napwha national association of people with HIV australia

RESEARCH AND REPRESENTATION:

The meaningful involvement of HIV-positive people in HIV research

Report authored by Dr John Rule, Ronald Woods and Dr Kirsty Machon, 2020.

RESEARCH AND REPRESENTATION: THE MEANINGFUL INVOLVEMENT OF HIV-POSITIVE PEOPLE IN HIV RESEARCH

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Acronyms

ARCHS	Australian Research Centre in Sex Health and Society, La Trobe University
ART	Anti-retroviral therapy
ASHM	Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine
CAB(s)	Community Advisory Board(s)
CBR	Community Based Research
CSRH	Centre for Social Research in Health, University of New South Wales
GIPA	Greater Involvement of People with HIV
KI	The Kirby Institute, University of New South Wales
MSM	Men who have sex with men
NAPWHA	National Association of People with HIV Australia
PLHIV	People Living with HIV
PRA	Peer Research Associate
PrEP	Pre-exposure Prophylaxis
QoL	Quality of Life
RCT	Randomised control trial
U=U	Undetectable = Untransmissible

Introduction

Rationale for this paper

Over ten years ago, Jeffrey Grierson and Peter Canavan[1] reflected on the diverse ways in which people living with HIV (PLHIV) and their representative organisations have interacted in the development of research programs and agendas in Australia. A decade later there have been significant shifts in the management of the HIV epidemic in Australia. Prevention efforts have had the combined impact of reducing overall HIV notification rates. While the reduction in transmission among gay-identifying men has been particularly marked, evidence suggests that transmission has increased among gay-identifying men and men who have sex with men (MSM) who were born outside of Australia, as well as among migrant and mobile populations, and within Australia's Indigenous population.

Many changes have happened over the past decade in the HIV response. Pre-exposure Prophylaxis (PreP) has been introduced as a form of biomedical prevention. The Treatment as Prevention paradigm has been widely adopted[2] and the empirical consensus that Undetectable = Untransmissible (U=U) has been incorporated into treatment protocols and has also contributed to positive changes to the quality of life of PLHIV. In Australia, there is an emerging picture of a group of people living longer with HIV, albeit with some concerns about what this means in terms of the complex management of co-morbid conditions as they get older.[3]

The workshop *Research and representation: Meaningful involvement of PLHIV in research,* which is the basis of this report, was convened at a moment of change within the epidemic, in which the nature of PLHIV visibility has also changed. Some would argue that PLHIV are less visible since what was once life threatening is now understood as a chronic manageable disease. There is perhaps a sense that successful management of HIV has enabled PLHIV to move out of an 'activist' mode, but the reality is that new concerns are emerging (e.g. living longer with HIV and co-morbid conditions) and some areas of concern have persisted (stigma and discrimination are still being experienced in health care settings). This has called for an updated approach to engagement of PLHIV in HIV-related research as well, providing the underlying rationale for holding the workshop.

Overview of the workshop

The workshop was held in Sydney on 2 May 2019. It was attended by two people from each of the NAPWHA jurisdictional and member organisations, as well as by researchers who worked closely with HIV-positive people and communities. Having the theme of *Research and representation: Meaningful involvement of PLHIV in research activities,* the group had by and large been selected or self-selected because of their interest and involvement in HIV-related research programs. The workshop agenda and list of attendees is attached (Appendix 1).

Leaders of the NAPWHA jurisdictional and member organisations provided updates on research activities in their respective communities (see Appendix 2). These updates suggested that the HIV-related research being conducted throughout Australia and New Zealand is generally designed to include the active participation of PLHIV and their representative organisations, sometimes as research partners, at others undertaking community research themselves. In the areas of clinical and basic scientific research PLHIV representatives have been invited onto various advisory committees and scientific advisory boards but the level of community participation in these has not been as consistent as in the social

1 Grierson, J. and Canavan, P., 2007. Social research with HIV positive populations: A conversation. In: Researching the Margins, Chapter 7, pp. 143–59, Palgrave Macmillan, London.

2 NAPWHA, 2019, Treatment Factsheet – Treatment as prevention, https://napwha.org.au/resource/treatment-as-prevention-tasp/

3 Woods, R., 2019, HIV and ageing in Australia: The new frontier, NAPWHA, Sydney, https://napwha.org.au/wp-content/uploads/2019/04/HIV-and-Ageing-in-Australia-New-Frontier-April19.pdf

sciences area. In HIV cure research it was noted there is a strong commitment for engagement from researchers and community, and some interesting models of engagement were developing, especially in Victoria.

In addition to the jurisdictional and member organisation reports, the workshop was provided with summary reports on current HIV-related research from researchers based at:

- Australian Research Centre in Sex, Health and Society and the Centre for Social Research in Health, La Trobe University, Melbourne (ARCSHS)
- Centre for Social Research in Health, University of New South Wales, Sydney (CSRH)
- The Kirby Institute, University of New South Wales, Sydney (KI)
- School of Public Health, University of Queensland, Brisbane.

Dr John Rule, Senior Research Manager, NAPWHA, facilitated introductions and suggested a set of principles for engagement in the workshop activities and further suggested that these principles could or should also be embedded in research conducted for and with PLHIV:

- Exploratory
- Dialogic and respectful
- Grounded in experience
- Co-constructing knowledges
- Moving from the known to the unknown
- Recognising structural limitations
- Opening up practices.

Setting the scene at the workshop and outlining aims for the day

Dr Rule acknowledged that participants were from different organisations and research institutions however the workshop offered an opportunity to step out of organisational roles and think collectively and critically about representation and research and the meaningful involvement of PLHIV in research.

Dr John Rule, Senior Research Manager, NAPWHA.

The Australian research context

Most attendees at the workshop have had a long history of engagement in HIV sector work or HIV activism, or have been engaged in HIV-related research in different capacities for many years. Participants at the workshop were quite well informed on the history of the broad 'HIV movement' in Australia. While the Australian research context, including its history, was explored by Professor Garrett Prestage in his presentation *Setting the research context* (see Appendix 3), workshop participants provided well- considered input, reflections, questions and comments on that history.

There was general assent by those present that early HIV activism in Australia had occurred on the back of an already established gay rights movement. The early HIV activists developed sophisticated strategies through making allies and developing links with those who were engaged in HIV-related research. The slogan 'nothing about us without us' was a rallying cry around which early HIV activists were able to demand that researchers did indeed actively involve affected communities, and that the biomedical research be translated in ways that community members could understand.

Social research projects have been instrumental in articulating the lived experience and needs of PLHIV since the early years of the epidemic. In research that was focused on HIV prevention efforts, it was generally understood that 'life was more than just risk avoidance' and that people had a right to live active sexual and social lives, even in the presence of the early HIV epidemic. This attitude helped prevent research from being uncoupled from community interests and experience.

With the advent of PrEP and the increasing dominance of biomedical approaches to prevention, the question emerged again of where PLHIV fit into the research agenda. This agenda was perhaps now more focused on prevention, combined with a general 'quietism' flowing from the understanding of post-ART HIV as a chronic manageable illness rather than an early death sentence. The question was raised: Have HIV and the needs of PLHIV become peripheral to research programs and activities?

It was noted that HIV is now positioned within a suite of responses to other blood-borne viruses and that priorities are set through mechanisms such as the National HIV and STI Strategies. These are intended to, but may not always, reflect concerns emergent at the community level. At the same time, experience over the past few years has shown that the involvement of PLHIV in research remains high. There are several examples of PLHIV-led community research and initiatives, such as the W3 Project[4] and the HIV Health Literacy Framework Project[5], that are supporting community and peer-led programs in Australia to adapt, scale up, and demonstrate their impact within the rapidly changing community and policy environment in Australia. Insights from these and other initiatives provide support for the arguments presented in this paper.

4 Australian Research Centre in Sex, Health and Society, 2019, How do we value the role of the community response to HIV?, La Trobe University, Melbourne. The project is described in greater detail in the following section of this paper.

5 NAPWHA, 2020, HIV Health Literacy Framework Project, https://napwha.org.au/health-literacy-framework/. The project is described in greater detail in the following section of this paper.

Communicating findings from the Control and Elimination within Australia of Hepatitis C (HCV) from people living with HIV (CEASE Study) to the workshop.

NAPWHA was a project collaborator on the CEASE Study and assisted in the recruitment of participants to the study. Here at the workshop Professor Matthews is reporting back on recent findings of the study. Data from CEASE will be used to guide future HCV elimination efforts in people living with HIV in Australia and overseas.

Professor Gail Matthews, Viral Hepatitis Clinical Research Program, Kirby Institute, UNSW.

What is meant by 'the meaningful involvement of communities' in HIV-related research?

Participation is political

Several models and frameworks for community engagement and involvement in research have been generated and are briefly discussed below. Fundamentally, meaningful involvement comes down to mutual respect, mutual responsibility for research outcomes, and a willingness to share power and control. As one might expect, this is not straightforward to achieve. As many participants pointed out at the workshop, the HIV sector arguably leads the way in community and academic research partnerships. This history tells us that activists demanded to be consulted about, and included in, research; research processes were slow, and the situation was urgent. In the early years of the HIV epidemic it was an issue of life and death, as well as of research ethics. At a fundamental level, it was political: participation was about challenging expertise and control within research institutions and with respect to funding bodies.

Accustomed as we are to it now, there was a time when this was hugely radical. Scientists or doctors consulting non-clinical people on the process of a clinical trial? There was no way that was done before HIV activists insisted on it. It wasn't done because people didn't think of it, but because academia, science and medicine are exclusive circles. People in these circles are afforded a level of credibility and authority that others aren't. People generally don't wake up one morning and decide to share this authority around, or if they do, their institutions or funders aren't necessarily well set up to allow for this. At the same time, there have always been activists who are also researchers, scientists or doctors, and many of them have been crucial as bridge builders.

In short, HIV changed a lot of things. While the world has changed a great deal, discussion on good practice models for working together – for meaningful involvement of people living with HIV in research – is still on many levels a discussion about politics. We can get bogged down thinking about the best framework for working together but ultimately the success of any model relies on willingness to collaborate and to recognise expertise on all sides and to share control or power.

Models for working together

Placing a focus on the political nature of participation in research serves as a preface for considering models for working together that have developed over the years. The following models are briefly discussed:

- Putting the Greater Involvement of People with HIV (GIPA) principle into practice
- A rights-based approach
- Participatory practices in biomedical research
- Community-based research (CBR)
- Current examples of participatory research; described as case studies.

GIPA in practice

The engagement of affected people, communities and other stakeholders has 'been a force for moving important research forward through advocacy, as well as a disrupter of research and its translation to practice when inadequate engagement creates possibilities of exploitation'[6]. First voiced by PLHIV in Denver, Colorado in 1983, there was broad discussion internationally on the role of the body positive in research in succeeding years. This was concretised in 2007 when the United Nations member countries endorsed the GIPA principle as part of the UN *Declaration of Commitment on HIV/AIDS*[7]. The Joint United Nations Programme on HIV/AIDS (UNAIDS) put forward specific advice on how GIPA might look in practice[8], summarised in Figure 1

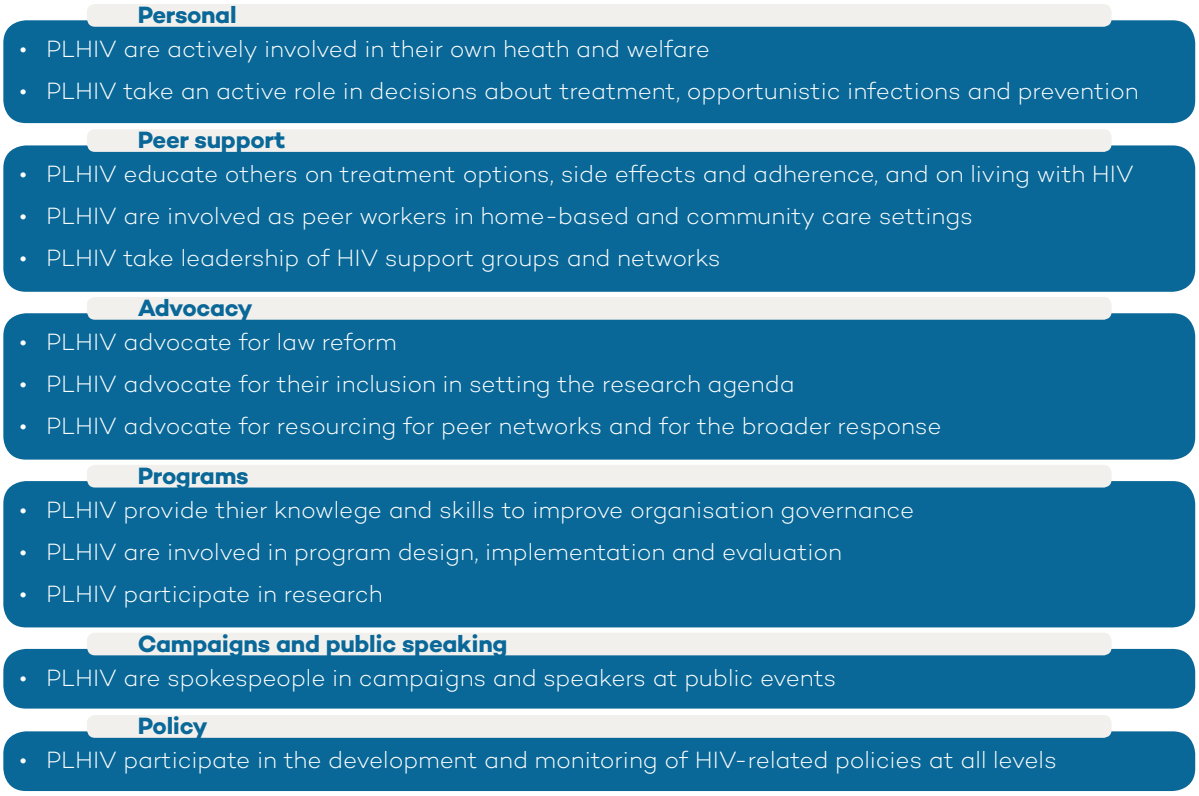


Figure 1: GIPA in practice Source: based on UNAIDS (2007)

As can be seen in Figure 1, the active inclusion of PLHIV in research emerges at several levels in this framework: advocating for their inclusion in setting the research agenda; involvement in program evaluation; and participation in research.

A rights-based approach

A rights-based approach, often adopted by community-based peer organisations, is one way of promoting the meaningful involvement of communities in HIV-related research. For example, in 2005 NAPWHA (then as NAPWA) put forward the *Declaration of Rights of People Living with HIV/AIDS*[9] in order to guide work on improving the quality of life of PLHIV, with benefits also for the community at large. The Rights were anchored within existing human rights laws and adopted, in large measure, the *International Guidelines on HIV/AIDS and Human Rights* of the United Nations Commissioner for Human Rights and UNAIDS. NAPWA's Rights centred on 'Life', 'Love' and 'Participation'. The NAPWA Declaration emphasised the right of PLHIV to 'participate at every level of consultation, decision making and implementation regarding HIV/AIDS advice, policy, laws, treatments, funding, research, education, resourcing and financing, and all other matters relevant to the HIV/AIDS response'.[10]

6 MacQueen, K.M. and Auerbach, J.D., 2018, It is not just about 'the trial': The critical role of effective engagement and participatory practices for moving the HIV research field forward. Journal of the International AIDS Society, 21(S7):

7 UNAIDS, 2007, The Greater Involvement of People Living with HIV (GIPA), Joint United Nations Programme on HIV/AIDS, New York.

8 Ibid.

9 NAPWA, 2005, NAPWA *Declaration of Rights of People Living with HIV/AIDS, 2005: Life, Love, Participation,* NAPWA, Sydney.

10 NAPWA, 2005, ibid, p. 19.

Participatory practices in biomedical research

PLHIV have been engaged in biomedical research since the 1980s, with a 'gradual progression from engagement mainly as a consultative mechanism towards fuller use of participatory practices'.[11] In 2011, UNAIDS put forward 'Good Participatory Practice' guidelines for biomedical HIV prevention trials,[12] which included guiding principles such as respect, accountability, and community stakeholder autonomy; and good participatory practices that could serve as benchmarks. These practices include having stakeholder engagement and education plans, protocol development, access to HIV care and treatment, and policies on trial-related harms.

Experiences over the past decade[13] suggest that the benchmarks are generally being put into practice, albeit with a tendency to focus engagement on the early stages of trial planning, rather than throughout the trial's trajectory. Ideally, community and stakeholder engagement should be viewed less as a method, and more as an 'orientation to research' that views such participation 'on a par with clinical, laboratory, regulatory and statistical components'.[14]

Community-based research

Community-based research (CBR) is a research approach and method that places community partnerships at the forefront.[15] When CBR is put into practice, representatives from the communities in which the research is taking place are full partners in all stages of the process. This means that community partners and academic experts work together to develop questions that are responsive to community needs, determine appropriate data-collection methods, and develop effective knowledge dissemination strategies.

CBR projects often use mixed methods and innovative data-collection strategies. At the workshop, for example, participants were given insights into a uniquely designed, longitudinal research project in Queensland which was examining the experiences of living longer with HIV in rural and remote areas of Queensland (Associate Professor Allyson Mutch and Dr Lisa Fitzgerald, University of Queensland; see Appendix 4). The study employed methods of data analysis that reflected the diverse expertise and experiences of the research team. This team included a representative from Queensland Positive People. The overall objective of CBR is to promote positive social change through empowering communities and bringing about policy changes. CBR can also contribute to the generation of basic knowledge. Ultimately, 'community-based research seeks to democratize knowledge by recognizing and valuing the unique strengths and perspectives of all members involved in the research process'.[16]

Findings from research carried out in Canada on CBR in relation to the implementation of GIPA[17] shed light on the complexity of involvement in research, the barriers that make meaningful PLHIV engagement in CBR difficult, and the factors that facilitate participation. These factors are illustrated in Figure 2.

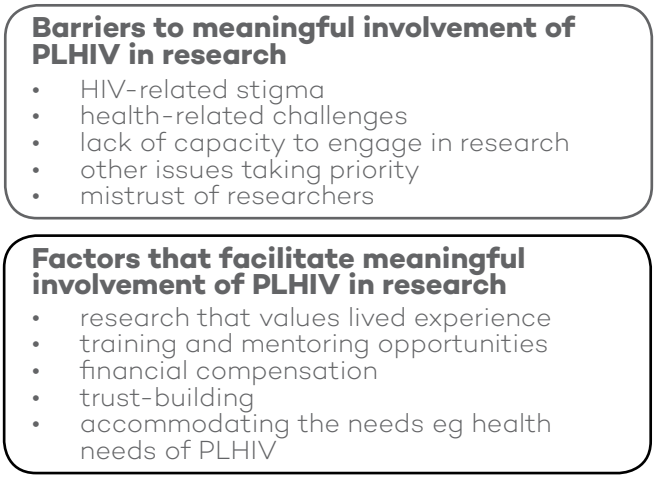


Figure 2: Meaningful involvement of PLHIV in research: barriers and facilitators

Source: based on Travers et al (2008)

In summary, this research found strong support for the GIPA principles in theory, but also found that practice often lags far behind. A concerted focus on addressing the barriers to meaningful participation, as well as paying attention to the facilitators, can assist when designing research studies.

11 MacQueen, K.M. and Auerbach, J.D., 2018, It is not just about 'the trial': The critical role of effective engagement and participatory practices for moving the HIV research field forward, Journal of the International AIDS Society, 21(S7), p. 1.

12 UNAIDS, 2011, Good Participatory Practice Guidelines, https://www.unaids.org/sites/default/files/media_asset/JC1853_GPP_Guidelines_2011_en_0.pdf

13 MacQueen and Auerbach (2018), op cit., pp. 2–3.

14 ibid., p. 3.

15 Pacific AIDS Network, 2020, *Research and Evaluation: What is community-based research?* https://pacificaidsnetwork.org/research-and-evaluation/what-is-cbr/

16 Ibid.

17 Travers, et al, 2008, The Greater Involvement of People Living with AIDS Principle: Theory Versus Practice in Ontario's HIV/AIDS Community-Based Research Sector, AIDS Care, 20(6): 615–24.

Case studies

The What Works and Why (W3) Project

The W3 Project[18] is a research initiative of the Australian Research Centre in Sex, Health and Society (ARCSHS) at La Trobe University. There has been collaboration within the context of the project with HIV peer and community organisations 'to develop a framework and tools to enable these organisations to adapt, scale-up and demonstrate their impact in rapidly changing community and policy environments'.[19] Utilising a systems theory approach, the W3 Project identified four key functions to articulate the role of community and peer-led organisations within their community and policy environment:

- **Engagement:** How the community organisation maintains up-to-date knowledge of the diversity and dynamism of needs, experiences and identities in its communities.
- **Alignment:** How the program picks up signals about what is happening in its policy and service sector environment and uses this to better understand how it works or what may need to change.
- **Learning and adaptation:** How the program constantly adapts and refines its understanding and approach based on insights from engagement and alignment.
- **Influence:** How the program uses existing community, social and political processes to influence and achieve improved outcomes in communities as well as the policy and health service sectors.

18 ARCSHS, 2019, *How do we value the role of community responses to HIV?*, https://www.latrobe.edu.au/__data/assets/pdf_file/0003/1064937/Bangkok-2019-Valuing-the-Community-Response-report.pdf

19 ibid, p. 1.

HIV Health Literacy Framework Project

NAPWHA's Health Literacy Framework Project is a three-year initiative (2019–2021) that addresses the role of HIV health literacy in improving HIV-related health care and quality of life outcomes for all PLHIV in Australia.[20] The study is based on the recognition that:

- HIV health literacy in the broader population may not have kept up to date with the profound changes that have characterised HIV and AIDS since the mid-1990s, with consequences for stigma, perceptions of risk, and transmission.
- Changes in HIV notifications (especially over the past decade) have contributed to changes to the make-up of the body positive in Australia.
- Peer-based community organisations such as NAPWHA play an important part in the HIV health literacy ecosystem.

The overall objective is to generate, put into practice, evaluate and revise, and disseminate a 'HIV health literacy framework' to support improved health literacy that would benefit diverse cohorts of PLHIV. Initially, the project has focused on positive women and heterosexual men, and there is a focus too on paying attention to HIV health literacy (or the lack of it) in the general community. A key intended outcome is that community-based peer organisations, beginning with NAPWHA itself, will enhance their own health literacy so as to have improved conversations with people from groups – now increasing as a percentage of the total body positive – who may have been less visible in the HIV health literacy ecosystem up to the present.

20 NAPWHA, 2020, HIV Health Literacy Framework Project, https://napwha.org.au/health-literacy-framework/

A strongly participatory and action research approach underlies the project, which is itself largely community-led, with NAPWHA guiding and managing the project. The NAPWHA-based project team engages the countrywide peer networks to recruit individuals from the key priority populations as research partners. These partners support the development of the health literacy framework – which includes a focus on messages as well as channels of health-related information – and they contribute actively to the research and evaluation associated with the project.

These 'community advocates', coming from all over Australia, are provided with training on: HIV health literacy and its links with the HIV Care Continuum; communication and group facilitation skills; and a systems perspective on health literacy interventions. Working as a team and individually, the community advocates reach out to other women and heterosexual men living with HIV in their regions. Using participatory action research combined with community development approaches, they seek to strengthen peer bonding. Drawing on these developing relationships, they work with the project team to build up a picture of how health literacy accompanies their peers on their journeys into living with the virus. This enables them to consider the strengths and shortcomings of current HIV-related messaging and platforms.

Based on the strengthened peer relationships and engagement with NAPWHA, community advocates/research partners suggest what changes could be made to improve health literacy and then put some of these changes into practice through helping NAPWHA improve its communications with women and heterosexual men. Supported by capacity-building approaches that include training and mentoring, they are also actively involved in evaluation of the project.

Working together. What works best?

Successful community-based research (CBR) projects share the following characteristics:[21]

- They are based on mutual respect and trust.
- Partners express a commitment to long-term, sustainable relationships.
- Flexibility and a longer-term vision are important.
- Projects build on existing strengths of the community.
- Methodological rigour and sound ethical practices are important.

Several of the factors that contribute to success are discussed, beginning with mutual commitment to the relationship between researchers and their CBR partners.

Commitment to the relationship

The most effective models of CBR are built upon commitment to long-term, sustainable relationships. When people collaborate on multiple projects over many years – and know each other through forums such as the *Representation and Research Workshop* – then there is a gradual building of awareness and respect for each other's skills and expertise. There are opportunities to discuss research priorities informally, to ask questions, and to ask for advice. The partners support each other to deliver research outputs, and to use those outputs to support outcomes relating to, for example, advocacy or service delivery.

The NAPWHA *Representation and Research Workshop* was a visible expression of the long-term relationships that have developed over decades in Australia. The fact that conferences – such as those organised by ASHM annually – include both research and community expertise, assists in this relationship-building. There are other models, always more effective when they are integrated into this long-term relationship focused on achieving long-term research goals. In some cases, they are a shorter-term arrangement.

Community-led research

We can talk about community engagement in research, but also about other models in which it is the researchers that are engaged to support community-led projects. Within the long-term relationships that characterise the sector, there are opportunities for this to occur on an informal basis. It relies on goodwill, as there is often no funding available for staff time (either for researchers or for the community). It is worth thinking about options for how this could be improved.

Community-led research places the direction of the research endeavour directly into the hands of community stakeholders. Researchers might provide advice or consultancy but are not ultimately responsible to funders for the output. This research can capture what organisations need to know, and organisations often have capacity to be more responsive, to move quickly and use existing funding to set up research. If community organisations are leading the research there is perhaps more scope to move more quickly.

At the workshop, Associate Professor Limin Mao (see Appendix 1) raised the question of the flow of funding for research. In a presentation focusing on the MyLife+

21 Pacific AIDS Network, 2020, op. cit.

app and eHealth management for PLHIV, she noted that it is sometimes best for the community to hold the funding and to ensure that the process works well. The result is that the community is accountable for the outcomes and ultimately holds power for decisions. Community stakeholders are not bound by the demands placed on academics to deliver a certain type of output. Responsibility for output can become a tension when funders are looking for outputs that don't align with what community think a piece of research should look like, leaving researchers often stuck between competing interests.

Dr Jennifer Powers (see Appendix 1) delivered a presentation on the mutual responsibilities of working together in research. She questioned the place that evaluation has in research careers, and a growing tendency to commission independent researchers to run evaluations. As Jennifer noted, this is happening a lot more: *'We are contract researchers and need to bring in our incomes. But we have to operate as academics and being able to publish independent research is central to what we are expected to do as academics – it's like journalists, independence is important'. One of the benefits of engaging external evaluators is that 'it is not just the skill set that you purchase but that you purchase a one-step removed evaluator – an independent evaluation'.* What happens though, if the findings are contested? How is that managed in the context of ongoing relationships?

Dr Powers continued by noting, in connection with the partnership approach adopted in HIV Futures:

> *I think I would say HIV Futures has worked with this partnership model since it is run by us, so it retains academic independence, which gives strength to advocacy claims. But it is also community driven in its origin. Community has retained a strong sense of ownership over this piece of research, which is hugely important because it is this that keeps people engaged in the study. It has history and connection to communities. So while I think the independence is important, it's actually only possible because of this long-term connection to community. A question that may be asked: Is this replicable?*

Sharing experiences from work in Canada, Dr Allison Carter talked about the operationalising community-based research.

Dr Carter said that the challenges of involving community can be considerable, but there are strategies to use and ultimately the research outcomes are more likely to be owned and relevant to the communities that are engaged. Among other benefits, CBR can provide the opportunities to address gendered and social marginalisation.

Dr Allison Carter, Research Fellow, Surveillance Evaluation and Research Program, Kirby Institute, UNSW.

Community Advisory Board (project level)

Appointment of a Community Advisory Board (CAB) to offer advice and expert input in connection with a discrete research project is a familiar model. With its positives and negatives, it is likely to be the model that is most used around the world in connection with LGBTIQA+ research and is seen a lot in the HIV research area. This is because the community is so diverse, and containing within it so many competing interests, that other models can become quite complex to manage. The CAB model is manageable and allows for a larger number of people to be involved by being nominated.

One limitation with CABs is that they are often set up only after the research has been designed and funded. This could lead to tight boundaries being placed on the role community advisors can play, for example, no input in the crucial early design phase. Also training and support is needed for people who come onto advisory boards; they may not be as familiar with processes as the researchers who are regularly working in the field. Ultimately these are 'advisory' roles and if different agendas start to emerge then the power generally lies outside the advisory structure, that is outside of community control.

Co-investigator model

Dr Allison Carter from the Kirby Institute presented on 'Operationalising community-based research: Challenges and opportunities for involving community' (see Appendix 1). She provided an overview of a study in which women were co-investigators – engaged as Peer Research Associates (PRAs). Important in this approach is the need for capacity-building. This includes training that focuses on issues such as ethics and informed consent, computer skills and skills in traversing roles; and ongoing mentoring and support. She noted that there was a hiring process and that from 70 applicants, a national team of 37 PRAs had been selected. Whereas HIV Futures[22] used to have PLHIV on an advisory committee, the study has now invited PLHIV to become involved as co-investigators and co-authors on papers produced from the research.

The PozQoL study, which aimed to develop, test and validate a short and freely available scale assessing quality of life (QoL) among PLHIV,[23] provides another example of research adopting a co-investigator model. It worked well because:

- All participants sat around the table doing data analysis (factor analysis)
- There was co-authorship
- Multiple interests and needs met by this study.

The question arises: Would a co-investigator model work with clinical research? The INSPIRE Project[24] tries to address the question of how to maintain community involvement at all stages of clinical trials in the area of HIV cure research. A model like this is being tried with researchers and community in Victoria.

Picking up on a point that Dr Lisa Fitzgerald raised in her presentation (see Appendix 4): the research enabled the accumulation of some valuable data sets, and there are increasing requests to make these datasets available to other research organisations, and possibly community researchers as well. When doing so, a host of ethical issues emerge on how to maintain confidentiality, safety and the integrity of data. This is something that can perhaps be added to the conversation, especially models of how to share such datasets safely.

22 ARCSHS, 2019, HIV Futures 9: Quality of life among people living with HIV in Australia, La Trobe University, Melbourne, https://www.latrobe.edu.au/__data/assets/pdf_file/0007/1058614/HIV-Futures-9.pdf

23 Brown, G. et al., 2018, Development and validation of PozQoL: A scale to assess quality of life of PLHIV, *BMC Public Health*, 18(1): 527, https://pubmed.ncbi.nlm.nih.gov/29678156/

24 http://hivcure.com.au/2019/07/25/inspire-community-engagement/

Getting the balance right

As a contribution to these debates, and drawing on insights from the workshop, the remainder of the text focuses on three areas that are considered important for achieving the objectives of community involvement in HIV-related research, while balancing all the issues and questions raised earlier. These areas of consideration are:

- PLHIV helping to set the research agenda
- Adopting a continuum approach to viewing community involvement
- Applying a research justice lens.

Helping to set the research agenda

When considering community involvement in research, questions arise on the extent to which research priorities should be determined by affected communities, if at all. In connection with HIV research, the question can be: What role do PLHIV have in setting the research agenda? At one level the answer is obvious. If research does not benefit the people most affected, what is the point of carrying out the research in the first place? If beneficial research is that which addresses the needs of affected communities, those communities surely have a stake in setting the research questions? However, it is more complex than this.

Mark Fisher, Executive Director, Body Positive New Zealand, making a point to the delegates.

Pictured with (from l to r): David Crawford, Positive Life NSW; Chris Howard, Queensland Positive People; and Cipri Martinez, NAPWHA President & Positive Organisation Western Australia.

Within the scientific approach, research independence is important. Explicitly maintaining a level of distance between research and advocacy promotes the credibility of research findings and gives the community sector the confidence that those empirical findings can be applied due to the professional, replicable and rigorous means through which they were generated.

Moreover, not all research is applied. Basic scientific research and theory development has a definite place within the research agenda, as does research of an exploratory and innovative nature. For example, theory-driven research on gay men's sexual cultures and practices has had an immense impact on the HIV response and on the ways in which sexual health promotion is now delivered for many different communities. The benefits of this research seem obvious today. At the time, this was not the case and if the focus had been fixed on the more immediate priorities of service delivery, this kind of research might not have been funded. Ultimately, researchers and academics should be innovative, and should have the scope to imagine well beyond the present.

This doesn't mean an absence of consultation with communities – the research agenda is always better when multiple lenses have been cast over its contents. As stated before, this is made easier in the context of a long-term relationship because trust has been able to develop through working partnerships and networking. The community has to be involved in setting the research agenda because this decision-making is always political. Examples include:

- Today, particularly in Victoria, there is a lot of research money available for LGBTIA+ research. This is because community activists demanded this and argued the need for it.
- Research in areas such as reproductive health – abortion, contraception, women's health, sex education – is driven by a political agenda in which researchers may have an influence, but not the ultimate determination.

An argument can be made that the community sector still holds responsibility in partnership with researchers to consider the research agenda (what research is needed) and advocating on behalf of this agenda with governments and funders. There is continued need for advocacy in a sector in which resources are slim – for example in the context of clinical funding (cure vs vaccine vs treatment). There is also continued need for social research in an era of biomedical prevention and quality of life concerns, also in connection with growing older with HIV.[25]

A continuum approach to research and representation

One way to approach community engagement in a research context is to view it as a continuum from the lowest to the highest levels of community involvement. Community representation in, and responsibility for, research comes in so many forms and shades of meaning that it is best mapped on a continuum, rather than being viewed as discrete, isolated categories.

As illustrated in Figure 3, studies would fall somewhere on this scale from very low community involvement in more traditional or mainstream research approaches, to very high community involvement in community-led research. A wide variety of community-placed, community-based, and participatory action research approaches lie in-between.

25 Woods, 2019, op.cit.

Figure 3: A continuum of community involvement in research

This continuum 'lens' can be applied when exploring the history of the engagement of PLHIV since the 1980s ('nothing about us without us'), including the idea that developed at the time that research is only useful if it can be used for advocacy – this strongly favoured community-led and participatory action research approaches. Other models have included:

- Having a resident researcher in peer-based organisations
- Ideas of 'mandated representation' due to the importance of context and persistent stigma
- Appointing community members as Peer Research Associates.

The continuum approach can also be useful as a strategic tool that guides a piece of research from the time it is conceived, ie determining fairly early on where it would be most meaningful on the continuum to place the involvement and responsibility of community partners. The rationale for this decision contributes to other decisions made in the research design and planning phase.

Continuum thinking can also be applied through an iterative process in which levels of community participation increase or decrease over the life of the project. These may shift according to decisions made on the 'research process', research outputs' and 'research outcomes', as illustrated in Figure 4.

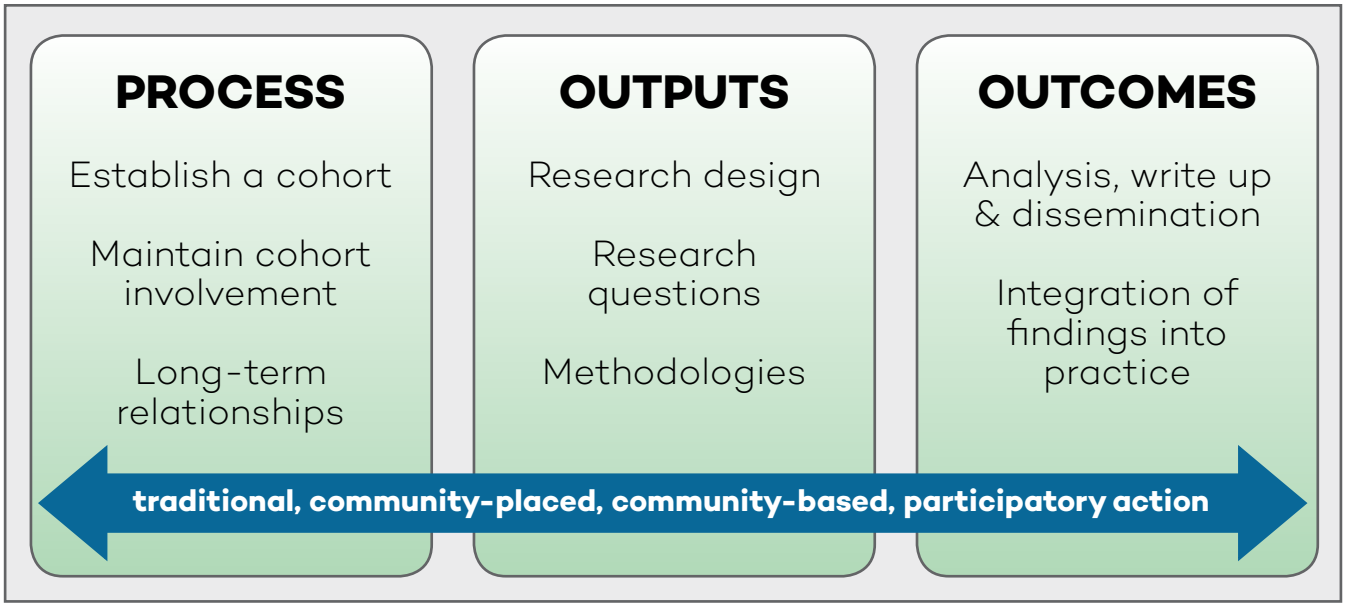


Figure 4: Applying a continuum approach to community involvement in research

For this kind of strategic and iterative thinking to work, attention needs to be paid to role definitions (eg community participants being 'consumers', 'advisors', 'co-producers' or 'leaders'); to the research funding issue, and what that means in terms of accountability and responsibility for deliverables; and also to questions about the nature of the research endeavour itself.

In terms of the latter point, HIV research in Australia can be considered as constituting:

- **Biomedical research,** with a focus on experimental research designs, quantitative data, and the randomised controlled trial (RCT) as the gold standard for generating evidence;
- **Social science research,** based in a wide range of social science disciplines, and adopting research paradigms that are closer to the 'natural' science approach in their privileging of quantitative data (positivism; post-positivism), or that critique the positivist approach as being limited in understanding complex social realities and adopt qualitative or ideally mixed qualitative and quantitative methods (constructivism; critical realism); and

- **Community-based research,** still a form of social science research, but with explicit applied and empowerment goals and a privileging of meaning-making and therefore qualitative data, as described earlier.

Adopting this broad view of research can contribute to discussions on topics such as the extent to which biomedical research outcomes are privileged, social science research is under-resourced, and community-based and community-led research often overlooked. It can also help in the strategic thinking that occurs when research studies are designed and implemented, right up to the point of considering the approach to the dissemination of research findings.

Effective responses for affected communities: research justice

Recognising that 5–10% of the body positive do not benefit from the research others are benefiting from, the question arises as to whether we are using the collective knowledge and experience, past and present, to drive outcomes that will benefit the body positive.

This raises research justice issues:

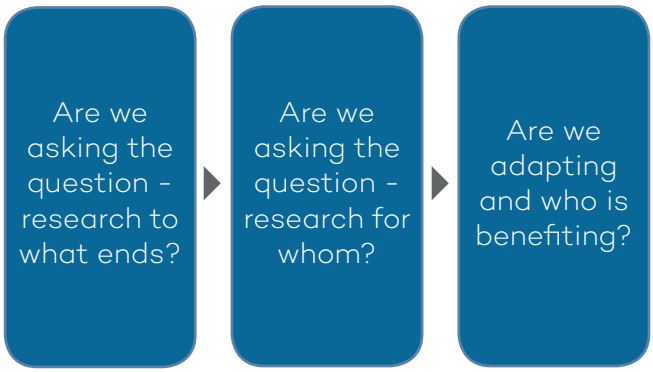


Figure 5: Research justice questions

Epidemiology is only part of the picture in research justice considerations: there are other goals. Ending HIV is a social process, and it needs to be for everyone. It's not just an abstract policy goal. Women and Indigenous people still remain invisible in many ways in research.

Challenges of a changed funding environment include:

- Diversified partnership (benefits, opportunities)
- Competitive funding environment
- More partners involved, more complexity, different expectations
- How to manage a cohesive environment
- Jurisdictional and institutional issues

Questions for the future include those concerning the best kind of model to bring engagement forward in this changed funding environment; and on better understanding centralised mechanisms such as CABs and positive research bodies. What would their roles be?

Conclusion

To conclude, we put forward some suggestions for where to move from here. Broadly speaking, these suggestions examine:

- The contributions HIV-positive people make to research
- Why HIV-positive people should (or should not) become involved in research
- Promoting active and critical engagement
- Principles for research partnering
- Improving science literacy
- Taking a 'research justice' approach.

Contributions HIV-positive people make to research

Simply asking the question 'what is it that PLHIV offer to research?' is perhaps a good place to begin. Figure 6 below considers broadly what PLHIV are able to offer to research:

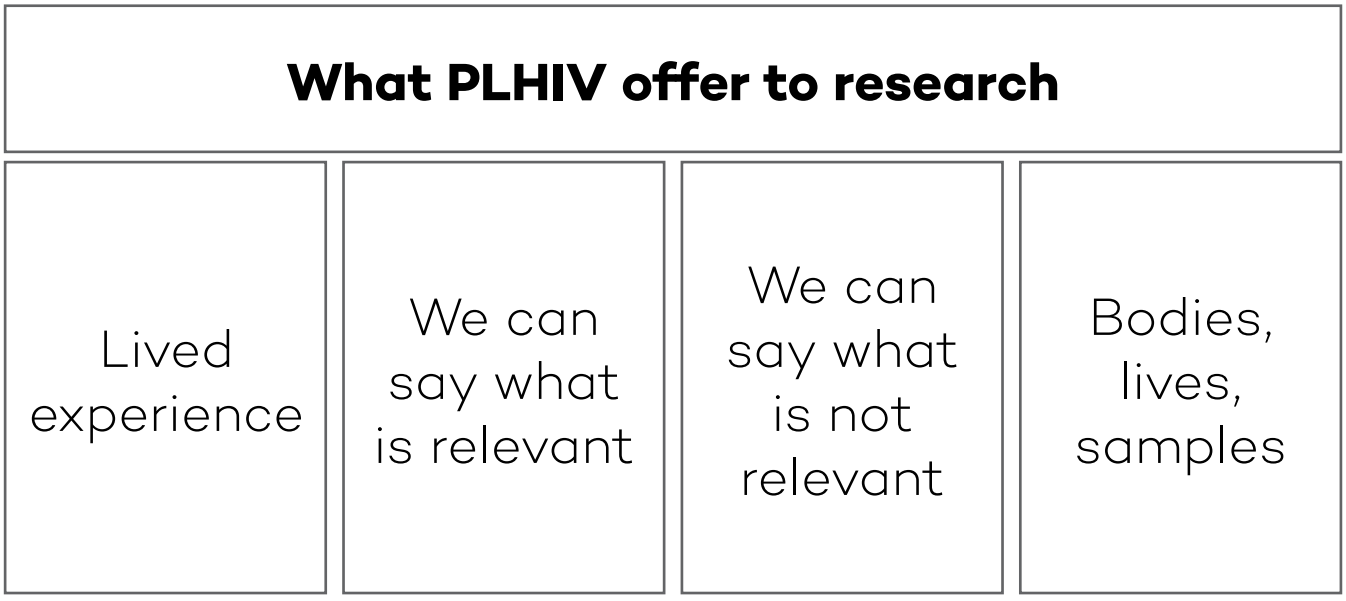


Figure 6: What do PLHIV offer to research?

Should PLHIV become involved in research?

Many factors come to mind when considering the basic question of whether PLHIV should become involved in research in the first place. It's important to consider how PLHIV are positioned within the given research study. As Prof Garrett Prestage pointed out (Appendix 3), historically this has included words such as 'dying', 'patients', and 'people with chronic illness'. It's important too to recognise that people with HIV have been living the ambiguity of acting on and defining research questions often before they were formulated as research

questions. Having their input from the very early stages of research certainly makes sense when considering the meaningfulness of research findings. PLHIV can also represent a diversity of perspectives and say who is missing out.

Bodies of knowledge are bodies of practice. Over the past decades, positive people have had a particular kind of power – the power of veto (has happened in the past): *no, we don't want that research; no, it's not our priority!* They also have the power of community: knowledge and confidence that these are the questions to ask (not those). It may be that people living with HIV have been 'over-researched' over the years. Many have freely given their time to participate in study after study, yet many may feel that they are still not getting the answers. Ultimately, PLHIV are protected by research ethics protocols – their informed consent needs to be given.

Relationships that need constant focus include the relationships that the body positive has with pharma, particularly through community-based peer organisations. In some quarters, this is still a concern, and it needs to be clear that communities are driving the agenda. Boundaries need to be set. With respect to relationships with institutions, there are outsiders and insiders; subjects and objects; participants and recipients. Finally, where is the reciprocity? What do researchers gain from engaging community members, and what do they offer back? How do practices change – is community engagement more than a 'government tick-box', as Wilo Muwadda commented during this discussion?

Active, critical engagement

In order to engage more actively and critically in research, community members need to know what is expected from them. Hopefully they gain the assurance that – linking to Wilo's point made in the workshop – their involvement is indeed more than an exercise in 'ticking the boxes'. PLHIV can choose not to answer clinical questions already answered, and press for research to drill down into the questions upon which more information is needed, for example on U=U, and on injecting drug use. They can push for action/change/policy outcomes on the basis of what research has already shown. For example: stigma sucks. The social determinants of health are more determinative of outcomes than HIV itself. We don't need more studies telling us that stigma is bad and that health is socially determined. We need some answers: Where to from here?

Active engagement requires resources to be put into capacity-building and outreach, which includes building health literacy, skills training and mentoring, and engaging small (non-MSM) communities and organisations. It requires an understanding that many organisations, including small ones, can have input, and that there is value in diversifying representation (being mindful of 'the other 5%'). It requires asking whether there are other communities of interest that should be engaged; and whether there is value in looking outside the sector for knowledge. It requires effort to be put into communication: between jurisdictions, with each other, inclusively, perhaps an argument for regular forums/meetings?

Principles

Principles for the partnering of researchers and members of the body positive include:

- Valued knowledge is that which can be acted upon to make lives better for people living with HIV.
- Knowledge is co-created and co-owned.
- Research questions are relevant and timely: responding to today's questions, not yesterday's.
- PLHIV are involved in research governance at all levels of the process: research agenda-setting, not only responding.
- Science privileges the unambiguous, but lives are often more complicated than that. Ambiguity: we need to live with it.
- The health literacy of PLHIV has been honed over many decades and communities have shown that they can and do act on information when it is seen as credible.
- Autonomy: people are not consumers nor subjects. The knowledge that is generated is for people.
- Understanding how we want to communicate the position of the community is a mechanism to also generate that community. This also requires a balance between representing general interests on the one hand, and having an individual perspective on the other.

- Research participation creates new leaders that contribute to the advocacy effort. What structure or structures would help to deliver on that?

Developing and improving science literacy

In order to be fully engaged as partners in research, community members should be given the opportunity to continue to develop their science literacy with the support of the professional researchers. This capacity-building should ideally be built into the program as an explicit aspect of the research partnership. Science literacy is about having some basic understanding of the scientific method, and being more aware of its successes and its limitations. It is about having a sense of the scientific imagination to enable full engagement in discussions about research ethics, research questions, the overall design of studies, data-gathering methods, and analysis (qualitative and quantitative), as well as of the cultural and political aspects of scientific discourse. Science is by no means an unquestioned authority in modern society. Community members and representatives don't have to become scientists, although some may be. Nonetheless, to engage meaningfully in research, a basic level of science literacy is needed, and this can be developed by those who are not scientists. Some of this is to do with confidence in presenting ideas in research environments. Community representatives would benefit from mentoring and support in order to develop the needed confidence.

Science literacy includes developing more nuanced understandings of concepts such as 'needs', and that this is different to talking about 'my needs'; of different approaches to sharing knowledge and communicating experiences, which is different to being a science writer or communicator; and of broader understandings of complex and evolving research processes and ethical dilemmas. These insights nevertheless remain at a depth that differentiates the community participant from the researcher or the biomedical ethicist. The ideal is for willing participants to be more informed and engaged as research partners, as opposed to being only consumers of research outputs.

Taking a 'research justice' approach

Research justice has been briefly discussed earlier. Some of the questions to weigh up when adopting a research justice approach are identified in Figure 8. As can be seen in the graphic, they are clustered into questions of the adequate and just representation of all who make up the body positive; and questions on the appropriateness of research questions, findings and applications to the lives of cohorts within the body positive that have been neglected until recently:

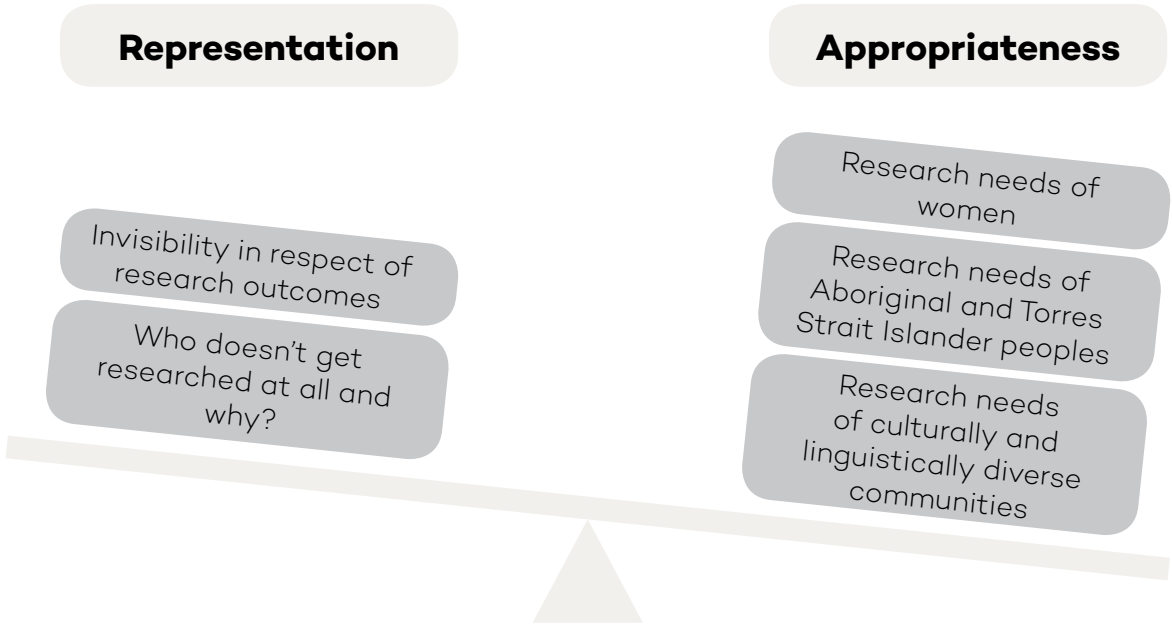


Figure 7: Questions to weigh up when adopting a research justice approach

Appendices

Appendix 1 – Agenda and List of Attendees

Agenda – Thursday 2 May 2019		
9:30 – 9:40		Acknowledgement of Country (Wilo Muwadda) and Introductions Aaron Cogle – NAPWHA Executive Director • [Aaron to talk about expectations for the day and desired outcomes]
9:40 – 10:40		**Research and representation: the meaningful involvement of people living with HIV in research activities – Setting the scene** Dr John Rule – Senior Research Manager, NAPWHA • [John facilitates presentations from the jurisdictional representatives about what kind of research is happening]
10:40 – 11:00		**Update on the CEASE Study** Professor Gail Matthews
11:00 –11:20		Morning tea
		Research around and with people with HIV: What's the context? Associate Professor Garrett Prestage
		Developing research relationships: What about the funding? Associate Professor Allyson Mutch and Dr Lisa Fitzgerald
		MyLife app: Looking at eHealth management for people with HIV Associate Professor Limin Mao
		Operationalising community-based research: Challenges and opportunities for involving community Dr Allison Carter
		Models of working together: responsibilities on both sides! Dr Jennifer Powers
1:00 – 1:45		Lunch break
1:45 – 2:15		**Research in clinical settings: a report from inside the clinic** Dr Robert Page
2:15 – 2:35		**Current state of HIV cure research clinical/biomedical viewpoints** Dr Jillian Lau
2:35 – 3:00		Facilitators: Dr John Rule, Dr Jeanne Ellard Discussants: Ronald Woods, Dr Kirsty Machon What is working and why? What counts as good representation? What are we missing out on in terms of research and representation?
3:00 – 3:15		Afternoon tea
3:15 – 4:00		What do HIV-positive people and their representative organisations offer to research? What do we bring? What do we need to be/do more actively? Developing our research literacy and representation skills.

Attendees				
1	Aaron	COGLE		NAPWHA – Executive Director
2	John	RULE		NAPWHA – Senior Research Manager
3	Saysana	SIRIMANOTHAM		NAPWHA – Communications and Liaison
4	Charlie	TREDWAY		NAPWHA – Consultant Social Media
5	Ronald	WOODS		NAPWHA – Consultant Research/Evaluation
6	Stephen	TURNER		NAPWHA – Volunteer
7	Richard	KEANE	VIC	Living Positive Victoria
8	Adam	EHM	VIC	Living Positive Victoria
9	Chris	HOWARD	QLD	Queensland Positive People
10	Katherine	LEANNE	SA	Positive Living South Australia
11	Danny	RYDING	ACT	NAPWHA – Board Director
12	Michael	LAMONT	ACT	Representative
13	Robert	MITCHELL	TAS	NAPWHA – Board Director
14	Scott	HARLUM	NSW	NAPWHA – Secretary
15	Sarah	FEAGAN	VIC	NAPWHA – Vice President
16	Dianne	LLOYD	WA	NAPWHA – Board Director/Positive Organisation Western Australia
17	Kirsty	MACHON	VIC	Positive Women Victoria
18	Lance	FEENEY	NSW	Positive Life NSW
19	David	CRAWFORD	NSW	Positive Life NSW
20	Craig	COOPER	NSW	Positive Life NSW (afternoon only)
21	Cipriano	MARTINEZ	WA	NAPWHA President/Positive Organisation Western Australia
22	Daniel	ALDERMAN	NT	Representative
23	Mark	HALTON	NT	Representative
24	Mark	FISHER	NZ	Body Positive New Zealand
25	Jeanne	ELLARD		Australian Federation of Aids Organisations (AFAO)
26	Wilo	MUWADDA	NSW	Positive Aboriginal and Torres Strait Islander Network

Appendix 2 – Jurisdictional Reports

ACT- *Danny Ryding* -
Reliant on AIDS Council, sometimes low buy-in from community. Social settings and inclusion are how they gather their feedback about challenges for PLHIV in ACT. Noting that in ACT people are coming and going regularly.

NSW- *Lance Feeny- PLNSW:*
Current partnerships and work: 'HIV prevention Revolution' Testing/PrEP/Treat. **NSW govt**- 3 monthly comprehensive information on testing & diagnosis etc. **SPANC study**- High level disease- anal HPV. **HIV ageing** – emerging topics to augment the next iteration of APPLES – over-55 study includes assessing functional impairment, provides a HIV neg vs. HIV+ comparison, and identifying care needs for the future and innovative models of care to meet these needs.
Community Research: Community survey- HPV + anal cancer. Community Surveys prove that their perception/ needs don't always align with high level research. **(traditional research vs community research)**. "Research is only useful if it can be used by us for advocacy"

NT - *Daniel Alderman* -
Engaged in RISE & Futures and promotion of National research.

NZ - *Mark Fisher- Body Positive NZ-*
GAPS/GOSS longitudinal data cancelled 4 years ago by government. And no data is being gathered to replace it. **FLUX study** is being undertaken. **Stigma Index with PozQual** added to the end is being undertaken with a small feasibility pool to be measured with opportunity for refunding for a more robust gather. **Gilead has pulled out of NZ** due to our introductions of generics with the advent of funded PrEP.

QLD - *Chris Howard -QPP*:
Chris spoke about various projects and pilots that have been successful such as **Peer Navigation, Research on HIV and Ageing and the HIV emergency Treatment Fund,** which has been so successful it has had its funding doubled and is now embedded in service.

SA - *Katherine Leane*- **Service closures by SA Government**. Loss of Positive life SA- they lost their networks and access to information. **400 members in HIV Futures study- People are actively engaged.**

TAS - *Robert*- **No direct research. 1 social research with a PhD student**. Qualitative not Quantitative. 180–200 PLHIV in Tasmania implies limitations on the use of statistical analysis within quantitative research designs, and broad reflection on various demographics is challenging. People are informed about and complete the Futures Studies run by ARCSHS.

VIC - *Richard Keane- Living Positive Victoria:*
Current partnerships & work: Dr Graham Brown- Researcher in residence- W3 Framework *(What Works & Why)*, Previously it had been anecdotal. **Tim Krulic**- Engaged with ARCHES PhD research. **HIV & Ageing**- partnership with *Thorne Harbour Health* for an online portal. "When you have the opportunity to be involved from conception it provides capacity for meaningful partnership"
Community research: Peer Navigation- interest in assessing the model now that it has been rolled out. The 'W3' model for evaluation of programs is excellent reference point.

VIC - *Dr Kirsty Machon- Positive Women Victoria:*
A study into African communities is being undertaken. They are engaging women in HIV Cure Research.

WA - *Cipri Martinez - Positive Organisation Western Australia* - getting organised to engage with research. Some local friction with the perception that services are cherry picking participants but are lacking in broad representation and meaningful involvement of people with HIV in many activities.

Appendix 3 – Extracts from report of Prof Garrett Prestage, The Kirby Institute, University of NSW

(Garrett Prestage is a sociologist who works in both quantitative and qualitative social and behavioural research and is committed to community-based research. He mainly works in the fields of risk behaviour and sexuality. Garrett's research interests include: HIV transmission and prevention among gay men; the roles of identity and community in understanding how individuals negotiate risk and pleasure in their lives; survey design and questionnaire development. Garrett has been actively involved in the gay community for over thirty years and has worked in gay community-based research since 1983.)

Social context in research matters:

For me, to do good research necessarily means ensuring that the people being researched are part of the research process, and that the research should ultimately be of benefit to the community. However, research can't be conducted without the expertise of researchers – and I'd argue it can't be done properly without social researchers, because social context matters.

Research findings aren't always welcome, and they can be used for good or ill; there's a necessary balance that comes from the collaboration between community and research that hopefully improves the quality of research outcomes for everyone.

Research is always political:

And that brings me to my second point, that research is always political.

Research is very powerful, and research findings are inevitably used as the basis for political and social change. Well-used research is hard to ignore. The people who comprised the early responders to HIV, at least within the gay community, were others like me who had cut their teeth within the gay movement. So, they had a natural inclination to demand community engagement and political leadership.

When the first HIV research initiatives were started – and that was very early in the response – these early HIV activists made sure that the research that was being conducted was done in ways that ensured community involvement in the process, and was used politically to the benefit of the community.

So, those twin principles were built into the HIV response from the outset. Of course, for the most part, the people in government, clinical research, and social research that we had to work with were good people who were open to these ideas anyway.

But I think it's important when we reflect on how the Australian partnership response came to be as it is, that we remember just how much our own community activists played a role in making sure that was the case.

Nothing about us, without us:

Nothing about us, without us – was something that was there from the start, though not articulated quite so succinctly. But I don't want to characterise this approach to research as consistently collaborative or beneficial.

There's been a lot of shifts along the way, and not least has been how people with HIV have been positioned. For the most part, HIV-positive men participating in the early clinical research were positioned as patients. At that time, HIV infection was mostly a death sentence. And, the gay community was a close community. The clinics involved were often led by doctors who were gay themselves, and even when they weren't, it was still very clear that the doctors involved felt very close to the men who were getting infected and then rapidly deteriorating, and dying, before their eyes. It was a crisis, and they just wanted to find something, anything, that might help.

A real tension emerged between researchers and community:

The efforts of clinical research were on finding, and testing treatment options. And a real tension emerged between researchers and community.

Clinical researchers felt bound by the requirements of gold standard clinical research. Yes, they wanted people with HIV to get treated as quickly as possible, but they needed to ensure that the treatments were properly proven to work. Community activists didn't disagree with this in principle, but in practice they often felt it was either too slow or it failed to account for the dire

circumstances of some individuals who were so sick or so close to death, that they felt it was worth trying even unproven treatments. This difference in approach was a recurring theme over several years. For the most part, compromises were worked out, even if there were confrontations along the way. And, just quietly, there was quite a bit of sidestepping the rules – on both sides.

Doctors finding some way to get treatments to patients with little hope otherwise, and patients figuring out who had the treatments and sharing them with those who needed them most. It wasn't good science, but it was human – and really, it didn't unduly impact the research.

Treatments back then were harsh, and complicated:

In the late 1990s, the fact that treatments now meant that people were no longer facing inevitable death from AIDS was fantastic, of course. Many of us have our Lazarus stories of friends who came back from their deathbeds. But the treatments back then were harsh, and complicated.

Clinical researchers wanted to reduce the burden, of course, but they also wanted the treatments to be effective. They offered multiple approaches over the years: hit hard and hit early; treatment interruption or delayed treatment until clinical markers indicated it was necessary...and back again. Mostly, people followed the guidelines provided by their doctors.

During the earlier periods, social research had a far larger role in understanding prevention than treatment:

Regarding people with HIV, social research mainly provided information about their experiences, as patients. Which was and is very useful, especially in helping support people with HIV get heard. And, when clinical research was focused on how best to implement treatments, social research has indeed been especially useful in highlighting just how important is personal experience, and the capacity of individual 'patients' to act on different treatment strategies. There is another way, though, that social research has been critical to understanding the experiences of people with HIV – how HIV positive people balance risk and pleasure to protect their partners.

I remember about 25 years ago, I mentioned how many Poz men in our cohort study weren't using condoms with each other, and that it was completely unsurprising. Why would they? Ross Duffin commented that, of course, Poz men had been doing that forever. But, at the time, that was simply not spoken about. On the one hand, because it didn't matter – the concern was all about transmission and so behaviours that didn't lead to transmission were mostly ignored. It was also unspoken because positive people's intimate lives, and the emotional well-being that follows from that, weren't always thought of as an essential precondition for effective treatment.

Since treatments, however, something fundamental happened:

This was in around how people with HIV came to understand that balance between risk and pleasure, in the decisions about protecting partners.

I was looking back over old questionnaires the other day, and I noticed in 1999 we were asking gay men a question about whether having an undetectable viral load reduced the likelihood of an HIV-positive man transmitting HIV to his partners. That's 20 years ago! And how long was it between then and when undetectable viral load was recognised as an effective basis for risk reduction? That's right – a long, long time. (And that's despite the fact that even in the late 90s it was known that if pregnant HIV-positive women were on treatment they could probably avoid mother-to-child transmission). So, similar to when I noted in the early 1990s that many Poz men were having condom-less sex with each other, many people with HIV could easily see the evidence about viral load.

Undetectable meant Untransmissible... why did it take so long?:

Over a decade ago, Asha Persson from the Centre of Social Research in Health at UNSW noted that many sero-discordant couples were discarding condoms when the positive partner had undetectable viral load. Because, as they could see it, despite the lack of advice from anyone to support them in their decisions, they were confident that undetectable meant untransmissible. And they were right – as I know some of you in this room can testify to and who haven't always been treated fairly for acting rationally based on the evidence. But, why did it take so long?

Now, yes, of course, the research had to be done, to

absolutely provide the proof. Of course, it did. Just as it had to be done in the search for effective treatments. But, just as with the treatments research, people can't always wait for proof – at least not for the absolute certainties that are usually mandated before policy can change. When logic dictates a well-informed interpretation of the available evidence, many people will act on it, ahead of the absolute proof. They aren't always proven correct, but in the case of HIV they often were. People make these decisions because life is more than just risk-avoidance. It's also about pleasure and intimacy.

Although, for people with HIV those things are always in balance against the possibility of endangering one's partner, and that's no small consideration for most Poz people who would find such an outcome to be deeply traumatic. At this point in the epidemic, however, I think people with HIV are in a very different position to what used to be the case.

HIV has become less and less of a marker of difference over time:

Treatments research remains important, but it's about making improvements to what for most people with HIV is a pretty good situation, and about identifying new options for the small proportion of people whose current options are limited. And, because the current situation is pretty good, that also means that most diagnosed people with HIV are undetectable, and therefore represent no risk for transmission.

On the other hand, the advent of PrEP means that considerations about HIV transmission risk are becoming less and less of a factor, at least for an increasing proportion of gay men. While HIV stigma is still clearly present, it's also obvious that there's less and less need for gay men to even discuss HIV. These are, of course, good things – profoundly good things. But, it leaves a question about where people with HIV actually fit in the research agenda?

In some ways, they have perhaps become somewhat peripheral to the HIV research endeavour. Indeed, there's also been a shift in the way people with HIV think of themselves over the past two decades. We started to notice in the early 2000s that Poz men were less likely to consider their HIV status as central to how they viewed themselves, or to consider themselves as part of a Poz community. And HIV has become less and less of a marker of difference over time. It still matters, of course, and that's very clear when you read the transcripts of interviews we conduct with recent seroconverters. No matter how much they had put HIV out of their mind beforehand, or how much they had thought of it as not being such a big deal anymore, once they receive that diagnosis then they realize just how much it does still matter. But, even so, the fact that they had previously often thought of it that way (or not at all), highlights just how peripheral HIV is becoming.

I've been left wondering if the issue is more: What's the role of the effectively treated, healthy person with HIV in HIV research now?

There are three categories of people with HIV that research is mainly concerned with these days: undiagnosed individuals; those who have been diagnosed but aren't yet treated and virally suppressed; and those for whom treatments have failed, or at least aren't working so well.

I could be cynical and say this is all driven by a prevention paradigm where individuals with HIV are just seen as vectors for potential transmission. I think there's some of that in the macro decision making process, but at the more personal level, individual researchers, and policymakers, are equally driven by the need to ensure all people with HIV have access to effective, and easy treatment

...they can't transmit HIV anyway, *so who cares?*

None of that, however, speaks to the role of healthy, effectively treated people with HIV in ongoing research agendas.

There are, undoubtedly, good reasons why people with HIV who are effectively treated need not always be considered separately anymore. Why should they be? Their overall health seems to not be especially different to many other people, probably better than most with ongoing health conditions. And, they can't transmit HIV anyway, so who cares?

Ah, but there's the rub. *Who cares!*

As long as anti-HIV stigma persists...

The trouble is of course, that a lot of people do still care, and care enough to be either fearful or rejecting.

Sure, it's happening less often than was the case in the past, but it's far from an insignificant issue. In the recent **Telling** survey, we found that even among men on PrEP many still avoid sex with Poz guys, if they knew. Stigma, regardless of its origin, or even motivation, is bad enough in itself. But, its demoralising effects on emotional well-being can do real harm, and can ultimately impact on things like treatment adherence. Stigma isn't the only thing at play here, although it's probably the single most outstanding issue that potentially impacts on all aspects of both treatment and prevention research.

There's a good case for why many effectively treated people with HIV quietly slip into the background to just be like other people without making HIV a visible presence in their lives. Despite that inclination by some, many others feel that HIV is still an important consideration in their lives. And as long as it makes some sort of difference, then it's important that people with HIV have a visible presence in decisions about research that affects them, even if it's not directly 'about them'. However, I suspect this means that the expectations of engagement that were often assumed in the past can't be expected to proceed in the same way, or at all.

Increasingly, as I see it, at least in relation to gay community based social research, our focus is less and less: on Poz men and more and more on gay men in general; or, in relation to PrEP, on neg men only; or, on undiagnosed men and how to get them diagnosed. But, in all of that, Poz men have key insights, and specific interests – or at least, they'll continue to have those interests as long as anti-HIV stigma persists.

So, what do I reckon is in the future for research among people with HIV?

Clearly, stigma remains the key issue, and it impacts on every aspect of HIV research. And people with HIV must be deeply involved in any research about HIV stigma. Beyond that, there are those three categories of people who have become the priority categories of people with HIV: undiagnosed; not yet treated; and ineffectively treated.

All three are small groups, and often not empowered to advocate on their own behalf.

So, it is of course incumbent on HIV community-based organisations to represent and protect their interests.

Appendix 4 – Sections from the PowerPoint presentation of Dr Associate Professor Allyson Mutch and Dr Lisa Fitzgerald, School of Public Health, University of Queensland

"Developing research relationships: what about the Funding?"

Lisa Fitzgerald, Allyson Mutch
School of Public Health,
The University of Queensland

Living Positive in Queensland

T2T

SHYQQ

Contemporary Queensland Context

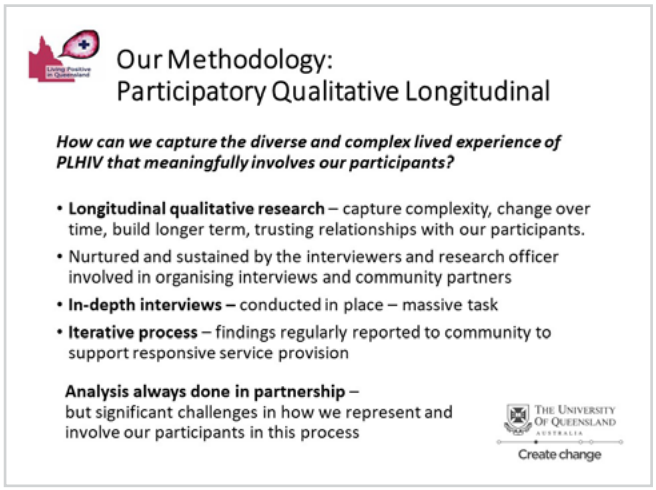
- Traditionally very conservative
- Geographically vast and isolated
- Limited national representation – i.e. No national research centre on HIV
- **In 2013:** Significant political upheaval that changed funding and service provision and greatly fractured community
- **In 2014:** The Qld HIV Foundation was established

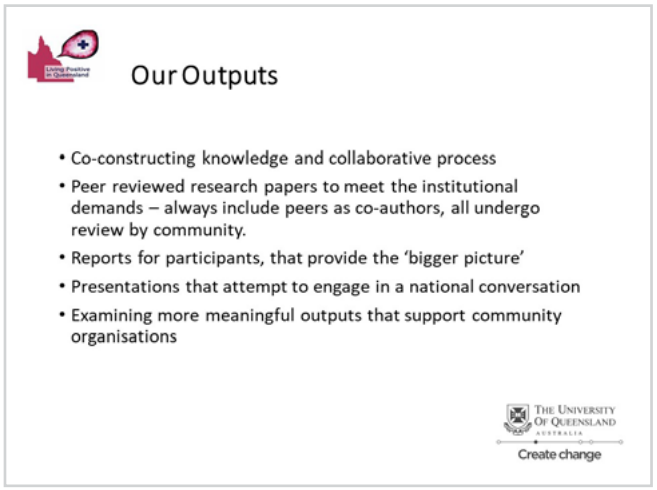
Queensland Context – Research funding

- Historically, University of Queensland (UQ) has strong service relationship with community through evaluation and education services.
- **From 2012:** Moved to partnerships with community, using small pockets of funds provided by community to conduct research on issues of concern for community.
- Provided opportunity for larger external partnership grants (ARC); questions driven by community.
- **In 2014:** New funding opportunities in research emerged through the HIV Foundation.
- **HIV Hub** – established at UQ with the Professorial Chair funded by the Foundation

Qld Context – The Social Research Dance

- HIV Foundation grants available from 2014.
- Priorities tied to National/State Strategies and the focus on 90-90-90 and Treatment as Prevention (TasP).
- The dance – navigating the TasP agenda to address questions; issues and research gaps for community in QLD?


Our Methodology:
Participatory Qualitative Longitudinal
How can we capture the diverse and complex lived experience of PLHIV that meaningfully involves our participants?
• Longitudinal qualitative research – capture complexity, change over time, build longer term, trusting relationships with our participants.
• Nurtured and sustained by the interviewers and research officer involved in organising interviews and community partners
• In-depth interviews – conducted in place – massive task
• Iterative process – findings regularly reported to community to support responsive service provision
Analysis always done in partnership – but significant challenges in how we represent and involve our participants in this process
The University Of Queensland
Create change


Our Outputs
• Co-constructing knowledge and collaborative process
• Peer reviewed research papers to meet the institutional demands – always include peers as co-authors, all undergo review by community.
• Reports for participants, that provide the 'bigger picture'
• Presentations that attempt to engage in a national conversation
• Examining more meaningful outputs that support community organisations
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Create change


Our Outputs: Challenges
• Meaningful outputs that support community organisations?
• Engaging those from smaller or more marginal groups
• How to tell different types of complex stories
• How we add value to the national research story?
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Create change

napwha national association of people with HIV australia

RESEARCH AND REPRESENTATION:

THE MEANINGFUL INVOLVEMENT OF HIV-POSITIVE PEOPLE IN HIV RESEARCH