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# Session II: Health and Communities

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Thanks so much to Susan and Stephen for the opportunity to speak. It's terrible to have to speak after Bernie. I'd like to start by acknowledging the traditional owners of the land that we're meeting on today, the Gadigal of the Eora Nation, and to pay my respects to Elders past and present and to the Aboriginal people who are here today.

I wanted to talk this morning about co-production, sometimes also referred to co-creation or co-design. I wanted to give one long-term example of my experience in being part of a co-design project. In co-design, it's often quite different from how researchers think about running a research project. They often talk about collaboration, but, in co-design, the stakeholders such as communities are integrally involved in all aspects of the research: generating the ideas, undertaking the research, and interpreting the findings. It's a much closer and a different way of working. I think it has the potential to draw on the expertise of communities about their lived experiences such as we've heard already today. And, really importantly, to mobilise partnerships for action.

I think that at the centre of co-production is a sharing of power: a recognition that everybody is bringing different but equal expertise to the table. That can often be challenging for us as researchers. It's not the usual way of doing business. It's not easy, it requires time, resources, commitment and not all research is amenable to a co-production approach.

I want to talk today about some work we've undertaken with urban Aboriginal communities. It's been going on for the last 20 years in New South Wales, a long-term historical look at some of the things that can be done using this approach. I think many people today have recognised the importance about long-term commitment in working with communities. I don't want to suggest that we are the only people who have done this.

The indigenous leadership of this work was really important. I'm slightly embarrassed to be the person who's up here talking about this today. I particularly wanted to talk about Sandra Bailey, who at the time we started this was the CEO of the Aboriginal Health and Medical Research Council of NSW. For those of you who are not in health, this is the peak body for Aboriginal community-controlled health organisations in New South Wales and plays a really important role. Those health services are really critical: they're often the hub in their community; they have a governance board elected by local community members; and they provide really holistic care. Particularly

1 This is an edited version of a transcript of the presentation.

2 Sally Redman AO is a New Zealand-born Australian public health researcher and was chief executive officer of the Sax Institute in Sydney, where she led the 45 and Up Study, a NSW-wide project with over 260,000 participants responding to questionnaires on healthy ageing.

in urban areas, they're really important components of the Aboriginal communities.

I also wanted to recognise Professor Sandy Bailey,[3] who'd be known to many of you as an indigenous research leader. She was the initial study director for this work. And the CEOs and the staff of the Aboriginal Community Controlled Health Services (ACCHS) were really fundamental and wonderful leaders. I learned so much during the course of this project, going back 20 years. At the beginning of this work, relationships between researchers and Aboriginal communities in New South Wales could only be described as poor. The feeling of many Aboriginal people that we spoke to at the outset is nicely summarised by what I think is a really powerful quote from Pat Anderson. She talks about the fact that research was done *to* Aboriginal people — we probably even used terms like subjects, for example. Although obviously that wasn't limited to Aboriginal people. We didn't talk about doing it *with* Aboriginal people and certainly not the research being done *by* Aboriginal people.

I think the most important part of this quote for me is that despite the fact that there was research happening, it wasn't resulting in any improvements in health or services. I think other people have reflected on that today as well. At the beginning, about 20 years ago, in discussions with Sandra Bailey, it was really evident that the Aboriginal Health and Medical Research Council wanted to do things in a different way. They wanted to see Aboriginal people playing a leadership role. They wanted real outcomes, and they wanted something that built capacity. Sandra was really way ahead of her time in describing an approach that we now refer to as co-design or co-production. Through her leadership, a collaboration was formed with a group of really committed researchers and four ACCHS. We asked them what they wanted to know, how could they see research being useful.

I'd imagine we'd start on something quite simple, but they wanted a long-term study of child health that would help identify opportunities to improve health and particularly to prevent health problems developing. We got started, and Sandy Bailey was really important in helping us attract funds for this work. But we spent a long time at the outset establishing a governance framework, remembering that this was quite early days. It was important to ensure that the ways that the researchers and the health services were going to work together was concretised, if you like. It was cemented that there was strong governance around it and that they were clear that they had the opportunity to lead decisions and all aspects of the study. I think, really importantly — then and now — is the agreement about how data will be managed.

Kalinda made some very important points about that. But I think importantly ACCHS wanted ownership of the data and to ensure that nobody could publish it without the ACCHS having signed off. This is quite timeless, is quite radical and possibly threatening for some of the researchers, but it's a really important principle. Moreover, the study staff were employed by the Abo-

3 Sandra Bailey is Chairperson of the Brien Holden Vision Institute Foundation. She is a Yorta Yorta woman and former CEO of the Aboriginal Health and Medical Research Council of NSW, a position she held for 25 years. Ms Bailey has worked as a Solicitor for the Victorian Aboriginal Legal Services, and served as Head of the Aboriginal Issues Unit of the Royal Commission into Aboriginal Deaths in Custody.

riginal Health Services. Again, that was really important. We set to work: we built a cohort of 1600 urban Aboriginal children. In New South Wales there's a very high rate of urbanisation of Aboriginal kids and most of the previous research at that time was focused on rural and remote Aboriginal communities. We followed the cohort over time and were able to provide some of the first data about housing, ear health, mental health, physical activity, many aspects of health and wellbeing and its causes among urban Aboriginal children.

The interesting part for me was that although the health services were interested in the data, they were much more concerned about how we could use them to bring about change. As researchers we often talk about that, but, for the Aboriginal Health Services, that's why they were in the research process to start with. We were just getting started really, once we saw the data emerge. Together we were able to use our networks to attract better services for participating Aboriginal Health Services across many areas, including mental health and housing. In particular, we had a lot of success in trying to improve services for ear health. A lot of these children also had the same kind of hearing losses that we see in rural and remote communities. Obviously, that leads to speech development and speech delays, which impedes progress in education and reduces employment opportunities later on.

Because the data from the study were powerful, we were able to attract funds for about 8,000 speech pathology sessions and we were able to encourage and support additional surgery — ENT surgery — to ensure that all Aboriginal children who were part of this larger in the urban area were offered ear surgery if they needed it and completely cleared the waiting list for those areas. But, perhaps even more importantly, the Aboriginal Health Services, which are so important in their communities, were able to use the data to improve their own programs. In one service, for example, they attracted funds for an audiologist because they could demonstrate that hearing loss was an issue for them. They also had the most fabulous state-of-the-art room for testing hearing. They also use it to lobby the local schools and preschools to help them understand why children weren't able to perform, and they were able to establish better programs for those children, acknowledging the hearing loss and speech delays.

Based on the data of this, AMS began delivering fresh food boxes, set up a community garden, and banned sausages at the community barbecues, which was really I think probably one of the harder things that emerged from the study. What about the co-production effort? I just want to end by talking a little bit about this, remembering that this was going back some time ago when we talked to the staff of the Aboriginal Health Services (AHS) about how it'd been to be part of this project. They talked about how important it was that we'd focused on outcomes, not on the research. They wanted to know how we could use data to change things, not just to study them. They talked about the fact that there'd been a genuine respect and valuing of different expertise. Almost everybody not indigenous associated with this project really learns so much from being part of it, and that we put in place and adhere to strong governance and shared decision-making processes. It was interesting that the staff at the AHS valued the fact that the team came back, that we chatted over coffee, that we came

to barbecues — even when the sausages were stopped — and participated in other community events. It struck me that these are the same kind of processes that I would use to build relationships with any people whom I valued and who are my colleagues. That was the fundamentally most important thing, I think.

Another important part of this is that two decades later we were still working together, and I thought, Bernie's comments about the long term were really important. You can't do this overnight because at the heart of it lies the concept of trust, which isn't something that you can earn quickly. Indeed, our collaboration has grown and now nine ACCHS are part of this work. We're working together on a much broader range of issues.

It's easy to talk about co-design and co-production. We really all recognise the importance of it. Doing it has to be a long-term endeavour. It's hard work but I think the benefits are absolutely huge. Thanks very much.