

AFAO/NAPWA HIV Educators' Conference 2004

New Technologies New Responses

May 20-21, Powerhouse Museum, Sydney

Search Stream Report

Positive in Prevention

Introduction

This document attempts to capture some of the wide-ranging and detailed consideration of Positive in Prevention that occurred at the conference. This document is limited by the process of transferring ideas to conversation, conversations to whiteboard notes, notes to this document, your reading and interpretation of what it means. At each stage of the process some of the detail, subtlety and nuance have been lost. Also it is important to note that workshops produce a diversity of suggestions provided with the aim of enhancing understanding. None of the material should be read as a specific criticism of any particular organisation or individual. I hope this document can serve to inform interested people as to some of the complexity and hopefully inspire many to act.

I would like to thank all of the participants in the search stream. The willingness, care and enthusiasm of all participants left me feeling empowered and inspired. I would like to especially thank Cipri, Peter and Phillip for facilitating the stream in a manner that lead to outcomes from a vast terrain of issues. Finally I would like to thank the organisers of the conference, NCHSR, AFAO and NAPWA and all who made this event possible.

There are defects in this document and I accept responsibility for them. If they irritate you please use the irritation to let people know how we can better achieve our goals.

Regards

Ian Rankin

Overhead presentation from Rapporteur's reports final plenary

Positive in Prevention

Search Stream feedback

Principles

- Do no harm – care for self and others
- We have a right to a full and satisfying sexual life – Sex positive.
- Entitled to understanding, access & use of prevention technologies in context of sex eg microbicides, vaccines
- Prevention - best achieved through collective response and mutual responsibility
- Acknowledge humanity, vulnerability and fallibility

Challenges

- Subverting Blaming, shaming and 'othering'
- Building self esteem
- See sex primarily as pleasure - not risk
- Skills building for orgs re: issues across all programs (no sero ghettos)
- Legislation punitive – needs reform & supportive community processes

Existing models

- Positive Health Promotion [expand to include prevention as part of programs]
- Programs holistic needs of +tve - beyond serostatus servicing
- Good time to re-affirm first principles – eg.Ottawa Charter

Gaps in programs

- Affirming sex positive and celebrate low levels of infection (focus on success not increases)
- We only reach known serostatus – how reach/talk to undiagnosed
- Positive involvement in planning, implementation and evaluation of programs
- Need to create different levels of opportunity to participate for +tve people
- Wholistic capacity building, refreshing our activities to PLWHA so they can play a central role in prevention and health promotion.

Potential new approaches

- Opportunities for safe spaces for free discussion
- Expansion of positive speakers bureau
- Inclusion of positive people in all prevention strategies
- Create supportive environments – use public events (eg WAD) to build community understanding

We condemn

- The USA approaches
 - That include Fear, Blame and Shame
 - Stigmatise Positive people
 - Forcing +tve people to shoulder all the prevention burdens
 - Make us fearful of sex

And DON'T WORK

HIV-positive men and women have significantly contributed to and continue to participate in HIV prevention and education. As the ‘body positive’ continues to grow, maintaining HIV-positive involvement in education and prevention strategies is vital in developing interventions that address the challenges of a shifting and ongoing epidemic, such as building ‘cultures of care’ between sex partners and drug users. But how do we create environments in which positive people want to participate? And should they even want to? How do we encourage collective responsibility for action and prevention while maintaining the individual rights of PLWHA, some of whom continue to battle poor health, stigma and discrimination? And how do we allow for the persistent influence of science, medicine and technology on the lived experience of being positive?

The idea of ‘positive in prevention’ implies an engagement with the ethics of positive sexual practice that examines both the rights and responsibilities of bearing ‘the virus’ when dealing with others. It also suggests that we attend to the ways that technology (such as testing, treatments and scientific expertise) both enables and constrains positive practice, and what that means for prevention efforts. For example, how does knowledge about viral load affect PLWHAs’ sense of being ‘infectious’ and decision-making about sexual practice? How do PLWHA experience both the promise of treatments (the chance of a near ‘normal’ future) and the ongoing uncertainties of resistance, toxicity and unexpected side effects?

What can we learn from existing models of positive participation in education and prevention? What new models are emerging here and overseas?

Recommendations:

- 1) Positive in prevention should sit within a broader Positive Health Promotion framework in Australia: ANET should facilitate a quick review of such efforts amongst AFAO and NAPWA efforts that identifies prevention components of Positive Health Promotion Campaigns and shares examples of effective efforts amongst organizations.**
- 2) Need to acknowledge and develop different health promotion strategies for +tve and –tve men. Differences may include: intensity of interaction (eg advertising versus one to one), subject matters, style and objectives.**
- 3) Need specifically tailored efforts for specific communities especially given community is understood differently in gay, straight, CALDB, Indigenous groups**

4) Need to create a background of interest in prevention across the Australian community and then within that specifically designed efforts that meet the needs of gay, positive, CALDB, Indigenous and other audiences.

Additional comments from search stream groups

- The USA response
 - o Increased surveillance, shifting of responsibility for prevention to +tve individuals, a ‘containment’ approach
 - o Leads to increased stigma and discrimination – faulty in terms of human rights and established effective educational strategies
- People who know their HIV status are burdened with exceptional responsibilities
- How can people who don’t know they are positive be reached in prevention efforts?
- Need to acknowledge difference between +tve and –tve cultural perspectives and lived experience
- Need for a general environment that supports shared responsibility perhaps “do no harm, care for self and care for others”
- Value in using +tve people, their experience and knowledge in education programs and initiatives
- Distancing of some people (notably younger people) from Gay identity challenges prevention strategies
- Three conversations/approaches –tve to –tve, +tve to +tve and +tve to –tve
- Loss of sense of community (including increasing splintering into sub group identities) allows for downplaying collective responsibility to address HIV issues.
- Need encouragement to affirm and celebrate our sexuality, vulnerability and humanity
- World AIDS Day still provides a useful opportunity to engage with the Australian community at large

What conditions are required to encourage positive participation? What are the barriers and how can they be overcome?

Recommendations:

- 5) Need to challenge stigmatized perceptions of +tve people as “dirty and promiscuous”**
- 6) Need to create multiple options for participation that allow for self determined levels of public disclosure and effort**

- 7) **Need to reflect on the different experience of living with HIV at different ages in the context of an aging positive population and to effectively address positive health promotion needs of different age groups**
- 8) **Need to address the location specifics of city - town - country and the impact geographic location can have on lived experience, access to structures and inclination to participate.**
- 9) **Research the range of motivations for positive people in prevention – to what extent does altruism, care, fear, habit etc play in positive sexual lives.**
- 10) **Establish a minimum skills and knowledge set for all HIV educators (paid and unpaid) regardless of their priority population.**

Additional comments from search stream groups

- Respect diversity in positive population – do not strive for a conformist image of the positive population
- It is useful to reflect on terms of self description, some now find PLWHA to be an out of date term
- Positive Speakers Bureau have proven they are of value for both the audiences and the speakers
- Language is important and needs to be inclusive of HIV+ people
- Need to create safer environments for disclosure
- Potential risks in talking about HIV treatments as “reducing community viral load” as HIV treatments a basic health right not just a prevention strategy
- Prevention efforts that focus on “HIV is terrible” conflict with positive health promotion efforts that advocate “HIV is treatable”
- Current Australian government focus on treatments is limiting as there is much more to Positive Health Promotion

What are the politics of encouraging greater positive participation in prevention? How do we subvert expectations of responsibility and pos/neg divisions to build coalitions for prevention?

Recommendations:

- 11) **AFAO and NAPWA members could review current program and address barriers to increased positive participation in prevention and share effective practice with other organizations.**

- 12) **Perceived ongoing shifting of responsibility from one group to the other – need to model and promote what shared responsibility involves on both sides of the sero divide.**
- 13) **Expand work on sero-discordant (magnetic) relationships and incorporate useful messages in broader prevention efforts**
- 14) **Explore, record and acknowledge different sexual ethics and understandings that arise from the experience of living HIV+**
- 15) **Has there developed an over identification with victim-hood in some poz people? Has the sector encouraged this? How are such people supported to move beyond claims for exceptional consideration (in cases where it is not justified)**
- 16) **Review barriers within the community sector for poz people to participate in programs and initiatives that are not related to their HIV status or playing the “Viral exhibit A” role.**
- 17) **Sex needs to be perceived as pleasure not risk**
 - **Provide solutions not problematize sex**
 - **Create environments for better and safer sexual expression**
 - **Affirm the safety of safer sex – try to minimize unwarranted fear of transmission**
- 16) **Support self-esteem initiatives across all program areas and work to promote cultures of care for self and for others.**
- 17) **Produce education tools that assist in dealing with the offer or request for bare-backing**

Additional Comments from search stream groups

- Use the voice of –tve people about their understandings and practices of shared responsibility
- Challenge myths and assumptions
- The limitations of HIV treatments (ongoing lifetime – not a cure) need to be better understood within wider and our own communities
- Create supportive spaces for +tve to +tve discussion of sex, transmission and other issues, recognizing there is likely to be considerable diversity of opinions and approaches.
- Need to acknowledge and respect the lack of risk in poz/poz sex and the impact this has on safe sexual habits and understandings
- Viral infection does not transmit personal responsibility to “save the world” – this needs to be respected

- Actively work to subvert blame messages and understanding and use education capacity to promote shared responsibility ethos
- Celebrate infections avoided to date rather than fetishizing new percentage increases.
- Provide effective, appropriate and non-judgmental support for individuals concerned about non-safe sexual events

How do scientific and medical technologies of HIV affect the experience and practice of being positive? How do we incorporate our understanding of these effects into prevention efforts?

Recommendations:

- 18) Positive people have a right to understand use and have access to medical technologies (including personal use of emergent technologies such as microbicides and future vaccines and their partners use of PEP and PREP), in the context of sex.**
- 19) Need to operate beyond medical conceptualization of being positive and ensure research includes lived understandings**
- 20) Need to promote wide ranging understanding of being positive (broad social impacts – mortality, uncertainty, infectivity, social exclusion) rather than narrow clinical understanding (viral load and pills)**
- 21) Need accurate information on new prevention technologies included in educational materials and strategies.**