

## **Improving HIV social research to better understand the needs of PLHIV from culturally and linguistically diverse communities**

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There is a vast amount of social and behavioural research on HIV prevention, testing and care that has been produced in Australia since the 1980s. For very good reasons given the pattern of the Australian HIV epidemic, this research has largely focused on Australian born gay men.

The Australian government has led the way internationally in developing a model for funding HIV social research – four government funded HIV social research centres have now received government funding for over 25 years. The significance of what has come out of this can't be underestimated. HIV social research (a lot of which has come out of Australia) revolutionised approaches to public health research.

It was HIV social research that connected humanities with public health. It joined the dots between culture, identity, sex and sexuality and medicine and disease prevention. It might seem obvious now, but this really unique. There was a lot of qualitative and mixed method research in HIV that had a big impact internationally.

This type of HIV social research contributed to Australian policy and practice and supported community leadership, which in turn also revolutionised public health in Australia.

The effectiveness of community driven health promotion, and the importance of community knowledge and leadership to drive health promotion and health care, is now often taken for granted in the public health.

The HIV response – alongside feminism and the women's health movement – was at the forefront of this unique approach to public health, health promotion and health care in Australia.

While HIV social research is still really strong in Australia, there has been a shift toward larger, quantitative and population studies that are driven by the 90:90:90 goals – of 95:95:95 goals as per the 8<sup>th</sup> Australian National HIV strategy.

The aim of this research is to increase uptake of testing and treatment and biomedical prevention (PrEP) which means the focus is on implementation science and upscaling. How do we make these things work on a larger scale for more people?

However, we know that there are groups for whom HIV prevention is not working. And we suspect that the care and support needs of people living with HIV is not adequate for many people in this “last 10%”.

In research we have done at ARCSHS, we have heard from many community organisations and service providers who feel that they are not adequately reaching culturally and linguistically diverse populations to provide social or practical support or representation. However, they are unsure how to do this.

So, it seems like there is a need for some detailed, qualitative social and needs assessment research to understand what is happening for people from culturally and linguistically diverse communities. Without this, achieving the virtual elimination of new HIV transmission in Australia will be difficult.

But does the model of research that has been so successful for HIV social research with gay men apply in these circumstances? Can the knowledge and skill base developed through years of quality social research on HIV prevention and care for gay men translate to HIV social research with culturally and linguistically diverse communities?

### **Getting research off the ground**

When it came to HIV social research with gay men in the 1980s and 1990s, there was a strong starting point. In Australia, we had a reasonably large number of men and geographic concentration (we knew where to find large enough numbers of gay men to make a study work).

We also had a highly motivated population. Gay men wanted to be involved in HIV social research because people understood the importance of this work. This doesn't mean it wasn't challenging to get it off the ground – it was a sensitive topic and it was new and ethics committees freaked out – but it was do-able. And importantly, we also had some highly educated gay men and lesbians working in academia or other organisations who could drive this research and/or who could be powerful advocates for this research to government (who agreed to fund it).

I know that is not the entire story but it is an important part of the reason we have had such good research on this topic in Australia and other western countries.

HIV social research with people from culturally and linguistically diverse communities in Australia has a really different starting point.

### **Diversity and small numbers**

As we know, when we talk about culturally and linguistically diverse communities we are talking about a wide diversity of population groups. I have been using this one term ('culturally and linguistically diverse') to refer to multiple different community groups from multiple different countries.

Australia attracts migrants from range of regions and countries. We don't have a concentration of one particular migrant group. There are many and there is very limited commonality between different groups geographically, culturally or linguistically.

When you also consider other factors such as gender or age differences, we see even greater diversity. It makes very little sense to group young heterosexual women from Indonesia with older gay men from the middle East.

There is no group.

However, as the numbers from each migrant community are generally very small, we have tended in Australia to group people under the banner of 'overseas born'. This tells part of the story of epidemiological patterns and informs national surveillance data but gives little insight into what is going on for people or how to overcome barriers to testing, improve care or enhance support programs.

I think most people know this. But we haven't found an easy way around this. I think this is because our approach to funding research is going in one direction (bigger, larger scale research) while the type of social research needed to explore issue for migrant communities is increasingly smaller in scale.

It is very difficult to find funding for research that relates to a population group of 50 people, or even 100 people. One of the first questions you are asked on a funding application is to demonstrate the significance to Australia as a whole. Why would we fund this study that applies to such a small number of people instead of a large project of relevance to 20,000 people?

So we try to create groups – a social research project exploring the care and support needs of people living with HIV from culturally and linguistically diverse communities (or migrant and mobile communities) – and we get nowhere because the group is false. There is no group. So the only conclusion you can really draw is that needs are too diverse to capture in one study or one program or one organisation.

### **Practical barriers to reaching people living with HIV**

But even if we go smaller scale and identify the group – eg. Asian born young women – it can be difficult to find people to invite to participate in HIV community research.

There are no community hubs for people living with HIV in most community or health services that are located in key area or which directly work with particular migrant communities.

And, while our large HIV community organisations are well equipped to engage with Australian born gay men, they haven't always been able to reach diverse communities. This is not for want of trying, it's important to note this. But there are multiple cultural and resourcing barriers to engaging with diverse communities. Large HIV community organisations may never be best placed reach people from all communities and all cultural backgrounds. No single organisation can be.

So we don't have a means to reach people from a wide range of communities to involve in research (it's a bit of a vicious cycle, because it also means we don't have the evidence base to demonstrate need for these programs).

There are also a range of other barriers that we are probably more aware of.

Language is a barrier to research participation, particularly for people living with HIV where not everyone wants to work with a translator for reasons including confidentiality or fear of disclosure.

And there are other concerns about stigma and confidentiality, or even engaging with research on topics related to sex, that make people reluctant to participate in HIV social research (in relation to prevention or the needs of people living with HIV).

In addition, HIV is often far down the list of priorities in people's lives and motivation to participate in research is low.

I think all the above are practical barriers that could be overcome with the right resourcing and enough time to build the right networks. But again, this isn't necessarily the way we approach research in Australia. We tend to receive funding for large projects that need to be delivered in a short timeframe. Smaller projects that are resource or time intensive are often almost impossible to get off the ground or, when you do, they can be very hard to deliver on time.

Also, relationship building is central to this research and that takes years and you need a funding base, as a researcher, to do this. You need a job.

### **Transferability of research skills and knowledge**

There also isn't necessarily a pool of researchers from culturally and linguistically diverse communities who are able to drive research on HIV or a pool of HIV social researchers who are experienced working with diverse communities.

In Australia, the fact that a lot of HIV social researchers were gay men meant that research projects were designed and delivered by people who had a lot of access to informal knowledge, shared sensibilities, networks and connections that made it possible to construct really good community engaged research. This is in part why HIV social research with gay men has been so good and so extensive in Australia.

However, HIV social research with gay men doesn't necessarily translate to a skill or knowledge base – or set of connections – that can easily be adapted to HIV social research with other groups.

So despite our strengths in HIV social research, we don't necessarily have a pool of researchers available in Australia who can easily engage with diverse communities on issues related to HIV prevention, testing or care.

As with everything I have raised here, this is not an insurmountable barrier. But it is a consideration if we are contemplating how to develop better HIV social research diverse communities. Who is driving this research agenda?

## **Conclusion**

So, to draw all these thoughts together:

- We need good, qualitative research on strategies to support HIV prevention among culturally and linguistically diverse populations and on the needs of people living with HIV from these communities.
- But as there is such diversity, no single research project will do this – qualitative or quantitative. We are talking about multiple very small projects. Social research is not going to get very far if our starting point is all ‘people born overseas’ grouped together – this is a meaningless grouping.
- But small, specific projects goes against current trends in research funding and the type of research that’s valued and publishable in academic journals, or given credibility in public and policy dialogue – where the emphasis is on larger studies and bigger populations.
- We often hear the argument that the major barriers to HIV social to research with culturally and linguistically diverse communities are related to language or hidden populations and stigma. This is not untrue, but I don’t think this is the major problem. I think we currently don’t have the right approach to funding that will support and motivate good research projects and build the skill base we need in Australia.