

## Constructing knowledge

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It's time to bring people living with HIV/AIDS more closely into the social research which seeks to understand their lives.

Social research is one of the ways, a quite powerful way, in which the experience of living with HIV/AIDS is constructed and represented. As social research creates an image of positive lives, I (and most positive people) want to take care about how that image is constructed.

The process could be described as one of 'co-constructing knowledges'. There could usefully be more attention paid to the way in which those knowledges about living with HIV/AIDS are co-constructed, and I want to position positive people at the centre of that process.

I have been working in NAPWA's HIV Living Project for nearly five years now. In defining the role of the project and that group of activities now called the NAPWA HIV Living Unit, engaging with Australia's major social research institutions has been one of my tasks.

At my desk I keep a folder where I place articles, papers and notes about the social research project and HIV and AIDS. In that folder I have a discussion paper written in 1998 by Gary Dowsett and Mark Davis on HIV/AIDS and collaborative social research. This paper addresses aspects of the relationship between research institutions, researchers, community based organisations, positive people, funding bodies and government instrumentalities.

Dowsett and Davis used the word 'co-research' in 1998 – they were exploring what 'co-researching' may look like. And when I look at the shape of the current institutional arrangements much 'co' work has gone on but it needs to go further.

In my folder I also have a copy of the speech delivered by Jon Willis at the 2001 NAPWA conference, where Jon's intervention strengthened the positive voice by reminding us that positive people are "more than the sum of their numbers." Jon argued that positive people finding their own speaking positions has led to some of the most valuable social research, but he was also brutally honest about the difficulties that arise when the experiences of positive people tend to be reduced to [clinical](#) [1]Pertaining to or founded on observation and treatment of participants, as distinguished from theoretical or basic science. markers, risk practices and disease statistics.

My folder also contains write-ups of workshops, presentations and articles by social researchers such as Asha Persson, Jeanne Ellard, Kane Race, Sean Slavin and Michael Hurley. I also have pages of scribbled notes from talks that I have heard at NAPWA workshops and a planning day in 2003 about influencing research agendas. Kirsty Machon, Jo Watson, Peter Canavan, Brent Allan, Mark Saunders, Jeffrey Grierson and many others contributed to these discussions.

What I'm trying to do by referring to this folder is to point to a history of connections and attempts by the people I have mentioned as well as many others to untangle what it is that social research is doing. These people do not shy away from the entanglements that make social research projects possible. In fact when I look at that folder what I get a sense of is that it is the entanglements that make the social research project construct knowledge.

I could quote any number of theorists about these entanglements in social research processes; in my own professional area of educational research and reading there are many writers who celebrate these entanglements. Many of these theorists suggest that the whole point of social/educational research is that it produces a series of relationships, and that in itself produces a story about research and how research should be carried out.

One of these writers, Cleo Cherryholmes, says "research findings tell stories." Cherryholmes is not only an authority in social research; she comes from a background in mathematics and basic science. In those disciplines there is also an acknowledgement that researchers tell a particular story line from the data which they are examining. I'll leave that science to others but I'll repeat her point: research findings tell stories.

I think it's time to ask and reflect on the stories that are being told about positive lives by the behavioural and

social research. Research constructs an authorised image, a narrative, story line and representation of what it is to be living with HIV and AIDS, and this representation has power in the media, at a policy level and also has the power of reflecting back. Sure, positive people themselves do their own image making, write about themselves and represent themselves in many ways, but positive lives are also very powerfully presented through social research data.

To be perfectly honest I am quite often nervous, uncomfortable and annoyed about some of the story lines produced.

I was at a meeting once where I was talking about the HIV Futures study data and I felt like I couldn't quite get my point across when Mark Saunders wrote a few words down on a bit of paper and shoved it across to me. "It's about giving some colour to the data," he wrote.

Mark understands that this colouring, layering and fleshing out of data is important work. The alternative is research products that convey a one-dimensional image of positive life – those that explain positive people in terms of risk or as a set of disease statistics.

I think there are many other storylines that could be explored (or perhaps deep in some social research program they are being explored but I think they need a bit more visibility).

What about the stories of resilience? What about the stories of the ability of positive people, despite disease and death, to continue a long history of community organisation and advocacy? What about the stories where positive populations and groups are shaping and making sense of their own lives rather than being subject to forces, technologies and social arrangements which position them as a problem for health and welfare services?

Why is it that I read so much social research which focuses solely on the sex acts of HIV-positive people when this is only one dimension of the story? I know there are other discourses and imperatives that cut across research agendas, and we sit within public health and legal frameworks that demand (quite rightly) a focus on containment and management of disease, so measuring the amount of times people engage in unprotected anal sex is important. But the whole of me wants to yell out that that is only part of the story.

At the [ASHM](#) [2] Australasian Society for HIV Medicine. The peak Australasian organisation representing the medical and health sector in HIV/AIDS and related areas. Conference this year we had a discussion about social research called 'Drilling into the Data'. Specifically in reference to the HIV Futures reports, this discussion recognised that there is a mass of data about positive lives that has been gathered over the years. The idea was not necessarily to demand more research or call for more data (although continuing data collection is absolutely essential) but the idea is to look at the data that is available and see what other stories that it may tell.

Specifically, NAPWA has been asking about care and support. At the National Centre in HIV Social Research there are years of data about positive lives collected in the [pH](#) [3] [Potential of Hydrogen] A measure of acidity or alkalinity. pH levels are expressed on a scale from 0 (most acid) to 14 (most alkaline). A pH level of 7 is neutral. study and other research projects. I'm wondering if it is possible to go back into that data – is there enough there for a big picture story to be told about quality of life after nearly ten years of the availability of [HAART](#) [4] Highly Active AntiRetroviral Therapy ??? aggressive treatment of HIV infection using several different drugs together.? And what conceptualisations of quality of life will be bought to that examination?

It is positive people – if they are asked, invited to, drawn back into the story – who could start that discussion about what quality of life might mean.

I think it is time for more reflexive stories. ('Reflexive' is a much-maligned jargon word, but what I mean by reflexive stories are those that bring the tellers of the story back into the story; those who 'provided the data' are bought back in.)

I'm not just talking about researchers adopting a reflexive methodology but about bringing positive people back in as the narrators, the producers of the documents, the writers of the stories, the co-authors of articles and the producers of the research. This would recognise, to use a social science term, our 'agency'. It would be, to use a word I am a bit wary of but which here is absolutely appropriate, 'empowering'.

I am not talking about this happening for a few individuals; I am talking about it happening at a structural and

organisational level with all the structural support mechanisms that would be required. Of course there are some details to be filled in about how this would happen, but first of all we need to the will to go there.

If the future is researchers and research institutions just 'consulting' positive people about research project directions, then the future will be more of the same. An exciting future would be a move towards this co-construction of knowledges which would push and maintain all our work at the critical edge where parts of it have often been.

Now is the time to do this; if it doesn't happen in the next few years the moment will be lost. The research centres have recently had their funding assured for another period of time. The 5th National Strategy has secured a whole set of relationships under which this move could be made. There is now a critical mass of HIV-positive people who are located inside and outside research institutions and who have a sophisticated, critical social research literacy. Working with this dynamic could enable positive people to consciously construct and narrate the experience of living with HIV/AIDS through the social research project, not just about positive people – there would be opportunities for learning from that which would impact on many areas.

- *John Rule is the Manager of the HIV Living/International Unit at NAPWA. This article is an edited version of a presentation given at the 2005 ASHM Conference in Hobart. The opinions stated here are the author's own.*

- [HIV Futures](#)
- [involvement of positive people](#)
- [social research](#)

**Links:**

- [1] <http://www.napwa.org.au/glossary/term/475>
- [2] <http://www.napwa.org.au/glossary/term/382>
- [3] <http://www.napwa.org.au/glossary/term/105>
- [4] <http://www.napwa.org.au/glossary/term/96>