

HIV research hinges on people living with HIV

By Miranda Smith and Brent Allan

Since it exploded into the human population in the early 1980s, HIV has been wrangled into some form of control through enormous advocacy and research efforts. Researchers, clinicians and community advocates have worked to identify the virus, to understand the disease it causes, and to develop and evaluate treatments. Prevention strategies have been developed, policy frameworks put in place, and research programs established all with people living with HIV present at every step.

The early days of the HIV epidemic set some important precedents for community involvement in research. HIV was first identified as a distinct pathogen following an unusual string of rare conditions in otherwise healthy gay men in the USA. The virus itself was isolated and identified by French researchers in 1983. In Australia, the first cases were identified among gay men in Sydney. Savvy clinicians, including the recently deceased and publicly mourned David Cooper, quickly realised that tackling the disease would mean not only addressing the clinical challenges of HIV infection, but also addressing stigma and fear. The Sydney AIDS Study Group was a cohort of homosexual men launched in 1983 almost the moment the first cases of HIV were diagnosed in Australia. At the same time, the AIDS Action Committee (later the AIDS Council of NSW and now

ACON) was set up. The National Centre in HIV Epidemiology and Clinical Research (NCHECR), now the Kirby Institute, was established in 1986. Tackling research from a social and behavioural perspective, the National Centre in HIV Social Research (now the Centre for Social Research in Health, CSRH) was established in 1990, broadening research capacity in HIV. The NCHECR led some of the earliest clinical studies of HIV infection, with working groups established to discuss research priorities and protocols. These working groups included people living with HIV, a practice that has become (almost) the norm for those researching HIV in all disciplines.

It is worth considering that the distinction between researchers and people living with HIV is often false. People living with HIV are sometimes also researchers. One outstanding example is the late Brett Tindall, whose life as a man living with HIV was intertwined with his work as a researcher. Brett was one of the first employees of the NCHECR. He worked with the Sydney AIDS Study Group on studies of seroconversion, primary HIV infection and early studies of antiretroviral therapies. Brett died from AIDS just before the modern era of antiretroviral therapy, and the Kirby Institute now host a yearly lecture in his honour.

The International Council of AIDS Service Organisations (ICASO) has recently issued a call to action for researchers to make an upfront acknowledgement of the role of people living with HIV at the beginning of any presentation of their work. This call to action comes from the slow simmer of people with HIV dissatisfied with being mentioned as an endnote in presentations and is based on the principles of greater involvement of people living with HIV or AIDS (GIPA). GIPA was articulated in the lead-up to the 1994 Paris AIDS summit, requiring acknowledgement of the humanity and agency of people with HIV, and ensuring their involvement in decisions affecting them. GIPA was first directed towards engaging people living with HIV in programmatic, advocacy and service responses to HIV but is also applicable to research. GIPA has since evolved into meaningful involvement of people living with HIV or AIDS (MIPA), which more specifically requires people with HIV to be at the centre of HIV activities and programs. The call to action is to ensure that people living with HIV are not merely donors of their time, their blood and other specimens, but are active participants in research. Most Australian researchers are no stranger to engagement with and involvement of people with HIV, so we sought their opinion of the call to action.

We spoke to a number of Australian researchers, and all agreed that acknowledgement of people living with HIV is an important principle. Our engagement highlighted a nuanced response to the call, with researchers concerned that such an acknowledgement not be a stand-alone gesture or delivered in a way that excluded other research participants. One critical concern was how a GIPA acknowledgement would sit with the convention for acknowledgement of country at the beginning of presentations. Professor Jenny Hoy from the Alfred Hospital and Monash University in Melbourne said, “it should be routine to acknowledge the involvement of people living with HIV and thank them for participation in our research, but the call should also encompass the meaningful involvement of people living with HIV in all aspects of research planning”. Professor Martin Holt from the Centre for Social Research in Health (CSRH) at the University of New South Wales in Sydney suggested that the call to action reflects the ongoing work to make GIPA a reality. He warned though that “blanket acknowledgements may exclude others who meaningfully participated in the research and may also be an excuse, a token gesture, for some researchers to feel they have done enough”. Professor Carla Treloar, Director of the CSRH at UNSW echoed this sentiment and agreed with the principles of the call, but also acknowledged that “a lot of research is done with mixed populations, not just HIV positive populations. In this case, it would be unfortunate for the acknowledgement of HIV positive contributors to overshadow those of other groups”. Dr Jennifer Power from the Australian Research Centre in Sex, Health and Society (ARCSHS) at Latrobe University in Melbourne neatly concluded that “people living with HIV are asked to participate in so much research. Acknowledging the time and effort that this takes is pretty basic.”

If an acknowledgement of people living with HIV in research presentations is one way of embodying the GIPA and MIPA principles, it is worth looking at what other types of engagement can underpin this simple act. The

involvement of people living with HIV on research advisory boards is a widespread practice among HIV researchers and is one way that people living with HIV can be engaged in the research process. Often, the community representatives on study steering committees or advisory groups are recruited through HIV community organisations such as the National Association of People with HIV Australia (NAPWHA) and state-based organisations. Jenny Hoy spoke of the effective Community Advisory Board associated with the International Network for Strategic Initiatives in Global HIV Trials (INSIGHT) network, which conducted the landmark SMART study leading to the global recommendation to start antiretroviral therapy as soon as possible. Jenny reflects “these (community) members were integral to the study design acceptability, and liaised with local people living with HIV, hearing their concerns and passing these along to the executive at their regular meetings.” Carla Treloar spoke of the Gay Community Periodic Survey as an example of good practice. While the survey involves the whole gay community, and not specifically people living with HIV, the community engagement principles are relevant. The survey has run for over 20 years and has a large advisory committee with multiple community representatives which reassess the survey questions each year. Paid community recruiters go to venues and events to enrol participants for the survey. These examples both underpin the importance of meaningful engagement, where people living with HIV (and other community members) are not only present but are empowered to contribute to decision making and study design.

There are multiple benefits to research that adheres to the GIPA and MIPA principles. Many researchers see community involvement as vital to their work. Martin Holt reflects, “I feel that I have built strong relationships with NAPWHA and its member organisations to the extent that I automatically include them in the research process and seek their input, and I think that gives me the confidence that the research I do with

people living with HIV is well informed and will not do harm.” Jen Power says simply that, “collaborating with people living with HIV in any research genuinely improves the project outcomes. People who have lived experience and good ideas are exactly what you need to make research better”. It is not only social researchers who see the benefit of community involvement. Jenny Hoy reflects that some clinical trials may not have been considered without the involvement of people living with HIV, such as trials on the use of soft-tissue implant Sculptra for Facial Lipoatrophy. Community engagement from the early phase of study development can also help with study recruitment, with community organisations able to promote research opportunities to their members. Genuine community engagement is especially critical for research that involves risks to the participants, or at least does not involve substantial personal benefit. This includes research towards an HIV cure, which is currently in its early stages. Cure research trials are mostly small, early phase studies which may include the possibility of treatment interruption to assess efficacy. One important outcome of community consultation on treatment interruption is the desire for Pre-Exposure Prophylaxis (PrEP) to be offered to sexual partners during interruption. While researchers can obviously benefit from community engagement, the community can also benefit through enhanced insight into the research process, informed participation in research studies and greater understanding and application of research findings.

Involving people living with HIV in all stages of the research process is an ongoing project requiring persistent engagement and adaptation. While there are many examples of useful and beneficial engagement, there is also room for improvement. One common concern raised by the researchers we spoke with is the lack of specific resourcing for community engagement. Jen Power stated that “often it is genuinely difficult to reach out to a wide range of people, including diverse communities, as part of a research project simply because this would take time and money that aren’t available.”

On a similar note, Jenny Hoy mentioned that “the National Health and Medical Research Council (NHMRC) are finally acknowledging the importance of consumer involvement, but still don’t include financial backing in their budgets”. Carla Treloar noted that at the CSRH, they usually seek community engagement through organisations with salaried staff, but they do consider remuneration of community representatives if they are engaged in a capacity beyond their paid position. Professor John Kaldor from the Kirby Institute identified some important gaps in engagement; he says, “the missing piece is generally in the context of research agenda setting, rather than the construction of a specific project. Also, dissemination of findings at various stages could be more directly with people living with HIV, rather than organisations.” Jenny Hoy reiterates this need for engagement in the planning stages and says, “maybe the best model would be to invite some people living with HIV to participate in HIV research planning days so they are aware of where our research is heading and we can hear what is important to them, what their concerns are, and we can plan meaningful research together.”

Opportunities for community engagement throughout the research cycle should be pursued and extended. Scientific conferences are major tools for disseminating research results and facilitating dialogue among multiple stakeholders including community. The Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (ASHM) has been rigorously pursuing GIPA/MIPA principles within its overall conference organising committee and across thematic areas. Scott McGill, the acting CEO of ASHM emphasises, “the annual ASHM conferences are an important venue for promulgation of this sort of advocacy and the engagement of people living with HIV.” ASHM initiatives include protected sessions with the main program; community driven practice-based abstracts; ensuring presenters acknowledge the contributions of community collaborators and participants and outline the benefit to them and the sector, and translational sessions focused on the community

implications of the work presented. These sorts of strategies could be considered and adopted more widely.

Acknowledgement of people living with HIV in research presentations is widely supported by Australian researchers. Many already incorporate this type of acknowledgement into their work. This sort of public acknowledgement needs to be underpinned by much broader and deeper community engagement in research. The Australian community of people with HIV should continue to push for involvement in all stages of the research process. Australian researchers recognise the benefits of engagement, but they also need to advocate for ongoing support for engagement processes and continue to reflect on their own research practices in relation to MIPA principles. The most effective engagement starts early and extends throughout the research process. An acknowledgement of the contribution of people living with HIV in research presentations should be routine, but definitely not the only form of acknowledgement. Until there is a cure for HIV, researchers and people living with HIV must continue to work in partnership.

Miranda Smith is the Project Officer for the Australian Partnership (for) Preparedness Research on Infectious (disease) Emergencies (APPRISE), and member of the HIV Cure Community Partnership, managing the website hivcure.com.au.

Brent Allan currently occupies two senior advisor positions focusing upon programs and policy for both the Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine based in Sydney (Australia) as well as with the International Council of AIDS Service Organisations based in Toronto (Canada).