COMMUNITY REPORT

Findings from an HIV social research project

The experiences of Aboriginal people in Western Australia who are HIV positive.
Just gettin’ on with my life without thinkin’ about it.

The experiences of Aboriginal people in Western Australia who are HIV positive.

Written by Maria Bonar, Heath Greville and Sandra Thompson.

This publication was originally produced with support from the Department of Health and Ageing, Office for Aboriginal and Torres Strait Islander Health by the Sexual Health and Blood-borne Virus Program, Communicable Disease Control Directorate Public Health and Clinical Services Division of WA Health.
Telephone: (08) 9388 4841
Email: shbbvp.gvh@health.wa.gov.au

This publication and the full report are available: ww2.health.wa.gov.au/SHBBVAboriginal

© Department of Health,
First published 2004.
This revised edition published 2015
Aboriginal people living with HIV just want to get on with their lives and most don’t want anybody to know about their infection, except their close friends and families. So we really appreciate their courage in talking about their experiences.

Thanks!

Thank you to John, Olivia, Shona, Bonnie, Jay, Darren, Charlie, Krysta, Yvonne, Nick, Tanya, Ross, Jayme, Carmen, Kimberley, Karina, Pauline, Denise, Carole and Frances for opening up your hearts and sharing your stories with us. You can be proud because your stories will help Aboriginal people who are HIV positive to know that they are not the only ones. We hope that this research will help improve your lives and the lives of other Aboriginal people who are HIV positive.
The facts

Each year in Australia, Aboriginal and Torres Strait Islander men and women are diagnosed with HIV.

2004

2005

2006

2007

2008

2009
A lot of things have been written about HIV. Research has been done on the virus, how it affects the body, how people can catch it, and how people can protect themselves from getting it.

Some people don’t know very much about HIV or how it is passed on. Some people living with HIV don’t even know that they have it, as sometimes it takes a number of years before a person infected with HIV has any symptoms.

A lot of people don’t think they are at risk of HIV, because they think that only gay men get HIV, or that HIV is not really a problem in Australia. In fact anybody who has unprotected sex, or shares injecting equipment with other people is at risk of getting HIV.

Young sexually active people and women are as much at risk as gay men of having HIV passed on to them.

Many people don’t know the difference between HIV and AIDS, and they think they are the same thing.

HIV is a virus that affects the body’s immune system. The immune system is what helps your body to fight off germs and diseases. People who have HIV can stay well for years and not have any symptoms.

Without taking treatment, HIV slowly damages the immune system. After a long time, the body’s immune system can’t fight off germs any more and people with HIV can get very sick. This is when they can develop AIDS, and get things like severe pneumonia, weight loss, or particular types of cancer.

There is no cure for HIV, but there are medicines now that help people stay well and live longer. Pregnant women who are HIV positive can take medicines to protect their baby from HIV.
Why did we do the research?

Many people in the world and in Australia have told their stories about living with HIV. But until now, there has been almost no research about HIV in Aboriginal people. HIV has been largely invisible to Aboriginal people in Western Australia. There is too much ignorance and shame about HIV and people don’t like talking about it.

It is hard for people to respond to issues that have never been described. In WA, more Aboriginal people are getting HIV and we want to stop this happening.

One of the ways to do this is to ask Aboriginal people who are living with HIV to tell their stories. How they feel, how HIV affects them and their families, how it was passed on to them, and how it changed their lives.

Most Aboriginal people who are HIV positive want to keep their condition a secret and worry that other people will find out about them. They may only want to tell family and friends that they can trust. Some people have never told anybody about their HIV infection and because they have not told anyone they can sometimes feel very much alone.
This is the first time Aboriginal people in Western Australia have had the chance to tell their own stories about living with HIV. We want to share their stories with you, without identifying who the people are.

The research was done in 2003 to record the stories of Aboriginal people who are HIV positive so that other people can understand what it is like for them. It is important to know that there have been a number of changes to the treatment and management of HIV since that time, some of which are listed at the end of this report.
Who told their stories?

When the research started, there were 44 Aboriginal people who had been diagnosed with HIV who were living in Western Australia, 17 males and 27 females. Sixteen other Aboriginal people diagnosed with HIV in WA had either died or moved interstate.

During 2003, twenty Aboriginal people volunteered to tell their stories about living with HIV. Thirteen of them lived in the country, six lived in the city and one was in jail.

There were 16 women and four men. HIV was passed on to all of them through sex. Two of the men got HIV through having male to male sex. All the other 18 participants got HIV through sex between a male and a female.

The youngest person to tell their story was 22 years old and the oldest was 54. Some people were only 16 or 17 when they found out they had HIV.

Some of the people interviewed had been living with the virus for eight or nine years. Others had only had the virus for a year or two.

A lot of the women who told their stories were young mothers. They talked about getting on with their lives, having babies and looking after their families.
What stories did they tell?

How did they catch HIV?

They all said it was passed on to them through sex.

Krysta: Oh I had sex with this fellow and I didn’t even know that he had HIV. He didn’t tell me.

Carmen: Um, well I went with one bloke, he didn’t tell me about himself. At the time I was a little bit drunk and I started gettin’ sick and things, but I didn’t catch on that I had it.

Denise: It was sex. Not using condoms.

How did they feel when they were first told they had HIV?

Most people said they were shocked, hurt or sad when they were first told.

Bonnie: Oh well, I got a shock at first. Really it took me by surprise. Yeah, it sorta hurt my feelin’s a bit, well the things that was goin’ in my head was very horrible, you know? Didn’t think very straight. Yeah, I was so down and couldn’t think any more, so it was a bit of a problem there. And it hurt my feelin’s in other words.
Tanya: I was thinkin’, “Why did I have to get it? Why couldn’t that person use protection if he had HIV instead of goin’ around spreadin’ it to every womans?” I was really hurt. Just felt like goin' off my head...goin' mad.

John: Yeah, it shocked me, yeah. I got drunk just thinkin’ about it. Drink the shadows away, yeah.

One woman was only seventeen when she was diagnosed. She said she didn’t have much of a reaction when she was told because she didn’t know anything about HIV.

Yvonne: I wasn’t upset, because I didn’t know much about it...I didn’t know nothin’. So, I wasn’t worried.

When they first knew they had HIV, some people thought they would die very quickly.

Jayme: I considered myself as a time bomb, you know.

Ross: Oh. “I’m gonna die.” I said, “Oh, no. How could it happen?”

Nick: I didn’t even realise the distinction between HIV and AIDS - to me it was the same thing. And you had a year’s life expectancy virtually and that was about it.
How do they feel now?

Some people said they have got used to it and that they just get on with their lives.

Charlie:  I was shocked at first, when I was told. Now I'm used to it.

Karina:  It's not such a big thing now. I just get on with it.

John:  Oh, you hear about it, you grow up around it and you find out you got it, so you talk about it when it hurts. And you live with it. Then you put it out of the way I suppose. You just keep goin', eh?

Some people still wonder why it happened to them.

Ross:  Oh I still feel “Why?” Ask the question, “Why me?”

Carmen:  In a way I do feel different. Like “Why me?” and like “How come they haven’t got it and I have got it?”

One man felt that he had wasted a lot of time sitting around thinking about HIV, because he didn’t expect to still be alive 10 years later.

Darren:  Life in general, yeah, I wasted so much, I just sat dwelling on it.
One person said her life is miserable sometimes because she gets too tired to do things she did before, like basketball and drinking with friends.

_Tanya:_ It would be different. I’d be a happy go lucky person like I was before, going out, mixing with friends, girls and that...which I do, mix up with girls I mean...I don’t drink no more, don’t smoke marijuana. I would enjoy life more...

_Some people make the most of every day._

_Jayme:_ I wake up every mornin’ ever since I found out I was positive, wake up every mornin’ thinkin’ okay, I’ve got this day, I’m lookin’ forward to it, see what it brings for me. I didn’t plan to have any children, but I’ve got one little boy now...

_Nick:_ More focused and more of a purpose for things I want to do now, yes...like not just wasting my time now, knowing that, you know, it could be limited, so make the most of every day in whatever you do.
Who did they tell?

Many of the people interviewed did not want too many people knowing about their HIV infection. They preferred to keep it a secret and only told people they trusted.

Ten people said they had told their families and friends about their condition.

Nick:    Well most of my closest friends and family know that I am positive now. So there is no feeling of having to hide things, so that makes it a lot easier. Yeah. Just being able to tell somebody, I think just get it off your chest was the way to do it, yeah.

Tanya:   'Specially my brothers. They gettin' that close to me now.

Carmen:  And I have got a lot more things out of them like, 'specially love from them.

Charlie: A couple of friends said “You right”, they still drink outta the same cup. They been really supportive.

Shona:   They go quiet then say, “Well we are not going to chuck you away and make you feel out of place, you just are always goin’ to be the plain old Shona that we knew for that many years.”

Six people only told two or three people like family or close friends

Pauline: I worry about people findin’ out. I only tell people I trust.
Three people had not told anybody at all.

**Frances:** I don’t talk about it, nothin’.

**Karina:** No. It’s too hard to tell people.

One man said he told his family, because people in jail knew about him and his family would get to know anyway.

**Darren:** …everyone already knew. And being like I said, being an Aboriginal and in jail. They just already knew...and being Aboriginal, even if you're not related to them, you know someone who is.

Five people said that a former partner, family member or friend had told other people without getting their permission.

**Jayme:** My cousin actually told some of her friends. And they've asked me and her friends have asked me about it and I’ve denied it. And I told my cousin, if I want people to know I’ll tell ‘em myself, I don’t need you tellin’ them for me.

**Ross:** My mate’s missus, she’s told a few people. Such and such told others and it goes on like that. There’s no stoppin’ it. It’s like the virus, you can't stop it once the story gets goin’. It’s unbelievable.

Some people said it was hard to keep a secret in the Aboriginal community.

**Jay:** …oh, a lot of people know from the Aboriginal grapevine. It’s like a one-man newspaper.
Did anybody have bad experiences or get treated differently?

Many of the people interviewed said that they sometimes get treated differently because other people are scared of catching HIV. Sometimes during arguments other people sling off at them.

**Jay:** I was being called a, “You are a A-C-C.” That means a AIDS carrying c-u-n-t, from females and males, your own family, like your cousin, your uncle. You can’t even touch your own niece, little baby or anything. Can’t even nurse, “Oh no, you’ll get AIDS.” They think that you can’t share from my drink or anythin’, because you’ll get that.

**Ross:** ...well there’s one woman in particular, she was screamin’ out from one side of the road to the other. “Go away you HIV bastard,” and all this, you know. “You’ve got AIDS.” And she’d have this biggest mob of people around her. Oh, it does, it makes you feel that small. I walk away from that. But every time you bump into them it’s on again, you know, you got to be careful which corner you walk.

**Carmen:** A couple of ladies slung off at me, and that sort of made me like I wasn’t the same as them, like it did hurt me. And all I could say was, “Oh, how do youse know?”

**Tanya:** One girl was callin’ me a A.C.C. They was fightin’, her and another girl. My name got mentioned an’ she called me a A.C.C. I said, “Why you fellas put my name into your argument for?”
What did they know about HIV before it was passed on to them?

Seven people said that they knew nothing about HIV before they got it.

**Interviewer:** You hadn’t seen anything on television about it or nothing in the community?

**Carmen:** No. Because all that time I have been out bush.

**Interviewer:** So you were living in a remote community?

**Carmen:** Yeah. That is where I was grown up, out there, out bush.

Seven people said they only knew a little bit about HIV before they got it.

**Tanya:** I only knew a bit of it, like “Safe Sex”, that’s the only bit I knew.

Six people thought they knew quite a lot about HIV before they got it.

**John:** Oh yes, it was all around the place. Yeah, through the AMS medical centre. Through the media, clinics, it’s everywhere. I remember a couple of years ago, the old fellas had a meetin’ and they was findin’ out from the nurse, so they was talkin’ to people about it so you’d go there, get tested, so they taught the town I suppose.

Although many of them knew about HIV, they didn’t think they would get it. They thought HIV was something that happened to other people, not to them and not to the people they mixed with.
What helped them cope with HIV?

The kinds of things that helped people cope with living with HIV were ignoring it; just keeping on doing normal things and getting on with life; getting love and support from families and friends; talking to other people who are HIV positive; counselling; getting support from Aboriginal health workers, doctors, nurses and social workers; and praying or believing in God. Some people drank a lot of alcohol or smoked gunja to help them cope when they were first told they had HIV, but most of them either stopped or slowed right down after a while so they could stay healthy.

Nick: When I first heard. Probably ignoring the fact helped me cope a lot better.

Tanya: Like I say, I don’t worry for it. Auntie told me, “The more you worry, the more it affects you. Don’t think about it all the time.” So, I don’t think about it.

Jayme: I just tried not to think about it a lot and just kept doing the normal thing, like going to college, going back to school, work experience. I just didn’t really let it pull me down because it’s somethin’ I can’t change and somethin’ that’s not gonna get better. So you either have to live with it or just let it pull you down altogether.

Families and friends were a big help in helping them cope.

Charlie: Well, having my two daughters mainly... helped me to keep strong... in myself.
Darren: I think just the people, the friends around me.

Olivia: I think what helped me was my sister. Also...being a Christian, that helps me.

Some people said they were drinking a lot at first, but they found out it didn’t really help them cope.

Carmen: Well at first I thought that drinkin’ would help me, but it wouldn’t. I had one of my relatives, she was very close to me and she caught on and tried to help me, like talk to me and said, “Oh, you are not the only one,” and all this and that. But I did drink a bit too much, but then as she kept on talkin’ to me I sorta slowed down a bit.

How did HIV affect their health?

None of the people interviewed had any serious health problems from their HIV infection. But then, people who feel very ill are not likely to want to be interviewed or to talk about their experiences with living with HIV so this research mostly got stories from people who are feeling well. Two people who had been thinking about telling their stories had to go to hospital and were too sick to be interviewed.

The most common health problems were tiredness and feeling depressed or stressed. The biggest effect seemed to be on their emotional and mental health. Most of them looked healthy.
Olivia’s healthy appearance had caused some comments.

**Olivia:** …they sorta expect that you’re goin’ to walk around real skinny and look sickly…I’ve known that someone has said to one of my closer relatives that you know, “She’s lookin’ pretty healthy.”

**What did they do to stay healthy?**

The main things they did to stay healthy were cutting down on alcohol and gunja, and eating well. Other things which helped people stay healthy were exercise, keeping up with normal activities, trying not to get stressed, getting involved in sport and getting medical treatment quickly when they got sick.

**Bonnie:** I was a alcoholic then. But after that, when I found out I slowed down on it…I didn’t wanna lose my life so early… Sometimes when I get the urge to drink, I’ll drink a little bit. Not all the time. Not like I used to. I used to be a alcoholic, used to drink every day, never stop. Wines are no good for your body.

**Interviewer:** Has HIV changed anything about drinking?

**Charlie:** Yeah, I gave it up for six years.

**Interviewer:** Why did you give it up?

**Charlie:** I decided to just stop and take the medications. Stayed off it for six years.
Eleven of the people interviewed were taking HIV medications. Five people had some problems with side-effects from their medications, things like anxiety attacks, memory loss, dizziness, headaches, problems sleeping and weight gain. Other problems with taking medications were forgetting doses, having to hide their pills and stopping taking their pills when they were drinking.

What did they think about the health care they got?

Most of the people interviewed were happy with the medical aspects of the HIV health care they got. The type of health services they liked best were small, confidential, and provided holistic care which met their emotional, welfare and social needs. They preferred staff that were respectful towards Aboriginal people and had an understanding of their culture.

Ross: Oh, it’s great, yeah. A good bunch of people down there. Yeah, very supportive…Ah, yeah. I can go there and have a talk with them anytime I feel down. Yeah, everythin’ really…like if I run out of medicine I just go and get some more medicine. It’s always gonna be there, not gonna say no to me or nothin’ like that…It’s good that I know that they’re there to help me.

Jay: They are a cheery mob. “Hello, good morning, what you doing?” They got that little happy…they’ve got the boost there. You know you may be down on your dumps and everything like and they see you come for an appointment and you sit back and you readin’ a book. You’re up there and next minute, “Hey, how you been keepin’?” you know. They give me that little booster.
There were some criticisms of one Perth HIV specialist clinic. Some of the people who attended this clinic felt that it was not a comfortable place for Aboriginal people. There was too much emphasis on clinical treatments and pills and not enough on emotional, social or personal needs. There wasn’t enough suitable HIV information available for Aboriginal people there.

Two people were critical of staff changes at a country health service. People liked to see familiar staff when they go to the clinic and not have new faces all the time. They don’t like more people knowing about their infection.

Only three people regularly went to Aboriginal Medical Services. There were two main reasons for this. One was that the people interviewed were happy with the HIV care they got elsewhere. The second reason was that some people had family working at the AMS and they didn’t want them to find out about their HIV.

Two people said that AMS staff had told other people in the community about their HIV infection.

**Bonnie:** It’s supposed to be confidential every file. But all the Aboriginal health workers there, they go right through your file and they tell anybody about your problems.

**Jay:** But the people, like they go along lookin’ through the files and they go along, talk to one and then the one will talk to the other and it’s like being a grapevine...I’m too shamed to go to AMS. Even if I walk past them, I go right around the block. And if I go past in the car there, we speed up...through, you know.
People wanted HIV health services where they were given respect and didn't feel shame.

All of the people interviewed had close family support. Almost half of them named their health providers as secondary sources of social support.

John: So I got a lot of help from AMS. I've got a lot of help from there because they’re Aboriginal. I’m still getting a lot of help from the doctors and nurses, the health workers and this health mob here now, helping me out.

What about having babies?

Sixteen Aboriginal women told their stories about living with HIV. Nine of them have had babies since they found out about their condition. Some women have had two or three babies. All those babies were born healthy because the mothers took medicines when they were pregnant and had regular antenatal health checks. They had specialist care when they were in hospital having babies. Their babies were given medicines to protect them for the first six weeks after they were born.
How did they think other HIV services could be improved?

The people interviewed suggested having hostel or other accommodation for Aboriginal people who are HIV positive. They thought this could be used as a meeting place. They would like to have camps, retreats and outings so that people can socialize together and feel less alone. They also suggested having a drop-in centre or outreach service and better access to HIV information.

One of the things they wanted was to have young people educated about HIV before they started having unprotected sex and before they started using drugs, because they were worried about them getting HIV or other sexually transmitted infections. They were also worried about girls getting pregnant when they are too young. They thought that it would be good to have some Aboriginal people who are HIV positive to talk to people at community meetings and in schools about HIV. This would help to educate Aboriginal people and help them be more understanding of people living with HIV.

Interviewer: What do you think the Aboriginal community should know about HIV?

Tanya: A lot. For the young ones...they should know about protection. A lot of young girls need to be told about it. Teenagers...there's one...14 years old and pregnant...

Interviewer: What would be the best way of telling kids about it?

Tanya: Get 'em all together in one big room. Get somebody to talk to them. How you catch it...how it spreads. Show a video of the virus. Show them what it's like, from day one, from when it gets in until you pass away, things like that.
What do they want to happen in the future?

**Darren:** They've just got to be cautious. It's not just a gay thing. I mean everybody loves sex and everyone does it you know, regardless.

**Bonnie:** I'd like to say I hope there's a cure for it. I hope one day it comes along. That will be the happiest thing in my life then and for everybody else.
Community involvement

Aboriginal people were involved in this research project, from the beginning to the end. There was Aboriginal representation on the Steering Committee and reference group. There was representation from Aboriginal people who were HIV positive, male and female, from the country and the city. The West Australian Aboriginal Ethics Committee approved the research and they were given regular reports during the research.

The research findings and the artwork were presented at an Aboriginal HIV positive women’s retreat to get their feedback and approval before anything was published. As far as possible, research participants were given a copy of the research reports and they were asked to tell the researcher if there was anything they wanted taken out of the reports.

Key stakeholders, including representatives from Aboriginal organisations, were given a presentation of the research findings before publication.
Conclusions and recommendations

Compared to other people in Australia who are HIV positive, the Aboriginal people in this study were much younger. There were more women than men and more of them lived in country towns and communities. For most of them, HIV was passed on through sex between men and women. Only two men said it was passed on to them through having sex with other men. Compared to other people in Australia who are HIV positive, young Aboriginal women are most at risk.

There was more unemployment among Aboriginal people who are HIV positive. They had less contact with organisations that provide HIV information and support than other positive people, because many of them felt that these were not comfortable places for Aboriginal people. Country people lived too far away to use city based services. Nineteen of the twenty people interviewed got most of their HIV information and support from workers at their health service rather than from HIV/AIDS organisations.

Most of them were satisfied with the HIV health care they received. HIV health care and medicines were free.

Aboriginal people who are HIV positive share many of the same experiences as other people who are HIV positive and living in Australia. But they have extra difficulties caused by financial hardship and lack of employment opportunities, social and geographic isolation, and living in small rural and remote communities with a disease about which they feel shame.
The people who told their stories want the Aboriginal community to learn more about HIV and how it is passed on, so that people can protect themselves. They would like the Aboriginal community to understand what it is like to live with HIV and how hurtful it can be to be called things like “a A.C.C.”

We hope that the information collected will be useful in improving services to Aboriginal people who are HIV positive, and in improving the quality of their lives.

Since this research was done in 2003, lots of changes have been made to make sure HIV specialist health services in Perth are culturally appropriate. These services are delivered by a team of health staff (including doctors, nurses, Aboriginal health workers and social workers) to help meet people’s needs. Services are also available for people in regional areas, and include visiting clinics for Aboriginal people living with HIV. Extra help is given to pregnant women to get the best health for the mother and her baby.

The Western Australian AIDS Council (WAAC) offers HIV education and training to groups, including Aboriginal community organisations. WAAC also runs the Sexual Health and Personal Empowerment (SHAPE) Program. SHAPE makes sure that people living with HIV get the physical and emotional care and support they need. More information about these programs can be found at www.waaid.com
More facts about HIV

HIV spreads through having sex without a condom, sharing needles or having blood-to-blood contact. You can’t tell if someone has HIV just by looking at them. People can look strong and healthy but have the HIV virus.

You can’t get HIV from:

- playing cards
- swimming pools
- kissing
- sharing cups or plates
- toilet seats
  - insects or pets
  - baths or towels
  - hugging
  - sharing smokes
  - just sleeping in the same bed.

HIV spreads more easily where there is a sexually transmissible infection (STI) present. STI inflammation and ulcers allow the virus to enter the bloodstream more easily.

It’s important to look after your own body so you don’t get HIV:

- Stick to one partner
- Use a condom and lubricant every time you have sex
- Use new equipment every time you inject and don’t share equipment
- Always use sterile equipment for body piercing or tattooing
- Use your own toothbrush and razorblades
- Don’t let other people’s blood get into your blood, e.g. sores, cuts etc
- Have regular women’s and men’s health checks.
Artwork by Deborah Bonar, Aboriginal graphic designer.

Title: A new day, living life to the fullest.

In the cover artwork, the pindan base represents the land. The figures are Aboriginal men and women telling their stories about living with HIV, waking up to a new day and looking forward to living life to the fullest.

The four waves represent links between Aboriginal people, their country, culture, families and communities, where they get love and support that helps them stay healthy.

The track and footprints symbolise Aboriginal people travelling round the familiar places of their mob and traditional healing places. The white dots around the tracks represent health services and medicines.