

# HUMAN IMMUNODEFICIENCY VIRUS POSITIVE

CHALLENGING HIV STIGMA  
PANEL FORUM  
DECEMBER 2018

## Event Summary Report



## Panel details

Date	Tuesday 18 <sup>th</sup> December, 2018
Venue	City Recital Hall, Sydney
Moderator	Dr Norman Swan – Producer/presenter of the Radio National <i>Health Report</i>
Panel	<p>Abby Landy – BGF Board Member (peer)</p> <p>Professor Carla Treloar – Director of the <i>Centre for Social Research in Health</i> and the <i>Social Policy Research Centre</i> at UNSW</p> <p>Dai Aoki – Community Health Promotion Officer, ACON (peer)</p> <p>David Crawford – Treatments Office, Positive Life NSW (peer)</p> <p>Karl Schmid – US based journalist, ABC Entertainment (peer)</p>
Video feature	David Polson (peer)



## Objectives of the forum

- Highlight the damage that stigma and discrimination causes to PLHIV
- Increase awareness that HIV is simply a manageable chronic illness and help to open up conversations in the wider community about what it means for people to be living with HIV
- Build a strong activist and ally network in the wider community to encourage trust, openness and acceptance for PLHIV
- Empower PLHIV to seek treatment and care
- Work collaboratively with ACON and Positive Life NSW to present a united HIV community organisation front



## Audience snapshot

As well as inviting contacts within the HIV and sexual health sectors (i.e. S100 Doctors, NSW Health, HARP, LHN), we specifically targeted people who work on the fringes of the sector – Members of Parliament, Shadow Ministers, Clinicians, Pharmacists, NSW Police, NSW Housing, Aged Care providers, Anti-Discrimination Board, Human Rights Commission, Health Justice Australia, Media and Emergency Services.

The demographic of the attendees was spread across PLHIV, Corporate Partners, Community Organisations, Clinicians, NSW Health staff, Research entities (Kirby, NSW Centre for Social Research), Pharmaceutical, NSW Police and other interested parties.

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## Findings

- Stigma is commonly experienced by PLHIV within the health care sector
- Self-stigmatisation occurs due to the way HIV is portrayed in mainstream media
- Stigmatisation within the gay community was a common experience among our LGBTIQ panel members
- The impact of stigma resulted in people living with HIV :
  - Not getting tested
  - Not seeking treatment from healthcare professionals
  - Having uncomfortable healthcare experiences
  - Retreating from social settings and becoming more isolated
  - Not feeling comfortable disclosing their status
  - Not seeking relationships for fear of a negative reaction
  - Living a substandard quality of life

To deal with stigma we need to consider multiple strategies:

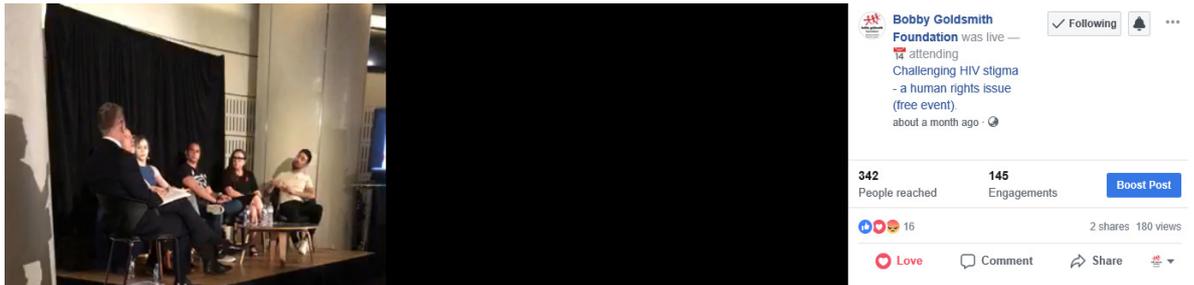
- Visibility
- Awareness
- Education for healthcare professionals
- Resilience programs for PLHIV
- Breaking down structural stigma

Actions:

- Identify HIV champions – opinion leaders who can be outspoken and strong
- Normalise the conversation around HIV
- Encourage PLHIV to talk openly
- Develop an Ally program to support PLHIV
- Provide education for healthcare professionals
- Promote testing so that people know their status

## Forum tangibles

- Stigma content map
- David Polson video
- Panel transcript
- Support Contacts card
- HIV Ally card
- Video recording of panel forum : 342 people reached | 178 views



## Anticipated outcomes/impact

Anticipated outcomes of the panel forum:

- An increased awareness that HIV is simply a manageable chronic illness, which will open up conversations about what it means for people to be living with HIV
- PLHIV will be empowered to seek treatment and care
- Trust, openness and acceptance for PLHIV can be encouraged by building a strong activist and ally network
- Opportunity to work with NSW Police Surry Hills Command to provide education around HIV
- Karl Schmid is keen to be an PLHIV Ambassador and happy to do more with us



## Content Map

### 1. Setting the scene

- a. Stories of people living with HIV
  - i. Why is stigma still an issue?
  - ii. Why is the discussion around stigma important?
  - iii. 30 years on, why have we not found an effective response to HIV-related stigma?
  - iv. How does HIV stigma impact other populations of PLHIV who don't have access to the resources and community available to the LGBTIQ sector?

### 2. What does stigma look like today?

- a. Personal experience
  - i. Do you feel that HIV has changed the person that you are?
  - ii. How does stigma affect your thoughts when deciding whether to disclose your HIV status? How do you address it? Once stigmatisation has been internalised, what can a person do to feel free from its grip?
- b. Blatant and covert stigma; Structural stigma
  - i. Have you personally experienced stigma and discrimination?
  - ii. What forms did they take?
  - iii. To access free HIV testing and supporting services, a risk assessment is made based on sexual identification and behaviour. What impact does this have on ongoing stigma and discrimination towards PLHIV? Does the impact differ in different, or hidden communities?
  - iv. What is your understanding of how stigma operates in CALD communities, and the impact on uptake of test, treat, prevent?
  - v. What are some ways that PLHIV may face stigma when it comes to food and nutrition literacy, and how can we minimise or combat this?
- c. Research around stigma
  - i. What does the latest research tell us about the broader lived experience of HIV stigma?
  - ii. Who is it impacting and how?

### 3. How to react or respond to stigma

- a. Resilience; Support Networks; Picking your battles
  - i. How do you explain stigma to someone without a lived experience of HIV?
  - ii. When did you find the confidence to be able to talk about your HIV so openly?
  - iii. How do you personally build resilience?
  - iv. Does the research show how resilience is developed?

- v. What lessons could CALD communities take away from the gay community's response to HIV in the 80s, regarding how to address HIV-related stigma?
- vi. Would you keep going to seek help from health care providers if you have experienced discrimination over and over?

#### 4. Looking forward

- a. What the future looks like for PLHIV; Aged Care and an ageing PLHIV population; Police engagement; Disclosure in the workplace
  - i. For many people in the population, HIV and AIDS has disappeared from awareness but stigma and discrimination continues. What NEW strategies should be considered to eliminate discrimination?
  - ii. What message would you give to PLHIV about stigma?
  - iii. What does your future living with HIV hold? What are your concerns? What do you look forward to?
  - iv. Is there a need to make HIV testing a regular part of a health check? In your opinion, would it aid the process of de-stigmatising HIV?
  - v. What steps can an NGO community and residential care provider take to end stigma?
  - vi. Recent increases in HIV diagnoses attributable to heterosexual sex has found lower HIV treatment uptake by heterosexual PLHIV. Other than to increase access to treatment as a means to address HIV-related stigma, what more can be done to tangibly address the health and social consequences for heterosexual PLHIV?
  - vii. Many employers are pursuing diversity and inclusion agendas to ensure diverse thought and contributions from employees. Do you think this is an opportunity to further reduce the HIV stigma that may still be around in the workplace?
  - viii. How do we know when we've solved the issue of stigma? What are the indicators that we've achieved this?

## Feedback on event

“I wanted to pass on my acknowledgement of the panel event in December as it was a brilliant event. Engaging, informative and raw. I left inspired and deeply touched by the honest engagement and many take-aways from the evening. You should all be commended.”

– Clare Pearson, CEO of Project Futures & BGF Board Member

“I thought it was an excellent event. Really interesting and engaging convo. Beautiful venue.”

– Karl Johnson, Manager Gay Men’s and Sexual Health Team at ACON

“Just had the opportunity to watch the panel discussion ... fabulous!”

– Jenny Heslop, Area Manager at HARP, Mid North Coast LHD

“Thank you very much and it was a privilege to be part of the panel.”

– David Crawford, Treatments Officer at Positive Life NSW

## Future ideas

Concepts	Opportunities
Launch a ‘Human Positive’ campaign with a range of faces and stories about HIV: support (casework, volunteers), love (family, friends, allies), funders (Health, donors)	Work with ACON & Pos Life
Create an HIV Ally campaign	Work with ACON & Pos Life
Continue to ‘normalise HIV’ across our social media platforms – promote it as a manageable chronic illness like diabetes or heart disease	Social Media
Promote HIV testing as part of regular health checks	Social Media
Promote U=U messaging	Social Media
Call out stigma when we see it (social media/use Nick’s voice)	Social Media/Press
Healthcare Professionals education program	Work with Gilead
NSW Police stakeholder engagement	GLLO