Episode 112: Counting us in: Assessing indigenous child health

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VOICEOVER
Welcome to Up Close, the research, opinion and analysis podcast from the University of Melbourne, Australia.

JENNIFER COOK
I'm Jennifer Cook, thanks for joining us. In today's episode we're talking about one of the most basic of all human rights - the right to be counted. Plato told us that a society can be judged on how well it looks after its most vulnerable member. Well today's guest is determined to make sure that one of the world's most marginalised groups, indigenous children, do not slip through the cracks. Associate Professor Jane Freemantle, from the Melbourne School of Population Health here at Melbourne University and the Onemda Vic Health Koori Health Unit says until we get accurate, up to date information on just how many indigenous children there, all the best intentions in the world won't help them. So how can we identify needs, develop publicity and implement programs if we don't know who we are doing it for and why? Professor Freemantle is on a quest to find a true north for accurate data collection on indigenous communities and the stakes for these communities, not only in Australia but also New Zealand, Canada and the United States is high with these children dying more often of preventable causes such as infection than the rest of the population. Professor Freemantle, thank you for joining us.

JANE FREEMANTLE
Thank you, Jenny.

JENNIFER COOK
Now, Jane, just how crucial is it that we get accurate data and what are the consequences for indigenous children if we don't?

JANE FREEMANTLE
Well, as UNICEF has said, which is the United Nations International Children's Emergency Fund, the true measure of a nation's standing is how well it attends to its children - their health and safety and their material security, their education and their
socialisation and their sense of being loved, valued and included in their families and societies into which they are born. These are very important antecedents to be able to achieve good outcomes for our children. Indigenous children do not benefit as well as non-indigenous children in so many of these measures. What we need to do it to be able to look at these measures, to be able to have a better and more accurate understanding about their level of them in the different communities and then to be able to address how we can actually improve some of these outcomes.

**JENNIFER COOK**
Can you give us some examples of where the health programs have been aimed at the general population and they've missed the mark completely with indigenous communities?

**JANE FREEMANTLE**
Well, let's take for example Western Australia, one of the largest states in Australia. Six per cent of Western Australian babies are indigenous. So if we consider that we look at all the data about births then we would miss a lot of what's happening amongst the indigenous population. A very good example of this is birth defects. If we actually look at particularly neural tube defects we see that these are happening at a great prevalence amongst the indigenous infant population. We know that in 1996 a very well resources education program was introduced that talked about the benefits of folate. Folate is a chemical that is responsible for closing the neural tube during pregnancy and this happens at six weeks. If the neural tube is not closed spina bifida and also anencephaly, absence of brain, occurs in children. Folate is available in green leaf vegetables and is also, obviously, available in bottled forms in chemists. But it is important to have this folate in the periconceptual period.

**JENNIFER COOK**
Jane, I've got a very vivid image of that ad campaign, you know that very healthy, beautiful, white, rosy-cheeked baby surrounded by all those leafy vegetables.

**JANE FREEMANTLE**
Absolutely and this was where the ad campaign had immediate respondse with a non indigenous population where there was a marked decreased in neural tube defects in the non indigenous population. However, when we looked at the data, very good population data in Western Australia that included every child that was born in Western Australia with very good identification of the indigenous identification, we found that there is no response from the indigenous population. So what that was telling us was that this ad campaign hadn't actually penetrated the indigenous population and particularly when we looked at our data and we separated it. We looked at children born in remote locations, locations where there was very little access to fresh food and green, leafy vegetables - all these wonderful food properties where folate is abundant - where there weren't chemist shops and the availability of little folic acid tablets. We realised that we needed to do something and we used this information to argue very strongly for putting folate into flour so that every woman had the opportunity to have the levels of folate in her system when she
was becoming pregnant.

JENNIFER COOK
The other thing too is, isn’t it, you were saying a lot the women in these remote communities weren’t discovering they were pregnant until, say, 12 weeks.

JANE FREEMANTLE
Absolutely and the horse has bolted when we consider that the neural tube closes over at six weeks. So this was a very fine example of how we need to be very careful about considering minority populations, indigenous population and making sure that all our health information and education programs are culturally appropriate for these minority populations.

JENNIFER COOK
So, Jane, just for our overseas listeners could you give us some kind of context of just the size of Western Australia?

JANE FREEMANTLE
Well, if we could actually put it in the context of the United States of America, Western Australia is one third the size of continental United States but it only has a 2 million population. So you can see it’s a very vast state. Its population tends to be centred around the southern part of the state but there are a number of pockets of communities where there might only be 400 or 500 people. So, again, the opportunity to actually provide services to these communities is sometimes very difficult. It’s the vastness of this state in relation to the rest of Australia and it’s so far away from the eastern coast.

JENNIFER COOK
This is Up Close coming to you from the University of Melbourne, Australia. I’m Jennifer Cook and our guest today is Jane Freemantle and we’re talking about the need to count every child in indigenous communities. Jane, you say in Western Australia, now we know it’s a big state, lots of remote communities, a very diverse population and geography. You were saying there that there was excellent data collection, you said that every indigenous child was documented. Now why isn’t this the template or the standard throughout the rest of the county and, indeed, why isn’t it just a given across the world?

JANE FREEMANTLE
Western Australia is a wonderful example of very good information gathering. It is very much the result of the visionary work of Professor Fiona Stanley and Professor Mike Hobbs who, back in the 1970s, realised the importance of bringing together population data so we could have a better understanding of what was actually happening in the population. And one of the major outcomes of this was the better identification of the indigenous people within these information data sets. The ability to actually bring all these data together means that you have complete data, no one is being left out, and it also gives us the opportunity to evaluate in the different data sets the levels of identification of indigenous people. So in data set A and data set B
we?re actually able to bring those two data sets together to actually see, for example, if John Smith is identified as an indigenous person in one data set and not in another. We bring in a third data set and he is identified in that in the third data set we would assume that indeed John Smith was indigenous.

JENNIFER COOK
Is that what you call data linkage?

JANE FREEMANTLE
It is. It?s actually bringing together information bringing different variables. So John Smith might have unique identifiers. So he is a male, he has got his surname, his date of birth and some other variables and then we match data set A with John Smith in it with data set B with John Smith in it and we work out whether these two John Smiths is the same. Smith is probably not a good example because that creates a few difficulties but if we use a name like Washinksy then we would probably have a very good idea that Washinksy in data set A was the same Washinksy in data set B. So the other important thing to note is this is done by automated data linkage. So it?s not done by people observing, it takes away the potential for people to be actually observing.

JENNIFER COOK
Now we have spoken about how transparent you are when you are doing this research, when you are collecting this data and you also spend a lot of time briefing your team, don?t you, as they go out into the communities to get this data? What kind of roadblocks and things do you face?

JANE FREEMANTLE
The work that we do, Jenny, is actually using population data that?s been collected through administrative or statutory data collections. We are not going out and collection individual data and that is the difference. That?s why this is important, so everybody is included in the work that we?re doing.
The other point that you made just previously is that it?s also important to let people who are collecting this information know why they are collecting it. They need to know that the information is really important for use in so many different dimensions. But they also need to have good information and education about how to collect the information. They need to do it respectfully and they need to do it in a context that is culturally appropriate. The people about whom the data are being collected also need to know about the data. They need to know why the data is being collected and importantly what is it going to be used for? How are we going to use this information that they are actually giving to a third party.

JENNIFER COOK
Because when you are dealing with indigenous communities, and this applies around the world, you?re usually dealing with communities that are rightfully suspicious of authority and governments taking their information.
JANE FREEMANTLE
Absolutely and I think this is probably the hangover of why we’ve probably had poor information over a number of years, is because people are very hesitant to give their information. A mother might be asked how many children does she have for a very good reason and she might not want to answer appropriately because she might be concerned that the children might be taken away. So we are very aware of this and so a lot of the work we do is going out to communities and tell them about why we are collecting this statutory, administrative data so they feel more comfortable about why they are giving up this sensitive information.

The other important issue is to let communities have access to the access to the information we’re collecting. So I will be collecting information, as I have in Western Australia, which describes every birth of every Western Australian child for the last 25 years, and we’ve also looked at the deaths. But this information is then aggregated into community groups. The communities can then have access to this very powerful data. How many teenage births are there? Where are these teenage births occurring? How many times does an indigenous child go to hospital with an infection and why is this so? So the communities then need to know that in giving their data to a statutory administrative data sets they can then get access to the data, themselves.

JENNIFER COOK
This is Up Close coming to you from the University of Melbourne, Australia, I am Jennifer Cook. Our guest today is Jane Freemantle and we’re talking about the need to count every child in indigenous communities.

Now how do we, Jane, define who is indigenous and how does this compare with other indigenous communities around the world, such as the Metis in Canada and the Maoris in New Zealand?

JANE FREEMANTLE
I think this where Australia again has been very fortunate. We have had a federal gazetted definition for a number of years. In Australia, Aboriginal and Torres Straight Islander people self-identify. So for an Aboriginal or Torres Straight Islander person to self identify there are three areas that have to be apparent. Firstly, the person must identify, must want to identify as an Aboriginal and / or Torres Straight Islander person. Secondly, the person must be identified as an Aboriginal and Torres Straight Islander person in the community within which he or she lives. Thirdly, the person must have genetic links to an Aboriginal or Torres Straight Islander ancestry. So those are the three areas in Australia and as I say we’re very lucky because that’s been a consistent definition for a number of years.

In America there is a lot of discussion and the definition is not so clear-cut. In Canada there are three major groups of indigenous people. There are the First Nations, there’s the Metis, that you mentioned before and there’s the Inuit. The Metis people who are of mixed European and First Nations parentage have a matrilineal inheritance. The Metis people have great concerns about their lack of recognition within official statistics and they believe they are often ignored. In fact, there is very little information about Metis infant mortality and this of great concern. Metis make up about 33 per cent of the indigenous peoples of Canada and there are
some amazing people working in Canada who are working to actually address this issue.

In New Zealand the Maori people, again, they have different definitions and unfortunately in New Zealand there have been changing definitions over the various census. So this makes it difficult to look at longitudinal data but there, again, a lot of work is being done by the statisticians and epidemiologists in New Zealand to try and correct this so you do have longitudinal and understanding of what has been happening in Maori births and deaths over the years. But one of the exciting parts of this work is that while we are looking at what? is happening in Australia and the Aboriginal and Torres Straight Islander population in Australia it? s really important to look in other indigenous communities particularly those colonised countries. What we are now going to do, and it? s very exciting, it? s actually working with the indigenous communities. The people I am working with in Canada, in Manitoba, in Alaska, in New Zealand are all indigenous people and we are going to determine for the first time more accurate understanding. We? re going to look and say what are we measuring? Who are we measuring? How accurate and complete is the information we? re measuring? So for the first time we won? t be saying we? re going to compare Australian with Canada. We? ll probably be comparing, say, Western Australia with Manitoba, one of the provinces of Canada and Alaska, one of the provinces of America.

It? s just in the beginning stages but it will actually give us far better information and far more accurate understanding of what is actually happening in each of these different colonised countries because do you know what? s interesting? What we do know is that none of these indigenous groups in these four countries have got any genetic relationship whatsoever and yet they are experiencing exactly the same levels of disadvantage and gaps between the indigenous and non-indigenous populations. So what is going on? Why is it happening? If we can actually look at these discrete communities and we might see where they are doing better or we can actually then galvanise what they? re doing, their policies and practices and see whether we can apply them in other areas. So it? s exciting work.

JENNIFER COOK
You talked earlier about the need to disaggregate the indigenous population so separate them off from the general population to get an accurate baseline. Just how important is this and how do you go about doing it?

JANE FREEMANTLE
It? s very important. As I mentioned before, if we take Western Australian data when we consider that six per cent only of the births are to indigenous mothers. Then you would assume that any statistics looked at that were aggregated would absolutely reflect what was happening in the other 94 per cent of the population. So it? s extremely important.

If we looked at the population again of Western Australia we would see that the major causes of infant mortality there, if we looked at all the people, were prematurity and birth defects. Now that? s great, we would then start to put our money into these areas to improve the outcomes for all infants. However, when we disaggregate, when we separate that information by indigenous status, we see a very different
picture. What we actually see there is the major causes of infant mortality are infection and SIDS. Both of these are potentially preventable. So immediately we have to say, right, we need to be putting our activities, our focus on preventing infection by going out into the communities and asking them what they know about the risk of SIDS.

JENNIFER COOK
And SIDS is sudden infant death syndrome.

JANE FREEMANTLE
It is sudden infant death syndrome or sudden unexpected death, which is a diagnosis of exclusion. It means when every other possibility has been looked at to see why this baby died they can find no reason. So that?s why it?s a diagnosis of exclusion and it?s sudden and unexpected. It?s a terrible thing to happen, so we were really keen to work out and see if we could do something about looking at SIDS because we saw when we disaggregated the data that an Aboriginal child was seven times, seven times more likely to die as a result of SIDS. So I worked with some wonderful Aboriginal colleagues and we went out to the communities and we asked them what do you know about SIDS? The answers came back - we don?t have SIDS, that?s a European disease. Or even more concerning - of course we don?t put our babies to sleep in cots because we know about cot death. Examples of why people are not going to take up messages when they don?t think it applies to them. So with this in hand, we went out to many communities in Western Australia. We work with SIDS and Kids, the peak organisation in this area, we work with our Aboriginal colleagues and we work with the government of Western Australia.

And what we have managed to do is to introduce and develop a number of wonderful education programs, education leaflets. The artwork is being done by an Aboriginal person so we don?t have these white Anglo-Saxon protestant looking babies. We have babies that truly reflect Aboriginal babies. The language is in the language that people identify with but what is important is the information is absolutely correct. Using this we?ve now gone to a number of Western Australian communities and we?ve actually put this information and education program into place and using the data we will be able to review the information in two or three years to see whether we?ve made a difference, has this worked? So if we hadn?t disaggregated that data we would never have known. We would have congratulated ourselves on how well we?ve done in reducing SIDS in the community where in reality we haven?t done as well in the Aboriginal population and we really now are doing something to address this issue.

JENNIFER COOK
So Jane how are you as a researcher? Are you positive about the way forward?

JANE FREEMANTLE
I am very excited about what we did in Western Australia and I am extremely excited about what we?re doing in Victoria, which is essentially replicating what we did in Western Australia. So we know it works, we know we can do it.
JENNIFER COOK
Let’s put Victoria in context as well, how does it compare to Western Australia?

JANE FREEMANTLE
Victoria would fit into the bottom pocket of Western Australia, it’s a much smaller state geographically and it’s population is actually larger with a few rural areas but much more urbanised compared with Western Australia where we have significant rural and remote populations that need to be considered when we’re talking about delivery of health services.

JENNIFER COOK
So in some ways they are very different worlds?

JANE FREEMANTLE
Very different worlds, very different climates as well.

JENNIFER COOK
Jane Freemantle, it’s been a pleasure, thank you so much for your time today.

JANE FREEMANTLE
Thank you, Jenny.

JENNIFER COOK
That was Associate Professor Jane Freemantle from the Melbourne School of Population Health here at Melbourne University and the Onemda Vic Health Koori Health Unit.
Relevant links, a full transcript and more info on this episode can be found at our website at upclose.unimelb.edu.au
Up Close is brought to you by Marketing and Communications of the University of Melbourne, Australia. This episode was recorded on Friday, 3rd September 2010 and our producers were Kelvin Param and Eric van Bemmel. Audio engineering by Russell Evans. Up Close is created by Eric van Bemmel and Kelvin Param. I’m Jennifer Cook, until next time, goodbye.

VOICEOVER
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