

30 Minutes with Bill Whittaker

Created 27 Nov 2009 - 3:13pm

'The reason Australia has been successful in gaining access to the latest treatments over the years is because we put a lot of effort into building a strong case. We did our homework, we were able to build the arguments, we knew the health and drug approval systems and we could present an analysis that usually won over government and the drug companies.'

Since the early days of AZT, Bill Whittaker has been one of the main reasons Australia has done well in getting access to the latest treatments and been included in most of the world's cutting edge clinical trials.

Bill's involvement in HIV advocacy began in 1985 when he was President of the Sydney Gay and Lesbian Mardi Gras – then the main gay and lesbian activist organisation in NSW. Authorities were talking of banning the event because of fears about the spread of HIV. So, Bill met with Don Baxter, Lex Watson and others from the AIDS Action Committee that had been set up to coordinate the NSW gay community's response. Bill then became the first Executive Director of ACON in 1986, working with the grand total of three staff initially but building that number up to more than 70 when he left in 1991.

OUTDATED APPROVAL SYSTEM

When AZT became available overseas in the late 1980s, Bill and other treatment activists started pushing the NSW government to provide compassionate access to the drug. The activists talked with leading doctors and researchers like Professor David Cooper from St Vincent's Hospital in Sydney. They all soon realised that Australia was not going to be at the cutting edge of new HIV treatment research with the Byzantine [clinical](#) [1] Pertaining to or founded on observation and treatment of participants, as distinguished from theoretical or basic science. trials approval system we had at the time. And unless the outdated drug regulatory system was reformed it would take too long for new drugs to find their way to people with HIV who needed them desperately.

The Therapeutic Goods Administration was full of long-ensconced bureaucrats who were preoccupied with 'never having another thalidomide' and treated all drug companies with suspicion.

'And AIDS activists were viewed as people from another planet,' recalls Bill.

'These bureaucrats insisted on maintaining an extremely complex clinical trial approval system. Any data submitted with a trial application had to be repeated here, rather than accepting it if it came from credible research in countries like the USA, Canada or the UK.'

Many attempts had been made to reform the Australian clinical trials and drug approval systems, through inquiries and reviews over decades, with no success.

'But we knew,' said Bill, 'that with new drugs like ddI and ddC being approved overseas in the early 1990s we had to step up our efforts to overhaul this system and fast.'

Our system was discouraging drug companies from considering Australia as a site for researching the latest drug trials. Things had to change.

THE ROLE OF ACT UP

To help add pressure for reform, ACT UP was formed in Australia in 1990. It was clear that very public and visible activism was a useful mechanism. It got the attention of the media, politicians and the public about a health crisis that needed an urgent response.

'ACT UP New York had managed to help change the US system, so we hooked up with them and I attended some of their meetings,' continues Bill.

'The good thing about the Australian ACT UP protests was that community groups like the AIDS Councils collaborated and focused on getting across messages that would get the attention of the public and politicians.'

The loud and often disruptive protests in front of politicians were always controversial. Bill felt some tension between his public face as Executive Director of ACON and the fact that most of his staff and volunteers were also members of ACT UP.

'I remember being interviewed by the media outside our office and trying to keep their attention off my staff who were returning from an ACT UP march carrying banners and wearing Silence=Death T-shirts,' he recalls.

'Of course, I had very much encouraged staff to participate in these actions and they were often organised out of ACON.'

Such pressure undoubtedly helped to change public opinion. Brian Howe, then the Labor government's Health Minister, took the courageous step of going against contrary advice and setting up an independent review of the clinical trials and drug approval system.

Bill was asked to sit on the review committee that recommended major changes to the system and the funding of initiatives to empower people with HIV to be fully involved with decision-making around their health.

This was a groundbreaking move away from the 'doctor-knows-all' approach which had existed until that time. And it led to ACON setting up a Commonwealth-funded treatments information project for people with HIV. The government, to their great credit, accepted all the recommendations of the McDonald Review for a quicker and fairer clinical trials approval system. This helped Australia become a much more attractive place to do treatment and other research.

They also called for a further review, under former Liberal Senator Peter Baume, to look at how to address the other recommendations including the fairly radical proposition that Australia should accept evaluations of new drugs done by credible overseas regulatory authorities.

Baume proved to be a brilliant choice and his report resulted in a stronger and fairer system, more sensitive to the needs of people with life threatening diseases. His recommendations included the introduction of the [Special Access Scheme](#) [2] Before a drug has been approved, manufacturers often provide the drug free of charge to people who cannot participate in a clinical trial and who meet certain criteria under a Special Access Scheme (SAS), where people failing their treatment regimens could get access to trial drugs (without placebos) while clinical trials of the drug were under way.

'Our drug approval and clinical trial approval systems are now widely regarded as pretty efficient and effective,' says Bill.

'There is a good balance between safety, [ethics](#) [3] (In clinical trials) The process of determining that a proposed clinical trial conforms to a wide range of moral, scientific and ethical standards, to ensure that participants in the trial are not abused, mistreated or unfairly taken advantage of. Before a clinical trial can go ahead, it must be given approval via an independent ethics process. and accountability issues and an excellent record of people [enrolling](#) [4] The act of signing up participants into a study. Generally this process involves evaluating a participant with respect to the eligibility criteria of the study and going through the informed consent process. in the latest research studies. We

couldn't have done all this without our outstanding doctors and scientists and particularly the support of the National Centre for HIV [Epidemiology](#) [5] The branch of medical science that deals with the study of incidence and distribution and control of a disease in a population. and Clinical Research ([NCHECR](#) [6] National Centre in HIV Epidemiology and Clinical Research. Based at the University of NSW in Sydney, NCHECR is one of Australia's leading medical research centres and is recognised internationally as a leader in the field of research into HIV/AIDS

and viral hepatitis.) in Sydney.'

ONGOING BATTLE FOR TREATMENTS

This collective effort by a small, very focused group of activists involved incredibly hard work, with tedious attention to detail and intense negotiations with drug companies and government.

'I doubt if many positive people realise that NAPWA has had to fight in international forums to get Australia included in the crucial clinical trials on offer,' says Bill.

Pressure from other countries to take our share has been intense. Our excellent record in conducting trials has helped but sometimes it is only the power of persuasive argument from our activists that has saved the day. Even today, this is still the case.

NAPWA is still involved in negotiating with drug companies for access to every new HIV drug we consider to be important. This involves arguing for our fair share of compassionate access programs for new treatments, discussing inclusion and [exclusion criteria](#) [7] The medical or social standards determining whether a person may be disqualified from entering a clinical trial. These criteria are based on such factors as age, gender, the type and stage of a disease, previous treatment history, and other medical conditions. It is important to note that inclusion and exclusion criteria are not used to reject people personally, but rather to identify appropriate participants and keep them safe. for trials and for the best possible access through Australia's health system.

'People don't see the table-banging and the arguments that occur in these negotiations. Sometimes supply was a problem so the best outcome we could get was a lottery to see who got access to the drug.'

SUCCESS WITH SCULPTRA

The involvement of community in initiating research into new therapies also has to be acknowledged. Bill reveals that it was NAPWA who initiated the push for Sculptra to be funded on the [PBS](#) [8] [Pharmaceutical Benefits Scheme] The federal government program which subsidises medication costs in Australia. Anti-HIV drugs are part of a special part of the PBS called Section 100 (S100) which is used for expensive, highly specialised drugs..

'We worked closely with NCHECR and sanofiaventis to get up a clinical trial to test the efficacy of the facial injections in reducing the effects of facial lipoatrophy. And many intense efforts and negotiations were made to get the technology funded through the PBS before it finally happened this year,' he says.

Access to Sculptra is a boon for people dealing with this body image problem. But as people live longer with the [virus](#) [9] A small infective organism which is incapable of reproducing outside a host cell. it is just one of a number of complex conditions that we are seeing. Others include complications associated with increased cardiovascular risk, higher rates of cancer, problems with bone density and [liver](#) [10] A large organ, located in the upper right abdomen, which assists in digestion by metabolising carbohydrates, fats and proteins, stores vitamins and minerals, produces amino acids, bile and cholesterol, and removes toxins from the blood. and kidney damage. They all increase the complexity of work activists have to do.

'We initiated work on developing new models of care to try to address the long-term needs of HIV positive people,' he says, 'rather than rely on outmoded crisis-driven forms of service delivery.'

Whilst talking about the breadth of the task for people involved in treatment and care, Bill despairs at the number still getting infected with HIV. And how casually people seem to accept the fact that 1000 new people are getting infected every year in Australia.

'I can't understand why people aren't jumping up and down about the level of new infections,' he says. 'Australia's new HIV strategy has to tackle this state of affairs head on and invest new resources in prevention. And activists need to make noise about it as well.'

'There is a perception that people newly infected with HIV are going to do well,' he continues, 'which is great. But there is unlikely to be an effective vaccine in the near future.'

While one focus for research will be on eliminating HIV from the body this will not be a cure. A cure implies restoration of the effects of HIV and this is not going to happen without some yet-to-be-discovered intervention. HIV does damage to people from the day it enters the body. As HIV treatments stand at the moment, people with HIV are unlikely to live without some effects of the virus over the long term, even with successful [antiretrovirals](#) [11]A medication or other substance which is active against retroviruses such as HIV..

'The best we can hope is that we can manage the damage,' concludes Bill, 'and limit the impact of the virus as much as possible.'

A PIONEER IN OUR HIV RESPONSE

I wanted to do this interview when I heard Bill was standing down from the role of Coconvenor of the Health, Treatments and Research Portfolio at NAPWA. I wanted to acknowledge the incredible effort he has made as a pioneer in the response to HIV in this country, as our preeminent activist in a wide range of policy areas as well as treatments. I wanted to recognise his leadership of a range of pivotal community-based organisations including ACON, Positive Life (previously PLWHA NSW), [AFAO](#) [12]Australian Federation of AIDS Organisations. AFAO is the peak non-government organisation representing Australia's community-based response to HIV/AIDS. AFAO's work includes education, policy, advocacy and international projects. , and NAPWA, and his stature as one of our most wellinformed and credible negotiators with government over the years.

I wanted to remind everyone that he was awarded an Order of Australia in 1992. I thought that maybe the intellectual rigour and wisdom that Bill has delivered to the HIV community for so many years might be lost as he contemplated a change to other things. But I was heartened to hear that he has accepted a role as an advisor to the NAPWA Board and that he continues to represent Australia in forums such as the Pacific Friends of the Global Fund – a meeting he was about to attend in New York before I did this interview.

'I need the intellectual stimulation,' Bill said of his continued involvement.

Let there be no doubt that we need people like Bill Whittaker in this epidemic and that without him our response to HIV and, particularly our access to treatments, would be much the poorer.

- [living with HIV](#)
- [NAPWA news](#)
- [news](#)

Links:

- [1] <http://www.napwa.org.au/glossary/term/475>
- [2] <http://www.napwa.org.au/glossary/term/112>
- [3] <http://www.napwa.org.au/glossary/term/498>
- [4] <http://www.napwa.org.au/glossary/term/489>
- [5] <http://www.napwa.org.au/glossary/term/490>
- [6] <http://www.napwa.org.au/glossary/term/408>
- [7] <http://www.napwa.org.au/glossary/term/495>
- [8] <http://www.napwa.org.au/glossary/term/121>
- [9] <http://www.napwa.org.au/glossary/term/125>
- [10] <http://www.napwa.org.au/glossary/term/102>

[11] <http://www.napwa.org.au/glossary/term/122>

[12] <http://www.napwa.org.au/glossary/term/385>