

ENDING HIV TRANSMISSION BY INVOLVING HIV-POSITIVE PEOPLE IN HIV PREVENTION EDUCATION

PREPARED ON BEHALF OF NAPWHA BY
DR JOHN RULE AND DR JEANNE ELLARD

NOVEMBER 2017

Published by National Association of People With HIV Australia
ABN 79 052 437 899
POSTAL ADDRESS PO Box 917 Newtown NSW 2042 Australia
TELEPHONE +61 2 8568 0300
WEBSITE napwha.org.au
EMAIL admin@napwha.org.au

© 2017 National Association of People With HIV Australia

First published in November 2017

All rights reserved. No part of this publication may be reproduced, stored in a retrieval system, transmitted in any form or by any means, electronic, mechanical, recording or otherwise, without the prior written permission of the publisher, except by a reviewer who may quote brief passages or sections in a review. Some sections have been reproduced with permission from other publishers; for reproduction please contact original publishers. Every attempt has been made to contact individuals included in photographs in this book and to gain permission for their use.

Written and edited by John Rule and Jeanne Ellard

National Library of Australia Cataloguing-in-Publication entry

Title: Ending HIV Transmission by involving HIV-positive people in HIV prevention education
Authors: John Rule, Jeanne Ellard

ISBN: 9780992468132 (paperback.)

Subjects: HIV-positive persons–Australia.
HIV-positive persons–Care–Australia.
HIV infections–Prevention–Australia.
AIDS (Disease)–Prevention–Australia
Sexually transmitted diseases–Prevention–Australia.
Disease management–Australia.

Other Creators/Contributors:

National Association of People with HIV Australia, issuing body.

Design Stevie Bee

CONTENTS

- 4** ACRONYMS | ACKNOWLEDGEMENTS
- 5** EXECUTIVE SUMMARY
- 7** INTRODUCTION
- 9** THE CONTEXT
- 11** THE LITERATURE
- 15** THE INTERVIEWS
- 21** CONCLUSION
- 22** REFERENCES

ACRONYMS

ARV	Antiretroviral therapy
GIPA	The Greater Involvement of People Living with HIV/AIDS
MIPA	The Meaningful Involvement of People Living with HIV
HIV	Human Immunodeficiency Virus
MSM	Men who have Sex with Men
NAPWHA	National Association of People with HIV Australia
PLHIV	People Living with HIV
PrEP	Pre Exposure Prophylaxis
TASP	Treatment-as-Prevention
UAI	Unprotected Anal Intercourse

ACKNOWLEDGEMENTS

We would like to thank Bill Paterson, NAPWHA Operations manager for his guidance in the preparation of this paper. We also thank the interview participants from around Australia who gave us their time, insights, and expertise. Finally we would like to thank the reviewers from the NAPWHA leadership who provided comment and feedback.

EXECUTIVE SUMMARY

This paper explores the role of People with HIV (PLHIV) in the HIV prevention response in Australia since the beginning of the epidemic. The National Association of People with HIV Australia (NAPWHA) commissioned this paper to inform ongoing work in the HIV prevention space. PLHIV in Australia and internationally have played a central role in HIV prevention; through educating others about HIV prevention and HIV transmission, using risk reduction strategies to prevent onward transmission, and also by challenging stigma and discrimination. PLHIV have also played key roles in promoting the early initiation of treatment with the Treatment as Prevention (TasP) message and advocating for access to other biomedical prevention technologies such as rapid and home HIV tests and Pre Exposure Prophylaxis (PrEP). As biomedical approaches to HIV prevention such as TasP and PrEP become the mainstay of prevention the individual and collective expertise of PLHIV in the use of antiretroviral therapy (ARV) will be invaluable. In addition, the new prevention landscape needs to re-engage with the concept of shared responsibility for HIV prevention that characterised the response to HIV in Australia in the early years of the epidemic. This paper is informed by consultations with the NAPWHA Secretariat and membership, a review of published literature from the last decade relating to PLHIV and prevention, and recent interviews with 20 PLHIV from different population groups across Australia.



PLHIV have a central role to play in the HIV prevention response in Australia but they must be supported to carry out that role.

The HIV research literature highlights the value of the meaningful involvement of people with HIV (MIPA) in the conceptualisation, design, implementation and delivery of HIV prevention programs. The benefits of MIPA include: empowerment of PLHIV, reduction in social isolation, changes in risk behaviour, reduction in stigma and discrimination and increased uptake of ARV therapy. Interviews conducted with PLHIV for this project show that they engage in a range of formal and informal prevention work. Formal prevention work is carried out through activities such as Positive Speakers Programs. Personal disclosure is a common example of informal education work where the disclosure of HIV-positive status to friends, colleagues and sexual partners creates the space for others to ask questions about HIV. Through disclosure to others (both those who do and those who do not have HIV) there are opportunities to share knowledge about HIV prevention strategies.

Both the literature and the interviews with PLHIV show that PLHIV have a strong sense of responsibility for preventing onward transmission of HIV and educating others about HIV. However, at times this responsibility is experienced as burdensome. Further, PLHIV do not always feel that they have the necessary skills that enable them to disclose their HIV status in an easy and comfortable way. PLHIV require support in disclosing their HIV status; particularly in light of ongoing stigma and discrimination and low levels of understanding about the meaning of undetectable viral load among HIV-negative people. The interviews and the literature also demonstrate that PLHIV have specific sexual health and prevention needs that go beyond a narrow conceptualisation of 'positive prevention' as something that directs PLHIV to act to protect others. The interview participants identified a number of specific programs and initiatives that they believed support the role of PLHIV in prevention by providing information about ARVs and promoting health and wellbeing. Examples provided by the participants included previous national projects such as the Treatment Roadshows and the Good Quality of Life campaign.

This paper suggests ways to think about Positive in Prevention in the contemporary Australian HIV prevention landscape. With reference to the literature that is currently available, and reflecting on the interviews with PLHIV, this paper argues that the broader definition of Positive Prevention, which we call 'Positive in Prevention' must begin with providing a supportive environment for PLHIV to manage their own health and wellbeing. This was neatly summarised by one of the participants who said:

When I have access to the right health services, information and support I can care for myself and then I can care for and educate others

PLHIV have a central role to play in the HIV prevention response in Australia but they must be supported to carry out that role.

INTRODUCTION

In April 2016 the NAPWHA membership devoted a special session of their biannual meeting to the role of people living with HIV (PLHIV) in HIV prevention. At that meeting the membership authorised the NAPWHA secretariat to commission a paper on the role of PLHIV in the HIV prevention response. The purpose of the paper would be to inform the future work of NAPWHA in HIV prevention. HIV prevention is not new territory for NAPWHA. In 2012 NAPWHA launched Start the Conversation, the first national media campaign in Australia promoting the health and prevention benefits of the early initiation of treatment. In 2013 a document on the vital role of PLHIV in prevention work was released by the NAPWHA PozAction Group (Poz Action Group, 2013). NAPWHA has always played a part in HIV prevention work, and now, with the advent of TasP and PrEP, it is timely for NAPWHA and member organisations to re-affirm this role.



This paper emphasises the value of involving PLHIV as leaders in the design, implementation and evaluation of all prevention strategies.

In this paper the term 'Positive in Prevention' is used in preference to the more commonly used 'Positive Prevention', to shift away from the often narrow interpretations of the latter. Positive Prevention as a concept and tool often targets PLHIV and focuses only on preventing the onward transmission of HIV (GNP+ & UNAIDS, 2009). This narrow definition excludes the health and well-being needs of the HIV positive person, in particular the delay of disease progression. The Global Network

of People Living with HIV (GNP+) have critiqued the many positive prevention approaches 'that appear to focus almost entirely on preventing onward transmission of HIV' arguing that this 'should not be the sole aim of any positive prevention programme' (GNP+, 2009, 6). We use the concept of Positive in Prevention to encapsulate the agency and energy of HIV positive people in setting the prevention agenda, and in designing, implementing and advocating for HIV prevention programs. Further, 'Positive in Prevention' is a term that better captures the 'myriad health and prevention needs of HIV-positive individuals' (GNP+, 2009, 6). The term Positive in Prevention is inspired by the GNP+ concept of 'Positive Health, Dignity and Prevention', and encompasses the elements identified by the GNP+ as central to 'positive prevention':

... health promotion; treatment access, sexual and reproductive health rights; prevention of transmission of HIV and other sexually transmitted infections (STIs); protection of human rights, including, stigma and discrimination reduction; gender equality; social and economic support and the empowerment of people living with HIV (GNP+, 2009,6).

This paper pays attention to the vital and unique role that HIV-positive people play in HIV prevention work, in the past, present and into the future. It proposes that approaches to HIV prevention need to include the prevention of illness progression and it emphasises the value of involving PLHIV as leaders in the design, implementation and evaluation of all prevention strategies. In addition, this paper articulates the needs of PLHIV at individual and community levels, it argues that HIV prevention is not simply something PLHIV do on behalf of others (service) but also includes interventions that recognise and address their specific health and prevention needs. Further, the paper underlines that HIV prevention is a shared responsibility between individuals of different HIV status, communities and governments.

THE CONTEXT

In the last few years there have been significant shifts in the Australian response to HIV management and prevention, changes characterised by sector-wide support for biomedical interventions such as treatment-as-prevention (TasP) and the use of Pre-Exposure Prophylaxis (PrEP) and National and International targets aimed at 'Ending HIV'.

A mid-term review of NAPWHA's Strategic Plan 2013-2016 confirmed that supporting access to treatments and promoting treatment literacy and adherence has always been NAPWHA's core business. NAPWHA's mid-term strategic plan review specifically directed members' attention to the role of PLHIV in prevention programs. In 2016 NAPWHA prepared an internal document for membership comment. This document was called the Positive Prevention Discussion Paper, 2016, and affirmed members' understanding that NAPWHA, as the national voice of PLHIV, plays an essential role in efforts to reduce the incidence of HIV transmission.

NAPWHA has a strong track record in national leadership in the field of HIV prevention and treatment. This is demonstrated by a number of national campaigns conducted (often in collaboration with other organisations) and, in the case of recent campaigns, (Start the Conversation, The Wait is Over, and Good Quality of Life) NAPWHA has taken the lead role. These campaigns have responded to a diversity of PLHIV populations and focused on the health and prevention benefits of HIV treatment. The campaigns include:

- Treat Yourself Right (see <http://napwha.org.au/living-hiv/treat-yourself-right>)

- Managing Side Effects
(see <http://napwha.org.au/publications/managing-side-effects>)

- Start the Conversation
(see <http://napwha.org.au/news-information/campaigns/start-conversation>)

- The Wait is Over
(see <http://napwha.org.au/health-treatment/hiv-treatment/wait-over>)

- Good Quality of Life (see <http://goodqualityoflife.com.au>)

Successive National HIV Strategies have positioned PLHIV as central in the HIV response. The current National Strategy and state-based strategies identify PLHIV as priority populations across all aspects of the HIV response in Australia. The Seventh National Strategy 2014-2017 acknowledges the diversity of PLHIV and therefore the need for tailored responses and 'effective and high quality health and community services covering prevention, management, care and support' (Commonwealth of Australia, 2014). Further, the strategy supports the meaningful participation of PLHIV in the development, implementation, monitoring and evaluation of HIV programs and policies and recognises this participation as central to the success of the Strategy and to the partnership approach which underpins the HIV response in Australia.

The Australian HIV partnership is unique and recognised globally (Plummer, et al., 2006; Bernard et al., 2008; Brown et al., 2016) and HIV-positive people have always played an important role in the partnership (Rule & Watson, 2014). The partnership approach in Australia has seen gay men, men-who-have-sex-with-men (MSM), sex workers, people who inject drugs, people living with HIV, and clinicians working with research, public health, and government to respond to HIV in Australia (Brown et al., 2016). However, in articulating and documenting Australia's response, the different processes or mechanisms which have enabled partnership have not always been made clear. The partnership narrative has written over some of the details of how partnership is achieved and maintained. Duffin, Watson and Flanagan in *Through our Eyes*, 2014 recount the ways in which PLHIV have been leaders in HIV community education, treatments education and HIV health promotion campaign development since the beginning of the epidemic. These authors note that ensuring the central involvement of PLHIV requires continual investment, support, encouragement and skills development. More recently, the What Works and Why - W3 project funded by the Commonwealth Government of Australia has been attempting to describe in detail the impact of community HIV prevention interventions. Specifically the 'peer-led' nature of interventions is being acknowledged and the role of 'peers' in prevention efforts, including PLHIV, is being documented (<http://www.w3project.org.au/>).

THE LITERATURE

In order to better understand what is currently known about the role and benefits of the meaningful involvement of PLHIV in HIV prevention a search of the peer reviewed literature was conducted. Literature written in English and published in the years between 2005-2017 was identified, using major sociological, public health and medical databases, including:

- Health and Society database
- Medline
- Science Direct
- Sociological Abstracts
- Social Science Citation Index

Relevant articles were identified using a combination of the following keywords and phrases and subject headings:

- Positive prevention
- PLHIV and peer prevention
- PLHIV and PrEP
- HIV peer prevention
- GIPA and prevention
- MIPA and prevention

It should be noted that much of the literature identified using these search terms does not address the role of PLHIV in prevention or the specific needs of PLHIV in terms of HIV prevention. Rather, the literature investigates prevention activities that target PLHIV in order to change sex and drug use behaviours that are perceived to place HIV-negative people at risk, namely condomless sex or the sharing or reuse of injecting equipment. This literature typically does not conceptualise HIV prevention targeting PLHIV as something that PLHIV are actively involved in developing or implementing, nor does it frame PLHIV as having prevention needs beyond halting onward transmission.

There is, however, a small body of literature that does provide evidence for the important role of PLHIV in prevention and that identifies some of the potential challenges faced by PLHIV in actively participating in the HIV response. Additionally there is literature that highlights that PLHIV have specific sexual health needs that should be embedded in HIV prevention and education interventions. The key points from this literature are discussed below.

The benefits of involving PLHIV

There is a commitment to the Greater Involvement of People Living with HIV/AIDS (GIPA) by the majority of United Nations member States (UNAIDS 2007). The benefits of GIPA are valued at the global level; however, there is little research that has explored the extent to which GIPA has been implemented (Maxwell et al., 2008) and the influence of GIPA on primary and secondary prevention. There is evidence of the broader benefits of GIPA, for both individuals and communities including the reduced social isolation of PLHIV, overcoming feelings of guilt and shame for those affected by HIV, reducing the stigma surrounding HIV infection and improving health through access to information about HIV treatments and prevention (Cain et al., 2014; Maxwell et al., 2008). The involvement of PLHIV in HIV service organisations has assisted services to be attuned to changing community needs, and to improve services and increase their credibility by drawing on the knowledge and experiences of PLHIV (Cain et al., 2014).

Researchers in Canada and the United Kingdom (Cain et al., 2014; Maxwell et al., 2008) have identified some potential challenges for positive people participating in the HIV response including health limitations, being further exposed to stigma, unwanted outcomes following disclosure and tokenism in program planning. Cain and colleagues found that renewed experience of good health was a challenge for some PLHIV in terms of involvement in community-based organisations, as some PLHIV no longer had the time to volunteer or participate due to paid work commitments. The research of Maxwell and colleagues, 2008, about the extent of involvement by PLHIV in strategic decision making across three areas in the United Kingdom, found variability in opportunities for involvement. The study found that one site had well established and well-resourced mechanisms for PLHIV involvement in decision making in relation to service delivery, while another site provided no opportunities for PLHIV to have meaningful involvement in decision making, relying primarily on a non-positive patient liaison person to represent PLHIV.

Aggleton and colleagues 2011, reflecting on the past 30 years of education in HIV/AIDS, observe the important role of treatment education in supporting adherence, understanding viral load and treatment failure. However, they note that all too often ARV awareness is passive and this limits its impact. They argue for the value of PLHIV as leaders in prevention as well as in care and support. Further, they observed that the involvement of PLHIV increases the confidence of other people to know their HIV status, protect their health and avoid passing on the HIV infection.

Peers

Peer education has been one of the primary community-based behavioural change interventions to prevent HIV transmission globally. It has been shown to be an effective strategy to decrease UAI and increase condom use in gay men and MSM, improve HIV knowledge and increase rates of HIV testing (Bavington, et al. 2013; Tobias et al., 2010). However, as Bavington and colleagues note, peer education programs are often not well evaluated and there is limited detail about the programs. Prestage and colleagues 2016, found that support from HIV-positive peers was associated with changes in sexual behaviour among men newly diagnosed with HIV in the four weeks after diagnosis, including reduced condomless sex with non-HIV positive partners and reduction in partner numbers.

A United States study (Safren et al., 2011) evaluated a peer-delivered, individually tailored HIV prevention intervention for HIV positive gay and bisexual men in their primary care setting. The study found that, among the men who reported transmission risk behaviour at baseline, there was a significant reduction in risk behaviour over the next year, attributable to the peer-delivered prevention intervention. Grov and colleagues, 2014, qualitative research on provider perspectives on best practice for HIV prevention targeting gay and MSM in Germany found that some organisations valued having staff and volunteers that were HIV-positive because it facilitated discussions, both with clients and within the organisation, about the social and personal issues that increase HIV transmission risks. These conversations increased the capacity of organisations to connect with PLHIV and understand the critical issues that were impacting on their target populations.

Positive prevention needs

Ridge and colleagues 2007, qualitative study of PLHIV in the United Kingdom (UK) found that HIV positive people have specific prevention needs, particularly around negotiating sex and risk. While many of the participants said that sexual partners should take greater responsibility for prevention, it was common for participants to describe taking additional responsibility for the protection of sexual partners. Another UK study observed that 'Positive Prevention' emphasises the need for PLHIV to take precautionary measures to ensure that they do not pass on HIV to their sexual partners and this approach places the burden of responsibility for prevention on PLHIV. They note the increasing recognition that rewarding sex, good mental health and positive wellbeing should be integral components of Positive Prevention (Bourne, et al., 2012). Bourne and colleagues identified a number of unmet sexual health needs among gay and MSM with diagnosed HIV including managing information about one's HIV status, and overcoming issues of self-esteem and self-confidence.

There is also a continuing need to eliminate stigma directed towards HIV-positive people as there is substantial evidence of the association between stigma and delayed testing, lower adherence to treatments and reduced access to care (Brown et al., 2017). Support and literacy in negotiating sex and risk, good mental health and

wellbeing, delay of illness progression, high self-esteem and self-confidence and the elimination of stigma about HIV are prevention needs for HIV-positive people. The literature suggests that these needs have to be met to ensure the success of contemporary HIV prevention efforts.

PrEP

Unsurprisingly, given that PrEP is a strategy primarily aimed at HIV-negative people, there is very little literature that investigates PrEP in relation to PLHIV. A French study exploring the perspectives of HIV-positive gay men and MSM about PrEP found that the men they interviewed almost always made links between PrEP and TasP. For some, PrEP offered an extra layer of protection, but for one participant, the prospect of a partner being on PrEP made no difference to him as he was entirely confident that his undetectable viral load protected his partners from onward transmission (Brisson & Nguyen, 2017). The HIV-positive men in the study shared a hope that PrEP would remove the stigma they currently faced from some HIV-negative men and create a sense of solidarity. Similarly a 2014 paper by Ted Kerr considers the potential of PrEP to neutralise HIV status divisions, but he also raises concerns that PLHIV are not being actively included in discussions about PrEP and that PLHIV need to become central to the conversation as they too are impacted by PrEP (Kerr, 2014).

What's missing?

The current literature provides evidence of the valuable role played by PLHIV in education and prevention. It also clearly establishes the ongoing need for prevention activities to include PLHIV and address issues such as stigma, disclosure and health and wellbeing, including the delay of disease progression. What is missing from the current literature is information about the prevention and negotiation skills required for the 'new safe sex environment' where condoms are no longer the only recognised form of safe sex – for example skills in navigating disclosure in the context of TasP and PrEP. Further, overall there is a lack of research documenting the different processes that underpin forms of effective prevention involving and targeting PLHIV or quantifying and qualifying the notions of 'shared responsibility' that underpin this paradigm. Some of the literature points in the direction of how contemporary HIV prevention should be conceptualised and practiced in order to meet the prevention needs of PLHIV. However, from this literature review we argue that an expanded definition of HIV prevention is needed. The predominance of available prevention literature does not reflect the fact that ending HIV transmission requires having an informed, enabled and healthy HIV-positive population who feel confident about themselves, and confident about sharing information about the contemporary realities of living with HIV and knowledge about HIV transmission with others. We propose that an expanded definition, 'Positive in Prevention', would include achieving a good quality of life for PLHIV and delaying illness progression as essential to ending HIV transmission.

THE INTERVIEWS

We used the stories of twenty PLHIV drawn from across Australia to gather information about what PLHIV think are promising directions in HIV prevention education. Extracts from the interviews are included in the report to illustrate key themes and issues. These interviews build on the knowledge already held within NAPWHA about the role of HIV positive people in prevention efforts.

Interviews were conducted with individuals who had contacted the NAPWHA Secretariat and volunteered their contact details after NAPWHA made a call out through member organisations and electronic networks. PLHIV provided their contact details and agreed to a one hour semi-structured interview. Each participant was asked whether they were comfortable with field-notes being kept by the interviewer and whether de-identified quotes and information could be used in a public document. Consent was verbal but noted by the interviewer, this consent was reviewed at the end of each interview to ensure that each person interviewed understood how the information was to be used. Each person was asked basic demographic questions and responded to a schedule of interview questions asking them to reflect on their efforts in HIV prevention work. Interviewees were also asked to provide feedback about what they thought was happening at a community level, to reflect on previous prevention strategies and campaign work and then to suggest ways forward for the inclusion of the voice of HIV positive people in future HIV prevention efforts.

The series of stepped questions moved through personal responses, then to observational comments about HIV prevention work and on to identifying potential programmatic responses.

Some of those interviewed asked for a copy of the field notes to re-check, whilst others authorised the use of information provided through consent obtained above.

The diversity of population groups, in terms of age, length of diagnosis and geographical location was reflected in a range of significantly diverse responses. Because of the amount of new information that has to be absorbed at both a personal

and community level about TasP, PrEP and combination prevention strategies, no assumption was made about the knowledge level of those interviewed. In fact, the demographic information gathered at the beginning of the interview indicated that some of those interviewed had strong and long-standing connections with community based organisations – about half of those interviewed – whilst the other half did not have any particular affiliations to community based organisations. In that sense also, the interviews captured a diversity of engagement.

So what were some of the commonalities that can be reported?

Taking self-care

There was a very clear sense that individual PLHIV felt they had to take care of themselves before they were able to take care of others. This resonates with some of the literature which identifies that HIV-positive people have their own prevention needs. That is, if HIV-positive people are to be part of the national effort to reduce HIV transmission, then their own health care, both physical and psycho-social needs, required foremost attention. As one participant expressed it:

I take my treatments, treatments are prevention, with treatments I have an undetectable viral load and can't transmit HIV. So it's simple. Take your medication and prevent HIV transmission.

For many of those interviewed taking treatments was taking care of themselves and this in turn was taking care of others.

Informal education/mentoring support of others

More than three quarters of those interviewed identified that they often took personal and context-driven opportunities to provide education and information to others, which they saw as prevention work. For these individuals this was perhaps the level of prevention 'intervention' with which they felt most comfortable. As expressed by a 65-year-old heterosexual man from Western Australia who said he had been living with HIV for 13–14 years and had very little contact with community based organisations:

I help by talking with friends and I try to educate them – informal education activities.

A woman described her decision to disclose her HIV status in her workplace, a women's refuge, because, it was an,

opportunity to transfer information [on HIV prevention] at work.

For her, this was an opportunity to share information about HIV in a context where

other women might be vulnerable to HIV and learn from this sharing of information. Even though it was not part of her job description, she saw it as important to educate other women about HIV transmission. Another person described their opportunities to act as an educator in the gay community in the following way:

I end up mentoring other people informally – quietly or discreetly I make it possible for them [other gay men] to ask questions about HIV or contact me [by disclosing my HIV status] – my personality, my job, my life skills allow me to do that, as well as my own personal networks.

It is worth noting that some of those interviewed said that there were limits to their willingness to do this 'all the time'. In particular, some of the gay men interviewed talked about the expectation of disclosure as 'being a burden'. These men said that it was deeply problematic that in their situation – being on treatments and with an undetectable viral load – they should be expected to speak out about their HIV status either socially or in the context of sexual encounters. However, for some participants, when they did disclose it was a chance to provide information about HIV transmission risks. The PLHIV who said they engaged in informal HIV prevention and education work, tended to rely on getting correct and current information from community organisations and their doctors – it is only then that they said they feel confident about the messages they are communicating. Those who said that they were willing to, . . . ***put themselves on the line***, through disclosing their status, said this was only possible because they felt well and confident in themselves.

Other participants described being in situations where they did not feel able to share their HIV status because they felt that . . . ***a kind of conservatism*** existed, either in particular geographical locations, or within their family and also within the gay community. In describing this conservatism they said that they feared they would be subject to discrimination or rejected for any one of a number of reasons, including that they would be perceived as undesirable sexual partners, even though they had an undetectable viral load. The fear that participants expressed in regards to these 'conservative environments' was that others around them had no understanding that HIV was now a manageable illness. For some participants, the communities in which they lived lacked basic knowledge about modes of HIV transmission, let alone knowledge that with current treatments PLHIV could have undetectable viral loads and therefore could not transmit HIV in sexual encounters. In these contexts, participants felt unable to carry the burden of conveying contemporary prevention messages alone. In these conditions, some participants felt invisible and they believed it necessary to keep their HIV status hidden.

Positive people as leaders in prevention education

Over half of those interviewed referred, positively, to the recent NAPWHA Quality of Life Campaign. Some also recalled previous campaigns of NAPWHA such as Start the Conversation and The Wait is Over. These were referred to in the context of the

messaging that the campaigns gave to the broader community about the diverse lives of PLHIV. The campaigns educated others about the lives of PLHIV and about HIV transmission.

The role of more formalised Positive Speakers projects were also noted as an important way in which those who are not living with HIV are given information about the current experiences of living with HIV. These speakers' projects, also known as bureaus, and the social media campaigns articulate a way of being a person with HIV, a way that involves medication adherence; retention in care; having friendship networks; enjoying a family life; having sexual and reproductive health rights; and perhaps a career and the possibility of experiencing love. Positive speakers and the social media campaigns are attempts to normalise the experience of living with HIV. HIV-positive people who participate in these activities provide leadership by demonstrating that HIV is a manageable illness and that people with HIV do not need to be feared.

Many of the participants felt strongly that PLHIV had played leadership roles in HIV education, prevention, policy and research throughout the epidemic and that this involvement needed to be continued in the emerging biomedical prevention era:

Positive people really took over as leaders with their knowledge of medication and the application of that . . . we were more than patients, we were leaders in prevention, education, research implementation and policy . . . now with an emphasis on achieving an undetectable viral load (which isn't always possible) . . . now more than ever we should be involved . . . we need to be involved.

Some participants felt that messages about undetectable viral load needed to come from a diversity of sources to ensure it was better understood:

There needs to be much clearer campaigns around undetectable = uninfected. This shouldn't just be the coming from positive people but also from other organisations who will promote that message

Another participant felt that PLHIV were carrying too much of the burden of educating others about undetectable viral load:

Individuals are fighting that battle by posting information about what undetectable means . . . but this message is not being given clearly by doctors and other organisations and whilst they don't do it, it's left to the positive community to do it themselves.

These accounts suggest that some PLHIV do not always experience HIV prevention as a shared project.

The current prevention needs of HIV-positive people

All those interviewed made reference to the negative influence of stigma on prevention for HIV-positive people. One interviewee observed that it was difficult for PLHIV to play **an upfront role in** HIV education and prevention if they lived in smaller jurisdictions – this is due to the discrimination that is often experienced by PLHIV outside of large cities, but also experienced by PLHIV in capital cities of smaller states and territories. They believed that a national campaign aimed at increasing knowledge of the contemporary experience of living with HIV among the broader Australian community would make **it easier for positive people everywhere**.

Another interviewee wanted to see Australia wide television advertisements that normalised HIV and treated it as part of health generally and sexual health in particular. A number of interviewees felt there was a need for information about the meaning of undetectable viral load in terms of onward transmission and this needed to be targeted primarily at non-positive people but also at PLHIV as levels of knowledge about TasP varied among PLHIV. A number of interviewees felt that on-line hook up sites and social media were likely to be effective sites for messaging around PrEP and undetectable viral load for gay and bisexual men; **social media is the answer, that's the way gay men talk now**. Other interviewees were less enthusiastic about explicit prevention messages in the on-line hook up spaces.

The calls for large scale media campaigns are suggestive of a sense of invisibility experienced by some PLHIV, and a desire for others in the Australian community to better understand what HIV is in contemporary Australia. These accounts show that PLHIV take seriously their role in educating about HIV and preventing onward transmission, but they also show that at PLHIV can feel burdened by the responsibility.



Prevention strategies have moved beyond 'use a condom every time', therefore prevention information to be communicated at the community level needs to be more sophisticated and nuanced.

Summary of the interviews

In terms of prevention activities carried out by PLHIV, there are individual efforts being made where possible and contextually appropriate. Individuals talked about being protective of their own health through taking treatments and their interest in protecting others from HIV transmission. Many talked about the importance of 'informal education' of other people as they meet them, either through sexual encounters or in the ordinary course of their daily lives. In the interviews conducted, more than three quarters noted that they educated others about HIV in 'informal' and 'opportunistic' moments.

PLHIV share information at a community level about current experiences of HIV treatment but they also share information about HIV prevention strategies generally. Prevention strategies have moved beyond 'use a condom every time', therefore prevention information to be communicated at the community level needs to be more sophisticated and nuanced.

Contemporary understandings of HIV at a societal level need to be updated and understood if the full benefits of TasP are to be realised. Unfortunately there is not widespread information about what an undetectable viral load means and its impact on HIV transmission risk. Nor is the contemporary lived experience of PLHIV well understood within the wider society. The recent Quality of Life campaign by NAPWHA is highly regarded as it constructs and deconstructs the myriad ways in which living with HIV today is done. If there are not clear understandings at a societal level, then HIV prevention efforts will 'miss the mark' and in turn HIV-positive people will be discouraged from being clear and open about the way they live their lives, and this includes their sexual lives. If HIV prevention efforts are to be successful, visibility and societal understanding of the lives of PLHIV, albeit hard to achieve, is necessary.

CONCLUSION

The literature, interviews and consultations identified a range of benefits of PLHIV participation in the conceptualisation, design, implementation and delivery of HIV prevention programmes. These include empowering PLHIV, reducing social isolation, changing risk behaviours, reducing stigma and discrimination, building resilience in PLHIV and increasing antiretroviral therapy uptake. PLHIV engage in a range of formal and informal prevention activities, yet they are often offered little to address their own prevention and sexual health needs. While many PLHIV understand HIV prevention to be a shared responsibility, in practice the burden for preventing onward transmission is often carried by PLHIV.

In this paper we have identified that HIV prevention often targets PLHIV only in terms of preventing onward transmission and as such does not recognise prevention as something that is also for PLHIV. Many positive prevention programmes exclude the health, wellbeing and prevention needs of PLHIV. We propose that a broader definition of positive prevention is required. We argue for a conceptualisation and practice of positive prevention, that draws on the unique expertise of PLHIV and recognises that health, wellbeing, and human rights are essential components of prevention. We propose the term 'positive in prevention' as a way to articulate the agency and centrality of PLHIV in ending HIV transmission.

PLHIV have played a central role in the HIV prevention response in Australia and internationally. In order to achieve the current treatment and prevention targets set out in the national and state-based HIV strategies, PLHIV must be meaningfully involved in the development and implementation of an integrated framework of prevention that includes testing and diagnosis, treatment, care and support.

REFERENCES

Aggleton, P., Yankah, E. & Crew, M. (2011). 'Education and HIV/AIDS: 30 years on'. *Aids Education and Prevention*, 23(6), 495-507.

Bavington, B., Gray, J. & Prestage G. (2013). 'Assessing the effectiveness of HIV prevention peer education workshop for gay men in community settings'. *Australian and New Zealand Journal of Public Health*, 37, 305-310.

Bernard, D., Kippax, S., & Baxter, D. (2008). 'Effective partnership and adequate investment underpin a successful response: Key factors in dealing with HIV increases'. *Sexual Health*, 5, 193-201.

Bourne, A., Hickson, F., Keogh, P., Reid, D. & Weatherburn, P. (2012). 'Problems with sex among gay and bisexual men with diagnosed HIV in the United Kingdom'. *BMC Public Health*, 12
www.biomedcentral.com/1471-2458/12/916

Brisson, J., & Nguyen, V-K. (2017). 'Science, technology, power and sex: PrEP and HIV-positive gay men in Paris'. *Culture, Health and Sexuality*, online first, doi:10.1080?13691058.2017.1291994

Brown, G., O'Donnell, D., Crooks, L., & Lake, R. (2016). 'Mobilisation, politics, investment and constant adaptation: lessons from the Australian health-promotion response to HIV'. *Health Promotion Journal of Australia*, 25, 35-41.

Brown, G., Leonard, W., Lyons, A., Power, J., Sander, D., McColl, W., Johnson, R., James, C., Hodson, M., & Carman, M. (2017). 'Stigma, gay men and biomedical prevention: the challenges and opportunities of a rapidly changing HIV prevention landscape'. *Sexual Health*, 14, 111-118.

Cain, R., Collins, E., Bereket, T., George, C., Jackson, R., Li, A., Prentice, T. & Travers, R. (2014). 'Challenges to the involvement of people Living with HIV in community-based HIV/AIDS organization in Ontario, Canada'. *AIDS Care*, 26(2), 263-266.

Commonwealth of Australia. (2014). *Seventh National HIV Strategy 2014-2017*.

Crowther, S., Ironside, P., Spence, D., Smythe, L. (2016). 'Crafting Stories in Hermeneutic Phenomenology Research: A Methodological Device'. *Qualitative Health Research*. 1049732316656161.

GNP+ & UNAIDS. (2009). 'Positive Health, Dignity and Prevention'. *Technical Consultation Report*, Amsterdam, GNP+.

Grov, C., Restar, A., Gussman, P., Schlemmer, K., & Rodriguez-Diaz, C. (2014). 'Providers' perspectives on the best practices for HIV prevention for men who have sex with men in Berlin, Germany: Lessons for policy and prevention'. *AIDS Education and Prevention*, 26(6), 485-499.

Kerr, T. (2014). 'Who is HIV for?' *Women's Studies Quarterly*, 42(3/4), 333-338.

Maxwell, C., Aggleton, P., & Warwick, I. (2008). 'Involving HIV-positive people in policy and service development: Recent experiences in England'. *AIDS Care*, 20(1), 72-79.

Poz Action Group (2013). The Vital Role of PWHIV in Prevention. <http://napwha.org.au/about-us/poz-action/poz-action-vital-role-PWHIV-hiv-prevention>

Plummer, K., & Irwin, L. (2006). 'Grassroots activities, national initiatives and HIV prevention: clues to explain Australia's dramatic early success in controlling the HIV epidemic'. *International Journal of STD & AIDS*, 17, 787-793.

Prestage, G., Brown, G., Allen, B., Ellard, J., & Down, I. (2016). 'Impact of Peer Support on Behaviour Change Among Newly Diagnosed Australian Gay Men'. *Acquired Immune Deficiency Syndrome*, 72(5), 565-571.

Ridge, D., Ziebland, S., Anderson, J., Williams, I. & Elford, J. (2007). 'Positive prevention: Contemporary issues facing HIV positive people negotiating sex in the UK'. *Social Science and Medicine*, 65, 755-770.

Rule, J. (Ed.) 2014, *Through our eyes: thirty years of people living with HIV – responding to the HIV and AIDS epidemic in Australia*. National Association of People with HIV Australia. Sydney. Available as flipbook at http://issuu.com/napwa/docs/through_our_eyes__flipbook_

Rule, J. & Watson, J. 2014, 'Stepping up the Pace: Let's Have Everyone in Step!', *Human Rights Defender*, vol. 23, no. 2. pp. 8-11 <http://www.ahrcentre.org/news/2014/07/21/611>

Safren, S., O'Cleirigh, C., Skeer, M., Driskell, J., Goshe, B., Covahey, C. Mayer, K. (2011). Demonstration and evaluation of a peer-delivered, individually-tailored, HIV intervention for HIV-Infected MSM in their primary care setting. *AIDS Behaviour*, 15, 949-958.

Tobias, C., Rajabium, S., Franks, J., Goldenkranz, S., Fine, D., Loscher-Hudson, B., Colson, P. & Coleman, S. (2010). Peer knowledge and roles in supporting access to care and treatment. *Journal of Community Health*, 35, 609-617.

UNAIDS. (2007). The Greater Involvement of People Living with HIV (GIPA). *UNAIDS Policy Brief*.

“VISIBILITY IS NECESSARY
BUT DIFFICULT.”

“I HAVE A SENSE OF
ALTRUISM TOWARD
OTHERS.”

“I HELP BY TALKING
WITH FRIENDS AND TRY
TO EDUCATE THEM —
INFORMAL EDUCATION
ACTIVITIES.”

“PEOPLE ARE GOOGLING
STUFF AND GETTING
INFORMATION FROM
WRONG PLACES.”