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Bringing sexy back into gay men's community empowerment for HIV prevention, care and support: The Poz & Proud approach

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## Bringing sexy back into gay men's community empowerment for HIV prevention, care and support: The Poz & Proud Approach

Leo Schenk and Gurmit Singh

### Abstract

*The fact that HIV prevention initiatives are likely to fail without the involvement of communities of people living with and affected by HIV is well known. Internationally, there are a variety of intervention programs designed to address this problem with a wide range of outcomes. Frequently, sustainable approaches are hampered by entrenched stigma and discrimination towards people living with HIV. This paper describes Poz&Proud in the Netherlands, a continuous community empowerment initiative that exemplifies how gay men living with HIV addressed this problem. It outlines the project context, rationale and design, and examines how Poz&Proud used the Internet to support real-time events to overcome the stigma and discrimination that prevented their community from enjoying and accessing rights to sexual, mental health and emotional well being. We argue that new digitally supported approaches, like Poz&Proud, can challenge the entrenched stigma and discrimination facing communities of people living with and affected by HIV. This is because Poz&Proud's approach connects with the lived realities of people living with and affected by HIV through ongoing, inclusive and relevant activities and events. Poz&Proud provides a replicable model by which other sexual minority and vulnerable communities can more effectively contribute to the public health goals of HIV prevention and care over current community mobilisation approaches more frequently reported on in the literature.*

**Keywords:** access to sexual health and rights, behaviour and social change, digital culture, gay community empowerment, HIV prevention, stigma and discrimination, structural interventions.

### The need to challenge negative perceptions of gay men living with HIV

The lives of millions of people around the world infected with HIV have improved with the advent of anti-retroviral treatment (ART) (Kippax, et al., 2007; Liu et al., 2006). However, social stigma (Goffman, 1963) persists in fuelling negative perceptions that perpetuate violence and homophobia towards gay men, other men who have sex with men (MSM), and transgender people living with HIV worldwide (MSMGF, 2010). One of the biggest failures of dominant public health-led community empowerment approaches to HIV prevention and care is that pervasive negative perceptions of the rights of gay men living with HIV still persist among themselves, in clinics, in the gay community and in the larger society. Condom usage remains the preferred prevention method after 30 years of the epidemic. Except for the work of AIDES in France or the Terence Higgins Trust in the UK, alternative risk reduction strategies are sparse. The negative images of people living with HIV as 'unhealthy, contagious, sexually deviant and addicted minority other' (Crawford, 1994:1347), are used to bolster arguments for

criminalisation and to create moral panics of HIV infection and spread. The media often implicitly and explicitly fuels these negative perceptions and discourses. Examples include HIV prevention campaigns such as those in French (Figure 1) and German public health adverts (Figure 2). By using fear-mongering and creating climates of anxiety, such approaches paradoxically reduce the impact of public health approaches to HIV prevention and care in vulnerable communities because they persist in blaming people living with HIV as responsible for the epidemic, and irresponsible for refusing to curb their desires for pleasure. Poz&Proud challenges the negative stigma often fuelled by the media and groups whose intentions are inherently good—to educate people about the risks of HIV—but often reinforce negative perceptions about gay men living with HIV.



Figure 1. Example of [AIDES HIV prevention public health campaign](#) in France

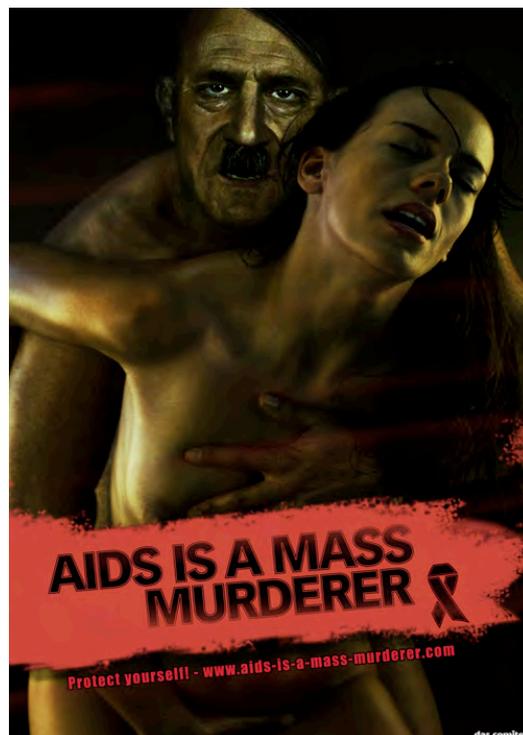


Figure 2. Example of [HIV prevention public health campaign](#) in Germany

## Conceptual Framework

### *Lack of effective approaches to HIV prevention for communities of people living with and affected by HIV*

Public health practitioners using biomedical and behavioural approaches currently lack clear guidance on the structural interventions (Altman, 2005; Auerbach, et al., 2010; Gupta, et al., 2008) now deemed necessary for sustainable and equitable access to HIV prevention and care in vulnerable communities, especially those living with and affected by HIV (UNAIDS, 2007).

In communities of gay men and other men who have sex with men (MSM), ‘rights-based approaches’ have been advocated (MSMGF, 2010). However, the diversity of perspectives on rights-based approaches (Chopra & Ford, 2005; London, 2008; Patterson & London, 2002) to HIV prevention and health improvement makes public health bureaucrats reluctant to engage in socio-political efforts needed to battle stigma and discrimination. One reason for this reluctance is the persistent dominance of the ‘evidence-based medicine’ culture in which public health bureaucrats conduct their research, design and delivery of HIV and AIDS interventions. In this clash of paradigms where opportunities for interdisciplinary collaboration with social sciences researchers are lacking (Kippax & Holt 2009), rights-based approaches sit uncomfortably, resulting in narrowly defined concepts of empowerment (Campbell & Cornish, 2010).

Community mobilisation is argued to be the most important success factor in tackling the wider social context needed to make a difference to HIV prevention and care interventions. Campbell and Cornish (2010) conceptualise this as the ‘4th generation of approaches’ to community mobilisation. They define effective community mobilisation as altering the limiting social, symbolic and material relations with the wider social context to affect the outcomes of behaviour change. This definition augments evidence from years of work highlighting the benefits of community mobilisation of people living with and affected by HIV, as partners and initiators of socio-behavioural research and empowerment efforts (Spire et al., 2008).

However, in the context of communities of gay men living with HIV in European countries, existing approaches to community mobilisation can fail because it is not easy to get a an analytic grip on the ‘community’ that is to be mobilised through participation for impact. This is particularly so when the community is not one homogenous whole, but a set of competing networks with contested interests, norms, and values. Ideologies of community empowerment to fight HIV are further challenged by the globalised political economy of health and social care (Altman, 1994, 1999). Contextualising the notion of community to today’s society, the sociologist Bauman argues instead, “communities - more *postulated* than ‘imagined’ - may be only ephemeral artifacts of the ongoing individuality play, rather than the identities’ determining and defining forces” (2000, p.22; emphasis in original).

Often, community mobilisation approaches also do not work because community participation through public health interventions is usually about control rather than empowerment (Rifkin, 2001, Pinell 2002). For example, public health professionals who create the opportunities for involving communities are regulated by a different set of values, concerns and discourses, which are a set of constraints completely outside their own control that can challenge ideals of actual ‘participation’. As a result of these constraints, these approaches do not always generate effective mechanisms to sustain the political will (Spire, 2010) required to mobilise communities living with and affected by HIV to challenge entrenched stigma and discrimination. Effective mechanisms to challenge stigma and discrimination need to consider how to increase the agency of

communities living with and affected by HIV. This includes the freedom to decide on their own thoughts and actions, and how to overcome the constraints of their social and political contexts so as to transform the hegemonic structures that entrench stigma and discrimination and reduce access to HIV prevention, treatment, care and support (Altman, 1994, Ogden et al., 2011).

A significant current challenge to effective HIV prevention approaches is how to confront the commercial interests entering the public health field through exploiting the relationship between sexual practices and technology (Davis, 2011). One example can be seen in the rise of online partner notification services to know the sexual health status of others. Sites like [safesexpassport.com](http://safesexpassport.com) offer services that compile the results of tests for sexually transmitted infections (Davis, 2011), while sites like [inSPOT](http://inSPOT) offer e-cards to inform partners. The rise of these Internet-based commercial and non-profit approaches to self-sexual regulation increases the reflexive identity management (Elford et al., 2010) of gay men and MSM living with HIV. These digital mediated practices challenge the causal relationship between community mobilisation and behaviour change to realise public health HIV prevention goals in existing biomedical and social behavioural approaches.

Another challenge is the fatigue from HIV prevention and safe sex messages among high-risk groups in the post-ART era (Rowniak, 2009; Stockman et al., 2004). Such fatigue, mostly caused by years of promoting the static public health 'always use a condom' mantra, without critically considering alternative risk reduction strategies or the actions needed to reduce vulnerability to HIV transmission in the broader social environment, has led to a change in attitudes towards prevention messages, changed sexual practices and increased risk-taking behaviour. These changes present challenges to designing HIV prevention that assume behaviour can be changed without looking at how sexual behaviour is intersubjectively and structurally produced and mediated by dynamic social practices in online networks in particular time and place (Kippax, et al., 2008; Bourdieu, 1987).

HIV prevention intervention designs relying on rational behaviour change approaches are further problematised by 21st century post-modern conceptions of reality. These have been variously depicted as consumer-driven, hyper-capitalist, individualised societies (Giddens, 1993), or the 'liquid modernity' (Bauman, 2000) of 'networked sociality' (Wittel, 2001). These post-modern realities have disrupted the nature and pattern of social organisation, identified as one of the major emerging issues in HIV social sciences research (Friedman, et al., 2006). This disruption is marked by the proliferation of access to information, opinion and support online, increasingly shifting and malleable social connections and interactions, more uncertainty in knowing how to assess the worth of knowledge online, and the increasing opportunity, desire and ease of performing multiple identities across various global and virtual social settings. These shifts have changed the ways in which people socially relate to one another and to public health and education discourses. Confronting these complex post-modern realities now requires rethinking the dominant epistemology and ontology on the nature of the social self and the causes of change to design effective interventions that mobilise community groups for HIV prevention approaches for critical impact (Walsh & Singh, 2012).

#### *Stigma and discrimination towards gay men living with HIV*

Social stigma leads to gay men living with HIV facing rejection and fearing to openly disclose their status to family, friends, colleagues and sexual partners (Stutterheim, et al., 2009). Stigma and discrimination also pushes gay men living with HIV underground, reducing the effectiveness of efforts to involve them. Stigma and discrimination further

contribute to poorer mental health and emotional well being among some gay men and MSM (MSMGF, 2010). These include “elevated risk of self-harm, suicidal thoughts, risky sexual practices and excessive substance use” (MSMGF 2010, p.3). Stigma accelerates the spread of HIV. In several parts of the world, the fear of stigma and discrimination is associated with a barrier to beginning ART, lower uptake of HIV testing, less willingness to disclose test results (Pulerwitz, et al., 2008; Spire, 2010), an increase in the spread of HIV (Peretti-Watel, et al., 2007), increased vulnerability (Israel, et al., 2008; Parker & Aggleton, 2003), and ultimately a negative impact on the sexual health of gay men living with HIV.

Stigma and discrimination cannot be addressed by biomedical and behavioural approaches to HIV prevention alone. Effective approaches to fighting stigma and discrimination require a human rights based approach, coupled with legal reform, to challenge laws and policies and tackle unequal access to social and healthcare services (MSMGF 2010). Given these challenges, approaches like Poz&Proud, explored below, are needed to identify unique models for community mobilisation that can contribute to developing the evidence-base on effective approaches that reflexively disrupt the daily stigma and discrimination faced by gay men living with HIV.

#### *The Internet as a challenge to community mobilisation*

Sexual and social networks are clearly central to the quality of lives of people living with and affected by HIV in the digital age. Yet they have been effectively silenced in building better theories of digitally-driven, community empowerment for HIV prevention because of the idealisation of the static ‘community’ metaphor as the locus of efforts. With the rise of global sex (Altman, 2002) in an increasingly fragmented networked social reality (Castells, 1996; Dijk, 1991; Wellman, 2001), gay men today, particularly in the West, live in dense, dissonant, divided and distributed computer-mediated sexual networks (Morris, 1997). Despite being a valued source of social capital, resilience, and capacities that can be mobilised for empowerment (Bourdieu & Johnson, 1993; Coleman, 1988), these ‘hidden’ networks are more likely to be targets to be monitored for surveillance by epidemiological researchers (Doherty, et al., 2005; Jolly, et al., 2001; Rothenberg et al., 1998), the ‘community’, and for marketing by commercial Internet providers and the media. Overall, this inexorable rise of Internet mediated social practices in sexual and social networks has become a challenge to traditional face-to-face and online information dissemination approaches to gay and MSM community mobilisation for HIV prevention.

#### *Call for new approaches*

The [aids2031 Consortium](#) initiated by UNAIDS in 2007 (aids2031 Consortium 2011) has argued that to tackle the social and political obstacles to successful HIV prevention, HIV practitioners now need “new strategic approaches for interventions that will effectively decrease vulnerabilities and create AIDS-resilient communities and health enabling environments.” (Fisher & Thomas-Slayter, 2009, p.7)

The project described here—Poz&Proud—represents a modest attempt to do this. With our local constraints and limited resources, Poz&Proud is situated in a long history of the changes to HIV prevention and sexual health promotion approaches. As the epidemic progressed, research approaches enlarged to incorporate social and biomedical research (Imrie, et al., 2007; Kippax, 2008; Moatti & Souteyrand, 2000), to document the complex ways to mobilise communities (Campbell & Cornish, 2010; Spire, et al., 2008) and to interrogate stigma and discrimination against gay men, other MSM, and people living with HIV (Beyrer, 2010; Herbst et al., 2005; Kidd & Clay, 2007). Other emerging trends in this trajectory include understanding the social practices that can

drive HIV risk (Adimora & Auerbach, 2010; Kippax, 2008), the impact of the use of the Internet on the sexual practices of gay men (Bolding, et al., 2005, 2007; Liao, Millett, & Marks, 2006) and for HIV prevention (Noar, Black, & Pierce, 2009).

The structural perspective Poz&Proud takes illustrates an emerging, and now well-established, attempt by a networked community of gay men living with HIV to get beyond the limited impact of existing biomedical and social sciences approaches in transforming social structures to fight stigma and discrimination. This low impact has been primarily caused by the fact that existing rationalistic approaches to challenging stigma and discrimination can end-up reproducing the hegemonic power structures which perpetuate the control of vulnerable populations (Bourdieu & Johnson, 1993).

One example is the global rollout of [The People Living with HIV Stigma Index](#). This intervention is designed to collect evidence on stigma through interviews and questionnaires, and to empower people living with HIV to advocate and catalyse change in their society. Using language from the positivist philosophy of science that underpins rational approaches to research methodologies, such as sampling, rigour, and reliability, reducing stigma to a measurable index does not account for how to analytically reconstruct the wider social structures and discursive practices which influence individuals' perceptions and experiences of vulnerability and stigma (Ogden et al. 2011). This limited explanation ends up assuming that deploying research tools to gather and build an evidence-base on stigma will change the social structures that entrench stigma through advocacy. It sidelines critical discussions on what the sociopolitical constraints to producing long-term change after collecting and disseminating data on HIV-related stigma might be. We do not know what kind of mechanisms could overcome these constraints. We need to know about and discuss these mechanisms explicitly as researchers and practitioners to ensure community-based approaches generate change at the macro- and micro-levels of society dynamically. Macro-level change in turn requires critical dialogue and discussion on the pedagogies of involving communities as political agents. As a result of this silencing and the uncritical adoption of positivist and interpretive research paradigms, approaches such as the Stigma Index, while community-based and led by people living with HIV, are reproductive rather than transformative, and do not transform the material and symbolic conditions that produce and perpetuate stigma and discrimination.

This concerns Poz&Proud because we have witnessed how, over the last 30 years of the epidemic, community groups fighting HIV have become slowly essentialised and reduced to service and care delivery providers for mainstream HIV organisations and public health bodies. In the process, many have lost their historical political activism capacities to reclaim power over their lives due to the closure of public spaces, and to resist the economic colonisation of affected communities' health and human rights. Together, these exclusionary mechanisms impede the prospects for transformative approaches required to challenge stigma and discrimination. Our approach is thus a start in producing new structures and an intellectually coherent plan to secure the relative autonomy of the contested 'field' (Bourdieu, 1998, p.31) of community empowerment to improve HIV prevention, treatment and care outcomes for gay men living with and affected by HIV.

#### *The persistent problem of access*

Our specific concern is to solve the problem of inequitable access to HIV prevention and care among vulnerable populations such as gay men and other MSM, and gay men and other MSM living with HIV (Ayala, et al., 2010; amFAR, 2008). Internationally, epidemiological studies have provided evidence of higher HIV prevalence in gay men and other MSM populations when compared to the general population (Caceres et al.

2008; Smith et al., 2009) suggesting a persistent lack of access to care for gay men and other MSM. While the rates of new HIV infection among gay men and other MSM continue to rise (Baral et al., 2009; Le Vu et al., 2010) and the relationship between HIV and social stigma against gay men and other MSM living with HIV within the gay community is well documented (Smit et al. 2011), there is no clear evidence on the Internet as a contributory risk factor to HIV transmission (Bolding, et al., 2005). In particular, addressing the self-stigma of gay men and other MSM living with HIV requires specific intervention approaches that tackle the social stigma within the gay community and wider society, as Poz&Proud initiated.

#### *The potential value of social networks as a locus for HIV prevention*

This article reports on Poz&Proud, a community empowerment project where gay men living with HIV tackle—head-on—the persistence of stigma and discrimination. We first outline the context of the project, as this was fundamental to how we shifted our conceptualisation of the issue of HIV. We then illustrate how, as activists working with Web 2.0 social networking tools, we worked to overcome stigma and discrimination through research, education and advocacy. Our approach addresses wider challenges for the sexual and mental health of gay men living with HIV by building a sense of community and reflexively producing the virtual social and symbolic capital of this vulnerable population's diverse, dynamic and shifting sexual-social networks. Poz&Proud works to continuously disrupt the socio-political status quo of entrenched stigma and discrimination in the Netherlands by improving access to HIV prevention, care and support for a community of gay men living with and affected by HIV.

## **Context**

#### *An epidemiological snapshot of gay men living with HIV in the Netherlands*

In the Netherlands, HIV incidence in the gay population has varied between 1 and 2% for several years (Dukers et al., 2007). HIV incidence has climbed gradually following increases in risky sexual behaviour since 1996 (Jansen et al., 2011). However, a recent study (SHM, 2011) has shown that the number of new HIV diagnoses among gay men appears to be decreasing. This is likely due to a decrease in risky sexual behaviour and an increase in HIV-testing among gay men. Unlike in other West European countries where early testing was common in the first two decades of the epidemic, early testing was discouraged in the Netherlands until 2001. This was due to a lack of effective treatment regimes, and because of the fear of stigma (Mooij, 2004). Currently, two thirds of gay men report always using a condom when having sex, but there appears to be an increase in unprotected anal intercourse among young gay men and gay men living with HIV (Empelen, 2010). In Amsterdam, with its thriving gay scene, between 10 and 15% of sexually active gay men are living with HIV (Hospers et al., 2008).

#### *The issues of gay men living with HIV in the Netherlands*

Thanks to longer life expectancy with ART, the average age of people living with HIV has increased (Hogg et al., 2008). This demographic shift has brought with it newer challenges. These include ageing, and co-morbidities, such as Hepatitis C and anal cancer. Older gay men living with HIV can face misunderstandings, with care providers in senior citizens homes often unprepared for gay men, and gay men living with HIV (Smit & Brinkman, 2009).

The increase in HIV testing among gay men has resulted in a dichotomy in the Dutch gay scene—between those who are living with HIV, and those who are HIV negative or do not know their status. Research has shown that HIV-stigma now divides

and fragments gay communities (Smit et al., 2011). Gay men who do not know their status and HIV-negative gay men are reported to claim that those infected with HIV should always disclose their status before sex because they have a greater responsibility in preventing the spread of HIV to others (Hospers et al., 2009). Yet, a lot of gay men living with HIV do not disclose their status because of the fear of being rejected. The detrimental effects of stigma and discrimination on the daily lives of gay men living with HIV remain a gap in HIV prevention efforts (Moatti & Spire, 2008). Despite this, a focus on HIV and sexually transmitted infections (STI) continues to define public health conceptions of the health needs of gay men living with and affected by HIV risk in the Netherlands.

With the arrival of the Internet, sexual practices have become technology-mediated (Davis, et al., 2006). A wide range of Internet-based possibilities now allow gay men living with and affected by HIV to access sex easily, cheaply, privately and anonymously (Liau, et al., 2006). In addition, the rise of virtual communities and online support groups has allowed people living with HIV to form networks (Mo & Coulson, 2010) to “share experiences, ask questions, or provide emotional support and self help” (Eysenbach et al., 2004, p.1). In the Netherlands, an online survey in 2010 showed that the Internet was the most used source for gay men to find information on sexual health issues, medications, drug interactions, coping strategies, as well as for sex partners (Empelen, 2010).

#### *Serosorting among gay men living with HIV in the Netherlands*

Because it is easier to find sex on the Internet, and gay men with HIV are living longer thanks to ART, their sexual behaviours are changing (Parsons et al., 2005). One Internet-mediated practice that has become common is ‘serosorting’, that is men who have sex without condoms with someone of the same HIV status. On gay dating websites like gaydar.com and gayromeo.com, gay men can indicate their preference for safer sex, or their HIV status. While there is debate on the effectiveness of this strategy in reducing HIV risk (Suarez & Miller, 2001), or as a public health approach (Kippax & Race, 2003), it is on the rise (Elford, 2006), despite the increased risk of sexually transmitted infections (STIs). For gay men living with HIV however, knowledge of HIV status has always been a key prevention practice (Kippax & Race, 2003).

Gay men living with HIV who serosort continue to face stigma in society, among prevention workers, care providers, and in the gay scene. People ask if they have not learnt the lessons from the deaths the gay community has lived through. Yet, research suggests that the pressure to use condoms and have safe sex causes a ‘crisis of agency’ in gay men living with HIV placed under surveillance by regulatory discourses and practices to manage their risk, when risk taking is an intrinsic part of the gay identity (Davis, 2002). Consequently, their persistent stigmatisation as ‘deviants’ could be perceived as a discursive, cognitive and structurally reproductive strategy by a society that refuses to accept that people take risks and blames those who do, rather than confront the issues of how to reflexively manage risk.

Ethnographic research into ‘circuit parties’ among gay men also suggests an alternative framing of the issue of risky sexual practices (Westhaver, 2005). As a result of their longer life span due to ARTs, the traditional ‘fear of dying’ assumption used in public health condom promotion interventions does not appear to hold among gay men living with HIV. Instead, pleasure, intimacy, and a desire for social recognition among their own kind appear to be productive and resistant expressions of the agency of gay men living with HIV. Such thoughts and actions disrupt their negative framings as ‘immoral’ when not wanting to use condoms by the wider social and health discourses. Therefore, as a sociological phenomenon, serosorting could be re-perceived as a reflexive

operation to improve the mental health and well being of gay men living with HIV who must manage love and risk of disease in their daily lives (Adams, 2012).

We have outlined the context that we faced in designing our intervention. In what follows, we give some sense of the dedicated way gay men living with HIV confronted stigma and discrimination by designing new approaches using the Internet to connect with our lifeworlds. We analyze how we confronted stigma and made significant changes to our identities in a short period of time with the support of Web 2.0 tools to network and build community. Our concept is a 'sexy community empowerment' approach that reconnects marginalised and vulnerable communities with their rights, selves, community and society. It does this through strategic interactions done in real-time and online social practices that provide access to targeted information, opinion, advice and support. New practices combined with an increased access to valuable resources increase the capacity for agency of gay men living with HIV. These processes produce dynamic changes in behavioural patterns to improve health, and overcome entrenched stigma and discrimination, as their ultimate outcome.

## Poz&Proud

*"Ultimately, we are working for a gay community in which gay men with and without HIV infection can live together in solidarity."*

*(Poz&Proud Manifesto, 2006)*



Figure 3: ©Poz&Proud logo

In 2006, a group of gay activists living with HIV founded Poz&Proud to liberate gay men living with HIV from stigma, and to collaborate in taking control to improve the quality of their lives. Poz&Proud is a community-based organisation for and by gay men living with HIV in the Netherlands, based in Amsterdam and hosted under the patients support structure of the Dutch HIV Association (HVN). It is run entirely by volunteers and receives an annual budget of €12,000 from the HVN to organise activities for gay men living with HIV in the Netherlands. A core of six gay men living with HIV runs Poz&Proud. About twenty more gay men living with HIV help out with our various activities. It has no membership at the moment, but it regularly organises meetings for gay men living with HIV to provide input on existing and future projects and activities. It produces a monthly newsletter for nearly 400 subscribers as of January 2012, up from 20 in 2006. Approximately 40% of the gay men that regularly visit our activities reside in Amsterdam, while the rest live across the Netherlands. Among them are men who are recently diagnosed, and men who have been living with HIV for over ten or more years.

The vast majority of Poz&Proud's activities are held in Amsterdam. This is complemented by annual weekends in other parts of the country, as well as presentations to other HIV networks and groups around the country.

#### *Main activities*

With the motto 'If we don't do it, no one will' Poz&Proud has three main activities.

Firstly, we provide information on sexual health and political matters that affect gay men living with HIV such as co-infections, legal rights and the situation of gay men living with HIV in the Netherlands and around the world. Secondly, we initiate advocacy to ensure that the needs of gay men living with HIV are met by HIV and public health organisations. Thirdly, we organise social activities where gay men living with HIV can meet other gay men living with HIV to network, share experiences, and reduce their sense of isolation. Through these activities, Poz&Proud can be imagined as building a home. Inside, we provide a safe space for gay men living with HIV to understand and express their needs and rights so that they are empowered to stand up for their needs. Outwardly, we communicate with the field of HIV professionals so that they are sensitised to the needs of gay men living with HIV.



Figure 4: Info brochure on HCV for gay men living with HIV, produced by HVN and Schorer, in cooperation with Poz&Proud (2009)

*Enhancing sexual rights*

A key platform of Poz&Proud is to enhance the sexual health rights of gay men living with HIV and struggling with stigma. Sexual health rights are universal human rights based on the inherent freedom, dignity and equality of all human beings. They consists (among others) of the right to sexual freedom, sexual equity, sexual information based on scientific inquiry, and sexual health care. Sexual health is the result of an environment that recognises, respects and exercises these sexual rights (14th World Congress of Sexology, 1999). Within this global policy framing, Poz&Proud perceives serosorting as an instance of the right to sexual freedom.

Enhancing sexual rights became critical in a climate of fear. A series of lawsuits against people with HIV who had unprotected sex without disclosing their sero-status ended – for the time being – in 2007 with the verdict of the Dutch Supreme court. The Supreme Court ruled that while having unprotected sex with a HIV-positive person could pose a risk, it was not justifiable that there would be a considerable chance of HIV transmission, or that anyone sustained physical injury (Supreme Court of the Netherlands-AY9659, 2007). Several HIV-organisations in the Netherlands (AIDS Fonds, SOA AIDS Netherlands, Schorer and HVN) also stated that people have a shared responsibility in trying to avoid HIV transmission (Aids Fonds, 2004). Together with the Supreme Court, these statements strengthened the belief of gay men living with HIV that they had a right to sexual health and are not solely responsible for trying to avoid HIV transmission.

□

*Ruling:*

*“De Hoge Raad sprak dinsdag een inwoner van Houten vrij die, hoewel hij wist dat hij seropositief was, onbeschermde seks had met zijn vriend. Hij had zijn partner bovendien voorgelogen over zijn besmetting. De vriend raakte besmet. De Hoge Raad oordeelde dat er onvoldoende bewijs is voor opzet. (...) De Hoge Raad vindt dat het risico op het overdragen van een hiv-besmetting niet zo groot is dat er kan worden gesproken van ‘een aanmerkelijke kans’. Om in een strafzaak ‘voorwaardelijke opzet’ te bewijzen, moet die kans worden aangetoond.”*

*Translation:*

“The Supreme Court on Tuesday acquitted a resident of Houten who, though knowing he was HIV positive, had unprotected sex with his partner. He also lied to his partner about his infection. The partner became infected. The Supreme Court ruled that there was insufficient evidence of intent (...) The Supreme Court found that the risk of transmitting HIV infection was not so large that it constituted a “substantial risk”. To prove “conditional intent” in a criminal case,

Figure 5: [News story from a Dutch news website](#) on the verdict of the Supreme Court in 2007.

*Social networking tools to challenge stigma*

Poz&Proud’s use of social networking tools aimed to address several issues.

Firstly, we had to overcome time and distance barriers and serve the needs of those who live far away from professional HIV organisations. Secondly, gay men living with HIV lacked access to honest and unbiased evidence-based information on HIV, sexuality, and sexual health, and lacked the skills to navigate the complexity of the information available online. Finally, while most were familiar with the Internet, many

were overwhelmed and uncertain of which websites and sources to trust. Poz&Proud decided to provide access to relevant and meaningful information, opinion and online peer support by and for gay men living with HIV.

#### *Online discussions*

A crucial first step was moderating online discussions on sexual health and rights on the HVN online forum. The discussion was structured to challenge negative perceptions of people living with HIV, and encourage participants to connect, share experiences, receive accurate information on sexual health, and integrate this practical knowledge into their lives.

The popularity of the online discussion made us aware that there was an unmet need for regular updates and social networking among gay men living with HIV, who wanted connections and intimacy, and not only chatrooms to meet for sex. To meet this need, we launched a [blog](#)<sup>i</sup> on 10th March 2007 to provide news and opinion on a variety of important themes that affect the sexual health of gay men living with HIV.

#### *Poz&Proud's Blog*

The impact of the blog in challenging stigma can be illustrated by examining content over the last few years.

An early example from the blog comes from a series we called '[The P of Proud](#)'<sup>ii</sup>. We started the series to let gay men with HIV write about the stigma they encountered when diagnosed with HIV, and if and how they overcame self-stigma. In one blog contribution, one of the founders of Poz&Proud recounts his experience with stigma. The media often interviews him whenever they want a story and picture of someone who is living with HIV. He has lipodystrophy, with his face as a reminder of his HIV infection. He doesn't have many problems with this effect of the HIV medication he takes on his body. *I just don't look in the mirror often, and loving yourself anyway helps.* People tell him how brave he is to get his picture taken for a national newspaper. But for him it is not just a matter of calling yourself Poz&Proud; it is also important to act that way. He tells of his lecture for medical students on the topic of aging with HIV. As he tells his story, he becomes emotional all of a sudden, as if he for the first time realises the extent of his sorrow: *I know now that the pain is still there, but that pain is also part of who I am right now. And I'm content with this.*

When gathering feedback from this initial effort, we found that gay men living with HIV were keen to share experiences and understand the risks of serosorting. Serosorting as a prevention strategy was largely ignored by the public health professionals wedded to rational behaviour change approaches to HIV prevention, while misinformation and fears were circulating on the gay scene. We organised [information-sharing evenings](#) to address perceptions of risks associated with sexual practices, including the sexual transmission of Hepatitis C Virus, (HCV) in 2008. The evening on HCV revealed that there was a double stigma for men who had both HIV and HCV. We decided to address this issue on the blog and offered support in coping with the side effects of the HCV treatment.

In 2008 a gay man living with HIV who became infected with HCV and was undergoing treatment started a series on the blog called '[HCV Diary](#)'<sup>iii</sup>. The diary coincided with the duration of his treatment. In this entry from 29th October 2009 he draws comparison with having HIV and having HCV. In the early days of the AIDS epidemic HIV was considered to be '*a slow but sure killer.*' Now he sees HCV as a killer. He thinks we need the same attention and action for HCV as was the case for HIV in the Eighties. Controlling the HCV virus might prove difficult, he says, but '*we as a community must be able to avoid the stigma that surrounds having HCV.*'

Anal health is important for gay men, with and without HIV. In 2009 Poz&Proud held an infotainment night on this subject, mixing information on anal pleasure and health with entertainment. One of the guests was a dermatologist, who was conducting research on the prevalence and treatment of AIN (anal intraepithelial neoplasia), pre-cancerous lesions that could develop into anal cancer. Gay men living with HIV are at higher risk for anal cancer, and there is a debate on anal pap smears for this group in the Netherlands. Gay men attending the evening were asked to enroll in this study on AIN. One of the men started a [series on our blog](#)<sup>iv</sup> about his experience with the treatment he received. This led to many reactions, questions and support of other men who either had experienced treatment in one of the two studies currently held in the Netherlands or who had anal difficulties themselves.

Gay men living with HIV appreciated having access to information on sexual practices written by people like themselves, in a language they could understand, and a safe space for discussion without judgement. Such online bonding in a safe space started a social network that allowed us to gradually draw in gay men living with HIV to our theme nights with sensitive discussions on drug use, anal health, mental health, and tackling discrimination in society over the next few years.

The number of regular readers on our blog increased from 50 unique visitors per week in 2007 to more than 1000 in 2011. This was extraordinary progress in a very short period of time, and from our point of view a clear instance of using social networking for sexual health promotion, reconnecting, and overcoming some of the fear and anxiety that often builds up after years of stigma.

### *Facebook*

With the success of the blog, we were encouraged to launch a Poz&Proud [Facebook](#) group<sup>v</sup>. We recognised that it is difficult for gay men living with HIV to disclose their status online except in dating sites or chat rooms. Their anxiety was understandable because of the persistence of stigma. To address these concerns, we outline below how the Facebook group became a key resource for challenging stigma.

We started our Facebook group in October 2008. We began by inviting gay men living with HIV we knew to join our group. As news spread, we followed up on the interests of our group members and began posting information on latest stories on our blog, as well as invitations to the various social and awareness-raising activities we organised.

As gay men living with HIV began to connect with one another through our events, they became comfortable disclosing themselves online and joining our Facebook group. As our membership grew from 6 to 200, we had a stronger online social presence and saw that we had created a high-trust enmeshed community to support one another continuously. Members were motivated to stay in touch and connect because it sustained the bonding created at our various social activities, including weekend retreats, drinks get-together, speed dating, and peer support groups.

These figures show how we integrated our social activities with social networking using Facebook. Unlike in the early years of the AIDS epidemic, these social events are not held behind closed doors, but in popular locations in the Amsterdam gay scene, such as trendy cafes, bars and clubs. Being seen together and openly showing membership in our Facebook groups have been key in overcoming isolation to challenge stigma and re-theorise living with HIV as a digitally networked social practice, rather than a psychological state to be managed alone. Within this framework, gay men living with HIV learnt different ways of being than the initial fear, denialism or hiding with a 'shameful' condition. Our members were hooked on the sense of community we had created and found meaning and value in seeing how others like them were coping

with the challenges of living with HIV. These shifts with social networking we argue have beneficial long-term effects on challenging stigma, in that gay men living with HIV are repositioned as they demonstrate to themselves (and to each other) that they can overcome the vicious cycle of shame and fear; they can change the negative perceptions and reconnect with others like them to contribute to the public health goals of HIV prevention and care.



Figure 6: Visitors of AMEN, the t-dance for poz men and friends. (Photo courtesy Henri Blommers, 2009)

#### *Community action*

To challenge stigma in the gay community, where HIV is largely invisible and difficult to talk about, a key aspect of our project design was to make gay men living with HIV visible as prevention activists. We planned an integrated online and real-time community action, [Test & Tell](#)<sup>vi</sup>. During this action, gay men living with HIV invite other gay men to get tested for HIV and STIs and disclose their HIV-status. The action aims at making HIV—and subsequently gay men living with HIV—more visible in the community. We put up information on our website and blog and disseminated it widely among Poz&Proud networks. Test & Tell is now an annual [community action](#)<sup>vii</sup> held during the Gay Pride in Amsterdam. We put up banners, invite visitors to the Canal Pride to fill in questionnaires, and give out buttons labelled +, -, or ?

Armed with better knowledge through our work, gay men living with HIV conducting the action were able to use these resources to support others to make informed choices in their sexual practices, and to encourage status disclosure. This increased visibility and active participation in HIV prevention were clearly ways in which gay men living with HIV felt empowered enough to challenge negative perceptions and stigma in the community.



Figure 7: Test&Tell banner on one of the bridges during Canal Pride in Amsterdam. (Photo courtesy Jan van Breda, 2008)

#### *Advocacy and Research to Educate*

In our project design, we shifted from viewing living with HIV as an individual problem to addressing the political and socio-cultural environment that affected our lives. One key annual public health approach that had an impact was the annual Schorer Monitor online sex survey conducted to collect and disseminate data to improve HIV prevention programs. In 2009, quantitative data released showed that gay men living with HIV were having unprotected sex. 63% of sexually active gay men with HIV had unprotected sex. This was almost the same percentage from the year before (2008: 62%) (Hospers, et al., 2008).

Given the stigma that still circulated in the wider society, Dutch [media](#)<sup>viii</sup> had in the past seized on this report to accuse gay men living with HIV of behaving irresponsibly. While such anxiety was understandable, their accusation—without richer social contextual and psychological understandings of why, how, and with whom gay men living with HIV were having unprotected sex—was not.

This is a typical example of how difficult it is to put aside blaming, naming and shaming with this negative media framing of gay men living with HIV as irresponsible and potentially dangerous to HIV prevention. As we became more empowered and adopted a research attitude towards our advocacy however, we were able to confront and disrupt these negative perceptions.

In response to the incomplete report from the Schorer Monitor and the negative media framing of gay men living with HIV Poz&Proud, together with the HVN and the Public Health Authority of Amsterdam (GGD), initiated a community-based research project to further our understandings of the risk reduction strategies of gay men living with HIV. This research was conducted through an anonymous online survey in November 2009. 307 gay men living with HIV were invited to participate, 231

participants returned the questionnaire of which 212 of them were filled in completely and could be used for the research.

This [research](#)<sup>ix</sup> was a key turning point in our advocacy towards changing how public health authorities perceived gay men living with HIV. While it showed that gay men living with HIV were engaged in unprotected sex with others like themselves, it also revealed the scope and breadth of risk reduction strategies that were missing from the Schorer survey.

Poz&Proud learned from the survey that gay men living with HIV use various risk reduction strategies (RSS) to avoid transmitting HIV to their sexual partners. Of the 212 participants, 142 (67%) reported having had unprotected sex after their HIV diagnosis. Of these, 68% reported serosorting, 42% practiced viral sorting (incorporating one's knowledge about his viral load in the decision to have unprotected sex) with a HIV positive partner and 33% with a HIV negative partner. Thirty-seven percent of the participants had practiced at one point strategic positioning, where they were the receptive partners. Many men applied more than one RSS.

Such research provided Poz&Proud a more accurate and complex understanding of the lives of gay men living with HIV that we now deploy in our advocacy to counter negative media perceptions. In future, we intend to share our findings with our members on our blog, with media and research stakeholders to encourage them to conduct future research and dissemination through critical participatory approaches, rather than courting media hype.

We engaged in conversation with public health officials on how this knowledge could be used to think differently about the resources gay men living with HIV have that could be used for HIV prevention and sexual health promotion. As a result, Poz&Proud now intends to produce a brochure for HIV prevention professionals to educate them on strategies towards gay men living with HIV to reduce their risk to Hepatitis C. We expanded our advocacy towards social care providers in ways that have increased their awareness on the problems of ageing with HIV.



Figure 8: A team meeting in 2007 on strategic planning for advocacy (Photo courtesy Jan van Breda, 2007)

With an evidence-based research, education and advocacy approach, we maximised our social impact by addressing the wider symbolic and material context (Campbell & Cornish, 2010, Bourdieu, 1989, 1990a, 1990b) that regulated our lives. We involved gay men living with HIV in collaborating on conducting research and in spreading the findings to challenge negative perceptions in their social networks. Together with our social activities and social networking, gay men living with HIV took charge of

representations of their lives in media, public health and society, in a meaningful and engaged stigma-fighting framework.

## Conclusion

*“Each time I speak with you, I become more convinced about being open with my positive status. I had never before believed that I could feel so at home in a group.”*

- Poz & Proud volunteer



Figure 9: Flyer celebrating five years of Poz&Proud (2011)

In this project we have demonstrated a digital-supported, sexy community empowerment approach to structural HIV prevention and sexual health promotion over the last 5 years by confronting three stubborn sources of stigma: self-stigma, stigma in the gay community, and stigma in the media and wider society. In every case, gay men living with HIV from a wide variety of social backgrounds stepped out of negative perceptions to move forward in designing community action that made a difference. Once we initiated our project, we produced powerful impact quickly.

We appreciate that gay men living with HIV cannot address HIV prevention and sexual health issues alone. Nevertheless, Poz&Proud’s aim is to produce demonstrable outcomes that can be sustained and transferred into innovative structural intervention designs for community mobilisation. Our members realised that what truly challenging stigma was about is more than attending an empowerment workshop, when the initial buzz soon fades away as people living with HIV return to daily lives. What worked was a sustained connection with a social network, where the Internet played a crucial role. Similarly, we thought further on how to challenge the wider social context without simply blaming our victimisers. This required us to deeply understand our intervention

at multiple levels; not only to focus on providing information, advice and opinion, with access to social activities, but repositioning gay men living with HIV as producers of new knowledge through research, and initiators of new practices as prevention activists. These changes increased the capacity of gay men living with HIV for agency over their lives, to disclose their status, and to acquire valued scientific, social and digital literacies.

*“Many of my friends are now members of the Facebook group,  
and know now that I am HIV+ as well.”*

*- Remark on the Poz & Proud Facebook page*

The digital-supported nature of this project sets it apart from other community-based research or top-down HIV prevention that involves community as partners. The project design was powerful in creating new online resources for gay men living with HIV to understand risk perceptions, sexual health, and stigma differently. Social networking tools effectively reached gay men living with HIV in rural and semi-urban areas, where stigma appears to be more pervasive and entrenched than in the large urban areas. Safe spaces, particularly online, for discussions and experience sharing overcome the initial lack of solidarity among gay men living with HIV. The blog, forum, and Facebook group allowed them to examine and disrupt the effects of stigma and discrimination on their lives, while respecting their sexual, social and virtual lives and their reflexive negotiation of identities (Davis, et al., 2006). Together with social activities, these digital approaches add value by continuously mobilising social capital to make a difference not only to felt and experienced stigma, attitudes and self-esteem, but also to overall healthcare outcomes.



Figure 10: The core group of Poz&Proud in 2011. (Photo by Johan Brouwer, 2011)

As the epidemic shifts, and dynamic interventions become more necessary to create 'AIDS-resilient' communities in a networked and digital world, Poz&Proud is committed to drawing on its success to continue addressing the issues of power and distribution of social and material resources that affect access to health and human rights. Poz&Proud is investing in international networks to foster closer collaboration with grassroots and community groups of gay men and MSM living with HIV. In May 2011 we organised an expert meeting with Dutch public health professionals on the concept of structural HIV prevention, and are creating new online resources and approaches to continue fighting stigma and discrimination.

We have learnt that we can overcome stigma and unleash latent energy by framing the problem of inequitable access to HIV prevention and care as persistent, complex, and in need of fresh solutions by people living with and affected by HIV. Gay men living with HIV framed their own empowerment supported by digital approaches within this larger collective goal, and came to understand that our integrated education, advocacy and research could make a significant contribution to wider goals of public health research and practice. Poz&Proud published a book, *25+*, documenting the narratives of gay men who have lived through 25 years of HIV/AIDS in the Netherlands. We presented our approach and ourselves at the International AIDS Conference, AIDS 2010. Such engaged practices link local social capital mobilisation with the larger historical and political goal of fighting stigma and discrimination for access to health for all.

While it is common to advocate for more funding and more research on what works in community mobilisation, one thing is clear for us – we will never again take stigma and discrimination as inevitable. It is not that Poz&Proud have solved the problem once for all, but we have started to develop a reflexive sociological (Bourdieu & Wacquant, 1992) analytic perspective on living with HIV that allows us to address the challenges of HIV prevention, care and support productively. And the success of the digital sexy approach we invented proves the need for radical game-changing innovations necessary for communities of people living with HIV to take charge for sustained social change in the 21st century.

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## **Further reading**

### [AIDS 2010 Poz&Proud Abstracts](#)

Stevens, A.H. (2010) Poz&Proud: bringing "sexy" back into grassroots advocacy for HIV-positive gay men (HPGM) in the Netherlands: claiming (sexual) rights, regaining lost territory. *XVIII International AIDS conference*, Vienna, 18-23 July, Abstract no.

MOPE0975 Retrieved from

<http://www.iasociety.org/Default.aspx?pageId=11&abstractId=200737784>

Pastors, A.H.M. (2010) Poz&Proud: GIPA 2.0 towards better understanding of the needs and comprehensive involvement of HIV-positive gay men (HPGM) in the 21<sup>st</sup> century: a Dutch example. *XVIII International AIDS conference*, Vienna, 18-23 July, Abstract no. TUPE0951 Retrieved from

<http://www.iasociety.org/Default.aspx?pageId=11&abstractId=200737913>

Clews, N. (2010) Growing old (un)gracefully - becoming aware of the complex issues of 'early aging', co-morbidity and frailty in the HIV-positive gay male population. *XVIII International AIDS conference*, Vienna, 18-23 July, Abstract no. TUPE0947 Retrieved from

<http://www.iasociety.org/Default.aspx?pageId=11&abstractId=200735891>

## References

- aids2031 Consortium, 2011. *AIDS: taking a long-term view*. Upper Saddle River, NJ: FT Press.
- Adimora, A. A., & Auerbach, J. D. (2010). Structural interventions for HIV prevention in the United States. *JAIDS Journal of Acquired Immune Deficiency Syndromes*, 55, S132-S135. doi: 10.1097/QAI.0b013e3181fbc38.
- Adams, B. (2012). Epistemic fault lines in biomedical and social approaches to HIV prevention. *Journal of the International AIDS Society*, 14(Suppl 2),S2,1-9. doi:10.1186/1758-2652-14-S2-S2.
- AIDS Fonds. (2004). *Penitentia of Preventie? Advies van de Bestuurscommissie Aidsbeleid en Strafrecht*. Amsterdam: AIDS Fonds.
- amfAR. (2008). *The MSM Initiative*. New York, USA: amfAR, The Foundation for AIDS Research. Retrieved from [www.amfar.org/uploadedFiles/Community/MSM.pdf](http://www.amfar.org/uploadedFiles/Community/MSM.pdf)
- Altman, D. (1994). *Power and community: Organizational and cultural responses to AIDS*. Basingstoke, UK: Taylor & Francis.
- Altman, D. (1999). Globalization, political economy and HIV/AIDS. *Theory and Society*, 28(4), 559-584.
- Altman, D. (2002). *Global Sex*. Chicago: University of Chicago Press.
- Altman, D. (2005). Rights matter: Structural interventions and vulnerable communities. *Health and human rights*, 8(2), 203-213.
- Auerbach, J. D., Parkhurst, J. O., Caceres, C., & Keller, K. E. (2010). Addressing social drivers of HIV/AIDS : Some conceptual, methodological, and evidentiary Considerations. AIDS 2031 Working Paper No. 24. Retrieved from <http://www.aids2031.org/pdfs/aids2031%20social%20drivers%20paper%2024-auerbach%20et%20all.pdf>
- Ayala, G., Beck, J., Lauer, K., Reynolds, R., & Sundararaj, M. (2010). Social discrimination against men who have sex with men (MSM): Implications for HIV policy and programs. Retrieved from [http://www.msmsgf.org/files/msmgf//Advocacy/Policy\\_Briefs/Stigma\\_EN\\_hi.pdf](http://www.msmsgf.org/files/msmgf//Advocacy/Policy_Briefs/Stigma_EN_hi.pdf)
- Baral, S., Trapence, G., Motimedi, F., Umar, E., Ipinge, S., Dausab, F., & Beyrer, C. (2009). HIV prevalence, risks for HIV infection, and human rights among men who have sex with men (MSM) in Malawi, Namibia, and Botswana. *PLoS one*, 4(3), e4997. doi: 10.1371/journal.pone.0004997.
- Bauman, Z. (2000). *Liquid Modernity*. Cambridge: Polity.

- Beyrer, C. (2010). Global prevention of HIV infection for neglected populations: Men who have sex with men. *Clinical Infectious Diseases*, 50 (Suppl 3), S108-113. doi: 10.1086/651481.
- Bolding, G., Davis, M., Hart, G., Sherr, L., & Elford, J. (2005). Gay men who look for sex on the Internet: Is there more HIV/STI risk with online partners? *AIDS*, 19(9), 961-968.
- Bolding, G., Davis, M., Hart, G., Sherr, L., & Elford, J. (2007). Where young MSM meet their first sexual partner: The role of the Internet. *AIDS and Behaviour*, 11(4), 522-526. doi: 10.1007/s10461-007-9224-9
- Bourdieu, P. (1987). The biographical illusion. *Working papers and Proceedings of the Centre for Psychosocial Studies, University of Chicago*, 14, 1-7.
- Bourdieu, P. (1989). Social space and symbolic power. *Sociological Theory*, 7(1), 14-25.
- Bourdieu, P. (1990a). *In other words: Essays towards a reflexive sociology*. Stanford, CA: Stanford University Press.
- Bourdieu, P. (1990b). *The Logic of Practice*. Stanford, CA: Stanford University Press.
- Bourdieu, P. (1998). *Practical Reason*. Stanford, CA: Stanford University Press.
- Bourdieu, P., & Johnson, R. (1993). *The field of cultural production: Essays on art and literature*. New York: Columbia University Press.
- Bourdieu, P. and Wacquant, L. (1992). *Towards a Reflexive Sociology*. Oxford, UK: Polity.
- Caceres, C. F., Konda, K., Segura, E. R., & Lyerla, R. (2008). Epidemiology of male same-sex behaviour and associated sexual health indicators in low- and middle-income countries: 2003-2007 estimates. *Sexually transmitted infections*, 84 (Suppl 1), i49-i56. doi: 10.1136/sti.2008.030569.
- Campbell, C., & Cornish, F. (2010). Towards a "fourth generation" of approaches to HIV/AIDS management: creating contexts for effective community mobilisation. *AIDS Care*, 22 (Suppl 2), 1569-1579. doi: 10.1080/09540121.2010.525812.
- Campbell, C., & Williams, B. (1999). Beyond the biomedical and behavioural: towards an integrated approach to HIV prevention in the southern African mining industry. *Social science & medicine*, 48(11), 1625-1639. doi: 10.1016/S0277-9536(98)00449-3.
- Castells, M. (1996). *The rise of the network society*. Oxford: Blackwell.
- Chopra, M., & Ford, N. (2005). Scaling up health promotion interventions in the era of HIV/AIDS: Challenges for a rights based approach. *Health Promotion International*, 20(4), 383-390. doi: 10.1093/heapro/dai018.
- Coleman, J. (1988). Social capital in the creation of human capital. *The American Journal of Sociology*, 94, S95-S120.
- Crawford, R. (1994). The boundaries of the self and the unhealthy other: Reflections on health, culture and AIDS. *Social science & Medicine*, 38(10), 1347-1365. doi: 10.1016/0277-9536(94)90273-9.
- Davis, M. (2002). HIV prevention rationalities and serostatus in the risk narratives of gay men. *Sexualities*, 5(3), 281-299, doi: 10.1177/1363460702005003002.
- Davis, M. (2011). *Sex, Technology and Public Health*. England: Palgrave MacMillan.
- Davis, M., Hart, G., Bolding, G., Sherr, L., & Elford, J. (2006). *Sex and the Internet: Gay men, risk reduction and serostatus*. *Culture, Health & Sexuality*, 8(2), 161-174. doi: 10.1080/13691050500526126.
- Dijk, J. V. (1991). *The network society: Social aspects of new media*. Houten: De netwerkmaastchappij Bohn Staflen Van Loghum.
- Doherty, I. A., Padian, N. S., Marlow, C., & Aral, S. O. (2005). Determinants and consequences of sexual networks as they affect the spread of sexually transmitted

- infections. *The Journal of Infectious Diseases*, 191 (Suppl 1), S42-54. doi: 10.1086/425277.
- Dukers, N. H., Fennema, H. S., van der Snoek, E. M., Krol, A., Geskus, R. B., Pospiech, M., & Prins, M. (2007). HIV incidence and HIV testing behavior in men who have sex with men: Using three incidence sources, The Netherlands, 1984-2005. *AIDS*, 21(4), 491-499. doi: 10.1097/QAD.0b013e328011dade.
- Elford, J. (2006). Changing patterns of sexual behaviour in the era of highly active antiretroviral therapy. *Current Opinion in Infectious Diseases*, 19(1), 26-32.
- Empelen, P. V. (2010). *Schorer Monitor 2010*. Amsterdam: Schorer. Retrieved from <http://www.schorer.nl/bestanden/paypernews/monitor2010/magazine.html>
- Eysenbach, G., Powell, J., Englesakis, M., Rizo, C., & Stern, A. (2004). Health related virtual communities and electronic support groups: systematic review of the effects of online peer to peer interactions. *British Medical Journal*, 328(7449), 1-6. doi: 10.1136/bmj.328.7449.1166
- Fisher, W. F., & Thomas-Slayer, B. (2009). *Mobilizing social capital in a world with AIDS*. Report from workshop of International Development, Community and Environment (IDCE). Worcester, MA: Clark University.
- Giddens, A. (1993). *Sociology*. Cambridge: Polity Press.
- Goffman, E. (1963). *Stigma: Notes on the Management of Spoiled Identity*. Englewood Cliffs NJ: Prentice-Hall.
- Gras, L., Sighem, A. v., Smit, C., Zaheri, S., Schuitemaker, H., & Wolf, F. d. (2010). *2010 Report monitoring of Human Immunodeficiency Virus (HIV) in the Netherlands*. Retrieved from [http://www.hiv-monitoring.nl/\\_site1134/images/101736\\_1-HIVM-RPRT10-WEB.pdf](http://www.hiv-monitoring.nl/_site1134/images/101736_1-HIVM-RPRT10-WEB.pdf)
- Gupta, G. R., Parkhurst, J. O., Ogden, J. A., Aggleton, P., & Mahal, A. (2008). Structural approaches to HIV prevention. *The Lancet*, 372(9640), 764-775. doi: 10.1016/s0140-6736(08)60887-9.
- Herbst, J. H., Sherba, R. T., Crepaz, N., Deluca, J. B., Zohrabyan, L., Stall, R. D., & Lyles, C. M. (2005). A meta-analytic review of HIV behavioral interventions for reducing sexual risk behavior of men who have sex with men. *Journal of Acquired Immune Deficiency Syndrome*, 39(2), 228-241.
- Hogg, R., Lima, V., Sterne, J., Grabar, S., Bategay, M., Bonarek, M., & May, M. (2008). Life expectancy of individuals on combination antiretroviral therapy in high-income countries: a collaborative analysis of 14 cohort studies. *The Lancet*, 372(9635), 293-299. doi: 10.1016/s0140-6736(08)61113-7.
- Hospers, H., Dörfler, T., & Zuilhof, W. (2008). *Schorer Monitor 2008*. Retrieved from <http://www.schorer.nl/46/schorer-monitor/>
- Hospers, H. J., Roos, E., & Zuilhof, W. (2009). *Schorer Monitor 2009*. Retrieved from <http://www.schorer.nl/398/schorer-monitor/schorer-monitor-2009/>
- Imrie, J., Elford, J., Kippax, S., & Hart, G. J. (2007). Biomedical HIV prevention and social science. *Lancet*, 370(9581), 10-11. doi: 10.1016/S0140-6736(07)61026-5.
- Israel, E., Laudari, C., & Simonetti, C. (2008). *HIV Prevention Among Vulnerable Populations: The Pathfinder International Approach Pathfinder International Technical Guidance Series Number 6*. Retrieved from <http://www.cominit.com/en/node/274584/347>
- Jansen, I. A., Geskus, R. B., Davidovich, U., Jurriaans, S., Coutinho, R. A., Prins, M., & Stolte, I. G. (2011). Ongoing HIV-1 transmission among men who have sex with men in Amsterdam: A 25-year prospective cohort study. *AIDS*, 25(4), 493-501. doi: 10.1097/QAD.0b013e328342f9e9.

- Jolly, A. M., Muth, S. Q., Wylie, J. L., & Potterat, J. J. (2001). Sexual networks and sexually transmitted infections: a tale of two cities. *Journal of Urban Health*, 78(3), 433-445. doi: 10.1093/jurban/78.3.433.
- Kidd, R., & Clay, S. (2007). *Understanding and Challenging HIV Stigma: Toolkit for Action*. Brighton, UK: International HIV/AIDS Alliance.
- Kippax, S. (2008). Understanding and integrating the structural and biomedical determinants of HIV infection: A way forward for prevention. *Current Opinion in HIV and AIDS*, 3(4), 489-494. doi: 10.1097/COH.0b013e32830136a0.
- Kippax, S., & Race, K. (2003). Sustaining safe practice: twenty years on. *Social Science & Medicine*, 57(1), 1-12. doi: 10.1016/S0277-9536(02)00303-9.
- Kippax, S. C., Aggleton, P., Moatti, J. P., & Delfraissy, J. F. (2007). Living with HIV: recent research from France and the French Caribbean (VESPA study), Australia, Canada and the United Kingdom. *AIDS*, 21(Suppl 1), S1-3. doi: 10.1097/01.aids.0000255078.01234.71.
- Le Vu, S., Le Strat, Y., Barin, F., Pillonel, J., Cazein, F., Bousquet, V., & Desenclos, J. C. (2010). Population-based HIV-1 incidence in France, 2003-08: A modelling analysis. *The Lancet infectious diseases*, 10(10), 682-687. doi: 10.1016/S1473-3099(10)70167-5.
- Liau, A., Millett, G., & Marks, G. (2006). Meta-analytic examination of online sex-seeking and sexual risk behavior among men who have sex with men. *Sexually Transmitted Diseases*, 33(9), 576-584. doi: 10.1097/01.olq.0000204710.35332.c5.
- Liu, C., Ostrow, D., Detels, R., Hu, Z., Johnson, L., Kingsley, L., & Jacobson, L. P. (2006). Impacts of HIV infection and HAART use on quality of life. *Quality of Life Research*, 15(6), 941-949. doi: 10.1007/s11136-005-5913-x.
- London, L. (2008). What is a human-rights based approach to health and does it matter? *Health and Human Rights*, 10(1), 65-80.
- Mo, P.K.H., & Coulson, N.S. (2010). Living with HIV/AIDS and use of online support groups. *Journal of Health Psychology*, 15(3), 339-350. doi: 10.1177/1359105309348808.
- Moatti, J. P., & Souteyrand, Y. (2000). HIV/AIDS social and behavioural research: Past advances and thoughts about the future. *Social Science & Medicine*, 50(11), 1519-1532. doi: 10.1016/S0277-9536(99)00462-1.
- Moatti, J. P., & Spire, B. (2008). HIV/AIDS: A long-term research agenda for social sciences. *AIDS Care*, 20(4), 407-412. doi: 10.1080/09540120801942776.
- Mooij, A. (2004). *Geen Paniek! Aids in Nederland 1982 -2004*. Amsterdam: Bert Bakker.
- Morris, M. (1997). Sexual networks and HIV. *AIDS*, 11 (Suppl A), S209-216.
- Noar, S. M., Black, H. G., & Pierce, L. B. (2009). Efficacy of computer technology-based HIV prevention interventions: A meta-analysis. *AIDS*, 23(1), 107-115. doi: 10.1097/QAD.0b013e32831c5500.
- Ogden, J., Gupta, G. R., Fisher, W.F. & Warner, A. (2011). Looking back, moving forward: Towards a game-changing response to AIDS. *Global Public Health: An International Journal for Research, Policy and Practice*, 6(Sup3), S285-S292.
- Parker, R., & Aggleton, P. (2003). HIV and AIDS-related stigma and discrimination: A conceptual framework and implications for action. *Social Science & Medicine*, 57(1), 13-24.
- Parsons, J. T., Schrimshaw, E. W., Wolitski, R. J., Halkitis, P. N., Purcell, D. W., Hoff, C. C., & Gomez, C. A. (2005). Sexual harm reduction practices of HIV-seropositive gay and bisexual men: Serosorting, strategic positioning, and withdrawal before ejaculation. *AIDS*, 19 (Suppl 1), S13-25.

- Patterson, D., & London, L. (2002). International law, human rights and HIV/AIDS. *Bulletin of the World Health Organization*, 80(12), 964-969. doi: 10.1590/S0042-96862002001200011.
- Peretti-Watel, P., Spire, B., Obadia, Y., & Moatti, J. P. (2007). Discrimination against HIV-infected people and the spread of HIV: Some evidence from France. *PloS one*, 2(5), e411. doi: 10.1371/journal.pone.0000411
- Pinell, P. (2002). *Une épidémie politique, La lutte contre le sida en France 1981-1996*. Paris: PUF.
- Pulerwitz, J., Michaelis, A. P., Lippman, S. A., Chinaglia, M., & Diaz, J. (2008). HIV-related stigma, service utilization, and status disclosure among truck drivers crossing the southern borders in Brazil. *AIDS Care*, 20(7), 764-770. doi: 10.1080/09540120701506796.
- Rifkin, S. B. (2001). Ten best readings on community participation and health. *African Health Sciences*, 1(1), 42-45.
- Rothenberg, R. B., Potterat, J. J., Woodhouse, D. E., Muth, S. Q., Darrow, W. W., & Klovdahl, A. S. (1998). Social network dynamics and HIV transmission. *AIDS*, 12(12), 1529-1536.
- Rowniak, S. (2009). Safe sex fatigue, treatment optimism, and serosorting: New challenges to HIV prevention among men who have sex with men. *The Journal of the Association of Nurses in AIDS Care*, 20(1), 31-38. doi: 10.1016/j.jana.2008.09.006.
- SHM (2011). *Monitoring Report 2011- Human Immunodeficiency Virus (HIV) Infection in the Netherlands*. Amsterdam: SHM.
- Smit, C., & Brinkman, K. (2009). *Aging with HIV*. Amsterdam: AIDS Fonds.
- Smit, P., Brady, M., Carter, M., Fernandes, R., Lamore, S., Meulbroek, M., Ohayon, M., Platteau, T., Rehberg, P., Rockstroh, J., Thompson, M. (2011). HIV-related stigma within communities of gay men: A literature review. *AIDS Care iFirst*, 108. doi: 10.1080/09540121.2011.613910.
- Smith, A. D., Tapsoba, P., Peshu, N., Sanders, E. J., & Jaffe, H. W. (2009). Men who have sex with men and HIV/AIDS in sub-Saharan Africa. *Lancet*, 374(9687), 416-422. doi: 10.1016/S0140-6736(09)61118-1.
- Spire, B. (2010). Test and treat – community perspectives. *Journal of the International AIDS Society*, 13(Suppl 4), O14.
- Spire, B., de Zoysa, I., & Himmich, H. (2008). HIV prevention: What have we learned from community experiences in concentrated epidemics? *Journal of the International AIDS Society*, 11(1), 5. doi: 10.1186/1758-2652-11-5.
- Stockman, J. K., Schwarcz, S. K., Butler, L. M., de Jong, B., Chen, S. Y., Delgado, V., & McFarland, W. (2004). HIV prevention fatigue among high-risk populations in San Francisco. *Journal of Acquired Immune Deficiency Syndromes*, 35(4), 432-434.
- Stutterheim, S.E., Pryor J. B., Bos, E.R., Hoogendijk R., Muris, P. and Schaalma, H.P. (2009) HIV-related stigma and psychological distress: the harmful effects of specific stigma manifestations in various social settings. *AIDS*, 23 (17) 2353-2357.
- Suarez, T., & Miller, J. (2001). Negotiating risks in context: A perspective on unprotected anal intercourse and barebacking among men who have sex with men—where do we go from here? *Archives of Sexual Behavior*, 30(3), 287-300. doi: 10.1023/A:1002700130455.
- Supreme Court of the Netherlands (2007). Ruling in the case of unprotected sex and HIV, February 20th 2007–AY9659. Retrieved from <http://www.wetboek-online.nl/jurisprudentie/ljnAY9659.html>
- UNAIDS. (2007). *Practical Guidelines for Intensifying HIV Prevention*. Geneva, Switzerland: UNAIDS.
- Walsh, C. & Singh, G. (2012). Building the HIVe: Disrupting Biomedical HIV/AIDS

- Research with Gay Men, Other MSM and Transgenders. AERA 2012.
- Wellman, B. (2001). Physical place and cyberplace: The rise of personalized networking. *International Journal of Urban and Regional Research*, 25, 227-252. doi: 10.1111/1468-2427.00309.
- Westhaver, R. (2005). 'Coming out of your skin': Circuit parties, pleasure and the subject. *Sexualities*, 8(3), 347-374. doi: 10.1177/1363460705053338
- World Association of Sexology. (1999). *Declaration of Sexual Rights*. 14th World Congress of Sexology. Hong Kong.

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## Endnotes

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- <sup>i</sup> [www.pozandproud.nl](http://www.pozandproud.nl)
- <sup>ii</sup> [www.hivnet.org/blogs/pozandproud/?p=2668](http://www.hivnet.org/blogs/pozandproud/?p=2668)
- <sup>iii</sup> [www.hivnet.org/blogs/pozandproud/?p=1507](http://www.hivnet.org/blogs/pozandproud/?p=1507)
- <sup>iv</sup> [www.hivnet.org/blogs/pozandproud/?p=9203](http://www.hivnet.org/blogs/pozandproud/?p=9203)
- <sup>v</sup> [www.facebook.com/groups/7773554937/](https://www.facebook.com/groups/7773554937/)
- <sup>vi</sup> [www.hivnet.org/index.php?option=com\\_content&view=category&layout=blog&id=421&Itemid=697](http://www.hivnet.org/index.php?option=com_content&view=category&layout=blog&id=421&Itemid=697)
- <sup>vii</sup> [www.youtube.com/watch?v=Z29qiWN9Wlw](https://www.youtube.com/watch?v=Z29qiWN9Wlw)
- <sup>viii</sup> [www.parool.nl/parool/nl/1/Home/article/detail/42470/2008/11/12/Homo--en-bimannen-vrijen-onveiliger.dhtml](http://www.parool.nl/parool/nl/1/Home/article/detail/42470/2008/11/12/Homo--en-bimannen-vrijen-onveiliger.dhtml)
- <sup>ix</sup> [www.hivnet.org/index.php?option=com\\_content&view=article&id=9784;niet-alleen-het-condoom-beschermt&catid=431:medisch-nieuws-2011&Itemid=422](http://www.hivnet.org/index.php?option=com_content&view=article&id=9784;niet-alleen-het-condoom-beschermt&catid=431:medisch-nieuws-2011&Itemid=422)