The people we won't treat

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There are several hundred positive people living legally in this country at the moment who have no funded access to health care items and drugs provided by Medicare. Instead, they are forced to either purchase their drugs overseas, plead with doctors to find alternative sources or decide that it's all just too hard and simply go without.

The people we're talking about are here on various visa authorities or are approved by Immigration but are waiting 'in transition' while their application for residency is being considered.

An infectious disease specialist I spoke with despairs of the difficulties she has encountered over the years trying to treat those deemed to be 'Medicare ineligible'.

'Many seeking residency will not go on treatments if they can avoid it because Immigration takes into account the likely cost to the taxpayer,' she said.

'But for some there is no choice. They present at hospital very ill, with cryptococcal meningitis or tuberculosis for example, and it may be some time before their HIV status is known. But in order to fix the other conditions we need to treat their HIV,' she continued.

Her hospital's policy to treat anyone who is ill is exceptional. In reality, government health departments direct doctors and pharmacies not to dispense drugs to any patients without a Medicare card.

'I have usually been able to persuade pharmacies to provide them with ongoing medication,' she said. 'Otherwise we see them return unwell again. 'They may be presented with a bill for all the hospital services but I can usually talk the hospital out of sending around the debt collectors.

'For other patients, I have sought the help of drug companies to provide HIV treatments on the Special Access Scheme. They have done this occasionally, particularly in the case of pregnant women to ensure the virus [1]A small infective organism which is incapable of reproducing outside a host cell. is not passed on to the child.

'But I don't have faith in recycling schemes (using other people's unused drugs) as such systems are unreliable and often fall through. HIV drugs must be provided on an ongoing basis to ensure patients continue to take them.'

The people we're talking about

There are a variety of visas which allow you into this country but will not cover your health care.

People brought here under sponsored worker programs are one example. Often health care is covered by the employer but if the job collapses then so does their cover.

Then there are those who are waiting for acceptance under family reunion schemes or as partners of Australian citizens.

People with HIV from overseas who apply to become a part of an interdependent relationship with an Australian citizen (either heterosexual or same-sex) may be rejected for permanent residency initially, but have the right to apply for a health waiver while their case is reconsidered. But their partner must agree to cover all their health costs until a bridging visa is given.

Sometimes these people can wait years while the immigration processes and the various legal negotiations occur, which places a considerable financial burden on the relationship, particularly if the overseas partner is not allowed to work. (SEE CASE STUDY 1)

And finally there are the access problems for people from countries with Reciprocal Health Agreements (such as the UK) who come here on tourist or business visas. Often they are under the impression they will get access to

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s100 drugs to treat HIV but then find they are only entitled to a fixed term which may only amount to a month's supply.

Policy issues

'Government policy review needs to focus on the people living under these various residency arrangements who become unwell and require medical care,' says Jo Watson, NAPWA's Executive Director.

'Since effective treatment and care are available in this country, it is just improper to say we cannot offer that to people becausethey do not have a Medicare card. Governments at both the Commonwealth and state level have agreed this is an area of shared responsibility, but the real sticking point is how to access the prescribed drugs – usually those on the PBS [2][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.. For HIV, viral hepatitis, and a range of other conditions there is a number of people who are legally residing in Australia, but who are being denied the same care available for the rest of the population.

'Not everyone who enters Australia is required to test for HIV, so may not be aware of their status, and then there are those who have been cleared before, but may find thatthey test positive with our more accurate testing methods. There are also those who seroconvert while in Australia,' Jo Watson points out.

'We all acknowledge that it is a difficult issue with broader immigration policy implications, but doctors, patients and frontline workers should not be left to deal with these barriers to fair clinical [3]Pertaining to or founded on observation and treatment of participants, as distinguished from theoretical or basic science. management on their own.

'The national HIV response in Australia is based on best practice standards of care for positive people. This has to be available for anyone living in this country for whatever period of time.

'Everyone accepts the importance of treating people with HIV once they reach certain critical clinical markers. The alternative is they get sick and have to be hospitalised. Providing effective treatments to positive people will reduce the risk of illness and help to contain the incidence of HIV in the community.

'But this is not just about HIV,' she stresses. 'Anyone who becomes sick should be provided with medical care and affordable treatments.'

The reality is that our residency policies and procedures are not in synergy with the public health practices we expect to be followed and maintained across the country. NAPWA, along with many other groups and public health authorities, has committed years to describing and monitoring this issue, but it is now time to take this outside of the communicable disease context; it is about Australian policy being confirmed that says we understand duties of care while we welcome people into the country, and we have ways of offering that care – if it is required.

Clinical trials and generic imports

Dr Virginia Furner has been at the frontline helping people who are ineligible for Medicare for the past ten years. In her clinic at the Albion Street Centre in Sydney, she has treated 'probably a hundred or so' people who don't qualify for HIV s100 drugs.

'Sometimes we're able to put them on clinical trials, where the drugs are free and sometimes, but only rarely, a pharmaceutical company might agree to provide the drug to someone on a compassionate basis.

'Things have improved somewhat since overseas manufacturers have been able to offer effective generic drugs for purchase online,' claims Dr Furner.

Virginia hasn't encountered any quality problems with generic versions as she has never had any of her patients 'break through' while taking them.

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But the infectious disease physician I spoke with earlier feels that online ordering has its limitations. The full range of protease inhibitors are not available nor are the drugs which best treat coconditions like TB. She also felt that the process of ordering online and waiting for deliveries was stressful, particularly for sick patients. (SEE CASE STUDY 2)

Consultants report

The issue has been considered by state and federal health officials for some time. In 2005, health bureaucrats from around the country, through the Blood Borne Virus and STIs [4][Sexually Transmissible (or Transmitted) Infection] Infections spread by the transfer of organisms from person to person during sexual contact. Also called venereal disease (VD) (an older public health term) or sexually transmitted diseases (STDs). Subcommittee (BBVSS) agreed to a scoping study to look at how big this problem was and to find possible solutions.

Consultants interviewed HIV s100 prescribing doctors around the country and it is clear that many doctors have been providing free services to people who are Medicare ineligible. More recent survey collation done by NAPWA has confirmed that this is continuing, and in some parts of the country, demand is increasing.

Doctors sympathise greatly with patients who can't afford to purchase all of their medications. But other than clinical trials – an option which is diminishing with fewer trials being put up and also one that has obvious ethical implications – they can offer little else.

The consultants report found that the number of people affected was significant enough for the issue to be addressed but not significant in terms of cost to the overall public health budget.

While the report was presented to BBVSS over a year ago, no final recommendations have been endorsed. It is understood the committee is still investigating options for access to treatments, and the Department of Health and Ageing is also working with the Department of Immigration and Citizenship to progress the discussions.

Meanwhile, at the coalface, HIV sector workers are not expecting a quick solution to this intractable problem. They are not seeing any let-up in the numbers of positive people needing treatment or the financial assistance to access it.

'When your prime worries are immigration and employment, HIV is not always your most immediate concern,' says Kate Reakes, the Service Coordinator at PozHet – a NSW health education and support service for people living heterosexually with HIV.

'But when HIV does become an issue and you cannot access Medicare related services and treatments, the undue stress placed on your health, relationships and basic quality of life can be intense.'

Jo Watson finally observes: 'Fundamentally, legal residency categories need to have some specifics assured, such as access to health care if it becomes necessary. The processes of how that is managed and seen to be accountable should be clearer for everyone.

'But in the meantime, we should not say no to providing that care and treatment.'

At the time of going to press, NAPWA was preparing a submission to the Commonwealth Migration and Disability Inquiry to highlight the effects of the current regulations for people with a disability or illness applying for residency.

Case Study 1

Jon on a bridging visa

In 2002, Robert and Jon applied to the Department of Immigration for Jon to be accepted for residency on interdependency grounds. While the couple waited to hear from the department, Jon's T-cells dropped to 120 and he developed symptoms of immune problems related to HIV, such as hairy leukoplakia and seborrhoeic dermatitis.

Without access to Medicare, Jon started on a treatment regimen from supplies of antiretrovirals [5]A medication or other substance which is active against retroviruses such as HIV. they garnered from a network of positive people

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who had surplus supplies.This turned out to be an unreliable way to get the drugs and the couple sought to purchase generic drugs via personal importation.

‘The Indian company only agreed to supply the treatments once the money arrived in their account,’ said Robert, ‘which started us worrying.

’Then, Jon, concerned about the quality of the drugs, started supplementing the Indian supply with recycled drugs he sourced here in Australia. Then the company stopped supplying Australia.

‘We were lucky that around that time Jon was granted a bridging visa and allowed access to a temporary Medicare (or blue) card. This entitles him to HIV drugs although he has to re-apply for the card every six months – providing documentary evidence each time that the case is still being heard by the Department of Immigration.

‘It is seven and a half years now we have been waiting to see if Jon will be granted residency. We have asked our local MP to intervene, which he has, but we are still waiting for this uncertainty to end.’

Case Study 2

Jessamin ordering HIV drugs online
Jessamin is an HIV positive woman from an African country who has been sponsored to work in Australia on a Temporary Protection Visa 457 for four years.

Under this visa, Jessamin’s employer was allowed to bring her into the country if they could assure the government that her health care costs would be met. For Jessamin this meant taking out private health insurance cover and buying her antiretrovirals online from a company in India.

‘I have some sympathy for the Australian Government. I realise they can’t cover all the health costs of people who come here who aren’t citizens,’ she said.

‘But the burden of my health care costs is considerable, particularly when I need other medical care.’

Recently, Jessamin had to be hospitalised and didn’t realise the doctor charged above the scheduled fee. After her health insurance cover was paid she was left $800 out of pocket. This was on top of the $400 she had spent online for her month’s antiretrovirals.

Jessamin is reasonably happy with the online company she uses (www.aids-drugs-online.com [6]) who she says are reliable – usually sending her drugs within a week of her order, providing it is accompanied by a script from her Australian doctor.

Australian customs will not allow the drugs in without a script from a doctor here. ‘I’m currently on generic versions of tenofovir, emtricitibane and efavirenz and so far there doesn’t seem to be any problem with quality.

‘But I find it difficult to meet my treatment costs,’ she admitted.

‘If there was some kind of safety net so that the government might help once I get to a certain level of expenditure, that would be very helpful,’ she added.

Case Study 3

Skilled migrants David and Sarah
David and Sarah are an HIV positive couple who have full-time jobs. David works in construction and Sarah in the health industry – two areas where the government is keen to accept migrants. However, because of their HIV status, Immigration has delayed processing their applications for permanent residency.

David arrived here as a student in 1997 and only found out he was HIV positive in 2001. He delayed treatment because the drugs then were very expensive but he worried about what would happen if he were to become ill.

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David applied for permanent residency in 2005 and he and his wife are still waiting. The couple were both given temporary blue Medicare cards which has allowed them access to HIV s100 drugs but David is concerned that when the card expires in September, that will be the end of their supply.

‘There has been so much uncertainty about our status as migrants here for so long,’ he said.

‘I understand that Australia doesn’t want to take on people who might be a burden in terms of health costs but we both contribute significantly to the economy and can easily pay expenses like the Medicare levy.

‘I think the government needs to show an element of compassion.

‘When you have a life-threatening condition like HIV there should be no question about being able to access treatment for it.

‘Life shouldn’t be treated solely in economic terms like this.’

- Culturally and linguistically diverse communities
- Medicare ineligibles

Links:
[1] http://www.napwa.org.au/glossary/term/125
[2] http://www.napwa.org.au/glossary/term/121
[3] http://www.napwa.org.au/glossary/term/475
[4] http://www.napwa.org.au/glossary/term/188
[5] http://www.napwa.org.au/glossary/term/122
[6] http://www.aids-drugs-online.com

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