

HIV Health and Wellbeing Programs Evaluation Report

Evaluation of the impacts of Bobby Goldsmith Foundation's Health and Wellbeing Programs on the quality of life of people living with HIV residing in Greater Western Sydney

June 2026

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Abbreviations

ART	Antiretroviral therapy
BGF	Bobby Goldsmith Foundation
CALD	Culturally and Linguistically Diverse
CALDSHAG	Culturally and Linguistically Diverse Sexual Health Action Group
HIV	Human Immunodeficiency Virus
LGBTQ+	Lesbian, Gay, Bisexual, Transgender, Queer/Questioning, and other sexual and gender diverse identities
LHD	Local Health District
NSW	New South Wales
PIS	Participant Information Statement
PLHIV	People Living with HIV
PozQoL	Positive Quality of Life
PrEP	Pre-Exposure Prophylaxis
PSMP	Positive Self-Management Program
PTSD	Posttraumatic Stress Disorder
QoL	Quality of Life
SESLHD	South Eastern Sydney Local Health District
SLHD	Sydney Local Health District
SWSLHD	South Western Sydney Local Health District

Executive Summary

This report presents findings from a mixed-methods evaluation of two pilot Health and Wellbeing Programs delivered by the Bobby Goldsmith Foundation for people living with HIV in Greater Western Sydney, New South Wales. The programs have been developed to support psychosocial wellbeing through community-based, structured interventions focusing on social connection, psychological wellbeing, and self-management, and were piloted in Greater Western Sydney to examine their transferability and outcomes in a different geographic context.

A pre–post evaluation design was used, with psychosocial wellbeing assessed using the PozQoL Scale to examine changes in quality of life over time. Baseline results (n=10) indicated lower scores in social wellbeing and health concerns compared with other domains. Post-program findings (n=8) showed improvements across all domains, particularly in psychological wellbeing and health concerns.

Qualitative feedback highlighted the importance of peer connection and community support. Participants valued opportunities for social engagement through the art-based and self-management programs. However, engagement was affected by several structural and logistical barriers, including transport limitations, digital access challenges, caregiving responsibilities, professional commitments, competing life demands, and stigma.

Program implementation was also shaped by recruitment and engagement challenges, including low response rates, scheduling difficulties, variability in digital literacy, and broader barriers to participation in group-based programs. Stakeholder feedback emphasised the importance of flexible delivery models, culturally responsive approaches, and stronger partnerships with community organisations to improve accessibility and engagement.

Key considerations for future program development include hybrid delivery options (in-person and online), enhanced digital support, culturally and linguistically tailored programming, and co-designed approaches with People Living with HIV (PLHIV) from diverse communities. Addressing structural barriers such as stigma, transport, and social isolation remains critical to improving participation and wellbeing outcomes.

Overall, this evaluation provides preliminary evidence that structured psychosocial wellbeing programs may support improved quality of life for PLHIV in Western Sydney. It also demonstrates the feasibility of delivering such programs in real-world service settings and highlights considerations for refining and scaling future interventions. Further evaluation with larger samples and longer follow-up is recommended to strengthen evidence on effectiveness and sustainability.

Background and Rationale

Global HIV prevalence and treatment context

Human Immunodeficiency Virus (HIV) remains a significant global public health issue despite major advances in prevention, diagnosis, and treatment. Although global HIV-related mortality and incidence have declined substantially since the peak of the epidemic, the number of people living longer with HIV continues to increase due to improved survival associated with widespread access to antiretroviral therapy (ART) [1].

This epidemiological shift reflects a transition of HIV from an acute life-limiting condition to a chronic, manageable illness requiring lifelong clinical and psychosocial support. In high-income regions, including Western and Central Europe, North America, and Australia, HIV prevalence is comparatively low but remains concentrated within key populations and urban centres [2]. Despite substantial advances in health systems and widespread access to effective antiretroviral therapy in high-income settings, inequities in HIV-related outcomes persist, with ongoing disparities among migrant, ethnic minority, and other marginalised populations [1]. Evidence suggests that migrants, ethnic minorities, and culturally and linguistically diverse (CALD) populations experience disproportionate barriers to timely testing, delayed diagnosis, and reduced engagement in HIV care [3].

HIV in the Australian context

Australia has a relatively low HIV prevalence among high-income countries; however, ongoing transmission indicates that HIV remains a continuing public health issue nationally [4]. National surveillance data indicate that new HIV diagnoses are increasingly occurring among overseas-born individuals and within metropolitan areas with high cultural and linguistic diversity [5]. Research among Asian and African migrants in Australia highlights gaps in HIV-related knowledge and prevention practices, contributing to reduced engagement with testing and prevention services [6]. These findings highlight the importance of addressing HIV beyond biomedical treatment alone, particularly in relation to ensuring equitable access to culturally responsive care.

Inequities influence risk of infection, timing of diagnosis, and access to prevention, treatment, and support services, as well as experiences of stigma and discrimination. Some populations continue to experience a disproportionate burden of new diagnoses. Even where current epidemiology does not show increased risk, culturally safe and inclusive services are essential to ensure equitable access to care. Ongoing gaps in information, healthcare, and social support may contribute to preventable infections and poorer outcomes in some groups [7].

In New South Wales (NSW), HIV notifications among gay and bisexual men have declined substantially over time, particularly in inner Sydney where prevention uptake, including HIV testing and pre-exposure prophylaxis (PrEP), has been highest, while more modest declines

in outer metropolitan, regional, and rural areas highlight ongoing geographic disparities in HIV prevention access and uptake [8].

HIV and culturally diverse communities in Western Sydney

Within Australia, Greater Western Sydney represents a key metropolitan region for HIV service delivery due to its high proportion of CALD and overseas-born populations. Although HIV surveillance data are not routinely disaggregated at suburb or local government area level, national and state-level evidence suggests that metropolitan areas with high cultural diversity experience a disproportionate burden of HIV-related vulnerability [5].

People living in outer metropolitan, regional, and rural areas face reduced access to prevention, testing, and treatment services, leading to geographic inequities [7, 9]. This includes longer travel distances, limited anonymity, fewer culturally appropriate and Lesbian, Gay, Bisexual, Transgender, Queer/Questioning, and other sexual and gender diverse identities (LGBTQ+) inclusive services, and concerns about stigma and discrimination, all of which can discourage engagement with care [10].

Research indicates that CALD communities may face intersecting barriers to HIV-related care, including language, stigma, concerns about HIV status disclosure, limited health literacy, and challenges navigating health and social service systems [11-14]. These factors, combined with migration-related stressors and social disadvantage, may contribute to late or delayed diagnosis and reduced engagement in care. Evidence from Australian qualitative studies further highlight the role that stigma, disclosure concerns, and social disconnection play in shaping HIV-related experiences among culturally diverse populations [11-13].

Psychosocial wellbeing and comorbidities among people living with HIV

With HIV now regarded as a chronic condition, there is increasing recognition of the importance of psychosocial wellbeing and quality of life among PLHIV. People living with HIV experience higher rates of both physical and mental health comorbidities compared to the general population, including cardiovascular disease, metabolic conditions, chronic pain, depression, and anxiety [15]. These comorbidities are associated with poorer health outcomes, reduced treatment adherence, and a lower quality of life.

Mental health conditions, particularly depression and anxiety, are highly prevalent among PLHIV and are influenced by both biological and social factors [15, 16]. Psychosocial stressors such as stigma, social isolation, and limited peer support further contribute to poorer wellbeing outcomes [16]. In addition, treatment-related side effects may also impact physical and psychological functioning [17].

Recent Australian evidence highlights the importance of integrating ongoing mental health support into routine HIV care, with findings indicating lower mental health-related quality of

life among people recently diagnosed with HIV compared to HIV-negative populations [18]. These challenges are further compounded by stigma, social disconnection, and mental health burden, which are key determinants of quality of life among people living with HIV, particularly among culturally and linguistically diverse communities [16]. Collectively, this underscores the need for services that prioritise psychosocial wellbeing and quality of life for people living with HIV.

Measurement of quality of life in HIV

Given the importance of psychosocial wellbeing, quality of life is increasingly recognised as a key outcome in HIV care and research. The PozQoL Scale is a validated instrument developed specifically to measure the quality of the lives of PLHIV [19]. The tool looks at four domains: health concerns, psychological wellbeing, social wellbeing, and functional wellbeing. The scale uses 5-point Likert response options, with domain and overall scores derived from item responses. Scores may be transposed to a 0–100 scale for interpretability, with higher scores indicating a better quality of life [19, 20].

Rationale for the current evaluation

In recognition of the psychosocial needs of people living with HIV, community-based Health and Wellbeing Programs delivered by the Bobby Goldsmith Foundation in Western Sydney are intended to support participant wellbeing and quality of life. Given the growing cultural diversity of people living with HIV in metropolitan Australia, understanding the contribution of such programs to psychosocial wellbeing is increasingly important.

Health and wellbeing Programs developed in inner-city Sydney have been widely implemented within specific urban contexts; however, less is known about how such models translate to other geographically and culturally distinct settings such as Western Sydney. Differences in social context, population diversity, and service access may influence how programs are experienced and engaged with by participants.

This evaluation was conducted within this service context, with data collected on participant wellbeing outcomes and experiences as part of routine program delivery.

Findings will contribute to a better understanding of the role of community-based wellbeing programs in supporting people living with HIV and will inform future service delivery in culturally diverse urban contexts.

Study Aim

The aim of this evaluation was to assess the psychosocial health and wellbeing outcomes of selected Bobby Goldsmith Foundation (BGF) Health and Wellbeing Programs among people

living with HIV residing in Greater Western Sydney. The evaluation also explored participant experiences of program engagement and perceived impacts on psychosocial wellbeing.

Project Timeline

The evaluation project commenced in early 2023 and progressed through several stages of planning, ethics preparation, implementation readiness, and program delivery. This is illustrated by the Gantt chart in Figure 1.

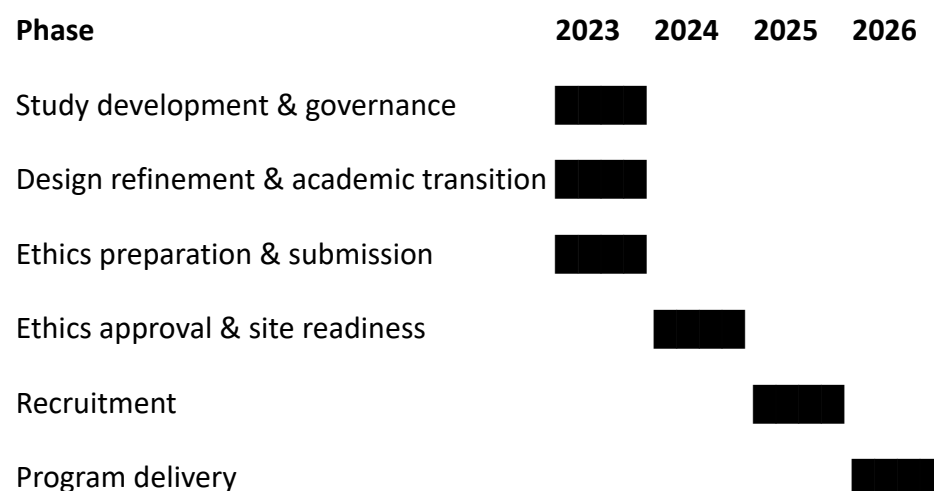


Figure 1: Project Gantt Chart

Phase 1: Initial project development and governance discussions (February–April 2023)

Following funding approval, initial discussions were held with academic collaborators regarding study design and governance pathways. During this period, clarification was obtained regarding the appropriate ethical approval mechanism given differences in interpretation of the study design and delivery. Engagement with external stakeholders during this phase was intermittent, and further guidance was sought to support alignment of the study design with appropriate ethical requirements.

Phase 2: Revision of study design and academic partnership transition (May–July 2023)

In May 2023, new academic support was established with Associate Professor Brahmaputra Marjadi at School of Medicine, Western Sydney University, facilitating refinement of the study design. The study was reoriented from its initial trial-based structure to a pre–post evaluation design, with an expanded qualitative component to strengthen understanding of participant experiences.

A Study Coordinator was appointed to support project implementation. The revised study design was agreed with the funding partner, and alignment was reached regarding the evaluation approach and intended outcomes.

Phase 3: Ethics preparation and submission (August–October 2023)

Study materials, protocols, and documentation were finalised in preparation for ethics submission through the REGIS system (2023/PID02370). The study involved coordination across multiple Local Health Districts located across Greater Western Sydney, each with varying governance requirements and research support processes. Ethics submission was completed following iterative engagement with relevant stakeholders and clarification of site governance requirements and approval pathways.

Phase 4: Ethics approval and site readiness (Late 2024 – Early 2025)

Ethics approval was received on 6 August 2024, and site governance processes were finalised during late 2024 to early 2025, enabling formal study activation across participating sites. This phase included confirmation of site access arrangements and readiness for participant recruitment and program implementation.

Phase 5: Participant recruitment (August 2025 – April 2026)

Participant recruitment commenced in August 2025, led by a newly appointed study coordinator, across approved community organisations and clinical sites. Recruitment activities were supported through community organisation client portals and clinical referral pathways, alongside broader engagement activities across relevant services. This phase focused on enrolling eligible participants into the study and confirming program participation.

Phase 6: Program delivery and evaluation (May–June 2026)

Program delivery commenced in May 2026 and continued through to June 2026. Participants engaged in a series of structured Health and Wellbeing Programs delivered across both in-person and online formats, depending on program type. This phase marked the active implementation of the evaluation, including delivery of psychosocial wellbeing interventions and collection of outcome data.

Overall summary

The project underwent iterative development across governance, ethics, and program delivery processes. Following initial delays related to ethics pathway determination and study design refinement, it progressed through ethics approval, site activation, participant recruitment, and program implementation. Delivery was successfully achieved within a real-world service context spanning multiple local health districts and community settings.

Methodology

This study adopts a concurrent mixed methods evaluation design [21], combining quantitative and qualitative approaches to assess the psychosocial health and wellbeing outcomes of a pilot program for people living with HIV. The mixed methods approach enables measurement of changes in psychosocial outcomes over time through a pre–post evaluation design, which is appropriate for pilot psychosocial wellbeing programs delivered in real-world service settings [22, 23], as well as an in-depth exploration of participant experiences, acceptability, and perceived program impacts.

The quantitative component used a pre–post intervention evaluation design to assess changes in psychosocial wellbeing before and after program participation. The qualitative component was originally designed as semi-structured interviews; however, due to project timeline constraints, this was adapted to an online questionnaire with closed- and open-text response items. The study protocol is available in Appendix A.

It is particularly suited to interventions targeting culturally and linguistically diverse populations, where qualitative insights are critical for understanding cultural relevance and contextual influences on engagement and outcomes. The evaluation is designed to inform future program refinement and potential scale-up, rather than to test efficacy through experimental comparison.

Setting and context

The study was conducted in Greater Western Sydney, New South Wales, a large metropolitan region located west of the Sydney central business district. The region is characterised by substantial cultural and linguistic diversity, with a high proportion of residents born overseas and many communities shaped by recent and long-standing migration patterns. Greater Western Sydney encompasses a diverse range of urban, suburban, and semi-rural communities and experiences considerable variation in socioeconomic circumstances, including areas of marked social and economic disadvantage. These demographic and social characteristics contribute to complex health and service needs across the region [24].

HIV-related services in Greater Western Sydney operate within a broader urban health system serving communities with diverse migration histories, settlement experiences, and levels of health literacy. National HIV surveillance data indicate that overseas-born populations comprise an increasingly important priority population within Australia's HIV response, highlighting the importance of culturally responsive HIV care and support services in culturally diverse metropolitan settings [4].

The combination of high cultural diversity, socioeconomic variation, and evolving HIV epidemiology makes Greater Western Sydney a relevant setting for evaluating community-based Health and Wellbeing Programs for people living with HIV [4, 24].

Ethics

Ethical approval was obtained from the South Western Sydney Local Health District (SWSLHD) Human Research Ethics Committee (Approval Number 2023/ETH02059) and has been included in Appendix B.

Funding

This project was funded by ViiV Healthcare through a competitive grant round. The opportunity to undertake this evaluation arose in response to this funding call.

Target population

Participants were eligible for the study if they were living with HIV; residing within the South Western Sydney, Western Sydney, and Nepean/Blue Mountains LHDs; aged 18 and over; able to communicate in English at a basic level; able to access reliable internet and/or mobile phone services; and able to provide a valid email address and a mobile phone number for ongoing communication.

Quantitative methodology

Design

The quantitative component is a non-experimental, pre–post intervention evaluation (quasi-experimental design) study. Participants enrolled in the pilot program were followed over time, with psychosocial health and wellbeing data collected at multiple time points. This design allows for the examination of within-participant changes in outcomes following exposure to the intervention, without the use of randomisation or a control group.

Data collection

Study flyers (Appendix C) were distributed across participating services and community organisations. As part of the enrolment process, interested individuals were contacted via email, phone call, or in-person contact, assigned a unique four-digit participant ID, and provided with a Participant Information Statement (PIS) (Appendix D) and consent form (Appendix E). Participants were asked to read the PIS and were given the opportunity to ask any questions or raise concerns prior to providing consent; where required, the study coordinator read the PIS to participants and clarified any queries. Following consent, participants were asked to complete the baseline PozQoL assessment (Appendix F). The study

coordinator was aware that some PozQoL items may be sensitive, and participants were offered the opportunity to debrief or speak with the coordinator after completion if needed.

Quantitative data were collected using standardised, self-reported measures assessing psychosocial health and wellbeing outcomes. Data collection occurred at baseline (prior to or at commencement of the program) and at a follow-up time point following program participation. Additional demographic information, including age, gender, home postcode, country of birth, preferred languages, cultural or ethnic backgrounds, and year of HIV diagnosis, was collected to facilitate contextual interpretation of results. Additional notes were made on age at the time of HIV diagnosis, the local health district the participants associated with, and source of referral (either clinical setting, community organisation, GP or word-of-mouth).

Psychosocial health and wellbeing outcomes were measured using the PozQoL scale, a validated quality-of-life instrument specifically developed for people living with HIV. PozQoL is widely used in Australian HIV research and service evaluation and is considered fit for purpose in community-based and culturally diverse settings.

The PozQoL instrument consists of 13 items and assesses wellbeing across four domains:

1. **Psychological wellbeing** – emotional health, mood, and mental wellbeing
2. **Social wellbeing** – relationships, social connection, and perceived support
3. **Health concerns** – physical health, HIV-related symptoms, and concerns about managing health
4. **Functional wellbeing** – capacity to carry out daily activities and roles.

Published guidance for PozQoL indicates that scores below established reference thresholds are suggestive of reduced psychosocial wellbeing and potential need for additional support. In this evaluation, PozQoL scores were used to examine baseline wellbeing and changes over time following participation in the pilot program, rather than for clinical diagnosis or individual-level decision-making.

The use of PozQoL aligns with the study's focus on psychosocial wellbeing and is appropriate for evaluating change in non-clinical, supportive interventions for people living with HIV, including those from culturally and linguistically diverse backgrounds.

Participant satisfaction with the PSMP and Art Therapy program was assessed using a structured questionnaire comprising key program evaluation items. Responses were recorded on a 5-point Likert scale (1 = highly dissatisfied, 2 = dissatisfied, 3 = neither dissatisfied nor satisfied, 4 = satisfied, 5 = highly satisfied). Items assessed perceptions of program content, delivery, facilitator engagement, and perceived impacts on psychological

health and quality of life. Weighted average scores were calculated for each item to summarise participant responses.

Outcomes

Primary quantitative outcomes focused on psychosocial health and wellbeing domains, including emotional wellbeing, psychological distress, perceived social support, and overall quality of life. Secondary outcomes included program engagement indicators, such as attendance and retention.

Analysis

Baseline characteristics were summarised using descriptive statistics, as illustrated in Table 2. Post-program PozQoL scores were summarised descriptively, as presented in Table 3. Pre- and post-program PozQoL overall scores were reported to examine changes over time (Figure 5). Qualitative data were analysed using inductive content analysis to identify key categories reflecting participant experiences of the program.

Qualitative methodology

Design

The qualitative component consisted of open-ended written feedback collected via a questionnaire from program participants via an online web-based survey platform. This approach was used to capture participants' perspectives on the program, including perceived impacts on wellbeing, cultural relevance, and acceptability.

Data collection

Qualitative data were collected through open-ended response fields embedded within a feedback form (Appendix G) completed by participants following program participation. The form explored participants' motivations for participation, experiences of the program, perceived changes in psychosocial wellbeing, cultural safety, and suggestions for improvement. This allowed participants to provide written reflections in a flexible format at their own convenience.

Analysis

Qualitative data were analysed using inductive content analysis (Appendix G). Written responses were coded to identify recurring patterns relating to psychosocial wellbeing, program acceptability, cultural relevance, and contextual factors influencing participation. Codes were then grouped into categories aligned with key program domains. Frequencies are

reported to indicate the number of participants endorsing each category, noting that responses could be assigned to multiple categories. Findings from the qualitative analysis were used to complement and contextualise quantitative results.

Integration of quantitative and qualitative findings

Quantitative and qualitative findings were integrated during the interpretation phase of the evaluation, and in reporting the study findings. This approach allowed for a richer understanding of how and why psychosocial wellbeing outcomes may change over time and how participants experience the program. The mixed-methods approach supported a balanced assessment of measurable outcomes and lived experience.

Recruitment and Participant Characteristics

Recruitment

A total of 44 potential participants were identified through the community organisation client portal, including current and past clients referred by caseworkers or through partnering clinical sites. In addition to this formal recruitment pathway, broader engagement and awareness activities were conducted through community and clinical networks (Appendix H), including dissemination of study information via posters, flyers (Appendix C), social media posts, and community organisation newsletters. The study coordinator also conducted outreach visits to ethics-approved clinical sites, where study information and flyers were shared with staff and made available to potential participants. Additional approved recruitment activities included distribution of flyers at amended sites across South Eastern Sydney Local Health District (SESLHD) and Sydney Local Health District (SLHD), as well as engagement at community and clinical events such as the Culturally and Linguistically Diverse Sexual Health Action Group (CALDSHAG) Symposium, The Western Suburbs Haven, and hospital-based settings in Western Sydney. These activities supported study visibility and facilitated informal engagement with people living with HIV across the region.

Of these, 29 individuals did not participate due to non-response to contact attempts, withdrawal after initial consent, or a decision not to participate. One individual was deemed ineligible for participation. 14 participants were ultimately enrolled in the evaluation. Of these, three participants withdrew due to scheduling conflicts. One additional participant did not formally withdraw but did not attend either program, resulting in a final sample of 10 participants.

Participants provided verbal consent for their contact details to be shared with the study coordinator for program coordination and follow-up purposes. Participants received e-gift card reimbursements for participation, including a \$5 voucher for completion of each study activity (PozQoL assessments, attending program sessions and feedback survey). In addition,

a \$30 travel allowance was available for participants requiring support with transport-related costs.

Participant characteristics

Ten participants were included in the evaluation. Table 1 illustrates the participant demographic characteristics. Participants ranged in age from 27 to 67 years, with most participants aged between 40 and 59 years. Participants represented diverse gender identities, including cis men, cis women, and one trans woman.

Participants reflected diverse lived experiences, including individuals from Māori/New Zealander, Sub-Saharan African, East Asian, Southeast Asian, South Asian, Middle Eastern, and Australian backgrounds. Several participants spoke languages other than English, including Bengali, Nepalese, Sinhalese, Mandarin, Arabic, and Persian/Farsi. One participant also identified with LGBT+ communities.

Most participants were referred through community organisations, while a smaller number were referred through doctors or clinical services. Participants also reported a range of co-existing health conditions and disabilities. Mental health related conditions, including depression, anxiety, posttraumatic stress disorder (PTSD), panic attacks, and broader mental health challenges, were commonly reported. Some participants additionally reported chronic physical health conditions, mobility limitations, and other long-term health concerns.

Table 1. Participant Characteristics

Characteristic	n
Gender	
Cis men	5
Cis women	4
Other/not stated	1
Age group (years)	
20–39	4
40–59	5
60 and over	1
Year of HIV diagnosis	

Characteristic	n
1989–1999	4
2000–2009	2
2010 onwards	4
Cultural and ethnic backgrounds identified with	
Australian	1
Middle Eastern (including Australian Lebanese)	1
South Asian (including Bangladeshi, Nepalese, Sri Lankan)	3
Southeast Asian (including Chinese, Thai, Vietnamese)	3
Sub-Saharan African (including Botswanan)	1
Māori/New Zealander	1
Preferred language(s)	
English only	5
English and another language	5
Referral source	
Community organisation	8
Doctor	2
Self-reported disability or health conditions	
Mental health related conditions	5
Physical health conditions and/or mobility limitations	2
No disability or health condition reported	3

Program Description

The psychosocial wellbeing intervention evaluated in this study draws on an existing suite of Health and Wellbeing Programs offered by BGF. These programs address multiple domains of wellbeing relevant to people living with HIV such as psychological, social, physical, and functional health. Programs delivered during the pilot period were selected from this suite based on participant availability, program scheduling, and alignment with psychosocial wellbeing objectives.

Psychological health

Cognitive Behavioural Therapy (CBT)

The CBT program is a four-week, online mental health intervention led by a trained psychologist. The program supports participants to identify, challenge, and replace automatic negative thoughts with more balanced and realistic perspectives. Strategies include journaling exercises, relaxation techniques, and cognitive restructuring, with the aim of improving psychological wellbeing and coping capacity.

Positive Self-Management Program

BGF's Positive Self-Management Program (PSMP), *Take Control of Your Health*, is a six-week, in-person program designed specifically for people living with HIV. The program aims to improve participants' understanding of health self-management and to explore practical strategies for living well with HIV. Content focuses on building skills, confidence, and agency to support long-term wellbeing across multiple life domains.

Collectively, these programs address multiple dimensions of wellbeing and reflect a holistic approach to supporting the psychosocial health of people living with HIV.

Social health

Art Therapy

Art Therapy is a six-week, in-person program that uses a combination of therapeutic activities and creative art practices to support participants in exploring their personal journeys with HIV. The program provides a structured and supportive space for self-expression, reflection, and shared experience, with a focus on enhancing social connection, emotional expression, and meaning-making.

Physical health

Iyengar Yoga (Gentle Yoga)

Iyengar Yoga is a five-week, online program delivered by a qualified instructor. This gentle form of yoga is adaptable to different bodies, lived experiences, and health conditions, making it suitable for people living with HIV. Sessions focus on movement, alignment, breath awareness, and relaxation, supporting physical wellbeing while also promoting mental calmness and stress reduction.

Functional health

Positive Money Management

Positive Money Management is a one-day, in-person workshop designed to build confidence and skills related to budgeting and financial decision-making. The workshop supports participants to explore practical money management strategies and reflects the broader role of financial stability in supporting overall wellbeing and reduced stress among people living with HIV.

Program Delivery

Baseline PozQoL scores for participants indicated a greater need for social, physical health, and psychological support. In response to these identified needs, along with facilitator availability and budgetary considerations, it was decided that two programs would be delivered as part of the study: PSMP and Art Therapy.

Although PSMP is traditionally delivered in person, participant preference indicated a strong interest in an online format. Accordingly, PSMP was delivered online via Zoom and was co-facilitated by two trained facilitators, both have lived experience of HIV. Prior to program commencement, participants were contacted to assess any support needs related to accessing the online communication platform (Zoom) and were encouraged to use pseudonyms during sessions. Participants were asked to keep their camera on and microphone accessible to support active engagement and were reminded of the importance of maintaining confidentiality, including not sharing information about other participants outside the program unless mutually agreed (e.g. for peer support).

Over the course of the program, facilitators conducted regular check-ins with participants to provide support and monitor engagement. Participants in the PSMP sessions were also offered the opportunity to buddy or pair-up with one another, on a voluntary basis, to enable informal peer check-ins between sessions. Art Therapy program was delivered in person at the BGF Parramatta office during evenings. Both programs consisted of six sessions delivered over six weeks. PSMP sessions ran for approximately 2.5–3 hours, while Art Therapy sessions were approximately 90 minutes in duration, with approximately 30 minutes allocated for refreshments or light meals and socialising.

Findings

Findings are presented across pre-program, during program, and post-program phases.

Baseline (pre-program) findings

Baseline quality of life was assessed using the PozQoL scale prior to program commencement as illustrated in Table 2. At baseline, PozQoL domain scores across participants involved psychological (7–16), social (3–13), health concerns (3–13), functional (4–15), and overall scores (25–49). Scores indicated variability in quality of life and psychosocial wellbeing across participants, with overall score of 35.8.

Table 2. Baseline PozQoL Scores (n = 10)

Domain	Mean (SD)	Minimum	Maximum
Psychological	11.1 (2.96)	7	16
Social	7.4 (2.95)	3	13
Health concerns	7.1 (3.70)	3	13
Functional	10.2 (3.77)	4	15
Overall	35.8 (9.17)	25	49

Across domains, participants generally reported lower mean scores in the social wellbeing and health concerns domains, suggesting challenges related to social connection and health-related concerns. Psychological and functional wellbeing scores showed moderate variation across participants, with some individuals reporting relatively higher levels of wellbeing in these domains. These findings informed the selection of Health and Wellbeing Programs delivered as part of the pilot, including the Positive Self-Management Program and Art Therapy, which were prioritised in response to identified psychosocial needs.

All participants who completed the online survey (n = 9) were invited to provide qualitative feedback. Responses were analysed using inductive content analysis and are presented alongside the corresponding quantitative findings to provide contextual understanding of participants' experiences across different stages of the program.

Participants reported having a range of starting points when they joined the program. Some participants came to the program already equipped with strengths such as *“my existing support networks ... [and] support I receive in my day-to-day life.”* Another participant shared:

“Being positive since [the 1980s], and with long term connection with the excellent team at [a sexual health clinic], I maintain a multi discipline medical and support team and have a regimented. With Apple iWatch and QANTAS Wellbeing App, I monitor multiple key indicators on exercise indicators with progressive notifications when I am below my targets.”

However, most participants reported suboptimal levels of coping and self-care:

“Before starting the program, I managed stress, low mood, and other difficult emotions using my own coping strategies and support systems. There were times when these feelings were challenging.”

“Time and circumstances forced me to adapt, teaching me to accept that progress takes time, even when I had to endure significant hardship on my own.”

“I was always procrastinating and reluctant to live outside my comfort zone.”

“I am someone who usually shuts down when things get too tough and ignore the issue until it cannot be ignored any further.”

“I survive, cope - but not well.”

Participants’ self-reported motivation reflected their needs and expectations from joining the program, such as:

“I need to feel a warmer welcome and people that are happy to see me. I joined BGF to be around more people, fun and activities.”

Program participation

Of those who completed the survey, two participants attended both the Positive Self-Management Program and Art Therapy, five attended PSMP only, and two attended Art Therapy only (Figure 2). Overall, participants reported high levels of satisfaction with the program/s they attended (Figure 3 for PSMP and Figure 4 for Art Therapy). Ratings were measured on a 5-point Likert scale ranging from highly dissatisfied (1) to highly satisfied (5).

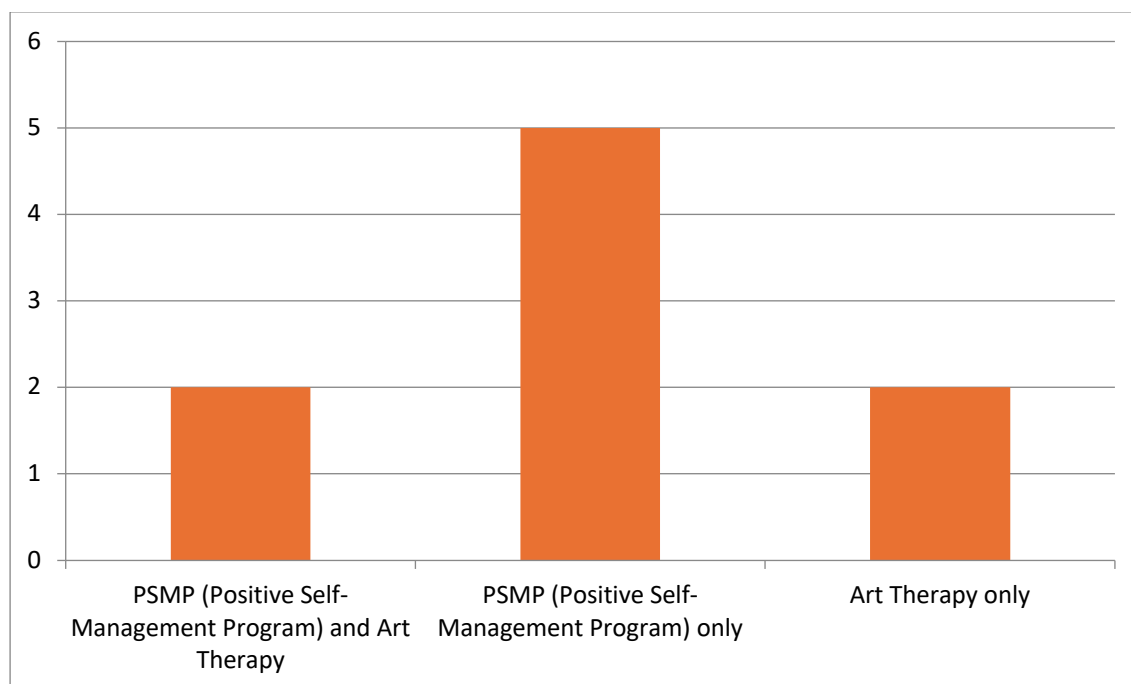


Figure 2. Number of participants who attended programs

As illustrated in Figure 3, participant satisfaction with the PSMP program was high across all evaluated domains. The highest mean scores were observed for presenter engagement and perceived improvements in psychological health (both 4.5), followed by program content structure and online delivery (both 4.25). Quality of life received a slightly lower but still high mean score (4.0). Overall, findings indicate consistently positive participant experiences across program components.

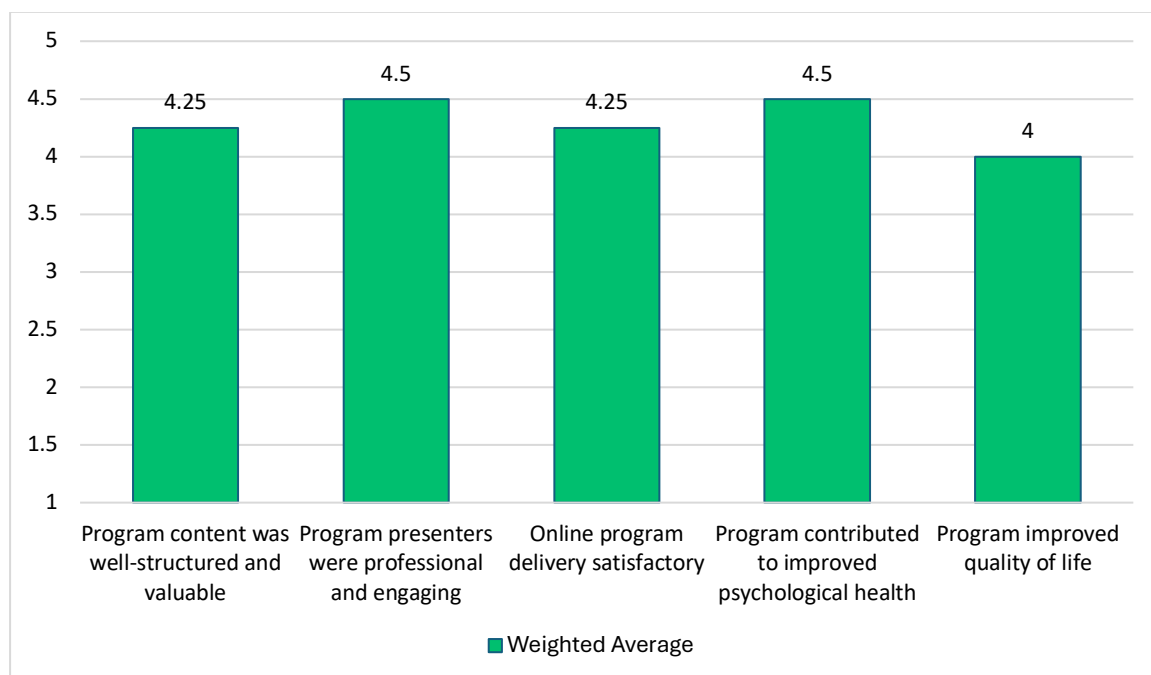


Figure 3. Participant satisfaction across Positive Self-Management Program

Participant satisfaction with the Art Therapy program was high across all evaluated domains, with mean ratings ranging from 4.0 to 4.75 on a 5-point Likert scale, as illustrated in Figure 4. The highest ratings were reported for presenter engagement and satisfaction with the program's in-person delivery (both $M = 4.75$), followed by perceptions of the program content ($M = 4.5$). Participants also reported that the program contributed to improvements in social health ($M = 4.25$) and quality of life ($M = 4.0$). Overall, findings indicate positive participant experiences and perceived benefits associated with the Art Therapy program.

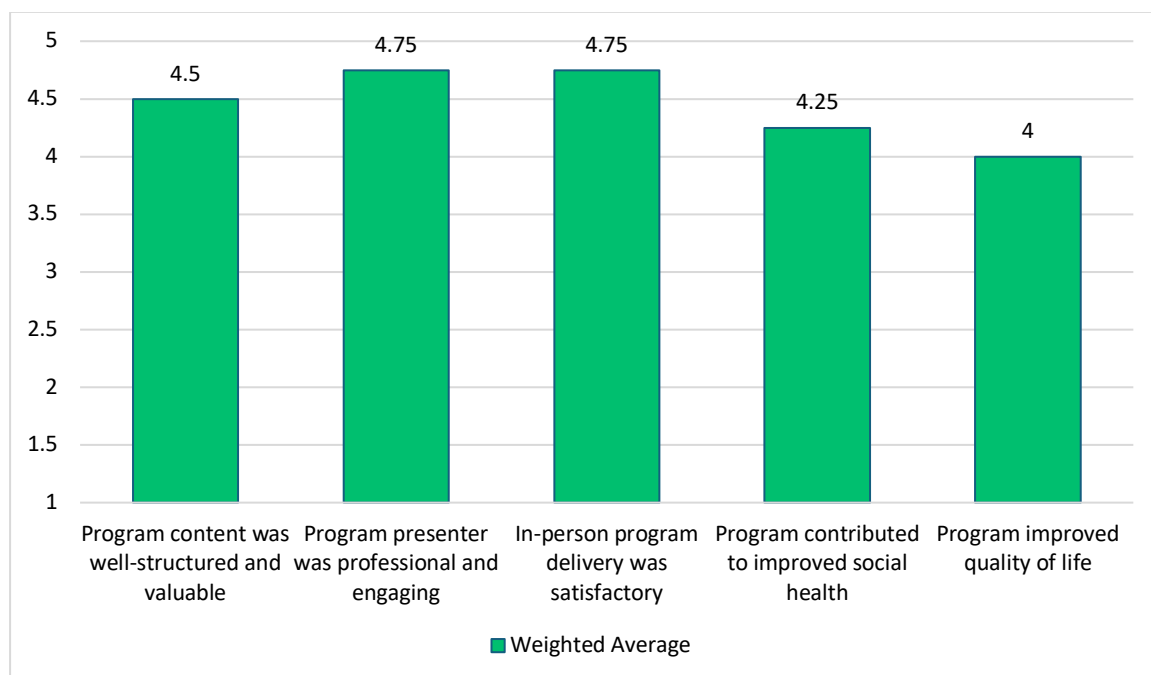


Figure 4. Participant satisfaction across Art Therapy Program

Impressions on program content and delivery

Participants described the program content as well structured, valuable, and relevant to their needs. The overall program environment was viewed positively, with participants valuing opportunities for interaction, shared learning, and structured activities.

Facilitators, presenters and study coordinator were consistently described as professional, respectful, and engaging:

“They were approachable, responsive, and willing to provide guidance when needed.” Participants highlighted empathic communication (“Counselling is listening which the study coordinator is good at”), effective engagement with diverse participant needs, and supportive group facilitation (“During the program, I felt supported by the study coordinator and facilitators”). The study coordinator was described as “very cooperative and friendly. Always reminded us of importance, information and deadlines on time.”

Another participant commented:

“[The programs coordinator] sent some additional information after the sessions for us to study or take action.” Some participants saw facilitators/presenters as role models, with feedback such as: “I see myself in [the program facilitator]. You put in your mind to it; you can do anything.”

The program delivery was also praised for creating a supportive and nurturing social environment for participants:

“They are welcoming, understanding, and accommodating of me well enough to make me feel comfortable being present in the sessions.”

Some participants also appreciated the flexibility of delivery formats. While in-person sessions were valued for social interaction, online delivery was described by some as more accessible, particularly for those in full-time employment or with transport limitations. However, technical issues and varying levels of digital familiarity were noted as occasional challenges. Embedding ‘buddies’ in the online program delivery was received positively by participants:

“To date, it has been a virtual connection with other participants, but the weekly check in with a “buddy” was good and enabled mutual support towards goals.”

Program impacts on participants

Participants reported perceived improvements in social wellbeing, psychological health, and overall quality of life. Many described feeling more open to social and community connection, more socially confident in reaching out to others, greater self-empowerment, increased accountability, contributed to a more positive outlook and more motivated to engage in health-promoting behaviours. The program was also described as supporting increased awareness of mental health and encouraging positive behavioural change through goal setting and peer encouragement.

Social connection was another benefit of joining the program which many participants praised, including those with relatively stronger start in the program:

“The program did not substantially change my health routines, as I already had established habits in place. However, participating in the program contributed positively to my overall wellbeing by providing social connection, a sense of community.”

Participants *“met new people and enjoyed the company”* and one participant expressed their wish to bring the social connection beyond the program: *“I really want to contact and chat with the participants [beyond the program] ... as I know that sharing with peer - happiness and sorrows - can help reduce stress.”*

Lastly, the importance of social connection to maintain achievements was poignantly shared by one participant:

“The program identified a number of processes and opportunities, but I feel without the support of the program and participants, I will probably sink back into my old

routine. I have learnt some important skills, but without ongoing connection with the program, or other programs, I believe I will end up slipping back to my starting point. I live alone and have no one I can come home to and get moral support, someone to discuss and share with."

Health routines were also positively influenced, particularly through increased social and emotional support. Participants reported improvements in physical activity engagement, health monitoring practices, medication management, and greater awareness of "diet, nutrition, exercise". One participant noted that they became "more aware of the importance of health routines in relation to medication and exercise," while another participant mentioned "goal setting and [becoming] more aware of what other medication options are available."

Participants further described improvements in coping with stress, grief, and low mood. This included strengthened coping strategies, reduced social isolation, and increased willingness to seek or accept support. Several participants emphasised the role of peer connection and shared experience in improving emotional wellbeing and resilience.

"The program had a significant impact on my overall ability to cope with stress, grief, low mood, or other negative emotions. Participating in the program provided a positive and supportive experience during the time I was involved."

"But through the PSMP, I have learned how to approach a problem or a challenge that I might be dealing with in a more practical way rather than ignore it until it is too late and because of that I would say my ability to cope has become much better."

Learning in various forms was often reported by participants. For some, what they learned from the program was focused and technical, such as "I have more resources now to help me with my daily tasks." One participant reported their learning:

"Nothing wrong with us. We are not sick people. With some help we can do it. Empowering oneself. Not the victim. Stand by us. ... the PSMP helped with focus and not hurt themselves, love themselves, self-love, see hope and something positive in life, optimistic, don't be hopeless."

Learning of various skills was reported by participants. One participant's coping skills had improved because "I have learned how to approach a problem or a challenge that I might be dealing with in a more practical way rather than ignore it until it is too late." Another participant shared their coping skills learning:

"My coping ability has gotten better because I learned the distraction technique to de-stress myself. Also I learned various ways to feel better during the sessions. ... I can now be honest with myself and face my shortcoming."

The learning from the program translated directly into improving participants' motivation and self-confidence:

"Both the programs that I participated in helped me step out of my comfort zone in a manner that was not too uncomfortable. It made me feel a bit more confident in being in social situations."

"Having the commitment to log in and participate in the group and having to report back on my goals for the week."

Self-awareness also improved:

"The PSMP really helped me identify the areas of my life that I needed to pay more attention to mainly my diet, nutrition intake and exercise."

Peer learning was highly valued by some participants. One person said,

"I was able to learn how other people take their medications and how exercises helped to keep them active and healthy."

The learning was supported by group interactions (*"Interacting with other people living with HIV did help me to become more honest and braver"*) and by peer role modelling (*"Some of the senior and experienced participants explained how important physical exercise is. The other participants were very motivating and inspired me greatly."*).

Hand-in-hand with peer learning is the peer support built into the program. One participant stated, *"By identifying the blockages and sharing them with people during the sessions. I was able to achieve my weekly goals with confidence and clarity."* Another participant reported:

"The peers were also supportive; they called me and asked me how I was doing with my weekly tasks. They encouraged me and educated me. They shared many personal stories about themselves. I was very happy to learn about their good habits, healthy routines and life ambitions."

The diversity of participants was reported as enhancing the peer learning:

"Before joining the program, I knew that it would include participant from different countries and diverse cultural background, I was more inspired when I realized that, despite our difference in appearance and language but suffering and experience are almost the same. A lot to learn from everyone's experience."

The appreciation of peers' role and benefits led to a desire to give back to peers through BGF:

"I want to involve myself in more BGF programs, uplift others. ... BGF is a great platform of connecting people."

Barriers to participation and completion

Despite positive experiences, several barriers to participation were identified. These included transport limitations, caregiving responsibilities, health-related constraints, competing life demands, and stigma. Digital access and literacy challenges were also reported, particularly in relation to online participation. One participant shared: *“The Zoom platform was so good and advanced, we felt like talking to each other in person,”* but at the same time also said: *“The most difficult part is sitting in front of the laptop for 2 hours. Maybe the breaks can be a bit longer.”*

In contrast, one participation expressed that they felt awkward in face-to-face programs because *“I can’t make myself comfortable around others.”*

Although the content language was challenging at times, facilitator support helped make it easier:

“English is our second language, so I feel very comfortable when facilitators ask questions at the end. Some of participants speak native English for them ok, for us very hard to understand.”

One participant noted that a lack of relevant content was a barrier:

“The most difficult aspect was that some parts of the program were not directly relevant to my personal circumstances or needs. As a result, I did not experience significant changes in some of the areas being measured by the study.”

Program engagement was further influenced by scheduling constraints and variable attendance, with some participants unable to complete all sessions due to ongoing physical or mental health issues. These structural and personal barriers highlight the complexity of sustaining participation in community-based psychosocial programs.

“One challenge I faced was attending sessions scheduled at 9:00 am every Saturday. I found the early start time difficult, particularly on weekends, which I usually use to rest and recharge. While I was still able to participate, a later start time may have been more accessible and comfortable for me.”

One participant’s account demonstrated how some challenges are inter-related:

“The program has opened up a number of opportunities for me to participate in, there are a lot of opportunities, but most are during the day, during the week, and most are in the CBD. There is a lot of support available that I was not aware of, but unfortunately my location and available hours do not allow me to participate. During this program, I attempted to participate in a program on offer through BGF, I took a day annual leave

to attend the first session, but timing did not permit me to get to the physical attendance in the inner Sydney suburbs.”

Areas for improvement

Participants identified several areas for program enhancement. Suggestions included increasing interactive and experiential components (e.g., group activities, icebreakers, and excursions such as museum or exhibition visits), and incorporating more varied session formats to sustain engagement.

“Tell them why they need to come next time, what can they get [out of the programs].”

“It would have been better to allow a bit more time for participant introductions and ice-breaking activities, such a background and how long been with [HIV].”

“One area for improvement would be to provide more flexibility or tailoring of content to better accommodate participants with different backgrounds, experiences, and goals.”

Some participants shared ideas for future programs, including a *“program around transition to HIV+ retirement,”* particularly for those living alone in Greater Western Sydney suburbs, and support with creating a *“Directive Care and Living Will”* for those interested. They also suggested health literacy and awareness programs that reflect lived experiences, address discrimination and racism, and provide stronger peer support. Additional ideas included organising outdoor activities such as biking and camping trips, as well as *“yoga and weekend retreat.”*

One participant noted the need for skills development and training programs to support employment opportunities:

“In the future, I would be interested in programs that focus on practical life skills, employment and career development, community connection, wellbeing, and building confidence in everyday situations.”

Participants also recommended increased frequency and duration of sessions, additional resources, and inclusion of guest speakers to diversify perspectives and content. Some suggested strengthening group interaction to enhance connection and participation, particularly in online settings.

“[...] other people such as older PLHIV who can come as guests to share their experiences and make it even better.”

“The facilitators could include more interactive activities and educational videos to watch, more cases or real stories to share.”

“Just maybe have a link to another program building on this one.”

“I need longer programs more programs, so I have more to do with BGF.”

Improvements in technical delivery and facilitation structure were also noted, including reducing technical issues in online sessions and incorporating more interactive activities during virtual delivery.

“The facilitators could include more interactive activities and educational videos to watch, more cases or real stories to share.”

Transport and financial barriers led to a suggestion for BGF to seek sponsorship or donation from rideshare companies *“to support clients for travel.”*

Post-program PozQoL Scores

Quality of life was reassessed using the PozQoL scale following completion of the program, as presented in Table 3. Post-program scores (n = 8) indicated an overall mean PozQoL score of 40.5 (SD = 7.74), with variation observed across domains of psychosocial wellbeing. Psychological wellbeing scores ranged from 11 to 16 (M = 13.5, SD = 2.45), while social wellbeing demonstrated a narrower range from 4 to 10 (M = 7.75, SD = 1.83). Health concerns ranged from 3 to 12 (M = 8.5, SD = 3.03) and functional wellbeing from 3 to 14 (M = 10.75, SD = 3.27). The scores showed variability across participants, with overall scores ranging from 26 to 51.

Table 3. Post-program PozQoL Scores (n = 8)

Domain	Mean (SD)	Minimum	Maximum
Psychological	13.5 (2.45)	11	16
Social	7.75 (1.83)	4	10
Health concerns	8.5 (3.03)	3	12
Functional	10.75 (3.27)	3	14
Overall	40.5 (7.74)	26	51

As illustrated in Figure 5, baseline PozQoL scores (n=10) indicated variation in psychosocial wellbeing across domains, with relatively lower scores observed in social wellbeing and health concerns compared with psychological and functional wellbeing. Post-program scores (n=8)

demonstrated increases across all PozQoL domains following participation in the Health and Wellbeing Program. The largest improvement was observed in psychological wellbeing (+2.4), followed by health concerns (+1.4), with smaller increases in functional (+0.6) and social wellbeing (+0.4). The overall PozQoL score increased from 35.8 to 40.5.

Given the small sample size and attrition between baseline and post-program assessments, findings are reported descriptively and should be interpreted as exploratory.

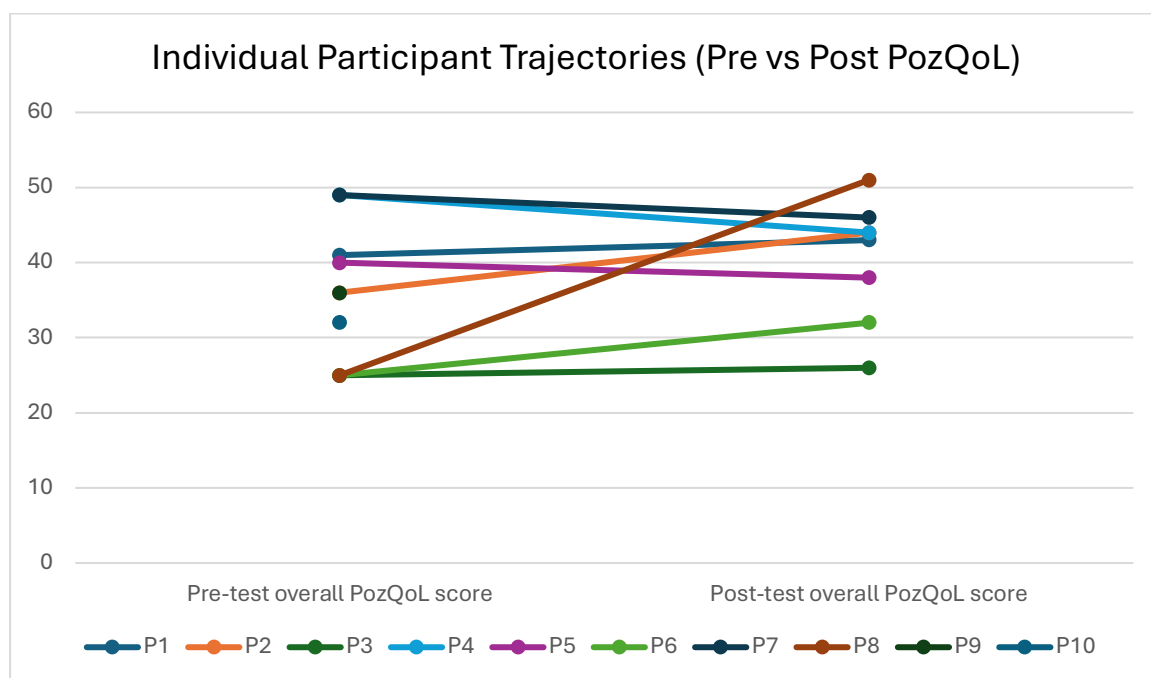


Figure 5. Pre- and post-program PozQoL overall scores among participants

Note: Each line represents an individual participant’s change in overall PozQoL score from pre- to post-program. Two participants completed the pre-program assessment only and therefore appear as baseline observations without a post-program score.

Although the mean overall PozQoL score increased from baseline to post-program assessment, individual trajectories varied, with five participants showing improvement and three demonstrating a decline, while post-program data were not available for two participants due to non-completion of the follow-up assessment. Given the small sample size, attrition, and short evaluation period, these findings are best interpreted descriptively as individual case trajectories, and no extrapolation to broader populations can be made.

Broader reflections

Overall, participants expressed largely positive reflections on the program experience, emphasising its role in fostering connection, empowerment, and improved wellbeing, while

also highlighting important areas for refinement in future delivery. When asked how they would describe their program experiences if they were to be interviewed in a radio talk show, the following accounts encapsulated the participants' general reflections:

"People are very nice and honest, by joining this group and sharing our real experiences, we felt we are not the only person to face so many challenges in life. And by working with each other, listening to each other and support others emotionally, we really have become happier and more productive. So, BGF did a good job for bringing people together!!"

"It was a well organised and facilitated program, covering basics but expanding on them with possibilities, strategies, and opportunities. It didn't dictate process but offered directions for participants to explore and discover what worked for individuals. I'm glad I had the opportunity to participate, and I benefited greatly from my participation."

"I would encourage all positive people, from all walks of life to attend this program, so it empowers you to be informed with every aspect of what being HIV+ looks like."

Discussion

This evaluation examined the impact and acceptability of two Health and Wellbeing Programs delivered by the Bobby Goldsmith Foundation for people living with HIV in Greater Western Sydney. The programs had previously been established in inner-city Sydney and were piloted in Western Sydney to explore whether comparable levels of participant engagement, satisfaction, and psychosocial wellbeing outcomes could be achieved in a different geographic and demographic context. The findings provide preliminary evidence that participation in structured psychosocial interventions was associated with improvements in selected domains of quality of life, particularly psychological, social, health, and functional wellbeing. These findings should be interpreted with caution given the small sample size and the constraints of delivering the program in a real-world service setting. Baseline PozQoL scores indicated variation in psychosocial wellbeing across participants, with lower scores observed in social and psychological domains for several individuals. This pattern is consistent with evidence indicating that people living with HIV experience elevated stigma, social isolation, and mental health burden, particularly within culturally and linguistically diverse populations [3, 5, 11, 12, 16]. Based on these baseline findings, program delivery prioritised interventions (Art Therapy and Positive Self-Management Program) targeting social connection, psychological support, and self-management skills.

The observed improvements in psychological wellbeing and health concerns domains following the two programs, suggest that participation in structured psychosocial programs may support emotional wellbeing and perceived health-related confidence among people living with HIV. Smaller changes in social wellbeing may reflect the short duration of the intervention and the ongoing influence of stigma, structural barriers, and social isolation experienced by participants in metropolitan and culturally diverse settings. These findings are consistent with the broader literature highlighting the multidimensional and socially embedded nature of psychosocial wellbeing in HIV care [16].

The modest overall increase in PozQoL scores suggests potential benefit from community-based psychosocial interventions; however, the findings should be interpreted cautiously given the small sample size and program attrition. The interval between baseline and post-program assessment was approximately six months, reflecting the time required for participant recruitment, program delivery planning, and implementation of the two interventions. The pilot nature of the study and small cohort size limit generalisability of findings. In addition, missing post-program data for some participants may have influenced observed trends.

The integration of Art Therapy and the Positive Self-Management Program provided a multi-domain approach to psychosocial wellbeing, addressing emotional expression, coping strategies, and practical health management. Preliminary findings from this report suggest that community and peer-based, non-clinical interventions appeared acceptable and relevant

for participants. However, engagement was shaped by logistical, cultural, and structural barriers, consistent with evidence from migrant and culturally diverse populations [25].

Participants emphasised that stigma, transport limitations, digital access, and competing life responsibilities significantly influenced participation. These findings are consistent with broader literature on HIV care engagement in culturally diverse metropolitan settings [3, 5, 11, 12].

Implementation challenges were a key feature of this evaluation. Recruitment was slower than anticipated and influenced by multiple system-level and individual-level factors, including service accessibility, participant readiness, and competing priorities. Despite these challenges, successful engagement across community and clinical networks demonstrates the feasibility of delivering psychosocial programs within real-world HIV service settings when supported by strong partnerships [5].

The study also highlights the complexity of delivering evaluation research across multiple Local Health Districts, with variability in governance processes, site readiness, and administrative requirements contributing to delays. These findings underscore the importance of flexible study designs and coordinated stakeholder engagement in community-based health evaluations [26].

A place-based approach is critical, as a one-size-fits-all model may not adequately address the diverse needs and circumstances of different communities [27]. Within Greater Western Sydney, participant feedback indicated preferences for flexible delivery models, including online options, reflecting both geographical and personal constraints. Travel distance, transport availability, caregiving responsibilities, fatigue, and weather conditions all influenced attendance, even where travel allowances were made available.

Digital access and literacy challenges further affected participation, with some individuals requiring additional support to engage with online platforms. These findings highlight the importance of hybrid delivery models, strengthened digital support, and culturally responsive adaptation of program materials, including in-language resources.

Collaboration with existing community organisations supporting people living with HIV in Western Sydney may further enhance engagement, trust-building, and sustainability. Integration with established community initiatives may also improve accessibility and reduce participation barriers.

Overall, this evaluation contributes to a growing evidence base supporting psychosocial and community-based interventions for people living with HIV in outer-metropolitan areas, particularly within culturally and linguistically diverse urban populations. Further research with larger sample sizes and longer follow-up periods is required to better understand sustained impacts on quality-of-life outcomes.

Challenges

Challenges to recruitment and engagement

Several challenges were encountered during participant recruitment, which contributed to lower participant numbers than originally anticipated in the study protocol. These challenges broadly arose from two sources: anecdotal feedback gathered during community and stakeholder engagement, and direct feedback from potential participants.

Recruitment and participation

Recruitment was initially impacted by a high number of spam or invalid email responses (approximately 30), which required additional time to screen and follow up but did not result in eligible participants.

Participant retention was also affected by scheduling constraints. Despite initial interest, some participants were unable to align program session times with work, study, or personal commitments, resulting in withdrawal prior to or early in program delivery.

Program delivery was affected by digital access challenges among some participants. Four participants had limited digital literacy and relied solely on mobile phones to access online sessions. In one case, a participant experienced difficulty downloading the Zoom application due to limited familiarity with device settings. These challenges highlight the importance of providing technical assistance when delivering online programs. Additional support was required to assist participants with access, and in some cases, these delays impacted timely attendance or led to lack of participation. These challenges highlight the importance of flexible delivery options and additional technical support when delivering online programs to diverse communities.

Challenges during program delivery also related to participant attendance. For example, attendance for the in-person Art Therapy sessions was lower than expected. Despite initial confirmations and reminder communications, several participants were unable to attend due to last-minute changes in availability, including illness and competing commitments. This reflects common challenges in real-world program delivery and highlights the need for flexible engagement approaches.

Anecdotal community and stakeholder feedback

During recruitment activities, including a visit to The Western Suburbs Haven, a charity-based respite service for people living with HIV in Blacktown, informal conversations with a small number of individuals provided anecdotal insights into perceived barriers to participation. Some individuals expressed reluctance to participate, citing concerns that the program

content may not be suitable for a lay audience. This was clarified at the time, with reassurance provided that the programs were designed to be accessible and appropriate for participants from diverse backgrounds and without professional training.

Additional logistical challenges were also raised, including limited capacity to travel (with attendance often restricted to infrequent clinical appointments), physical fatigue, and difficulty engaging with digital platforms such as Zoom. Preferences for weekday daytime programs were noted, alongside limited interest in regularly checking emails or responding to phone calls. In relation to incentives, some individuals expressed a preference for physical vouchers rather than e-gift cards.

Clinical and sector perspectives

Further anecdotal feedback from a hospital-based social worker in Western Sydney, along with insights shared during the CALDSHAG Symposium 2025, highlighted broader recruitment and engagement challenges for people living with HIV in the region.

Low reimbursement and incentive amounts were frequently identified as insufficient to motivate participation. Persistent stigma surrounding HIV in Western Sydney continues to discourage PLHIV from engaging in group-based activities or disclosing their status, even within clinical settings. Many patients were described as time-poor, particularly those from non-English-speaking backgrounds, with a preference to attend medical appointments and leave promptly.

It was also noted that PLHIV in Western Sydney are more likely to have received a later diagnosis compared with long-term survivors in inner-city areas such as Surry Hills, where communities have historically been more involved in HIV activism, awareness, and rights movements. This difference was perceived to influence confidence, social connectedness, and a willingness to participate in group programs.

Community engagement challenges

Feedback consistently highlighted limited social connectedness among PLHIV in Western Sydney, with many individuals expressing fear of meeting others living with HIV or being identified within their communities. The geographic spread across Western Sydney suburbs further limited access, even though transport allowances were available, due to the absence of shuttle or pick-up/drop-off options.

Digital access and literacy were also raised as barriers, particularly among older age groups who may feel less comfortable using online platforms. Cultural preferences were noted to vary widely; for example, food-sharing activities were perceived as more appealing when held in informal settings with trusted family and friends, rather than formal group environments where disclosure may feel implied or unavoidable.

Program design considerations

BGF's Health and Wellbeing Programs were described as pioneering within Western Sydney and recognised as structured and leading in this space. However, some stakeholders noted that the programs may be perceived as "city-centric" or lacking cultural diversity. There was strong support for the development of language-specific or culturally tailored groups, including for Indian, Vietnamese, and Chinese communities.

Suggestions for more inclusive activities included group walks, tai chi, and stretching, which were viewed as potentially more accessible than yoga for some participants. Shorter sessions (approximately 45 minutes), followed by opportunities for food and informal socialising, were considered more effective than longer 90-minute program formats. Conducting a broader needs assessment was also suggested to support more tailored program design for multicultural communities across Western Sydney.

Observations and sector insights

Stakeholders emphasised the time required to build trust and sustained engagement within communities. The regular luncheon held by Positive Life NSW was cited as an example of an initiative that took several years to establish, highlighting the importance of long-term relationship-building in building trust and encouraging participation.

Additional anecdotal comments from patients reflected competing life priorities. Some individuals reported feeling overwhelmed by the number of available programs, while others shared that their focus was on family responsibilities and rebuilding their lives, rather than engaging in additional services.

Lessons Learnt

Recruitment and engagement in Greater Western Sydney proved to be challenging, highlighting the complexity of delivering psychosocial wellbeing programs within a geographically dispersed and culturally diverse population. These challenges suggest that traditional public health outreach strategies alone may not be sufficient to effectively reach and engage people living with HIV in this region.

The evaluation indicates that a more coordinated and multidisciplinary approach may be beneficial. In particular, collaboration across public health, community engagement, marketing, and social science expertise may strengthen the design and communication of future outreach strategies, ensuring messaging is better tailored to the needs and preferences of the target community.

Although a formal comprehensive needs assessment was not conducted as part of this program, the qualitative component of this evaluation provided useful insights that partially functioned as an informal needs analysis. However, this alone is not sufficient to fully

understand community preferences, barriers, and engagement pathways. While community consultation is valuable in principle, attendance can be inconsistent, highlighting the ongoing challenge of engaging participants in needs assessment processes themselves.

To address these challenges, future work could consider leveraging partnerships between service providers and academic institutions. Short-term collaborations with universities, including student-led or research placement projects, may provide additional capacity to explore effective engagement strategies, communication approaches, and culturally appropriate program design.

Overall, these findings highlight that improving recruitment and engagement in Western Sydney requires sustained, iterative, and co-designed approaches, rather than relying on single outreach methods or short-term recruitment strategies.

Future Directions

This evaluation highlights several directions for future program development and research to strengthen the delivery and assessment of psychosocial wellbeing interventions for people living with HIV in Greater Western Sydney.

Program accessibility and delivery models

Future iterations of the program may benefit from continued emphasis on flexibility and accessibility to better accommodate the diverse needs of participants. While the current program model provides a strong foundation for structured in-person engagement, future adaptations may consider expanding delivery formats, including enhanced online and hybrid options. Such approaches may further support participation for individuals experiencing geographical, mobility-related, or time-related constraints.

Language and cultural responsiveness

There is potential to further strengthen program reach through the development of additional language-based and culturally tailored program offerings. Expanding delivery in multiple languages, alongside culturally responsive adaptations, may enhance accessibility and engagement for culturally and linguistically diverse communities. Co-design approaches involving people living with HIV from these communities may further support relevance and acceptability.

Engagement and participation pathways

Future work may also focus on strengthening engagement strategies for individuals who experience barriers related to stigma, social isolation, and competing life responsibilities. This may include continued development of peer-supported outreach approaches, strengthened collaboration with related HIV-community organisations, and diversified communication methods that reduce reliance on digital-only engagement pathways.

Research and evaluation design

Further evaluation with larger sample sizes and extended follow-up periods is recommended to better understand longer-term impacts of psychosocial wellbeing programs. Future studies may also benefit from more structured longitudinal designs to capture changes over time and better inform program refinement.

Implementation and system-level considerations

This evaluation also highlights the importance of coordinated implementation across multiple service settings. Future program delivery would benefit from streamlined governance processes and continued collaboration across health districts and community organisations to support efficient and timely implementation of community-based interventions.

Recommendations

Observations from this study highlight that BGF programs may benefit from further tailoring to better meet the needs of diverse participant groups, particularly older people living with HIV in Greater Western Sydney. Feedback indicated that some individuals may be less inclined to engage in structured, group-based programs, emphasising the importance of designing content that is relevant to their lived experiences. Suggested areas of focus included mobility and physical health (such as falls prevention), cognitive health, and addiction-related support, including alcohol, substance use, smoking, and gambling. At the same time, it is important to recognise that some individuals reported feeling adequately supported within their existing networks and were not currently interested in additional program participation, suggesting that more targeted approaches to recruitment and engagement may be beneficial.

In addition, several participants experienced difficulty aligning program schedules with work, study, caregiving responsibilities, or travel commitments, which in some cases contributed to withdrawal or inconsistent attendance. These experiences highlight the potential value of offering more flexible delivery options, including varied session times and a combination of in-person and online formats, to better accommodate competing demands and support broader participation.

Barriers related to digital access and literacy were also observed. Some participants required additional support to access online sessions, while others only had access to mobile phones and limited familiarity with digital platforms, which affected their ability to participate consistently and confidently. These challenges highlight the importance of providing practical technical support and simple guidance materials when delivering online programs. In this context, online program delivery may remain appropriate where participants are provided with adequate support to enable meaningful engagement.

Finally, preferences for more informal and familiar modes of social interaction may be preferred among some participants, particularly those from culturally and linguistically diverse backgrounds. Activities such as food sharing could be perceived as more appealing in informal settings with trusted peers or community members. In contrast, structured group programs may be viewed as less comfortable, particularly where there are concerns about privacy, stigma, or being identified as living with HIV. Adopting more flexible and culturally responsive approaches to program design may help create a more inclusive and supportive environment for participation.

Conclusion

This evaluation provides preliminary evidence that a pilot Health and Wellbeing Program delivered by the Bobby Goldsmith Foundation may support psychosocial wellbeing and quality of life among people living with HIV in Greater Western Sydney. The findings highlight the importance of addressing psychological, social, and functional wellbeing alongside biomedical care, particularly in culturally and linguistically diverse communities.

While implementation was shaped by recruitment challenges, system-level constraints, and variability in participant engagement, the study demonstrates the feasibility of delivering structured psychosocial interventions in real-world settings.

Overall, this evaluation functions as a small-scale pilot case study of program delivery and participant experience. Findings are descriptive in nature, reflecting individual trajectories within a limited sample, and should be interpreted as indicative rather than generalisable.

These results support the continued development of culturally responsive, accessible, and flexible wellbeing programs for people living with HIV. Future evaluations with larger samples and longer-term follow-up are needed to strengthen evidence on sustained program impact.

Appendices

- Appendix A: Study Protocol
- Appendix B: Ethics Approval
- Appendix C: Study Flyer
- Appendix D: Participant Information Sheet
- Appendix E: Participant Consent Form
- Appendix F: PozQoL Form
- Appendix G: Qualitative Data Analysis
- Appendix H: Recruitment and Outreach Networks

Appendix A: Study Protocol

PROTOCOL TITLE

Evaluation of the impacts of Bobby Goldsmith Foundation's Health and Wellbeing Programs on the quality of life of PWHIV residing in Greater Western Sydney

Sponsor

Bobby Goldsmith Foundation (BGF)

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1. SUMMARY

Study Title	Evaluation of the impacts of BGF's Health and Wellbeing Programs on the quality of life of PWHIV residing in Greater Western Sydney
Aims/Objectives	<p>Primary: Establish evidence to demonstrate the efficacy of BGF's programs to improve the quality of life of study participants</p> <p>Secondary: Identify any:</p> <p>changes in their social engagement;</p> <p>changes in adherence to HIV treatment and other health routines;</p> <p>changes in the quantity and quality of trusted support in participants' lives;</p> <p>changes in coping mechanisms for depression, grief and survival stress.</p>
Study design	This is a sequential explanatory mixed-methods evaluation study using pre-post repeated measures of quality of life (quantitative data), followed by semi-structured qualitative interviews.
Planned sample size	55
Inclusion criteria	People who are a) living with HIV; b) residing within the South Western Sydney, Western Sydney, and Nepean/Blue Mountains LHDs; c) aged 18 and over; d) able to communicate in English at a basic level; e) able to access reliable internet and/or mobile phone services; and f) able to provide a valid email address and a mobile phone number for ongoing communication.
Study procedures	Once participants have returned a 'signed' EPICF, they will complete the first of three PozQoL (Quality of Life -

	<p>QoL) assessments, the first one being to establish their baseline QoL score.</p> <p>Based on their scores, two Health and Wellbeing Programs will be suggested as being the most appropriate to attend to derive a benefit in their QoL.</p> <p>Participants will then undertake their programs, receiving small value (\$5.00) vouchers as incentives for attendance to mitigate attrition however not to be seen as unduly coercive.</p> <p>As soon as possible after completion of their chosen programs, participants will be required to complete their second PozQoL assessment, the results of which will indicate the extent to which they have benefited, or otherwise, in the short term from the programs they attended. The study coordinator will ensure any lag between completion and assessment is minimised so as to avoid the results being skewed.</p> <p>After a period of 6-8 weeks, a third and final PozQoL will be undertaken, this one showing the longer term or sustained effects of the programs on their QoL.</p> <p>Based on their three score trajectories, participants will be invited to participate in a short, open-ended interview that will provide the researchers with rich qualitative data on any changes they experienced during the course of their involvement in the study.</p>
<p>Analysis considerations</p>	<p>For the quantitative arm, pre- and post-program PozQoL scores will be analysed using appropriate repeated-measure statistical procedures with alpha of 0.05. Potential confounders will be managed using appropriate stratification and/or multivariate statistical procedures.</p> <p>For the qualitative arm, interviews will be recorded electronically, transcribed verbatim, and analysed using Content Analysis.</p>
<p>Study duration</p>	<p>Estimated at 12 months</p>

2. BACKGROUND AND RATIONALE

The value of this study is that it brings together three forces into a single cohesive project as follows:

Firstly, it provides a focus on Quality of Life (QoL) for people living with HIV (PWHIV). QoL is now a key strategic focus of the current NSW Health HIV Strategy, with a target of 75% of people living with HIV reporting a good quality of life as measured by PozQoL;

Secondly, it harnesses the value of BGF's Health and Wellbeing programs to bring about improvements in the QoL of PWHIV.

- BGF has been delivering free Health & Wellbeing Programs to PWHIV for approximately 15 years. Early programs included Art Phoenix (workshops wherein participants are invited to share stories as a PWHIV through various art media) and Creative Writing workshops such as Haiku Poetry.
- PSMP (Positive Self-Management Program) was developed as an anchor program in 2013 to improve participant's health literacy. PSMP emerged from research at Stanford University.
- Since 2019, BGF's Health and Wellbeing Programs have been developed based on the identified social determinants of health.
- An informal focus group involving community members identified their needs and interests and so began the brainstorming of concepts for future Health and Wellbeing Programs.
- Following the completion of each program, participants are sent an electronic link to an impact evaluation survey. The survey is comprised of statements and participants can record the degree to which they agree or disagree. There is also a section for written feedback, suggestions and critique. The impact evaluation statements have been a valuable tool in how BGF has designed and implemented their Health & Wellbeing programs to meet the needs of participants.
- BGF's Health & Wellbeing Programs were included in the organisation's recent annual client satisfaction survey, with 88% of respondents reporting they were 'satisfied' or 'highly satisfied' with the delivery of Programs, 85% with the outcomes of the programs they attended, and 86% reporting 'high satisfaction' with the degree the programs they attended improved their overall health and wellbeing.
- With the available resources, the suite of programs offered as part of this project are designed to address each one of the four domains measured by PozQoL; Social Health, Financial Health, Physical Health and Psychological Health. These programs will be delivered by qualified facilitators to bring about positive changes to the components impacting QoL (Quality of Life) - such as peer connection, social isolation, resilience and knowledge/skill development in areas of community interest.
- Each Program has been designed to address a primary health domain: Physical, Psychological, Social or Financial. Existing research shows

addressing these domains leads to an improvement in overall quality of life (Alford, et al. 2023; Frederickson, et al. 2015; Mendonca, et al. 2023).

- Some participants in the Program/s have received Case Management from the BGF Psychosocial Support Team and/or intervention from other services for PWHIV. PozQoL was initially administered to better manage clients' QoL. The PozQoL results obtained could not be isolated to determine the impact of BGF's Health and Wellbeing Programs and therefore have not been analysed to inform the present study.
- All programs are offered free of any costs or charges.
- To the best of our knowledge, there are no competing organisations offering a similar suite of programs that are targeted specifically towards improving the quality of the lives of PWHIV;

Thirdly, the opportunity to work with PWHIV in greater Western Sydney who have not as yet had the opportunity to participate in these programs for a number of reasons – when held in person they have been undertaken in locations such as the City of Sydney, the Eastern Suburbs of Sydney and the Inner Western suburbs of Sydney, all for largely historical reasons and for the concentration in the past of the epidemiology in these areas – BGF has not fully established its presence in the Western suburbs of Sydney until recently when it established an office in Parramatta, notwithstanding that case management has been undertaken for complex clients living out west since 2017.

This study will enable evidence to be established as to the value such programs can offer people living in suburban western Sydney, a broad expanse that has received disproportionately less focus and support than the areas where the epidemic was centred from the outset in Sydney. Whilst we understand the value these programs bring to those who have attended them to date, this study enables us to better understand their effectiveness with a naïve cohort, ensuring that the findings enable us to develop more tailored and targeted programs in the future.

The gap we have identified is that we are lacking any evidence of BGF's programs being successful when delivered in greater Western Sydney. These programs have achieved considerable success in improving attendees QoL when run in the city and surrounding suburbs. Will this success translate when delivered in a different geo-demographic cohort?

We can find no evidence that a study of this nature has been undertaken previously however cannot comment on whether or not a similar study is underway elsewhere or planned for the future. This study therefore is the first evaluation of the efficacy of programs to improve the QoL for PWHIV.

Literature review summary:

People living with HIV (PWHIV) experience higher rates of mental and physical co-morbid health conditions than the general population (Morales et al. 2022), and often experience physical and/or psychological side effects as a result of HIV treatment/s (Treisman & Kaplin, 2002). Psychosocial factors including social isolation, stigma, and lack of peer support increase the severity of depression and anxiety for PWHIV, often negatively impacting individual's social, financial, physical and psychological health domains and overall QoL (Quality of Life) (Mendonca et al. 2023). In the proposed Project, the PozQoL scale (an empirically validated QoL assessment tool for PWHIV (PozQoL Project, 2023) is used to measure PWHIV's QoL prior to, at the completion of, and 10 weeks following participants' engagement in health and wellbeing programs designed to address the social, financial, physical and psychological health domains and facilitate psychosocial support.

3. STUDY AIMS/OBJECTIVES

Primary Objective: Establish evidence to demonstrate the efficacy of BGF's Health and Wellbeing programs to improve the quality of life of study participants

Secondary Objectives: Identify any:

- changes in their social engagement;
- changes in adherence to HIV treatment and other health routines;
- changes in the quantity and quality of trusted support in participants' lives;
- changes in coping mechanisms for depression, grief and survival stress

4. PARTICIPATING SITES

- South Western Sydney Local Health District (SSA)
- Nepean Blue Mountains Local Health District (SSA)
- Western Sydney Local Health District (Access only)

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- South Eastern Sydney Local Health District (Access only)
 - Sydney Sexual Health Centre
 - The Albion Centre
 - A-Test Centre, Oxford Street
 - Short Street Centre
 - Waratah Clinic at St George Hospital
 - The Kirkton Road Centre
- Sydney Local Health District (Access only)
- Northern Sydney Local Health District (Access only)

5. STUDY DESIGN

- 1) Quantitative
 - a. Observational
 - i. Cohort study (prospective)
- 2) Qualitative
 - a. In-depth interviews

5.1 Study Type

An evaluation study combining quantitative and qualitative research

5.2 Expected Study Duration

The study will start upon receipt of ethics approval, and end following the completion of the analysis of the qualitative data and writing of the findings paper. As per the study design, recruitment will continue until the sample size has been reached.

5.3 Data Source and Population

- The study group is a single group of people living with HIV residing in greater western Sydney. Insofar as the numbers in this group are concerned, it is estimated that there are in excess of 550 PWHIV with complex care needs residing in greater Western Sydney (universe) based on the Berino Report¹. The total number of PWHIV residing within the catchment areas of the 3 LHDs is uncertain at this time.

- CALD and ATSI PWHIV are encouraged to participate in the study, subject to their meeting the inclusion criteria. The study team recognises the epidemiology of HIV in the western suburbs of Sydney, that approx. half of all new diagnoses are overseas born, mainly from Asia. The resources required to deliver the study in a way that caters to up to 5 or more specific Asian languages, including translation of all materials relevant to the study and programs, facilitators, and study team are beyond the scope of this project's funding. One possible outcome from the study's findings is that learnings can be applied in future similar studies to targeted CALD groups.
- Fifty five (55) participants

1. Consultancy on HIV Complex Care in NSW, Berino Consultancy, Rick O'Brien, Lance Feeney
<https://www.positivelife.org.au/wp-content/uploads/2020/10/plnsw-sb2018-plhiv-complex-care.pdf>

- For the quantitative analysis, a sample size of 55 participants is seen as the minimum number of participants required. The sampling approach is a non-probabilistic, convenience/consecutive, and time-based approach. The process will conclude when the total number of participants (sample saturation) and /or the time limit (time saturation) is reached.

For the qualitative analysis, a maximum variety sampling approach will be undertaken whereby 3 respondents will be randomly selected from each of the following 5 groups based on their 3 PozQoL scores:

- PozQoL 1 < PozQoL 2 = PozQoL 3 (initial improvement with sustained impact on follow up)
 - PozQoL 1 < PozQoL 2 < PozQoL 3 (ever-increasing)
 - PozQoL 1 < PozQoL 2 > PozQoL 3 (initial increase but not sustained)
 - PozQoL 1 = PozQoL 2 (program not making impact)
 - PozQoL 1 > PozQoL 2 (decline after program participation)
- Matching is not applicable. Sampling strategies have been outlined above. Potential bias and confounding factors can be detected from demographic data and managed using stratified or multivariate analysis. Statistical power calculation is not applicable.
 - As part of the recruitment process, a combination of geo-demographic data variables will be collected to ensure communication effectiveness and to facilitate data analysis. Subsequently, data by way of PozQoL scores will be collected to determine quality of life measures at baseline and at subsequent intervals e.g. immediate post-program measure and delayed post-program (6

weeks after previous PozQoL assessment) to determine effectiveness of programs on QoL in the short and medium term, and to enable participants to be selected for interviews, ensuring a maximum-variety sampling approach.

- Data variables to be gathered will comprise the following:
 - participants' names (first name and surname)
 - email address
 - telephone number (mobile phone only)
 - age
 - gender (as per ACON recommended community-indicators for research)
 - year of HIV diagnosis
 - Health and Wellbeing programs selected to attend
 - Attendance record at programs
 - PozQoL scores (baseline, second and third)
 - Responses to qualitative interview questions.

5.4 Recruitment and Screening

Potential participants will nominate themselves to participate in the study by way of responding to the study posters and flyers that will be placed in the clinics within the study sites by members of the study team.

These study materials contain relevant but limited information to attract the interest of potential participants who are invited to scan a QR code on the poster/flyer that will take them to a secure 'study' web page hosted by BGF where they can find more detailed information about the study.

Similarly a hyperlinked URL in targeted social media posts will take those seeking further information to the secure web page.

From the information page, potential participants will be required to send an email to a designated email address (study@bfg.org.au) indicating their interest in participating in the study. The study coordinator will respond to their email by way of forwarding them a Participant Information Sheet (PIS) and a Consent Form.

One email follow-up will be sent to the enquirer with an offer to answer questions they may have regarding the study. If the enquirer does not respond to either of the

emails sent by the Study Coordinator, it will be considered they are no longer interested, and no further contact will be made with them to ensure that they do not feel they are being coerced into participating.

Once the Study Coordinator receives the 'signed' consent form, they will contact the sender to a) confirm receipt and b) capture all of the participant's geo-demographic information for entering into the study database. This process will form part of an initial screening to ensure the participant meets the inclusion criteria for the study. If it is apparent the participant is not able to converse in English, they will be informed they do not meet that selection criterion and therefore not able to proceed. They will be asked what their preferred language is, and a note will be made of this in the database.

At this point, the Study Coordinator will request the BGF Administration Officer (not part of the study team) create a randomised study ID for the participant. This ID will be passed back to the Study Coordinator to populate the study database. Any identifiable data will be removed from the database and only the study ID will be used to identify the participant in all subsequent engagements other than when the Study Coordinator is required to communicate with the participant in which case the participant's given name will be used. The Study Coordinator will maintain a separate file for this purpose, linking the Study ID with the participant's given name. This file will be password-protected and stored in the cloud.

The Study Coordinator will next email the participant their first PozQoL assessment to complete, using the study ID to identify them in the database. The PozQoL assessment is a short, 13 statement quality of life scale that will establish the participant's baseline quality of life score. The scores from PozQoL surveys help service providers better understand the areas of the participant's life that may be improved by support services. The research team will use the PozQoL score to establish the participant's baseline measure (of their quality of life) and determine if their quality of life could be improved by one of BGF's Health and Wellbeing Programs. The Study Coordinator will notify the participant of the outcome of this assessment.

5.5 Inclusion Criteria

- People who are
 - living with HIV;
 - residing within the South Western Sydney, Western Sydney, and Nepean/Blue Mountains LHDs;

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- o aged 18 and over;
- o able to communicate in English at a basic level;
- o able to access reliable internet and/or mobile phone services;
- o able to provide a valid email address and a mobile phone number for ongoing communication.
- o Willing to provide informed consent
- o Willing to participate in and comply with study protocols

5.6 Exclusion Criteria

- Anyone who has expressed a preference not to be considered for research purposes (often those with complex needs or living in challenging situations);
- Anyone who has previously undertaken any BGF's Health and Wellbeing programs, the reason being to ensure only naïve participants are recruited to the study. Clients who have previously undertaken programs will have undertaken a PozQoL before consenting to take part in the study. We are exploring the participants' full experience with programs from beginning to end. Examining any data held from previous program participants i.e. long-term data is outside of the scope of this study;

5.7 Consent Process

- Informed consent will be obtained after the prospective participant has read the PIS and if necessary, asked any questions of the Study Coordinator that relate to a better understanding of the project. The Consent Form will be sent electronically to the prospective participant together with the PIS, with the appropriate, then 'sign' the electronic consent form before emailing it back to the study coordinator. Consent provided is for an extended period of time.
- As outlined above, informed consent will be undertaken remotely and via an e-consent process. The prospective participant will have opportunities to ask questions regarding the project of the study coordinator. No paper consent forms will be available as it is a requirement of participation in the study that all participants have a valid, current email address to facilitate electronic communication throughout the study.
- As mentioned above in 5.4 Recruitment and Screening, the EPICF will be sent to the prospective participant once they have responded to the study advertisement (poster/flyer/social media post) by way of scanning the QR to obtain further information, and then emailing the study coordinator at study@bqf.org.au to request the EPICF.

- There are no specific timelines associated with this other than if after two weeks the consent form has not been received, the study coordinator will send one email reminder to the prospective participant, offering to answer questions they may have. If after this email no response ('signed' e-consent) is received, it will be considered that the prospective participant is no longer interested in participating in the study.
- By virtue of their having emailed the signed PICF to the study coordinator, the participant will have a copy of the attachment to their sent email, thus serving as their copy.
- Once the e-PICF is received by the study coordinator, the study database will be updated to record its receipt, and the form will be stored in a separate file on a server in the cloud that is password protected.

There are no different participant groups in this project. Participants will be reminded of the PICF at the time each PozQoL assessment is undertaken and prior to the qualitative interviews (for those being interviewed), emphasising their right to withdraw at any time from the study without any negative consequences to their future engagement with the sexual health clinics and BGF.

This process will be undertaken by the study coordinator. The process will require the participant to send an email confirming their decision to opt-out. Any participant wishing to withdraw from the study will be asked if they wish any previously collected data to be deleted from the study database.

5.8 Study Procedures

- Once the PozQoL baseline has been established, the individual domain scores obtained will be used to identify which of the programs on offer could potentially improve the participant's quality of life. Each participant will be notified of three of the five BGF programs on offer which their baseline scores indicate would benefit their quality of life the most and be asked to enrol in two of these that best suit their individual circumstances at the time.

The suite of Health & Wellbeing programs offered and the domains they impact are as follows:

- o Social Health

- o Art Therapy: a 6-week in-person program that uses a combination of therapeutic activities and art practices to explore participants journey with HIV.

- o Financial Health

- o Positive Money Management: is a one-day, in-person workshop that will help build confidence in budgeting and explore new ideas around money management.

- o Physical Health

- o Iyengar Yoga: a 5-week online program run by a qualified instructor. Iyengar Yoga (Gentle Yoga) can be adapted for all bodies, lived experiences and conditions. In Iyengar Yoga, you will move, open the body, tune into the breath, and calm the mind.

- o Psychological Health

- o CBT: a 4-week online mental health program led by a trained psychologist from RewireMe. The program identifies, challenges, and replaces automatic negative thoughts with more objective, realistic ones, through strategies such as journaling, relaxation techniques, and mental distractions.
 - o PSMP: BGF's Positive Self-Management Program's "Take Control of Your Health" workshops are designed to improve the understanding of health management for people with HIV and explore healthy ways to live the best life possible. This is a 6-week in-person program.
- Participants will enrol in and commence attending their selected programs.
 - Participants will be incentivised to attend all sessions of the programs they have enrolled in. Each session attended will earn the participant a \$5.00 redeemable voucher. Incentivisation is necessary to ensure program participation is sustained, in many instances up to 6 weeks. The value of the incentive is considered appropriate in that it is not excessive to appear

coercive however sufficiently attractive to consider ongoing attendance The study coordinator will manage this process entirely.

- A \$30.00 travel allowance is available to any participant requiring financial support to cover travel costs. This has been disclosed in the PIS. It must be applied for and substantiated. This amount is over and above any attendance incentives.
- Once the programs have concluded, the participants will be sent a second PozQoL assessment to complete and return at their earliest opportunity to ensure no lag between program completion and assessment. Their scores will be calculated and entered into the study database alongside their baseline score. This measure provides the researchers with information as to the extent to which the programs have had an immediate or short term impact on their quality of life. Participants will receive a \$5.00 voucher for completing this assessment.
- 6- 8 weeks after the second PozQoL has been completed, a third and final PozQoL assessment will be sent to participants to complete and return. Participants will receive a \$5.00 voucher for completing this assessment too. This final assessment will provide researchers with a score that will indicate any long-term improvement or deterioration in their quality of life. The scores will be entered into the study database alongside the previous two scores and will be used by the researchers to identify suitable candidates for the final stage of the study being the qualitative interviews.
- Participants for the qualitative arm of the study will be invited to attend a short meeting to be interviewed on their experiences during the study. Using the interview guide questionnaire, interviews will be recorded and transcribed. Following the interviews, the interviewer will confirm participants' answers by summarising the main points from the answers at the end of the interview. Participants will be given the chance to rectify and/or clarify any errors in interpretation of their answers prior to the interviews being concluded.
- All statistical analysis will be undertaken by the principal researcher, A/Professor Brahm Marjadi, University of Western Sydney. This will ensure there is no conflict of interest between data analysis and the institution providing the programs.
- For the quantitative arm, pre- and post-program PozQoL scores will be analysed using appropriate repeated-measure statistical procedures with alpha of 0.05. Potential confounders will be managed using appropriate stratification and/or multivariate statistical procedures.
- For the qualitative arm, interviews will be recorded electronically, transcribed verbatim, and analysed using Content Analysis. Synthesis of quantitative and qualitative data will occur at the discussion stage where the qualitative data will illuminate the interpretation of quantitative findings.

Outcome measures:

Overall success of the project will be measured through improved PozQoL scores at the immediate conclusion of their program participation, with that improvement being sustained 10 weeks post-program via a subsequent PozQoL assessment.

Supplementary outcomes will be measured via questions as part of the qualitative interviews, to determine:

- o Any changes in participant's social engagement;
 - o Any changes in adherence to HIV treatment and other health routines;
 - o Any changes in the quantity and quality of trusted support in participants' lives;
 - o Any changes in coping mechanisms for depression, grief and survival stress.
-
- Ideally the final sample size will be sufficient to allow for withdrawals. A sample of 55 respondents with 10% attrition will result in 50 valid responses. Withdrawals will reduce the power of the quantitative arm of the study and the richness of the qualitative data. To minimise these impacts, we will recruit participants throughout the study period. We may use statistical techniques such as Survival Analysis to maximise what we could learn from the data up until withdrawal (point of attrition) as well as for those whose later enrolment into the study means they may not have finished the programs when the study period is over.
 - As per the National Statement: Ethical Conduct in Human Research 2023 – Opt out of research 2.3.6e, a reasonable amount of time will be made available between data provision and data analysis, thus allowing consent to be withdrawn before analysis begins.

5.9 Randomisation (if applicable)

Not applicable

5.10 Data Linkage (if applicable)

Not Applicable.

5.11 Consumer and Community Involvement (if applicable)

Not applicable.

6. TISSUE COLLECTION/BIOBANKING (IF APPLICABLE)

Not applicable

7. ETHICAL CONSIDERATIONS

7.1 Study Procedure Benefits

Research will be ethically acceptable only if its potential benefits justify those risks.

- The primary benefit for conducting the project is to the individual participating in the study by way of their quality of life improving following participation in BGF's Health and Wellbeing Programs. A secondary benefit of conducting the project is building a knowledge base from which further program delivery can be undertaken to benefit others living with HIV in the future.

7.2 Study Procedure Risks

- Whilst the study team does not envisage any risk for distress during the course of the project, there is always the possibility that distress may arise. Should the study team become aware of such an issue, they will mitigate the risk by managing their interactions using a trauma-informed approach. Participants will have a clear understanding of the study design before consenting to participate. Should the participant wish to withdraw from the study due to feelings of distress, they are able to do so freely without any negative consequences to their future engagement with BGF or the sexual health clinics.

Mitigation of any psychological distress or harm encountered can be addressed by either contacting and discussing concerns with a member of the study team who can then provide referrals to appropriate support services such as those listed below, or by contacting any one of the following organisations as outlined in the PIS directly, namely:

Beyond Blue for 24/7 Mental Health Support

Lifeline Australia for 24/7 Crisis Support

Headspace – the National Youth Mental Health Foundation

The study team will be available to respond to participant enquiries pertaining to the study itself, and/or the programs being offered/undertaken however enquiries or contact from participants experiencing distress or harm will be referred to the list organisations for professional support and advice.

- No dual relationships are envisaged between participants and any members of the study team, including facilitators of programs. Should a dual situation

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arise during the course of the study, advice to the participant will centre on reassuring them of their privacy and confidentiality, and the option to withdraw from the study. Insofar as coercion is concerned, participants will be provided with a comprehensive PIS following enquiry about participation and will be required to provide informed consent in the clear knowledge that their participation is voluntary, that they are not being coerced into participating, and that they have the opportunity to withdraw from the study at any point without providing a reason. Insofar as inducement is concerned, participants will receive incentives to continue participation in programs to ensure the full benefit of the programs is achieved. Two of the five programs being delivered as part of the project run over 6 weeks, the fifth being a single day event. To mitigate attrition in participation and thus potentially negatively impact the benefits of program participation, participants will be incentivised to attend each program session in return for receiving a \$5.00 voucher. We believe that by providing incentives in small denomination increments, and as vouchers, this will not constitute coercion to continue participating, rather a reward for making time available to attend a session. Again participants will be reminded at all times that they are free to withdraw at any time for any reason without prejudicing any future engagements with BGF or their local sexual health clinic. We believe these strategies are appropriate for mitigating the risks of coercion and inducement.

- Consent will be highly informed by way of a detailed PIS, and expressly given by the participant. The PIS, leading to a clear understanding of the project and the study processes, will ensure that consent will only be given after all information has been read and understood. Further mitigation of any risk is that the participant will have the opportunity to discuss- and ask questions of the study coordinator relating to any aspects of the study they have questions or concerns about. The pre-requisite for participation of the participant being able to communicate in English at a basic level will mitigate any concerns that the participant was not clearly informed of all aspects of the project before consenting.
- As previously stated, the primary benefit for conducting the project is to the individual participating in the study by way of a hypothesised quality of life improvement following participation in BGF's Health and Wellbeing Programs. Secondary benefit of conducting the project is building a knowledge base from which further program delivery can be undertaken to benefit others in the wider HIV cohort in the future.
- During the conduct of the study there may arise from time to time the risk of distress to the participant. This could arise externally to the project, or due to information gathered during the course of the study. Either way, the study team apply a trauma-informed approach to all engagement with participants to mitigate the effects of such distress. Participants will be afforded the opportunity to withdraw from the study should the effects of their distress not be managed to the point where they feel comfortable to continue.

- Unrealistic to expect any physical harm to result as a result of participation in the study. Psychological harm has been addressed previously.
- Risk and harms after mitigation:
 - Likelihood - low
 - Impact - low
- On balance, the benefits of participation in the project far outweigh the risks which are considered to be minimal at best.

7.3 Confidentiality and Privacy

- Following receipt of the 'signed' consent form from the participant, the study coordinator will contact the participant to enrol them in the study. This will involve firstly confirming receipt of their consent, and secondly, obtaining relevant geo-demographic data from the participant then entering it into a study database. The coordinator will also ensure there are no outstanding issues to be addressed in response to any questions the participant may have about the project. The database file will be stored in the cloud at an external server of the IT service provider. Refer 7.4
- A randomly generated study ID will then be assigned by a member of BGFs administration team, captured and stored alongside the participants record. Once the randomly generated study ID (number) has been allocated, it together with the first (or preferred) name of the participant will be passed back to the study coordinator to populate a database to capture the PozQoL scores and to monitor payment of incentives relative to attendance. Any identifying data will be removed by the Study Coordinator. The first (or given) name will be stored with the Study ID in a separate password-protected file to enable the study coordinator to effectively communicate with the participant via email or telephone regarding any study related issues.
- There is no non-negligible risk or burden.
- No data linkages are proposed
- No identifying information will be provided to researchers. Only the participants' study IDs will be provided along with the three separate PozQoL scores to enable selections to be made for the qualitative arm of the study.
- Only the study coordinator has access to the identified data gathered. The coordinating principal investigator and principal investigator have access to the de-identified data during the study fieldwork, however only the principal investigator will have access to additional data when undertaking the qualitative analysis to account for confounding factors.

7.4 Data Storage and Record Retention

- The data gathered will be stored in a password-protected database file stored in the cloud hosted on Microsoft's Azure datacentres within Australia. Adventus, BGF's outsourced IT provider, will establish a separate private SharePoint site exclusively for the study, to which only the research team will have access. SharePoint is an industry standard platform with best practice for data security. Additionally, Adventus follow the ACSC Essential 8 guidelines for cyber security.
- Consent forms are electronic, stored similarly on the organisations cloud-based server.
- Data will be captured and held by the sponsor organisation (BGF). There is not transfer of data envisaged as such.
- The platform the data will be stored has not been approved by the LHD/Cyber Security team.
- As mentioned previously only the study coordinator has access to the identified data gathered. The coordinating principal investigator and principal investigator have access to the de-identified data during the study fieldwork, however only the principal investigator will have access to additional data when undertaking the qualitative analysis to account for confounding factors.
- No data transfer is envisaged
- Data will be retained indefinitely to be reused under 'gated access' for future similar studies, using extended consent
- As consent provided is extended, no data will be disposed of.

8. SAFETY REPORTING (IF APPLICABLE)

CLINICAL TRIALS ADVERSE EVENT REPORTING

Not applicable

9. Data Safety and Monitoring Board (Clinical Trials only)

Not applicable

10. Early Termination (IF APPLICABLE)

Not applicable

11. BLINDING AND UNBLINDING (if applicable)

Not applicable

12. CONFLICT OF INTEREST

- No benefits (financial or otherwise) will flow to the investigators as a result of the conduct of this study.
- No benefits (financially or otherwise) will accrue to the investigators from the outcomes of the study. The benefit to the sponsor is the evidence provided by the outcome of the study being that either BGF's Health and Wellbeing programs improve the quality of life of PWHIV living in Western Sydney, or not. Should the evidence indicate an improvement, the benefit to the sponsor would not be of a financial nature given that BGF's programs are delivered free of any charges. The benefit would therefore be the knowledge that delivery of programs to this cohort in this area will improve their quality of life.

13. FUNDING

- The study is being partially funded by way of a grant from a pharmaceutical company, the balance being contributed by BGF. Whilst the funder is a marketer of HIV medications, no mention of either the funder or any of their HIV medication brands are mentioned in the study. The funder has a strong interest in quality of life initiatives for PWHIV ('4th 90'), which is why they are keen to fund a study such as this that evaluates the efficacy of Health and Wellbeing Programs on the QoL for PWHIV in Western Sydney. In response to the committee's concerns that continuing the services/courses after the research is completed may involve cost to the participants, there are NO costs to clients for services and courses provided by BGF. Furthermore, BGF's Health and Wellbeing Programs have not nor will not be funded by My Aged Care or NDIS packages, and similarly have no participants with My Aged Care or NDIS funding plans.
- The obligations to the funder are the completion of the study as outlined in the protocol with a final report paper written and submitted clearly stating the outcomes of the evaluation.

14. RESEARCH OUTCOMES

- Participants will be provided with their three PozQoL scores at the conclusion of the third and final PozQoL assessment.
- Participants will have the opportunity to read the final report via a hyperlink sent to them in an email at the conclusion of the study.
- Project outcomes will be disseminated to all participating LHDs, NSW Health, other community organisations working in HIV, and published on BGF's website.
- The findings of the study could also be of value to other community organisations by way of a presentation at forums/conferences etc.
- All materials gathered relevant to the study will be archived in BGFs cloud-based servers, under strict password protection.
- The data, which will be obtained under extended consent, will be available for sharing with other researchers who have ethics approval to conduct similar or related studies.
- There is currently no plan for secondary or additional data analyses and follow-up research.
- Publication in leading health-related journals and/or relevant conferences (such as the annual ASHM conference) is envisaged.

15. REFERENCES

Literature Review for project:

Evaluation of the impacts of BGF's Health and Wellbeing Programs on the quality of life of PWHIV residing in Greater Western Sydney

It is essential that people living with HIV have access to services that focus on improving quality of life (QoL) and wellbeing as the prevalence of co-morbid health conditions including mental, physical, and emotional health among people living with HIV (PLHIV) is significantly higher than the general population (Morales et al. 2022). Results from a study in Australia (Mendonca et al. 2023, pg. 545) "indicated that HIV-related stigma predicted poorer QoL... conversely, social connectedness improved QoL".

Psychosocial factors - such as isolation, stigma, discrimination, reduced physical and mental health, poor social connectedness, lack of support, financial stress, limited health literacy and drug and alcohol use - can contribute to feelings of depression and anxiety in PLHIV (Mendonca et al. 2023). In turn, these issues significantly negatively impact the wellbeing and quality of life of PLWHIV. For example, it has been shown that PLWHIV with symptoms of depression can have a higher risk of poor adherence to antiretroviral therapy and complications in their clinical care (Asrat et al. 2020). In addition, HIV treatment can cause a wide range of side effects on the central nervous system, including depression, nervousness, euphoria, psychosis, and hallucinations (Treisman & Kaplin 2002).

A recent Australian study highlighted the importance of "continued mental health support as part of routine care" as "HRQoL (quality of life) related to mental health may be lower in men recently diagnosed with HIV, compared to their HIV-negative peers" (Yan et al. 2023, pg. 313). This emphasises the importance of providing services to HIV-positive people that are centered around improving their QoL.

This project seeks to improve the quality of life of PLWHIV by learning through program participation. Following completion of the Health and Wellbeing programs, participants will be reassessed to determine the extent to which their quality of life has improved, using a specific quality of life assessment tool - PozQoL.

There is an increasing awareness of the importance of providing psychosocial support to PWHIV therefore, PozQoL was developed to respond to the increasing demand "to incorporate a stronger focus on the quality of life (QoL) of PWHIV into HIV prevention policy" (Brown et al. 2018, pg. 1). PozQoL is a freely available

13-item scale assessing QoL among PWHIV. The PozQoL development and evaluation study “displayed excellent construct validity and very good reliability, including consistency and temporal stability” (Brown et al. 2018, pg. 10). Using the PozQoL scale in our evaluation study will accurately capture participants' QoL and assist us in determining both the successes and limitations of BGF's Health and Wellbeing Programs in improving QoL.

Existing literature demonstrates the significant role that psychosocial support plays in improving the QoL of PWHIV. Our project seeks to evaluate how successful a tailored suite of Health and Wellbeing Programs is in improving QoL for PWHIV through learning and social connection, both in the short and medium term.

Reference List

Asrat, B, Lund, C, Ambaw, F, Garman, EC, & Schneider, M, 2020 'Major depressive disorder and its association with adherence to antiretroviral therapy and quality of life: cross-sectional survey of people living with HIV/AIDS in Northwest Ethiopia', *BMC Psychiatry*, vol. 20, no. 1, pp. 462–462, DOI: 10.1186/s12888-020-02865-w.

Brown, G, Mikołajczak, G, Lyons, A, Power, J, Drummond, F, Cogle, A, Allan, B, Cooper, C, & O'Connor, S, 2018,, 'Development and validation of PozQoL: a scale to assess quality of life of PLHIV', *BMC Public Health*, vol. 18, no. 1, pp. 527–527, DOI: 10.1186/s12889-018-5433-6.

Mendonca, CJ, Newton-John, TRO, Alperstein, DM, Begley, K, Hennessy, RM, & Bulsara, SM, 2023 'Quality of Life of People Living with HIV in Australia: The Role of Stigma, Social Disconnection and Mental Health', *AIDS and Behavior*, vol. 27, no. 2, pp. 545–557, DOI: 10.1007/s10461-022-03790-7.

Morales, DR , Moreno-Martos, D, Matin, N 2022, 'Health conditions in adults with HIV compared with the general population: A population-based cross-sectional analysis', *eClinicalMedicine*, vol. 47, pg. 1-10, DOI: <https://doi.org/10.1016/j.eclinm.2022.101392>

Treisman, GJ, Kaplin, AI, 2002 'Neurologic and psychiatric complications of antiretroviral agents', *AIDS (London)*, vol. 16, no. 9, pp. 1201-1215, DOI: 10.1097/00002030-200206140-00002.

Yan, D, McMahon, J, Lee, S, & Giles, ML, 2023 'Quality of life in people living with HIV (the fourth 90) - are we there yet in Australia?', AIDS Care, vol. 35, no. 2, pp. 306–315, DOI: 10.1080/09540121.2022.2129562.

Appendix B: Ethics Approval

From: no_reply@regis.health.nsw.gov.au <no_reply@regis.health.nsw.gov.au>
Sent: Tuesday, August 6, 2024 1:55 PM
To: Andrew Buchanan <Andrew.Buchanan@bfg.org.au>
Cc: Romilly Rae <Romilly.Rae@bfg.org.au>
Subject: 2023/ETH02059: Application HREA - Approved ****ETHICS APPROVAL ONLY **SITE SPECIFIC AUTHORISATION REQUIRED****

Date of Decision Notification: **06 Aug 2024**

Dear Andrew Buchanan,

Thank you for submitting the following Human Research Ethics Application (HREA) for HREC review;

2023/ETH02059: Evaluation of the impacts of BGF's Health and Wellbeing Programs on the quality of life of PWHIV residing in Greater Western Sydney

This Application was reviewed as a **Greater than low risk review pathway** and was initially considered by the **South Western Sydney Local Health District Human Research Ethics Committee** at its meeting held on 19 February 2024.

The project was determined to meet the requirements of the National Statement on Ethical Conduct in Human Research (2023) and was **APPROVED**.

This email constitutes ethical and scientific approval only.

This project cannot proceed at any site until separate research governance authorisation has been obtained from the Institution at which the research will take place.

This project has been Approved to be conducted at the following sites:

- **Liverpool Hospital**
- **Blue Mountains District ANZAC Memorial Hospital**
- **SWSLHD Community Health Centres**

The following documentation was reviewed and is included in this approval:

Document	Version	Date
Human Research Ethics Application	9.0	20.06.2024
Protocol	4.0	13.06.2024
Literature Review for project	N/A	N/A
MASTER Participant Information Sheet	2.0	13.06.2024
MASTER Consent Form	3.0	13.06.2024
Data Management Plan	N/A	N/A

Recruitment Poster	N/A	N/A
Interview Questionnaire for semi-structured qualitative interviews	N/A	N/A
PozQoL Scale	N/A	2021

[Application Documents](#) - (link will only be active for 14 days from the decision date. The approved documents are also available to download from forms section of this project in REGIS)

The Human Research Ethics Application reviewed by the HREC was:
Version: 1.09
Date: 18 Jul 2024

The approval is for a period of 5 years from the date of this e-mail (**06 Aug 2024**)

Please note the following conditions of approval:

****Condition of approval: Please ensure that the restrictions and social distancing for COVID-19 are followed until the restrictions have been lifted****

1. The Principal Investigator will immediately report anything which might warrant review of ethical approval of the project in the specified format, including: any serious or unexpected adverse events; and unforeseen events that might affect continued ethical acceptability of the project.
2. The Principal Investigator will report proposed changes to the research protocol, conduct of the research, or length of HREC approval to the HREC in the specified format, for review. For multi-centre studies, the Chief Investigator should submit to the Lead HREC and then send the amendment approval letter to the investigators at each sites so that they can notify their Research Governance Officer.
3. The Principal Investigator will inform the HREC, giving reasons, if the project is discontinued before the expected date of completion.
4. The Principal Investigator will provide an annual report to the HREC and at completion of the study in the specified format.
5. The Principal Investigator must reassure participants about confidentiality of the data.
6. Proposed changes to the personnel involved in the study are submitted to the HREC accompanied by a CV where applicable.
7. The Principal Investigator is responsible for ensuring the research project is conducted in line with relevant NSW Health, South Western Sydney Local Health District and Hospital policies available from: <https://www.swslhd.health.nsw.gov.au/ethics/policies.html>

Interpreter use: If this study will involve the use of interpreters, you are required to contact SWSLHD Interpreter Services on 8738 6088 and/or swslhd-interprettersbookings@health.nsw.gov.au. This is required even if you have access to interpreters for clinical purposes, as SWSLHD Interpreter Services are required to review and approve the use

of interpreters for any research work. Once you have contacted SWSLHD Interpreter Services, please ensure that you include the provided quote/s (if any) with your SSA submissions for your project.

Should you have any queries about your project please contact **our office** on the telephone number 8738 8304. The HREC Terms of Reference, Standard Operating Procedures, membership and standard forms are available from the SWSLHD website:

<https://www.swslhd.health.nsw.gov.au/ethics/>

Please quote the above Ethics number in all correspondence. The HREC wishes you every success in your research.

Yours faithfully,

Dr Cameron Lutman

Research Ethics and Governance Manager

on behalf of

Professor Murray Killingsworth

Chairperson, SWSLHD Human Research Ethics Committee

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Human Research (2007)*. The processes used by this HREC to review multi-centre research proposals have been certified by the National Health and Medical Research Council.

Please don't hesitate to contact us if you have any questions.

Kind regards,

Jia

Dr Jia Ying Ooi

Research Ethics and Governance Coordinator

Tel 02 8738 8152 | Mob 0418 114 563

Research Directorate | South Western Sydney Local Health District (SWSLHD)

Locked Bag 7279, Eastern Campus, Liverpool BC, NSW 1871

SWSLHD-Ethics@health.nsw.gov.au | <https://www.swslhd.health.nsw.gov.au/ethics/>

Research Ethics and Governance team

Telephone no.

Dr. Cameron Lutman, Research Ethics and Governance Manager

0499 972 501

Ms. Malina Peng and Ms. Jia Ying Ooi, Research Ethics and Governance Coordinator

0455 060 242 and
0418 114 563

Ms. Tayla Hibbs, Research Ethics and Governance Administrative Officers

0409 151 623 and
0400 181 958

'I acknowledge the traditional owners and custodians of the land that I live and work on, as the first people of this country'

This email has been scanned for spam and viruses by Proofpoint Essentials. Click [here](#) to report this email as spam.

Appendix C: Study Flyer



Bobby Goldsmith
Foundation

Want to improve the quality of your life?

Consider taking part in a study aimed at improving your social, mental, physical and financial health and wellbeing.

What's involved:	To be eligible you need to be:	What you'll receive:
<ul style="list-style-type: none">• Complete 2 free BGF Health & Wellbeing Programs• Undertake 3 short assessments• Agree to be interviewed (if selected)	<ul style="list-style-type: none">• A person living with HIV• 18 years or older• Living in Western Sydney• Able to speak/write in English	<ul style="list-style-type: none">• Gift vouchers for attending program sessions, doing the assessments and participating in the interview• An improved quality of life

All data gathered in the study is completely confidential and anonymous. Your participation is voluntary – you can opt out of the study at any stage.

Interested in finding out more? Simply scan the QR code, visit www.bgf.org.au/study, email study@bgf.org.au or call/SMS the Study Coordinator on 0406 645 724 to express your interest



2023/ETH02059

Appendix D: Participant Information Sheet

Participant Information Sheet

Study Name: Evaluation of the impacts of BGF's Health and Wellbeing Programs on the quality of life of PLHIV residing in Greater Western Sydney

SWSLHD Human Research Ethics Committee Approval Number: 2023/ETH02059

What is this evaluation study about?

You are invited to take part in an [evaluation study](#) that will assess the impact of Bobby Goldsmith Foundation's (BGF) Health and Wellbeing Programs on the quality of life of people living with HIV (PLHIV) residing in Greater Western Sydney.

The project aims to contribute to the knowledge and practice of delivering health and wellbeing programs to PLHIV to improve their quality of life. You have expressed an interest in participating in this study, which is why you are receiving this Participant Information Sheet (PIS). You may benefit from participating in the study by attending programs that aim to improve your quality of life through learning and social connection.

Who is conducting the study?

Coordinating Principal Investigator: Andrew Buchanan, Policy, Research and Evaluation Manager, Bobby Goldsmith Foundation (BGF)

Principal Investigator: A/Prof Brahm Marjadi, Associate Professor of Community Engaged Learning, Western Sydney University

Research Funder: The majority of the funding for this project is being provided by ViiV Healthcare.

Who is the Bobby Goldsmith Foundation?

The Bobby Goldsmith Foundation is a not-for-profit charitable institution that provides support and services to PWHIV residing in New South Wales and South Australia. The foundation is the longest serving community-based HIV charity in Australia having been founded in 1984 when friends of Bobby Goldsmith, a well-known Australian swimmer was diagnosed with HIV/AIDS, rallied around him to provide support and dignity in his final days. Since then, the organisation has gone on to assist hundreds of PWHIV with financial, practical and emotional support in many different ways. Today BGF delivers case work and case management, home care supports, financial counselling and health and wellbeing

programs to hundreds of PWHIV. BGF's mission is to assist PWHIV to thrive, with a particular focus on improving their quality of life.

Before you consider whether or not to participate in this study, we need to ensure that you are eligible to take part. The study is looking to recruit people who meet the following criteria:

- Living with HIV
- Residing in greater Western Sydney, specifically within the Western Sydney, South Western Sydney, and Nepean/Blue Mountains Local Health Districts.
- Aged 18 and over
- Able to communicate in English at a basic level
- Have reliable internet and/or mobile phone/computer access
- Able to provide a valid email address as well as a mobile phone number for ongoing communication

People who meet the following criteria will be excluded from the study:

- If you prefer not to be contacted for research/evaluation purposes
- If you have previously participated in BGF's Health and Wellbeing programs

If you meet the above inclusion/exclusion criteria you are eligible to participate in the study, should you wish to do so.

Do I have to take part in this study?

No. Participation in this study is entirely voluntary. If you do not want to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the study at any stage, without any repercussions or restrictions on receiving support from any of the organisations involved in the study.

If you decide you want to take part in the study, you will be required to:

- Read this participant information sheet carefully, asking questions if necessary to obtain clarity on matters you may wish to know more about to ensure a full understanding of the study; and
- Read, sign and return the consent form (signing and returning will be undertaken electronically)

What if I want to withdraw from the study after I have consented to take part in it?

After you have consented to participate, you may withdraw from the study at any time without any questions being asked. To withdraw your consent, send an email to study@bfg.org.au providing written notification of your request to discontinue your participation in the study.

Your decision not to participate or to withdraw from the study will not affect your relationship with BGF or any of the sexual health clinics. Once you decide to leave the study, the study team will not collect any further information from you. You can request that any identifiable information about you be deleted, as well as any data that has already been collected from you.

What does participation in this evaluation study require? Are there any risks involved?

Firstly, you will be asked to sign a consent form which has been sent to you together with this PIS and return it to study@bfg.org.au. The study coordinator will then contact you to obtain your name, age, postcode, contact details etc. You will then be assigned a randomly-generated Study ID. The researchers will only receive your given name and Study ID to communicate with you and analyse your data, without linking it with your full identity.

You will then be asked to complete a PozQoL survey electronically. PozQoL is a short quality of life assessment tool where you express how you feel about 13 statements about daily living. It should take you less than 5 minutes to complete. There will be an incentive for your participation in this first PozQoL.

The scores from PozQoL surveys help service providers better understand the areas of your life that may be improved by support services. In our study, the research team will use your PozQoL score to establish what is known in research as a baseline measure (of your quality of life) and determine if your quality of life could be improved by one of BGF's Health and Wellbeing Programs. The Study Coordinator will notify you of the outcome of this assessment. The study coordinator will discuss with you which of the 5 BGF programs being offered will best assist you in improving your quality of life:

1. **Art Therapy (Social Health):** A 6-week in-person program that combines therapeutic activities and art practices to explore your journey with HIV.
2. **Positive Money Management (Financial Health):** A one-day in-person workshop to build confidence in budgeting and explore new ideas around money management.
3. **Iyengar Yoga (Gentle Yoga) (Physical Health):** A 5-week online program run by a qualified yoga instructor. The program can be adapted for all bodies, lived experiences and conditions. In Iyengar Yoga you will move, open the body, tune in to the breath, and calm the mind.
4. **CBT (Cognitive Behaviour Therapy) (Psychological Health):** A 4-week online program led by a trained psychologist from RewireMe Psychology. The program identifies challenges, and replaces

automatic negative thoughts with more objective, realistic ones, through strategies such as journaling, relaxation techniques, and mental distractions.

5. **PSMP (Positive Self-Management Program) (Psychological Health):** BGF's "Take Control of Your Health" workshops are designed to improve the understanding of health management for PLHIV and explore healthy ways to live the best life possible. This is a 6-week in-person program.

After the discussion, you will be enrolled in two (2) Health and Wellbeing programs that are most appropriate. All programs are delivered by highly qualified and experienced facilitators who have delivered similar programs previously. All facilitators have signed a confidentiality agreement with BGF and agree to abide by BGF's Privacy and Confidentiality Policy.

You will receive a \$5 voucher for each program session you attend.

You may request a reimbursement of up to \$30 for travel costs to attend programs. You will need to apply for this allowance and substantiate your claim.

At the end of the programs, you will be asked to complete a second PozQoL assessment to be returned to the study coordinator. The score from that assessment will determine the extent to which your program participation has impacted your quality of life in the short-term. There will be an incentive for your participation in this second PozQoL.

Two months after your post-program PozQoL (second) submission, you will be asked to complete a third and final PozQoL assessment to be returned to the study coordinator. The scores from this PozQoL will be used to measure the longer-term impact of the programs on your quality of life. There will be an incentive for your participation in this final PozQoL.

You may be invited to participate in an interview that will explore the barriers and facilitators for a continuous or sustained improvement in your quality of life. The interviews will also identify the programs' strengths and areas for improvement. Interviews will be recorded. Should you be selected for this part of the study you will receive an additional incentive to participate.

If you are selected to participate in an interview, at the end of the interview the interviewer will confirm your answers by summarising the main points from the answers provided by you. You will be given the chance to rectify and/or clarify any errors in interpretation of your answers prior to the interview being concluded.

Should you wish to enrol in future BGF Health and Wellbeing Programs outside of this study, you are welcome to do so. Such programs are offered free of any charges.

Risks - Psychological distress

If you experience any discomfort or feelings of distress while participating in the study and you require support, you can stop participating at any time. No questions will be asked. You simply need to send an email to the study coordinator indicating you would like to withdraw from any further participation in the study.

If you feel your distress is temporary, you can also tell a member of the study team, and they will provide you with assistance. You can also reach out directly to the following services:

Beyond Blue – 24/7 Mental Health Support Service	Call: 1300 22 4636
Lifeline Australia – 24/7 Crisis Support	Call: 13 11 14
Headspace (for 12-25 years old only)	Call: 1800 650 890

What are the possible benefits of taking part in this study?

Whilst there may be no direct personal benefits from your participation in the study, you may learn new life skills, make new social connections and experience an overall improvement in health and wellbeing leading to an improvement in your quality of life.

The evaluation of the effectiveness of the programs on your quality of life will benefit other PLHIV who may need health and wellbeing support in the Greater Western Sydney area.

What will happen to the information you gather about and from me?

When you submit the consent form this means that you are providing your permission for the study team to collect and use information about you for the study. The information collected from you throughout the study will comprise the following:

- Demographic information (name, contact details, age, gender, year of HIV diagnosis, cultural identities)
- Health and Wellbeing programs you attend
- PozQoL scores (baseline, second and third)
- Responses to qualitative interview questions (if selected to participate).

All of your data will be stored in a password protected database in a cloud server being SharePoint, which is the industry standard platform with best practice for security. Only the researchers will have access to the database. We will make every effort to protect the confidentiality of your data under BGF's

Privacy and Confidentiality Policy, and Confidentiality Agreement between BGF and non-BGF researchers.

The researchers are asking that you agree to supply your information (data) for use in this project and to also agree to allow the data to potentially be used in future research projects. This request is in line with current government policy that encourages the re-use of data once it has been collected. Collecting information for research can be an inconvenience or burden for participants and has significant costs associated with it. Sharing your data with other researchers gives potential for others to reflect on the data and its findings, to re-use it with new insight, and increase understanding in this research area.

You have been asked to agree to Extended Consent. When you agree to Extended Consent it means that you agree that your data, as part of a larger dataset (the information collected for this project) can be re-used in projects that are

- an extension of this project
- closely related to this project
- in the same general area of this research.

The researchers will allow this data to be used by similarly themed projects in future, i.e. projects evaluating the effectiveness of BGF support programs. The stored data available for re-use will not have information in it that makes you identifiable. The re-use of the data will only be allowed after an ethics committee has agreed that the new use of the data meets the requirements of ethics review.

You are welcome to discuss these issues further with the researchers before deciding if you agree. You can also find more information about the re-use of data in research in the [National Statement on Ethical Conduct in Human Research 2023](#).

How and when will I find out what the results of the research study are?

The research team intends to report and publish the results of the research. The findings will be published in a way that will not identify you. The final report from this study will be sent via email to you.

Complaints Contacts

If you have a complaint regarding any aspect of the study or the way it is being conducted, please contact your local health district from the list below:

- South Western Sydney Local Health District Research Office
Email: SWSLHD-Ethics@health.nsw.gov.au

Phone: (02) 8738 8304 OR (02) 8738 8314

- Nepean Blue Mountains Research Office

Email: NBMLHD-Ethics@health.nsw.gov.au

Phone: (02) 4734 1998

- Western Sydney Local Health District's Research Office

Email: wslhd-researchoffice@health.nsw.gov.au

Phone: (02) 8890 9007

What should I do if I have further questions about my involvement in the research study?

The person you may need to contact will depend on the nature of your query. If you require further information regarding this study or if you have any problems which may be related to your involvement in the study, you can contact the Study Coordinator at the following address: study@bgf.org.au

Thank you for taking the time to read through the PIS. It is intended to provide you with all the information you require to make an informed decision about your participation or not.

Appendix E: Participant Consent Form

Participant Consent Form

Study Name: Evaluation of the impacts of BGF's Health and Wellbeing Programs on the quality of life of PLHIV residing in Greater Western Sydney

SWSLHD Human Research Ethics Committee Approval Number: 2023/ETH02059

Coordinating Principal Investigator: Andrew Buchanan, Policy, Research and Evaluation Manager, Bobby Goldsmith Foundation (BGF)

Principal Investigator: A/Prof Brahm Marjadi, Associate Professor of Community Engaged Learning, Western Sydney University

Study Coordinator: Deena Mehjabeen, Bobby Goldsmith Foundation (BGF)

Project Funder: ViiV Healthcare (in part)

Locations: South Western Sydney Local Health District, Nepean Blue Mountains Local Health District, Western Sydney Local Health District

Participant providing own consent

Declaration by the participant

- I understand I am being asked to provide consent to participate in the above study;
- I have read the Participant Information Sheet (PIS), or it has been read to me in a language that I understand;
- I understand the purposes, study tasks and risks of the research involved in the study, and as outlined in the PIS;
- I consent for my data and information provided to be used in this project and other related projects for an extended period of time;
- I agree to BGF storing my de-identified responses to assessments and survey questions with the intention to share them with study investigators, and for possible future use in relevant research projects;
- I understand that, if necessary, I can ask questions to seek clarification about the study, and a member of the study team will respond to my questions timeously.

I consent to:

- Participating in an interview should this be required of me
- Having my responses to any interview audio recorded

I consent for my data and information provided to be used in this project and other related projects for an extended period of time.

I understand that my involvement is confidential, and that the information gained during the study may be published and stored for other research use but no information about me will be used in any way that reveals my identity.

I freely and willingly agree to participate in this evaluation study as described in the PIS.

I understand that I am free to withdraw at any time during the course of the study and that my withdrawal will not affect my relationship with any of the named organisations and/or study team members.

IF YOU AGREE TO TAKE PART IN THIS STUDY, PLEASE FOLLOW THESE INSTRUCTIONS TO PROVIDE CONSENT

1. Save this document as a Word file with the file name as follows: 3-digit participant ID (see below).doc or docx. For example, xxx.doc or docx.
2. Next, create a new email message with the title 'Consent Form for Participant xxx (xxx being your 3-digit participant ID), attach the file you have just saved, and send the email to study@bgf.org.au as a record of your having consented to participate, and serve as a record of you having done so.

By doing the above it is assumed that you have read and understood the information above, agree freely to participate in this anonymous and voluntary evaluation study, and provide your informed consent without duress or coercion.

Participant ID:

Appendix F: PozQoL Form

PozQoL (Quality of Life) Assessment #1

Study ID: _____ Date completed: _____

Instructions: Please place a tick or cross in the box that most accurately reflects how you are feeling about each of the 13 statements listed.

Please ignore the numbers under each of the boxes, they are used to calculate the quality of life score

	Not at all	Slightly	Moderately	Very	Extremely
I am enjoying life	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
I worry about my health	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
I lack a sense of belonging with people around me	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
I feel that HIV prevents me from doing as much as I would like	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
I feel good about myself as a person	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Having HIV limits my opportunities in life	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
I worry about the impact of HIV on my health	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
I feel in control of my life	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
I am afraid that people may reject me when they learn I have HIV	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
Managing HIV wears me out	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
I feel that HIV limits my personal relationships	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
I fear the health effects of HIV as I get older	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
I am optimistic about my future	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

Appendix G: Qualitative Analysis

Qualitative Survey Responses and Findings including Content analysis from participants on the BGF Health and Wellbeing Programs study undertaken in Western Sydney

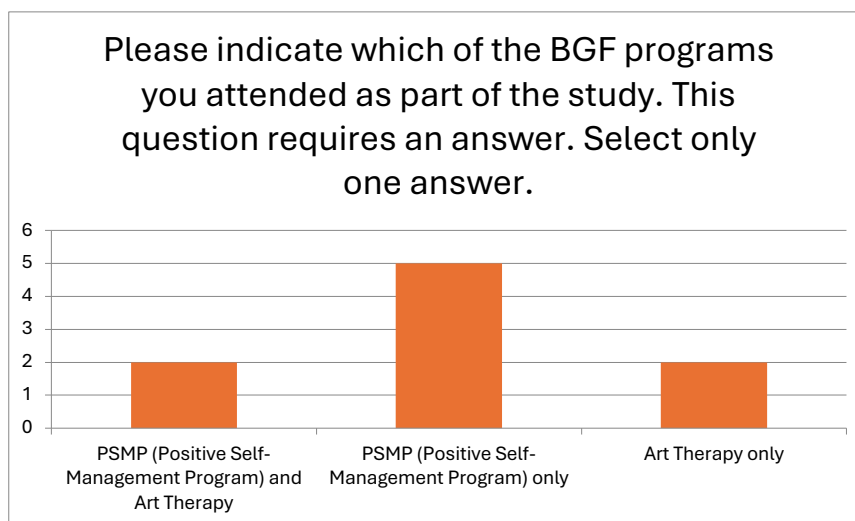
Limitations

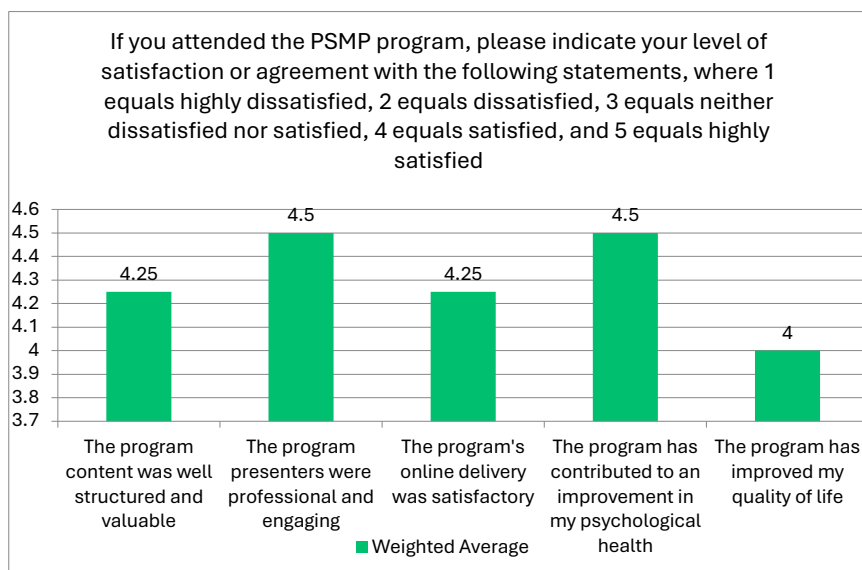
Due to various constraints, the qualitative study design could not be undertaken as documented in the study protocol. The protocol stated that a sample of participants using pre- and post-PozQoL scores were to be selected to undertake the survey, however due to low participant numbers all participants were invited to undertake the survey. In this case n = 9, with 2 participants undertaking both programs being offered namely PSMP (Positive Self-Management Program) and Art Therapy, 5 participants undertaking PSMP only, and 2 participants undertaking Art Therapy only.

A further limitation was the lack of time available to undertake face-to-face interviews following the completion of the final program session. In response, the interview guide was modified into a questionnaire whilst retaining the aims and objectives of the original design.

All participants in the study identified as CALD (Culturally and Linguistically Diverse) with English as their non-dominant language spoken at home. Due to cost limitations, the study protocol required all participants to be able to communicate in English at a basic level. Participants in the qualitative survey were given the option to respond in their preferred (home) language rather than English however all participants chose to respond in English.

The following pages chart the responses received from participants. A copy of the questionnaire used can be found as Section A.





Additional Comments per statement:

The program content was well structured and valuable:

- Ongoing physical and mental health problems so couldn't attend fully although the program was amazing
- The organisation and facilitation of the program was above expectation

The program presenters were professional and engaging:

- The presenter's challenge is understanding the language of the participant's mind, and I noticed this was handled particularly well during the session.
- The presenters were respectful and empathic with all participants

The program's online delivery was satisfactory:

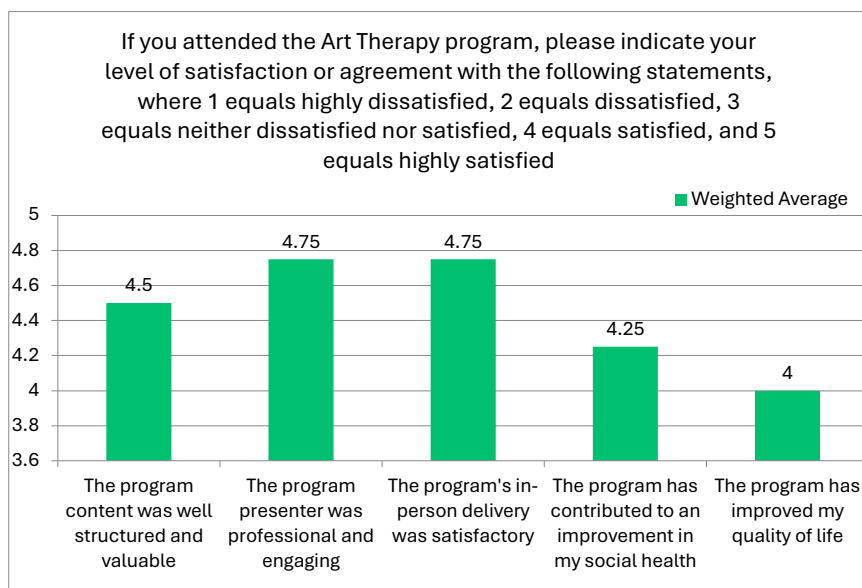
- At the end, experienced technical issues
- The facilitators could include more group interactive activities during the sessions
- Whilst personally not used to video meetings, this was much better than having to travel to the CBD to participate. The weekend (Saturday) delivery permitted those who are in regular fulltime employment to participate

The programs have contributed to an improvement in my psychological health:

- I'm aware of my mental health most of the time
- I remember the program, and when I go to exercise or do any physical activity, it inspires me a lot

The program has improved my quality of life:

- More awareness and thoughts
- Yes, by setting weekly goals during the workshop sessions, we encouraged each other to complete their weekly tasks and goals



Additional Comments per statement:

The program content was well structured and valuable

- Excursion related to art and outdoor events would be better such as exhibitions and museums
- More time more interaction, more freedom, more classes, listen to ideas and implement them to keep whoever, interested

The program presenter was professional and engaging

- A special guest would be good to have some new and exciting ideas
- More funding, more materials, more much more frequent so it doesn't feel wasted time

The program's in-person delivery was satisfactory

- More interaction and engagement, more active sessions, instead of sitting down, warm up session, ice breakers to introduce people to each other they are excited to meet each other

The program has contributed to an improvement in my social life

- Feel open to reach out and we feel positive to be with each other, it all depends on the vibe

The program has improved my quality of life

- Overall, it was positive to get out of the comfort zone, reach out to people for help, since a lot of people in the community feel afraid to connect. Not to feel sad about your situation, it already happened, it's normal and get out of the darkness. Make them come out of their shell.

Content analysis

(Note: each response can have multiple categories attributed)

Social Engagement

Social Engagement is when one has contact with others in one's community and feeling connected to your surrounding world. Please comment on any changes to your social engagement during or after the program/s you attended. Have the changes been positive or negative? Or has there been no change? If the changes are positive, to what extent have the program/s contributed to the changes? Which program has contributed the most to this change? How have the changes made you feel now? (n = 6)

- Community and Social Connection (4)
- Social Confidence and Stress Reduction (2)
- Peer Support and Accountability (2)
- Participant Engagement and Goal Setting (2)
- Self-Empowerment and Positive Outlook (1)

Health Routines

Health Routines are activities that contribute to your overall wellbeing such as daily physical exercise, HIV medication adherence etc. How has participation in the program/s you attended influenced your health routines? If the influence is positive, which program influenced you the most? (n = 7)

- Community and Social Support (5)
- Physical Activity Engagement (3)
- Medication Management (2)
- Diet and Nutrition Awareness (1)
- Health Monitoring Technology (1)

Support

Firstly, looking at the issue of support you receive in your day-to-day life. What score would you give to the level of support you received prior to starting the program/s, where 0 means receiving no support at all, to 10 means you are fully supported in every aspect of daily living. (n = 6)

Mean score: 67.33

Minimum score: 30

Maximum score: 100

Now looking at the issue of support, please provide answers to the following questions):

1. How would you describe the support you received during the program/s from the study coordinator, facilitators and peers?
2. How would you describe the support you receive now?
3. If you feel your support has improved, what has changed? Is it more support (quantity)? Is it better support (quality)? Or is it both?

(n = 6)

- Peer and Emotional Support (3)

- Information and Communication Support (3)
- Program Access and Resources (2)
- Program Environment Quality (2)
- Post-Program and Basic Needs (2)

Stress, Grief, Mood

We would like to understand more about your ability to cope with stress, grief, low mood, and other negative feelings that we all have from time to time.

1. How would you describe your ability to cope before starting the program/s?
2. What impact, if any, has/have the program/s had on your coping ability?
3. How do you feel about any changes in your ability to cope where 1 equals much worse, 3 equals no change, and 5 equals much better.

(n = 6)

- Peer and Community Support (4)
- Social Isolation and Stigma (2)
- Coping and Stress Management Skills (2)
- Program-Dependent Coping (2)
- Attitudes Toward Progress and Vulnerability (2)

General Feedback

Please share any feedback you have about the study you consented to participate in and have just completed. This question requires an answer. Some aspects you might like to consider are:

1. the enrolment process
2. any challenges you faced in attending the program/s, whether in-person or online
3. what you found most helpful
4. what you found most difficult
5. what could be improved
6. any future programs you would like to see.

(n = 9)

- Program Structure and Logistics (6)
- Session Accessibility and Facilitation (5)
- Social Interaction and Group Dynamics (4)
- Content Quality and Engagement (4)
- Retirement Planning Support (1)

Study Endorsement (Radio Interview)

If you were being interviewed on radio about the study, what would you like to say about it? (n = 9)

- Program Structure and Delivery (3)
- Peer Empowerment and Mentorship (3)
- HIV Awareness and Stigma Reduction (2)
- Social Support and Connection (2)
- Art-Based Coping Strategies (1)

Section A

Evaluation of the impacts of BGF's Health and Wellbeing Programs on the quality of life of PWHIV residing in Greater Western Sydney - Participant Survey

Thank you for taking the time to complete this survey.

Your feedback will help us to better understand your experience of the program and improve future services. There are no right or wrong answers.

The survey aims to identify any changes you have experienced during the study period, as well as your views on the study as a whole.

The survey is in 3 separate sections:

Section 1 gathers some personal information that helps us analyse the results. You will not be identified in any way as this survey is completely confidential.

Section 2 asks you about how your participation in the programs you attended has influenced your quality of life. There are 4 areas that will be looked at separately namely:

1. Social Engagement
2. Health Routines
3. Support
4. Coping Mechanisms

Section 3 asks you to comment of the study itself, i.e. what you like most about the study, what you liked least etc.

The survey should take you between 15-20 minutes to complete. All responses will be kept confidential

If you need help completing the survey, please contact Deena (Study Coordinator) on 0406 645 724, who will be happy to assist.

* 1. Some questions ask you to write your thoughts in your own words. You may respond in the language you are most comfortable with. Responses will be translated into English if needed.

Please indicate the language you are using in the box below.

* 2. Please enter your participant Study ID number (note: this is the number assigned to you at the start of the study to ensure your confidentiality). This question requires an answer.

* 3. Please indicate which of the BGF programs you attended as part of the study. This question requires an answer. Select only one answer.

- PSMP (Positive Self-Management Program) and Art Therapy
- PSMP (Positive Self-Management Program) only
- Art Therapy only

4. If you attended the PSMP program, please indicate your level of satisfaction or agreement with the following statements:

	Highly Dissatisfied	Dissatisfied	Neither Dissatisfied or Satisfied	Satisfied	Highly Satisfied
The program content was well structured and valuable	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Please feel free to add any further comments you may wish to make about this statement					
<input style="width: 100%;" type="text"/>					
The program presenters were professional and engaging	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Please feel free to add any further comments you may wish to make about this statement					
<input style="width: 100%;" type="text"/>					
The program's online delivery was satisfactory	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Please feel free to add any further comments you may wish to make about this statement					
<input style="width: 100%;" type="text"/>					
The program has contributed to an improvement in my psychological health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Please feel free to add any further comments you may wish to make about this statement					
<input style="width: 100%;" type="text"/>					
The program has improved my quality of life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Please feel free to add any further comments you may wish to make about this statement					
<input style="width: 100%;" type="text"/>					

5. If you attended the Art Therapy program, please indicate your level of satisfaction or agreement with the following statements.

	Highly Dissatisfied	Dissatisfied	Neither Dissatisfied or Satisfied	Satisfied	Highly Satisfied
The program content was well structured and valuable	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Please feel free to add any further comments you may wish to make about this statement					
<input type="text"/>					
The program presenter was professional and engaging	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Please feel free to add any further comments you may wish to make about this statement					
<input type="text"/>					
The program's in-person delivery was satisfactory	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Please feel free to add any further comments you may wish to make about this statement					
<input type="text"/>					
The program has contributed to an improvement in my social health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Please feel free to add any further comments you may wish to make about this statement					
<input type="text"/>					
The program has improved my quality of life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Please feel free to add any further comments you may wish to make about this statement					
<input type="text"/>					

6. Social Engagement is when one has contact with others in one's community and feeling connected to your surrounding world.

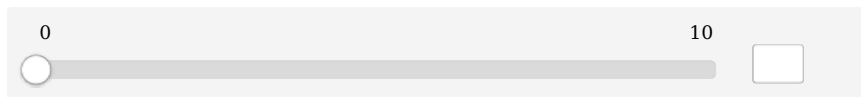
Please comment on any changes to your social engagement during or after the program/s you attended. Have the changes been positive or negative? Or has there been no change? If the changes are positive, to what extent have the program/s contributed to the changes? Which program has contributed the most to this change? How have the changes made you feel now?

7. Health Routines are activities that contribute to your overall wellbeing such as daily physical exercise, HIV medication adherence etc.

How has participation in the program/s you attended influenced your health routines? If the influence is positive, which program influenced you the most?

8. Let's look at the issue of support you receive in your day-to-day life.

Firstly, what score would you give to the level of support you received prior to starting the program/s, where 0 means receiving no support at all, to 10 means you are fully supported in every aspect of daily living.



9. Continuing to look at the issue of support, please provide answers to the following questions:

1. How would you describe the support you received during the program/s from the study coordinator, facilitators and peers?

2. How would you describe the support you receive now?

3. If you feel your support has improved, what has changed?

Is it more support (quantity)?

Is it better support (quality)?

Or is it both?



10. We would like to understand more about your your ability to cope with stress, grief, low mood, and other negative feelings that we all have from time to time.

1. How would you describe your ability to cope before starting the program/s?

2. What impact, if any, has/have the program/s had on your coping ability?

3. How do you feel about any changes in your ability to cope where 1 equals much worse, 3 equals no change, and 5 equals much better. Please explain your answer in the box below (optional).



* 11. Please share any feedback you have about the study you consented to participate in and have just completed. This question requires an answer.

Some aspects you might like to consider are:

1. the enrolment process
2. any challenges you faced in attending the program/s, whether in-person or online
3. what you found most helpful
4. what you found most difficult
5. what could be improved
6. any future programs you would like to see.

Please use the numbering above when answering

12. Finally, if you were being interviewed on radio about the study, what would you like to say about it?

Thank you for taking the time to complete this short survey. Your feedback is greatly appreciated and will provide valuable insights into the success of the study, as well as inform future program development.

A final report of the study will be prepared. Should you wish to receive a copy of the Executive Summary, please contact BGF on 02 9283 8666 and one will be made available for you.

With our very best wishes for your future, and ongoing quality of life.
The Study Team

Appendix H: Recruitment and Outreach Networks

Community organisations	Type of organisation
Acceptance Sydney for LGBT+ Catholics	LGBTQIA+ Support Group
ACON, ACON Asian Gay, Bi+ + Queer Men's Project	LGBTQIA+ Support Group & HIV Support Service LGBTQIA+ Support Group
Aarows	Sex On Premise Venues
Asylum Seeker Centre	Migrant and/or refugee service
Australia and New Zealand Tongzhi Rainbow Alliance (ANTRA)	LGBTQIA+ Support Group
Australian GLBTIQ Multicultural Council (AGMC Inc)	LGBTQIA+ Support Group
BlaQ Aboriginal Corporation	LGBTQIA+ Support Group
Bodyline Spa & Sauna	Sex On Premise Venues
CALD Sexual Health and HIV Action Group (CALD SHAG)	LGBTQIA+ Support Group
Chilenos LGBTQI en Australia	LGBTQIA+ Support Group
CORE Community Services	Migrant and/or refugee service
Family Planning NSW	HIV Support Service
FLAGCOM (Filipino Lesbian and Gay Community and Friends)	LGBTQIA+ Support Group
FOBGays+	LGBTQIA+ Support Group
Forcibly Displaced People Network (FDPN)	Migrant and/or refugee service
Headspace	Mental Health Support Service
Gay and Married Men's Association (GAMMA)	LGBTQIA+ Support Group
Hepatitis Australia	Alcohol and Other Drugs Service
Hepatitis NSW	Alcohol and Other Drugs Service
Indonesian Queer Collective	LGBTQIA+ Support Group
Korean Queer Society	LGBTQIA+ Support Group
LHD drug health services	Alcohol and Other Drugs Service
LikeMind	LGBTQIA+ Support Group
Medically Supervised Injecting Centre (MSIC)	Alcohol and Other Drugs Service

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Community organisations	Type of organisation
Migrant Resource Centres	Migrant and/or refugee service
Mission Australia	Mental Health Support Service & Alcohol and Other Drugs Service
Multicultural HIV & Hepatitis Service (MHAHS), NSW	HIV Support Service
National Association of People with HIV (NAPHWA)	HIV Support Service
National Drug & Alcohol Research Centre (NDARC)	Alcohol and Other Drugs Service
Needle Exchange Programs (across LHDs)	Alcohol and Other Drugs Service
Network of Alcohol and Other Drugs Agencies (NADA)	Alcohol and Other Drugs Service
NSW Users and AIDS Association (NUAA)	Alcohol and Other Drugs Service
Oceania Rainbow Network	LGBTQIA+ Support Group
Odyssey House NSW	Alcohol and Other Drugs Service
OneDoor	Mental Health Support Service
Parents, Family and Friends of Lesbians and Gays	LGBTQIA+ Support Group
Population Health HIV and Related Services	HIV Support Service
Positive Life	HIV Support Service
POZHET (HETEROSEXUAL HIV SERVICE) Primary Health Networks	HIV Support Service
Rainbodhi	LGBTQIA+ Support Group
Refugee Health Services	Migrant and/or refugee service
Scarlet Alliance, Australian Sex Workers Alliance	Sex On Premise Venues
Selamat Datang Indonesian Community	LGBTQIA+ Support Group
Settlement Services International (SSI)	Migrant and/or refugee service
Sex Workers Outreach Project (SWOP) NSW	Sex On Premise Venues
Shequ	LGBTQIA+ Support Group
Sydney ARCO IRIS Latin American & Hispanic Community (SAILAHC)	LGBTQIA+ Support Group
Sydney Queer Muslims	LGBTQIA+ Support Group
The Albion Centre	HIV Support Service

Community organisations	Type of organisation
The Bookshop Darlinghurst	LGBTQIA+ Support Group
The Gender Centre	LGBTQIA+ Support Group
The Kirketon Road Centre	Alcohol and Other Drugs Service
Transcultural Mental Health Centre (TMHC)	Mental Health Support Service
The Western Suburbs Haven Inc	HIV Support Service
Trikone	LGBTQIA+ Support Group
Twenty10	LGBTQIA+ Support Group
Uniting	Mental Health Support Service
Universities' Ally Networks	LGBTQIA+ Support Group
Western Sydney Rainbow Connection	LGBTQIA+ Support Group

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