

2021 workshop evaluation survey report

**People living with HIV
who identify as heterosexual**





Acknowledgements

Positive Life NSW acknowledges the support of the NSW Health Ministry of Health, The Albion Centre, the HIV/AIDS Legal Centre (HALC), the Bobby Goldsmith Foundation, Clinical Nurse Consultant Gary Keogh, Dr Prital Patel, staff from the Heterosexual HIV/AIDS Service NSW (Pozhet), staff of Positive Life NSW and the brave and resilient members of the NSW Body Positive living with HIV who identify as heterosexual.

Author: Positive Life NSW

Further Information

For further information on this community survey report, please contact:

Email: contact@positivelife.org.au Phone: (02) 9206 2177

August 2021

All images used in this publication are sourced stock photography posed by models and are used for illustrative purposes. They do not imply any particular HIV status, sexuality, attitudes, or behaviours

Contents

Executive Summary	2
Introduction	3
Discussion	6
Appendix	10

Executive Summary

The combined Positive Life NSW/ Pozhet Heterosexual Workshop held in June 2021, was an opportunity for people living with HIV who identify as heterosexual to connect with each other and share experiences, in a safe, confidential and understanding peer support environment.

Participants heard from a range of speakers who offered options and strategies regarding legal and health topics, especially around COVID-related issues. Participants also heard from others living with HIV (peers) sharing their own experiences, questions and solutions fostering a sense of community for an otherwise disparate and isolated group of people.

“TO KNOW EACH OTHER’S WITH SAME PAIN. I WAS ALONE PASSING VERY HEARD (SIC) TIME BUT GET TOGETHER FEELING MORE HOPE AND CONFIDENT.” – PARTICIPANT

HIV related topics – Workshop topics ranged from legal, financial, health and wellbeing, HIV treatments, COVID-19 considerations, including issues of disclosure, social isolation, planning for retirement, managing interactions of prescribed and over-the-counter medications, and vaccine hesitancy. All these topics were well received by participants with a desire for more information despite some critical issues of time pressure, effectiveness and availability.

Connecting with peers – Many participants living with HIV expressed the value of peer connecting, sharing and being present with their peers in a safe, confidential environment with the aim of reducing isolation and maintaining up-to-date awareness of the latest HIV related information. Participants appreciated being “able to interact freely” without concerns about what “the person sitting behind me might hear”. Despite some challenges such as “getting up the nerve to go”, participants overwhelmingly expressed a number of positive impacts of interacting with their peers.

“I was able to interact freely without caring the person sitting behind me might hear what I am saying.”

Introduction

On Saturday 5 June 2021, Positive Life NSW (Positive Life) in partnership with the Heterosexual HIV/AIDS Service NSW (Pozhet) conducted a workshop for people living with HIV who identified as heterosexual.

Approximately forty (40) men and women living with HIV attended the forum and the room was laid out with chairs surrounding large circular tables with the aim of encouraging inclusion, discussion and to contribute to the free-flowing conversation dynamic amongst all participants. The forum was held at in Ultimo, so people could easily attend the forum and access the venue via public transport (buses, trains, light rail, Uber, taxi etc.).

Positive Life CEO, Jane Costello welcomed forum attendees, followed by Yvonne Weldon who conducted a *Welcome to Country*. Positive Life Deputy CEO, Neil Fraser ran an introductory session to the day for approximately twenty to twenty-five minutes which addressed participants' expectations for the day.

Large blank sheets of paper were distributed to groups of four to six attendees including staff members gathered around the tables. Attendees wrote on the sheets addressing two main questions: What do you want to get out of today? and What are your concerns about today?

This activity generated discussion between people which was supported by Positive Life and Pozhet staff members. After these sheets were collected by Positive Life staff, topics were collated and are presented at *Table 1: Introductory Session – Participants' Expectations and Concerns* (page 4).

Once the introductory session exercise was completed, Jane Costello offered a brief overview of Positive Life as a peer-led peer-run agency, including the various services and programs available by and for all people living

with HIV. She directed attendees to the list of resources available in their workshop bags that participants had been given on arrival. This resource included a curated list of HIV services tailored to people living with HIV who identify as heterosexual, including a resilience and self-empowerment handout from The Albion Centre, copies of the Positive life Talkabout magazine and Pozlite magazines, and items for self-care including a book on mindfulness, relaxing essential oils, herbal tea and a mug, a candle, chocolate, and a notebook and pen.

Positive Life Communications Manager, Craig Andrews offered a brief outline of the benefits of Positive Life membership, and highlighted how attendees could receive timely information about social inclusion activities and events. Pozhet staff, Brooke Dailey and Susan McGuckin provided a brief overview of Pozhet services which was followed by morning tea.

After morning tea, Senior Clinical Psychologist from The Albion Centre, Dr Shiraze Bulsara, addressed the group discussing mental health, managing anxiety and the value of mindfulness. Dr Bulsara offered a handout to participants at the conclusion which contained links, and further contacts for support. This session concluded with lunch and time for networking and discussion which lasted an hour. During lunch, some afternoon presenters also joined the group for lunch and conversation.

The first session after lunch was called '*Do I have to tick the box, and which box do I tick?*' Two separate presenters spoke during this time.

The first was Alexandra Stratigos, the Principal Solicitor from the HIV/AIDS Legal Centre (HALC) NSW. Alexandra spoke to issues of disclosure, stigma and discrimination and how HALC can assist people living with HIV to address these from a legal perspective. This

Introduction

Table 1: Introductory Session – Participants' Expectations and Concerns

Expectations

- Updates on HIV treatments
- Understanding COVID-19 vaccines
- ARV medication and side effects
- Meeting new people (heterosexual) living with HIV and looking forward to reconnecting with the old ones
- When and how to disclose HIV status
- Disclosure of HIV status while applying for work /services.
- Sharing experiences
- Nutrition and healthy eating
- Planning ahead when travelling for a long period (medication and insurance)

Concerns

- Side effects of COVID-19 vaccines
- Overcoming stigma and discrimination
- How to respond to reactions after disclosure
- Concern of the mental health and anxiety of the future
- Health professional attitudes towards people living HIV
- Living with HIV and COVID-19 vulnerability
- Social isolation particularly during COVID-19 and what's PLNSW organisation doing to address this issue.
- Ageing with HIV and drugs effects
- What happens after life especially for the one isolated from families and friends

Hopes

- Social events which are less structured
- More fun events (e.g. bowling, yoga, craft days}
- Good food
- More events like this

Introduction

discussion generated some personal accounts, questions, answers and reflections from participants.

The second speaker was Barry French, Financial Counsellor from Bobby Goldsmith Foundation (BGF). He addressed the benefits of financial counselling for people living with HIV, including the value of saving to prepare for retirement and older age, including paying down debt, building superannuation and practical actions people can take before the financial year ends.

The second session was titled '*Drugs, Dosages and Dilemmas...*' also presented by two speakers. The first speaker was Gary Keogh, Clinical Nurse Consultant who spoke using a PowerPoint presentation about the multiplicity of medication and treatments, medicine interactions and complementary therapies. He also touched on upcoming HIV treatments such as long-acting antiretroviral injectables.

Gary was followed by Dr Prital Patel, a Research Fellow with The Kirby Institute, UNSW Sydney who discussed the issue of COVID-19 vaccine hesitancy and the different concerns people have about the COVID-19 vaccine. She discussed the differences between various COVID-19 vaccines, and stressed the importance that people make the decision that they feel comfortable with.

This session was followed by afternoon tea where most of the speakers remained available to speak one on one with participants.

The day concluded with a final 'Next steps' discussion which was cut short by venue staff who requested we relocate to a common area to conclude our discussions.

Participants gathered to reflect on the day in the light of the two main questions posed at the beginning of the day: What do you want to get out of today? and What are your concerns about today?

During this time, some participants raised some concerns around disclosure, admission to hospital especially when living in the community as an immigrant to Australia without the usual networks of familial support. Anecdotal responses from participants included positive commentary on the sessions, and the strong degree of connection with each other.

Amid last minute sharing of email addresses with phone numbers with new friends or Positive Life staff for future contact and support, participants expressed an agreed desire to engage with more regular workshops for people living with HIV who identify as heterosexual during the year rather than a single annual event, and a desire to connect up with each other through regular social inclusion events.

Positive Life is immensely thankful to participants who attended the workshop and demonstrated their courage to show up, live well and remain engaged socially despite their very real ongoing fears and concerns around HIV stigma and discrimination.

Discussion

From Wednesday 9 June 2021, all participants were invited via email to complete a short eight question SurveyMonkey survey titled '2021 Heterosexual Workshop Evaluation'. The survey was closed on Tuesday 6 July 2021 with 16 responses.

Respondents were made up of 10 female respondents and 6 male respondents, ranging in age from 29 years to 67 years of age.

Fourteen out of 16 respondents indicated their level of agreement with statements (listed below) about the workshop based on a five-point Likert scale from 'strongly disagree', 'disagree', 'neutral', 'agree', and 'strongly agree'. Two respondents skipped this section entirely.

'The workshop provided ways to share personal stories and information'

The majority of respondents indicated 'agree' or 'strongly agree' with the statement (87.72% n=12).

'Attending the workshop made me feel less isolated and alone'

14 respondents indicated 'agree' or 'strongly agree' with this statement (100%).

'This workshop offered me strategies to live well with HIV'

12 respondents indicated 'agree' or 'strongly agree' with this statement (85.71%).

'The workshop was a good way to connect with others living with HIV'

13 respondents indicated they 'agree' or 'strongly agree' with this statement (92.86%).

'This workshop was a good way to stay up to date with the latest information'

14 respondents indicated they 'agree' or 'strongly agree' with this statement (100%).

'What did you enjoy the MOST about the workshop?'

Participants were invited to record free-form comments in response to the question 'What did you enjoy the MOST about the workshop?' and 14 participants provided comment.

Many participants mentioned they enjoyed the opportunity to meet other peers living with HIV such as "Interaction with other participants", "The connection of people living with HIV", "meeting others", and "To know each other's with same pain. I was alone passing very hard (sic) time but get together feeling more hope and confident."

A respondent particularly enjoyed the presence of services at the workshop:

"THE WHOLE WORKSHOP WAS AWESOME! I LOVED IT HOW THERE WAS A REAL PRESENCE OF THE PEOPLE WHO WERE STAFF POSITIVE LIFE AND STAFF AT THE OTHER SERVICES IT MAKES THEM EASY FOR ME TO CONTACT OR APPROACH IN THE FUTURE."

Others mentioned they particularly enjoyed the information and topics in the workshop such as "the information from different organisations and the social aspects", "I Enjoyed (sic) the whole format and delivery of the workshop. The most enjoyable was the information on the health aspect", "The topics were well chosen and very enlightening", "Current and relevant information presented very well", "The provision of information especially concerning legal and covid matters", "Information about treatments", "The researcher talking about covid vaccines and the talk about drugs and the liver", and "Budgeting and update confidentiality of people living with hiv".

The peer nature and privacy of the workshop was appreciated by a number of respondents and expressed in the following ways: "I was able to interact freely without caring the person sitting behind me might hear what am saying", "Listening to people story's, learning what's helpful and being accepted in a classroom for who I'm. (sic)" and "See (sic) that we have a community and learn about all the information and services that people like me can access."

'What did you enjoy the LEAST about the workshop?'

Once again participants were invited to record free-form comments in response to the question 'What did you enjoy the LEAST about the workshop?' and 13 respondents provided feedback.

Five respondents reported there was nothing they could report about not enjoying the workshop. These comments were a mixture of the following: "N/A", "Nothing", "It was all great!" and "It was perfect." One respondent reported "Getting up the nerve to go and travelling there."

Three respondents referred to workshop topics or aspects of the interaction they found least enjoyable. These included "The financial talk although there was some useful information", "New information, how to facing (sic) and passing with COVID 19" and "Listening stories about people depression. (sic)"

Five respondents reported issues related to logistical aspects of the workshop as elements they least enjoyed. These included equipment issues "Not having enough microphones to hear what the questions were and softly hearing the answers."

Other respondents referred to the timing aspects of the workshop. These comments included "structure of the day did not allow enough time for connecting with others",

"Perhaps the seven hours duration", and "It felt rushed."

Despite some criticism about the length of the workshop, one respondent stated:

"THE TOPICS WERE TOO MANY TO BE COVERED WITHIN SEVEN HOURS (7HRS) BEARING IN MIND THERE WERE BREAKS IN BETWEEN. THIRTY MINUTES FOR EACH TOPIC WERE NOT ENOUGH, I WAS LEFT CRAVING FOR MORE INFORMATION."

'Extra feedback'

The respondents were invited to make other comments or feedback to share about the workshop and reminded their remarks would be completely anonymous. 14 respondents adding extra commentary in the survey. These comments can be grouped thematically as into feedback about personal impact of the workshop, suggestions for future workshops, and general logistical feedback.

Comments regarding personal impacts of the workshop included "Makes me confident and strong", "It was an important day for me to acknowledge information and meet with nice people who share the same health condition.", "Enjoyed a fresh and very informative day. Great speakers with useful and relevant information.", "I enjoyed the brainstorming at the start, the interactions with other participants that I have not met before", and "It was a great day with so much useful info and i (sic) learn something new everytime I attend an event. I loved being with everybody and sharing."

Some of the commentary focused on offering suggestions for future workshops. These included the following remarks. "I think the lectures should have been interspersed with more informal discussion groups.", "Slides / handouts for the topics covered should be made available for the participants who might be interested", and "We need more time even though there is a lot of information to absorb but more time will elivate (sic) the pressure."

Discussion

Two respondents made considered lengthy contributions about the day:

“THE INFORMATION WAS GOOD, THE DAY WAS GOOD - THANK YOU TO STAFF, VOLUNTEERS AND PRESENTERS FOR THE FOR THE EFFORT, THOUGHT, AND TIME YOU ALL PUT IN TO THE DAY. PERHAPS A WELL FACILITATED SESSION (OR A DAY?) TO FOCUS ON THE PEOPLE AND MAYBE SOME SHARING OF STORIES/CHALLENGES FOR THOSE PREPARED TO DO SO (NOTING THAT STIGMA AND ISOLATION DID COME UP DURING THE DAY). THANK YOU AGAIN FOR THE WORK AND CARE PUT INTO DEVELOPING THE WORKSHOP AND MAKING IT HAPPEN.”

and

“IT WAS PROFESSIONALLY CONVENED; THE INFORMATION WAS EXTREMELY GOOD; IT WAS GREAT TO SEE NEW PEOPLE; I ENJOYED THE OPPORTUNITY TO SPEAK TO OTHER POSITIVE PEOPLE; MAYBE IT NEEDED SOMETHING LIKE TEAM BUILDING OR FUN, LIGHTEARTED ACTIVITY AT THE BEGINNING, SOMETIMES THESE THINGS CAN FEEL A BIT DRY, EVEN SOMETHING SILLY LIKE A GAME A COUPLE OF TIMES DURING THE DAY. I'D LIKE TO THANK POSITIVE LIFE FOR THE EFFORT AND TIME THEY HAD PUT INTO THIS WORKSHOP.”

Some remarks were about the logistical aspects in general such as “Venue was good with sunny deck and good food.” One respondent gave considerable feedback:

“WE RAN OVER TIME QUITE A BIT. I THINK THE PRESENTERS COULD HAVE KEPT THEIR SLIDESHOWS REALLY SHORT (5MINS) THEN ANSWERED QUESTIONS BECAUSE THIS DISCUSSION WAS REALLY IMPORTANT BUT IF THERE WERE, NO QUESTIONS/ TIME LEFT OVER, THEN THE PRESENTERS COULD HAVE GONE BACK TO THE REST OF THEIR SLIDE SHOW. THIS WAY WE COULD HAVE ALL LEFT ON TIME...SOMEONE SAID NAME TAGS MIGHT BE A GOOD IDEA FOR NEXT TIME.”

Conclusion

The evaluation survey completed by approximately 40 per cent of attendees provided an insight into attendee's reflections on the workshop.

The overwhelming benefits of the workshop as expressed by attendees was twofold: the mitigation of social isolation and access to latest HIV-related information.

Suggestions for future workshops include more informal opportunities for discussion, more opportunity for structured sharing of stories and strategies overcoming challenges, and increased access to slides and handouts. This valuable feedback will ensure all elements can be addressed in future workshops.



“The information was good, the day was good - thank you to staff, volunteers and presenters for the for the effort, thought, and time you all put in to the day.”

Appendix

2021 Heterosexual Workshop Evaluation Survey



2021 Heterosexual Workshop Evaluation

Introduction

On Saturday 5 June 2021, Positive Life NSW (Positive Life) in partnership with the Sydney Local Health District Positive Heterosexual Service (Pozhet) held the 2021 annual Heterosexual Workshop from 9am to 4pm, for all people living with HIV who identify as heterosexual.

Positive Life invites everyone who participated in this workshop to share your views, opinions and thoughts about the workshop in the following short 8-question survey. **All your comments and feedback are anonymous and no questions are compulsory.**

Positive Life will use your feedback to guide any future workshops or events that we put on for people living with HIV who identify as heterosexual including any topics you would like to discuss or on which you want further information.

This survey will be open from Wednesday 9 June and close Friday 18 June at 5pm.

If you know of anyone who would like this survey in a different format (printed format, telephone conversation, etc) please contact Craig Andrews, Communications Manager on (02) 9206-2177, 1800 245 677 (freecall outside metropolitan) or contact@positivelife.org.au

Estimated time to complete survey: 4-5 minutes.

2021 Heterosexual Workshop Evaluation

Let's get started with you

1. My postcode

2. My gender

- Female
- Male
- Other: (Please specify)

3. My age (years)

4. I attended the 2021 Heterosexual Workshop on Saturday 5 June.

- Yes
- No

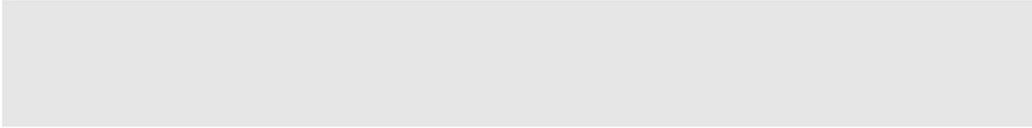
2021 Heterosexual Workshop Evaluation

My feedback about Talkabout

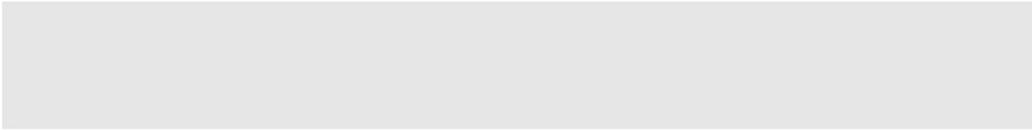
5. Please rate how you feel about each statement

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
The workshop provided ways to share personal stories and information	<input type="radio"/>				
Attending the workshop made me feel less isolated and alone	<input type="radio"/>				
This workshop offered me strategies to live well with HIV	<input type="radio"/>				
The workshop was a good way to connect with others living with HIV	<input type="radio"/>				
This workshop was a good way to stay up to date with the latest information	<input type="radio"/>				
Talkabout was a good way to stay up-to-date with the work of Positive Life NSW	<input type="radio"/>				

6. What did you enjoy **the MOST** about the workshop?



7. What did you enjoy **the LEAST** about the workshop?



8. What other comments or feedback would you like to share about this workshop?
(Your comments will be completely anonymous)



2021 Heterosexual Workshop Evaluation

Thank you for your time and sharing your thoughts.

Your comments and responses will help guide us in our planning for the next steps, workshops and events for heterosexual people living with HIV in NSW.

If you have any questions, please contact Craig Andrews, Communications Manager on (02) 9206-2177 or 1800 245 677 (freecall outside metro) or email contact@positivelife.org.au



The voice of all people living with HIV

For more information phone 02 9206 2177 or 1800 245 677 (freecall)
or visit www.positivelife.org.au