore the intersection of discrimination based on race and sexuality among Black men who have sex with men (MSM) in the US, and consequent negative health outcomes, including lack of HIV prevention access.⁴⁷ Recent research has also explored the concept of ‘intersectional resilience’, which is based on the idea that people with multiple marginalised statuses possess unique strengths that may confer protective effects.⁴⁸

It is also important to point out, however, that there are critiques of current intersectional stigma framings. Bowleg, for example, argues that the way intersectional stigma is often now conceptualised “obscures interlocking oppressive social-structural systems such as structural racism, sexism, and heterosexism”.⁴⁹ She believes this obscuring is in part related to the current focus on identities rather than power structures, and notes that identity was not a focus of Berger’s⁴⁵ original definition of intersectional stigma. She argues that focusing on multiple stigmatised *identities* creates a sense that there are stigmatised people “but alas no people, systems, or structures, enacting the stigma or being held accountable for doing so”.⁴⁹ Most intersectional analyses, for example, focus on stigma from the viewpoint of the person experiencing stigma rather than that of the enactor. This critique also connects with that of Tyler and Slater (mentioned above), which points out how stigma research has become increasingly descriptive and technical, thereby overlooking stigma’s power dynamics, including the producers and beneficiaries of stigmatising and discriminatory practices.²¹

EFFECTS OF HIV-RELATED STIGMA

There has been a wealth of research on the negative effects of stigma. The most commonly reported effects relate to decreased mental health and quality of life.^{2,14,39,50-58} Deterioration in mental health as a result of HIV-related stigma – especially overtly expressed stigma such as avoidance, and verbal or physical abuse – is also associated with increased risk of suicide.⁵⁹⁻⁶¹

Experienced and anticipated stigma are associated with indicators of physical health and well-being (i.e., CD4 count less than 200 and chronic illness comorbidity).¹⁴ The increased depressive symptoms associated with internalised HIV stigma (in particular the internalisation of negative thoughts about one’s HIV status) may also lead to poorer overall health (i.e. including physical health).^{2,50} In addition to negative psychological outcomes, experienced stigma, (notably exclusion as sexual and romantic partners) contributes to other forms of stigma including internalised stigma, anticipated stigma, and poor self-image.^{57,58} And the more stigma is internalised the greater the negative impact on psychological wellbeing.²⁴

Disclosure of HIV status has a complex relationship with HIV stigma. Whereas PLHIV who choose to be open about their HIV status experienced more stigma,⁶² non-disclosure is understood to be detrimental to wellbeing⁵³ and more psychological distress.⁶²

There has been increasing focus in recent years on the impact of HIV stigma on progression through the HIV care continuum.⁶³ Stigma is associated with lower rates of HIV testing and diagnosis.⁵³ Stigma is associated with lower retention in HIV care,^{11,52,64-68} including both expressed and internalised HIV stigma.^{14,69,70} People who experience or perceive higher HIV-related stigma, including internalised stigma, are also less likely to commence antiretroviral therapy⁷⁰ and to have poorer adherence to their antiretroviral regimens.^{52,53,64-66,71-73} Interestingly, however, greater concerns about public attitudes toward HIV can be associated with *higher* adherence.⁷² Finally, increased levels of both overall stigma and personalised stigma are associated with a lower likelihood of viral suppression.^{51,72}

Because HIV-related stigma has detrimental effects on health, avoiding contexts of expressed stigma could be a means of mitigating stigma's effects.² Similarly, because HIV is largely concealable, not disclosing one's HIV status in social settings (or care settings) can reduce experienced HIV stigma, but is associated with other negative effects such as higher levels of internalised and anticipated stigma. However, this avoidance obviously can lead to much poorer health outcomes in the long term.^{2,74}

HIV STIGMA INTERVENTION APPROACHES

The approaches and logic of HIV stigma interventions are described below. There are seven different approaches described, although many interventions draw on more than one approach. The categorisation presented here is influenced by previous analyses, for example from Brown et al.,⁷⁵ Stangl et al.,⁷⁶ and Ellard et al.,⁷⁷ although the latter was specific to healthcare settings, so the additional categories have been added here to encompass a broader range of settings, including community settings and campaigns. One of Stangl's⁷⁶ approaches – biomedical – has been excluded because although biomedical developments may create the conditions for reducing HIV-related stigma, they are not primarily pursued for this purpose.

This categorisation also varies from the 2016 review by Hopwood, which provided a greater focus on theoretical approaches, and only on intervention evaluations that had been evaluated via randomised-controlled trials or quasi-experimental designs.⁷⁸ This review focuses instead on the aims of different empirical approaches, using examples from the HIV field from Australia and elsewhere, although theoretical approaches are mentioned where this information is available.

1. Increasing knowledge and awareness

Education and awareness interventions aim to reduce stigma by increasing knowledge and reducing misinformation – and myths – about HIV. This approach is based on the assumption that stigma is primarily the result of amplified fears of HIV and PLHIV due to misunderstandings about the likelihood of transmission. The majority of examples of this approach target the general population, however some also target specific groups such as healthcare workers and gay community members.

Although many such interventions are straightforward, fact-based messages, the delivery style or genre can vary significantly. For example, a playful approach from Canada called *#Smashstigma* challenges attitudes to HIV in the general community. A 2017 iteration of the campaign, based on a finding that 53% Canadians would avoid eating food if it was prepared by someone living with HIV, involved a pop-up eatery staffed by HIV-positive workers, which included messages on their aprons, such as: "I got HIV from pasta. Said no one ever."⁷⁹ (More on this campaign in the next section.)



Images: From the *#smashstigma* campaign's pop-up eatery staffed by HIV-positive workers.

Another example is *LOLS@stigma*, which was a 2016 intervention in the UK (a one-off live show using local comedians from the local Black community).⁸⁰ Its evaluation suggested positive effects, notably as providing a way of thinking about HIV, that facilitated emotionality, as well as generating collectivity, described as affective "alter" politics.⁸⁰

Some interventions are based on specific theoretical approaches, such as Diffusions of Innovation.⁸¹ This approach has been tested among health-care workers through training popular opinion leaders (POLs) to educate their peers about HIV.⁸²⁻⁸⁴ Findings suggest lower levels of avoidance and prejudice, and greater likelihood of compliance to universal precautions.

Since 2016, the U=U campaign has been attempting to reduce stigma – especially avoidance of PLHIV as sexual partners – by increasing people’s knowledge and awareness of the results of large, observational studies that found there was no risk of HIV transmission to sexual partners when PLHIV had a sustained undetectable viral load result. According to the campaign’s developers, the U=U (undetectable equals untransmittable) campaign aims to transform the lives of PLHIV by reducing shame and the fear of sexual transmission to their partners, as well as reducing expressed stigma, notably exclusion and avoidance (especially sexual exclusion).⁸⁵ The logic of U=U is also that this information will reduce internalised HIV stigma and also subsequently improve health outcomes.³⁹

A recent review found that information U=U has diffused widely among men who have sex with men (MSM) populations in many regions of the world, however it also noted that disbelief related to U=U still widespread among HIV-negative men in these communities.⁴³

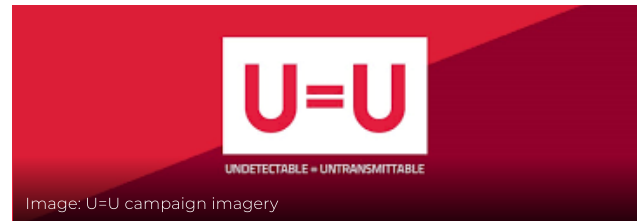


Image: U=U campaign imagery

Here too, we see a focus on delivery style. A brief experimental intervention examining two approaches found that evidence-based message framing of information about U=U was associated with lower levels of stigma towards PLHIV at post-intervention compared to opinion-based message framing.⁸⁶

2. Creating connections with affected groups

Another approach to reducing expressed HIV stigma involves facilitating contact with affected groups.⁷⁵ A well-known example of the approach in Australia are the *Positive Speakers Bureaux*, run by several PLHIV organisations. These programs literally provide a human face to HIV, as invited speakers about lived experience, to schools, workplaces, and so on. Campaigns that include personal testimonies – of PLHIV, and serodiscordant couples – also fit into this category, as they aim to reduce stigma by building empathy with specific individuals and with PLHIV as a marginalised group.

Broady and colleagues tested a stigma intervention (a short video depicting lived experiences of PLHIV) among the general public. Participants reported a decrease in negative attitudes immediately after watching the video. At three-month follow-up, there were also demonstrated improvements in relation to ‘personal distance’.⁸⁷ An earlier review that included evaluations of interventions that provided participants with opportunities for direct contact with PLHIV, also found that such interventions produced an effect both in terms of increasing participants’ knowledge and in improving attitudes towards PLHIV.⁸⁸ The effectiveness in improving attitudes toward PLHIV was significantly higher in stigma reduction programs with multiple sessions, suggesting that brief or one-off interventions may be of limited value and/or their effectiveness will not be durable.

The Fear Less, Live More campaign⁸⁹ included messaging that challenged (especially younger) HIV-negative gay men’s assumptions: 1) that they don’t know any PLHIV; and 2) that it’s possible to recognise a person living with HIV. In this way, it aimed to create empathy with PLHIV among its target audience.

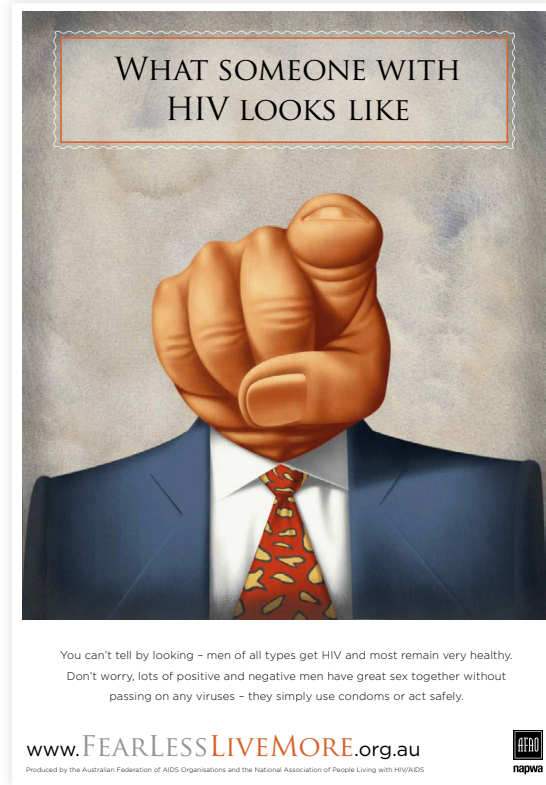


Image: Campaign poster from AFAO’s *Fear Less Live More* campaign

The *#Smashstigma* intervention described in the previous section also comprised elements that aimed to build connections, or empathy, with PLHIV. In 2020, responding to findings that over 60 million North Americans would prefer to see their favourite television character die than be diagnosed with HIV, two iconic sitcoms, *Friends* and *The Office*, were rewritten to include an HIV-positive lead character. The aim of revising these scripts was to demonstrate the stigma experienced by PLHIV.⁷⁹ Scenes included experiences of these characters disclosing their HIV status in the workplace and in social settings.

Alongside the two TV show episodes were [six short documentaries](#) of people living with HIV talking about their experience with stigma amongst family and friends.

Among those who viewed the episodes, 88% reported feeling greater empathy for PLHIV afterwards.



Image: Campaign banner for the docuseries *Untold Stories of Stigma* as part of Casey House's *#smashstigma* campaign

3. Improving language and communication

Another approach to reducing HIV stigma involves attentiveness to language and framing. These interventions are usually explicit in their aims. An example is the *HIV Media Guide*, which aims to provide journalists with tools to ensure that media reports on HIV in Australia are accurate and sensitive.⁹⁰ The guide includes tips for best practice, particularly in relation to language use and medical information, as well as principles for reporting on HIV, and suggestions how to approach common news stories.

Language attentiveness can also be applied to specific contexts, for example, hook up apps or casual sex encounters in general. Examples of this approach are included within some elements of the *Fear Less, Live More* campaign, and the *It's Time to Think Positive* campaign (discussed more in the next section). They ask the audience to consider the impact of language related to HIV status and disclosure when negotiating hook ups. They also encourage gay men to reflect on the language used, especially when rejecting a potential sexual partner based on HIV status and how this might impact on willingness to reveal HIV status in the future.

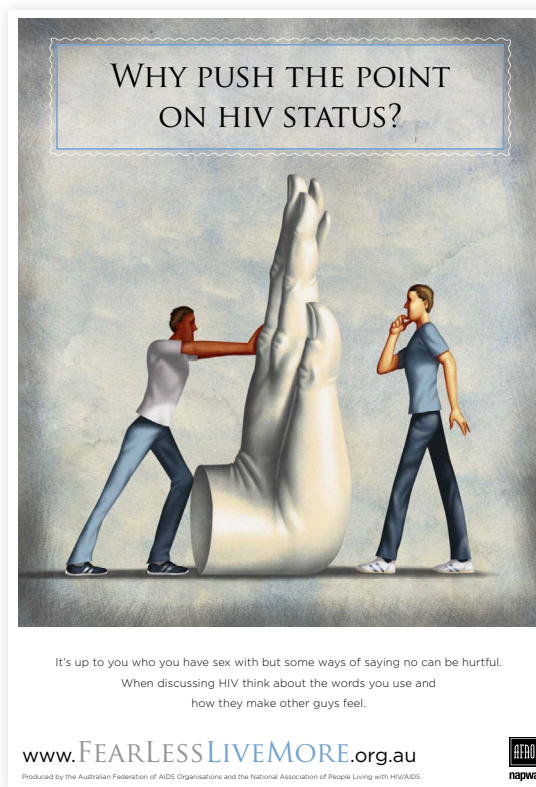


Image: Campaign poster from AFAO's *Fear Less Live More* campaign

4. Promoting alliances (i.e. Allyship)

Being an ally refers to the conscious decision to support and advocate for the interests of marginalised groups.⁷⁷ Allyship is typically undertaken by individuals, but can also be promoted by groups, services, organisations, and institutions. An example of an ally-focused intervention in the HIV sphere is the 2021 campaign, *It's Time to Think Positive*.⁹¹ The campaign aims to provide a blueprint for people in the community to support people who are living with HIV. It acknowledges that changes in behaviour are fundamental to addressing HIV stigma. The campaign focuses on four different areas in which allyship could be expressed: sexual encounters; relationships; friendships; and family.



Images: ACON's campaign *It's time to Think Positive*.

It is the context of (potential) sexual encounters that this ally-building campaign is arguably the most innovative. Focusing in particular on gay, bisexual and queer-identifying men using hook-up apps, it encourages users to reflect on the language they use when constructing their profiles, and when communicating with potential partners. It encourages consideration of how language can exacerbate stigma and shame, and asks users, for example, to reflect on how someone with HIV might feel when they see a profile that insists partners are “clean”.

Interestingly, it also addresses the terminologies used to discuss HIV prevention. Specifically, it asks users to consider how a question commonly asked in exchanges on apps i.e. “*Are you on PrEP?*”, may be experienced by someone living with HIV, and suggests asking instead, “*What are your HIV prevention strategies?*”, which is more neutral and helps facilitate a more open dialogue. The campaign therefore clearly comprises approaches other than allyship, in particular, *Increasing knowledge and awareness, and Improving language and communication*.

Another example of an allies approach is the CDC's *Let's Stop HIV Together* campaign, which encourages people to publicly pledge to support PLHIV on a general level – as family member, partner, or work colleague.⁹² It includes *Stop HIV Stigma* pledge cards, which commit people to promoting awareness, understanding, and acceptance of people with HIV, and also provides tips on how to be a good ally in different contexts. It is intended that positive attitudes will diffuse throughout the community via people recognising their own attitudes and perceptions as a result of allies' pledges.

As noted by Chambers et al.'s review, many stigma-reduction strategies require the support of others affected by HIV: friends, families, partners, communities, and advocates within health care environments.² Stigma management is therefore a collective and communal project.

5. Building resilience (and other strengths-based approaches)

Another approach to HIV stigma reduction involves resilience building and other strengths-based approaches. Strategies that fall within this category seek to work on changing the deeply held negative core beliefs that underly HIV-related internalised stigma. Some approaches that fall within this category also seek to ameliorate stigma experienced by PLHIV by building the skills and capacity to identify expressed – and structural – stigma, and to advocate for policy and other change (for example in the delivery of health services).

Community-based, HIV peer-support activities – intensive workshop-style programs, peer navigation programs, and one-on-one peer support or counselling – fit within this approach. As noted in NAPWHA's stigma and resilience framework, the aspirational qualities of these programs or interventions is to build confidence, to develop skills in disclosing in sexual and social contexts, and to share personal experiences with others. Research findings suggest that such interventions are likely to be effective. Numerous studies have found that social support is associated with lower levels of internalised stigma.^{24,26,93,94}

Other types of structured intervention have also been found to be effective in reducing internalised stigma. *iENGAGE*, an individually tailored four-session intervention to improve information, motivation, and behavioural skills to promote treatment adherence and viral suppression, was found to reduce internalised HIV stigma among new-to-HIV care individuals in the United States.⁹⁵ Another intervention, *Healthy Choices*, which used Motivational Enhancement Therapy – an adaptation of Motivational Interviewing – was also found to reduce self-stigma among young PLHIV.⁹⁶ However, an earlier review of 23 intervention studies reported more mixed results, with only fifteen studies reporting a positive effect in reducing self-stigma.⁹⁷

Resilience approaches are also used in campaigns targeting PLHIV. An example is the *Fear Less, Live More* campaign from AFAO, which was developed in response to findings mentioned earlier about sexual exclusion based on HIV status among gay men in Australia.⁸ One particular component of this campaign sought to increase resilience among PLHIV by enhancing coping responses to rejection by potential sex partners as a result of revealing their positive HIV status. As noted in research among gay men living with HIV, self-compassion can moderate the association of HIV-stigma on mental health outcomes, and compassion-focused practices should be explored as a means of increasing resilience in this group.⁵⁶ The campaign was focused on reducing internalised stigma, however, arguably could have done more to challenge some of the negative core beliefs associated with internalised stigma, and to address anticipated and perceived stigma

The ENUF program (2012–2017) is an Australian example of using a resilience – or strengths-based approach – to reduce HIV stigma. (Although it could be argued that ENUF also draws on other approaches – notably, allyship and advocacy – it is included in this category because the campaign's developers argue it is explicitly targeting PLHIV.) To that end, it is relatively demanding, in the sense that it invites PLHIV to pledge to challenge HIV stigma whenever and wherever they see it. ENUF was a multi-faceted program that in addition to the pledge, comprised an ambassadorship component, community arts and cultural engagement, and a peer-led anti-stigma campaign. Its evaluation suggests effectiveness in reducing internalised, anticipated, and perceived stigma, in its finding that

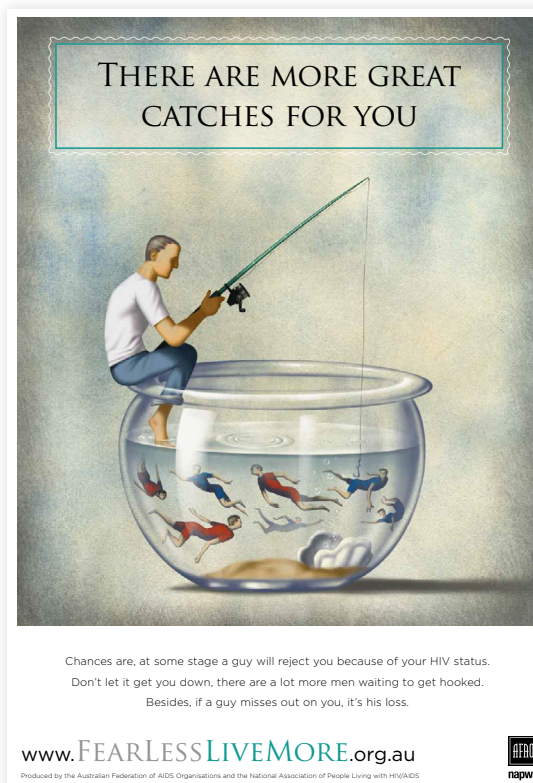


Image: Campaign poster from AFAO's *Fear Less Live More* campaign

some PLHIV reported the campaign had changed the way they think about themselves and the way they think about disclosure.⁹⁸ Another analysis also found the campaign was successful in highlighting PLHIV *experiences* of stigma.⁹⁹ However, the same analysis suggested the campaign did not necessarily provide long-term strategic direction on *how* to fight stigma.

A cognitive behavioural therapy group intervention for HIV-positive Latinx sexual minority men in the US attempted to improve coping with intersectional stigma, as well as improve antiretroviral treatment adherence and decrease medical mistrust.¹⁰⁰ Evaluation of this eight-session intervention, *Siempre Seguiré*, found it improved treatment adherence and significantly lowered medical mistrust. In terms of outcomes related to coping strategies in response to intersectional stigma, the intervention had an effect in only one area, which was a marginal reduction in negative religious coping beliefs (i.e. underlying spiritual tensions/internal struggles).



Images: Living Positive Victoria's anti-stigma campaign 'ENUF' 2012-2018

There have, however, been criticisms of 'resilience' approaches. These critiques point out that resilience approaches are primarily concerned with the personal skills and coping strategies of individuals, and fail to sufficiently problematise deficit discourse because they remain informed by concepts of individual responsibility.¹⁰¹ They therefore view internalised HIV stigma as largely "occurring in a cognitive and psychological vacuum" and focus on individual-level factors such as self-esteem and cognition rather than social and structural factors.¹⁰²

Critiques of research on intersectional stigma note that work in this area is often deficit focused, ignoring empowerment and resistance, which are important aspects of intersectional politics.^{48,103} Recent research has therefore also explored the concept of 'intersectional resilience', which is based on the idea that people with multiple marginalised statuses possess unique strengths that may confer protective effects.⁴⁸

The socio-ecological model, however, conceptualises stigma-reduction interventions as needing to operate on three levels.^{76,78,104} In addition to individual-level interventions (above) are interpersonal level interventions (focused on dyadic or small group interactions), and, structural level interventions (focused on the socio-political environment).

As noted earlier, the U=U campaign aims to transform the lives of PLHIV by reducing shame and the fear of sexual transmission to their partners. A recent study from the Netherlands suggests effectiveness in this regard.¹³ U=U contributed to PLHIV having better self-image and reducing self-stigma as a result of accepting that they were not infectious. Importantly, the study also found that, for participants, U=U made explaining HIV to others easier and therefore they were also more likely to be open about their HIV status.

6. Improving systems, standards, and guidelines

This approach is primarily related to service provision. It is based on the logic that appropriate systems, standards and guidelines can significantly reduce the impact of stigma that PLHIV – and people affected by other blood-borne viruses and STIs – encounter in healthcare and other service-provision settings, and that reducing stigma is a key issue in improving quality of health care. National and state HIV strategies include an emphasis on providing systems within healthcare settings in order to achieve safe, equitable and quality care.

A related example is the renewed emphasis on universal precautions in health care settings. Treloar et al. argue that a universal-precautions approach to reducing stigma – which draws on health system principles of equity, access and quality of care – can improve outcomes for individuals and for population health.¹⁰⁵ They posit that a universal-precautions approach provides a unifying logic that prioritises stigma-reduction within health systems by focusing on policies and processes that highlight equity, access, and health care quality. This approach emphasises the delivery of health care in a non-judgemental and respectful way, which in turn “enhances the health and well-being of individuals as well as delivering benefit to society at large”.

A recent mapping of HIV-related stigma-reduction activities undertaken by HIV prevention and/or treatment services organisations in New York City found that the greatest facilitators of stigma reduction included integrating health services, as well as staff training, and hiring staff who represent the communities from which clients are drawn.¹⁰⁶ This analysis found, however, that intersectional framings were lacking and that intersectionality was mainly thought of by staff through the lens of service integration, with a particular focus on integrating HIV clinical services with mental health and substance use services. Also, there were few examples of interventions to address the convergence of racism and HIV stigma.¹⁰⁶

7. Advocating for structural reform

Advocacy and law reform approaches to tackling stigma and discrimination consist of organised efforts to change the social and political arrangements that produce stigma.⁷⁷ Advocacy and law reform approaches differ from individual and service-level approaches in the sense that their scope is much broader. Examples of efforts to address HIV stigma and discrimination at this level include campaigns to change laws related to compulsory disclosure of HIV status to potential sexual partners. In the area of healthcare, advocacy approaches seek to change laws and policies that are not necessarily directly related to service provision but nevertheless shape patients’ experience of and access to healthcare.⁷⁷ A recent review of stigma and its implications for HIV services design and delivery found that although people situated at intersections of marginalised identities face multiple injustices, few intersectional approaches have been focused at the level of structural change.¹⁰⁷

As noted by Brown et al.,¹⁰⁸ a systems perspective can be used as a basis for designing structural stigma interventions, as well as promoting leadership by PLHIV. However, advocacy for change can also occur in other areas and at other levels. Green’s analysis of Grindr users’ resistance to the demands of that platform’s digital architecture is a case in point. Based on a pre-TasP understanding of risk, Green argues that “Grindr’s design relies on a long-held prioritisation of HIV disclosure in public health initiatives”.¹⁰⁹ Nondisclosure is therefore “*an intentional rhetorical practice, one informed by situated and contextual understanding of risk among those living with HIV*”. As Tyler & Slater note, analysing stigma comprehensively obliges us to investigate where stigma is produced and who benefits.²¹ In this instance, Grindr’s design “insulates users from acknowledging that their seemingly individual sexual preferences actually reflect deeply embedded systemic relations of power”.^{109,110}

FINDINGS FROM OTHER FIELDS

Reviews of stigma-reduction interventions in other fields reveal a predominant focus on the *stigmatised* rather than the *stigmatisers*, similar to that noted earlier.⁴⁹ Many of these reviews come from the field of mental health, which have shown reductions in internalised stigma and coping.^{111,113} Drawing on interventions to specifically reduce shame (i.e. internalised stigma) related to a variety of issues ranging from drug consumption to eating disorders, Goffnett et al.'s review found the majority resulted in reductions in shame immediately after the intervention, although only about a quarter reported sustained reductions over time.¹¹³ The most common intervention types were based on Cognitive Behavioural Therapy and mindfulness approaches. In what may be of interest for readers from the HIV field, Burke et al.'s review found that peer-facilitated group interventions resulted in significant (albeit small) improvements in empowerment and self-efficacy, however evidence of any positive effect was inconclusive for one-on-one peer support.¹¹²

Another review from the mental health field suggests that interventions drawing on knowledge-attitudes-behaviour practice (KABP) approaches – often also including social-contact aspects – have only limited effectiveness.¹¹⁴ In addition, anti-stigma interventions in this area have little or no long-term effects, and may in fact have unintended consequences, including the continuation of “othering” practices that differentiate individuals with experiences of mental illness from the general public.

MEASURING HIV-RELATED STIGMA

This final section addresses the way in which HIV-related stigma is measured. It is included in this paper because it provides an overview of some of the most commonly used tools, as well as some of the issues related to measuring stigma and its sub-domains. Previous reviews of the measures used in research of HIV-related stigma have drawn attention to the wide assortment of stigma measures and instruments.^{115,116} This variety reflects: 1) the multiple processes involved in stigmatisation; 2) the different contexts in which stigmatisation occurs, including the different actors involved; and 3) differences in the origins and the ways stigma is expressed and experienced. It is therefore important to ensure that when evaluating interventions, their impact and effectiveness is measured according to the specific dimensions of stigma that they seek to address. However, this focus on specificity needs to be weighed up against the need for practicality, and therefore measures that can be used in different communities and contexts may enable comparisons of perceptions, experiences, attitudes, and practices.

An important distinction is whether stigma measures are designed for PLHIV, or for people who may be potential stigmatisers, for example, the general public. Within the set of measures that target each of these populations, further distinctions can be made. Regarding stigma measures for PLHIV, reviews have noted that assessments of perceived/felt, experienced/enacted, or internalised stigma are common.^{115,116} Numerous studies have been conducted to develop, validate, and culturally adapt scales to measure stigma as perceived, experienced, and internalised by PLHIV.^{116,117-119}

Experienced HIV stigma has commonly been measured by the HIV Stigma Scale,¹¹⁷ which is a 40-item scale comprising four subdomains: 1) personalised stigma; 2) disclosure concerns; 3) concerns about public attitudes; and 4) negative self-image.

Shorter versions of the scale exist, and recently a 12-item short version of the HIV Stigma Scale has been developed. It has been found to be less sensitive compared to the full-length scale, however may be used when a shorter instrument, is needed.¹²⁰ It contains all the four subdomains of the original scale.

Specifically regarding negative-self-image (or core beliefs) component, a seven-item version has been developed.¹²¹

- *Having HIV/AIDS makes me feel that I'm a bad person.*
- *I feel I'm not as good as others because I have HIV/AIDS.*
- *Having HIV/AIDS makes me feel unclean.*
- *Having HIV/AIDS is disgusting to me.*
- *People's attitudes about HIV/AIDS make me feel worse about myself.*
- *I feel guilty because I have HIV/AIDS.*
- *I never feel ashamed of having HIV/AIDS.*

Also for measuring internalised HIV stigma is another scale, called the Internalised AIDS-Related Stigma Scale (IA-RSS),¹²² a six-item measure (e.g. *"I am ashamed that I am HIV positive"*). Other items have sometimes been added, for example an additional item measuring self-blame in a recent Australian study (*"It is my own fault that I have HIV"*).²⁴

Regarding potential stigmatisers, measures cover attitudes towards PLHIV and social distancing practices,¹¹⁶ as well as indicators of discriminatory practices, services, and legislation.¹¹⁵ Measures of HIV-related stigma for non-PLHIV have traditionally not been directly comparable to measures of stigma perceived or experienced by PLHIV.¹²³ This lack of comparative measures of HIV-related stigma for PLHIV and non-PLHIV has led to an inability to compare perspectives as well as to explore the extent of social desirability bias in self-reported stigma and discrimination by non-PLHIV. This lack of comparable instruments has also been noted by others. Visser et al. adapted an existing instrument to develop parallel scales of personal stigma, stigma attributed to others and internalised stigma.¹²⁴

As noted, there is a surprising lack of HIV stigma research among GBQ+ men, and in particular, HIV stigma among HIV-negative men. One study sought to measure anticipated stigma among HIV-negative gay men i.e. negative personal and interpersonal consequences if they were to contract HIV in the future.¹²⁵ In the 16-item scale, ten were adapted from the HIV Stigma Scale for use with HIV-negative men (from the negative self-image and disclosure concerns components), and the six additional items were developed to tap further into potential forms of stigma that one might anticipate with regard to HIV, especially related to internalised stigma and perceptions of others' stigmatising practices, including changes in interpersonal relationships that might result from HIV infection.

A scale developed in Australia, sought to develop parallel scales of experienced and expressed HIV-related stigma among gay men.⁸ It includes the critical components of stigma that recur across other scales, and allow for a relatively brief measure of HIV-related stigma in general (i.e., not pertaining to issues specific to particular individuals/communities): 1) blame and judgment; 2) social distancing; and 3) negative emotions.^{6,7} Items were derived from previous research and existing scales.^{3,117,122,124,126-129} The final scale(s) included 19 items, covering four separate components: 1) attributions of responsibility (e.g. *"HIV-negative people that I know think I got what I deserved/HIV-positive people got what they deserve"*) (six items); 2) social distancing (e.g. *"They are careful not to touch me/I am careful not to touch them"*) (seven items); 3) negative emotional reactions (e.g. *"To what extent have you experienced [anger] from HIV-negative people in relation to you being HIV positive?/To what extent do you experience [anger] when interacting with HIV-positive people?"*) (four items); and 4) exclusion of PLHIV as sexual and/or romantic partners (e.g. *"They refuse to have sex with me/I refuse to have sex with them"*) (two items).

Regarding intersectional stigma, the Intersectional Discrimination Index (InDI) has been found to be a valid and reliable tool – when used in combination with sociodemographic information – in examining the role of discrimination as a mediator of health inequalities.¹³⁰ It is not specific to HIV, however. Recently, Kalichman et al. attempted to develop a new tool for measuring experienced intersectional stigma, based on a literal approach, whereby self-rated experiences of stigma based attributes including gender, race, sexual orientation, and HIV status can be recorded on independent scales to calculate their intersection.¹³¹ A recent review also found measurement of HIV-related intersectional stigma and discrimination focuses primarily on the intersection of two identities – race and gender – as well as being conducted mostly in high-income countries.¹³²

SUMMARY

This paper sought to provide a framework for the developers of interventions in the area of HIV-related stigma to consider how to develop and evaluate these activities. Although the introduction and background of the paper provided an extensive description of stigma – as well as its origins and mechanisms – the approaches and examples of HIV-related stigma interventions provided were organised empirically rather than theoretically, with the intention of making them more accessible for the intended readership (and to provide examples of actual interventions).

The analysis identified seven approaches pursued in HIV-related stigma interventions: 1) increasing knowledge and awareness; 2) creating connections with affected groups; 3) improving language and communication; 4) promoting alliances; 5) building resilience (and other strengths-based approaches); 6) improving systems, standards, and guidelines; and 7) advocating for structural reform. Developers of interventions should therefore consider what they are seeking to achieve when they design a stigma activity.

Similarly, when developing interventions, it is necessary to consider the socio-ecological level being targeted. These levels can be referred to as: individual; interpersonal; organisational; community; and public policy.⁷⁶ Developers of stigma interventions should also consider the domain they are seeking to act on. Is it: 1) drivers (e.g. fear, prejudice, stereotypes)^{76,133}; 2) facilitators (e.g. punitive laws, or cultural and gender norms)⁷⁶; or 3) manifestations (e.g. attitudes, or agreement with discriminatory statements).⁷⁶

This paper has also drawn attention to the diversity of tools for measuring HIV-related stigma. It is important that appropriate measures are used to evaluate interventions – including calibration of the measures to match the *approach*, the *domain*, and the *level* at which the activity or program is seeking to intervene. Although the paper has focused on quantitative measures, it is important to note that data may be collected in a number of different ways, for example through qualitative methods (e.g., in-depth interviews, focus group discussions, questionnaires) and by using protocols to collate indicators.¹¹⁵

Finally, there is a need to consider the impact of stigma interventions on the health and well-being of PLHIV. As noted by Stangl et al.,⁷⁶ few studies have investigated whether HIV stigma interventions have had an impact on HIV-related health outcomes. While it may be difficult to measure and/or attribute such outcomes to specific interventions, it is an important consideration in designing activities and programs.

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