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Hermes A, Wiersma M, Kerridge I, Easteal S, Light E, Dive L, Lipworth W. 2021. Beyond platitudes: A qualitative study of Australian Aboriginal people's perspectives on biobanking. *Internal Medicine Journal*.

## **Beyond platitudes: A qualitative study of Australian Aboriginal people's perspectives on biobanking**

### **Abstract**

#### *Background:*

Biobanks are vital resources for genetics and genomics, and it is broadly recognised that for maximal benefit it is essential that they include samples and data from diverse ancestral groups. The inclusion of First Nations people, in particular, is important to prevent biobanking research from exacerbating existing health inequities, and to ensure that these communities share in the benefits arising from research.

#### *Aims:*

To explore the perspectives of Australian Aboriginal people whose tissue—or that of their family members—has been stored in the biobank of the National Centre for Indigenous Genomics (NCIG).

#### *Methods:*

Semi-structured interviews with 42 Aboriginal people from the Titjikala, Galiwinku, Tiwi Islands, Yarrabah, Fitzroy Crossing, Derby, One Arm Point, and Mulan communities, as well as a formal discussion with AH, an Indigenous Community Engagement Coordinator at the NCIG who had conducted the interviews. The interviews and the structured discussion were double coded using a procedure informed by Charmaz's outline of grounded theory analysis and Morse's outline of the cognitive basis of qualitative research.

#### *Results:*

In this article, we report on AH's interviews with members from the above Aboriginal communities, as well as on her personal views, experiences, views and her interpretations of the interviews she conducted with other community members. We found that participation in the NCIG biobank raised issues around broken trust, grief and loss, but also—somewhat unexpectedly—was perceived as a source of empowerment, hope and reconnection.

#### *Conclusions:*

This research reminds us (again) of the need to engage deeply with communities in order to respond appropriately with respect for their cultural values and norms, and to develop culturally relevant policies and processes that enhance the benefits of biobank participation and minimise potential harms.

## **Introduction**

Biobanks are collections of human material (including DNA, cells, blood, bodily fluids, tissues, and whole organs) that can be used for the purpose of medical research, diagnosis, screening and education.<sup>1</sup> It is increasingly recognised that biobanks need to incorporate samples from different ancestral groups, both for scientific and ethical reasons.<sup>2</sup> Larger populations are made up of diverse ancestral groups, and since disease and prevalence vary across different groups, it is important to study broadly representative data.<sup>3-5</sup> Furthermore, inclusiveness is consistent with contemporary ideas of cultural respect and safety.<sup>6-8</sup> Inclusion is also important to prevent biobanking research from exacerbating existing health inequities, and to ensure that these communities share in the benefits arising from research.<sup>2, 6, 8-9</sup> While such cross-ancestral expansion ensures the integrity of biobanks and magnifies their scientific power, it also generates a range of ethical and socio-political challenges.<sup>10-11</sup> These challenges are most acute when it comes to the inclusion of populations that have historically been marginalised and exploited, particularly First Nations people that have been subject to adverse effects of colonisation.<sup>12</sup>

On the surface, it would seem relatively easy to predict what these challenges might be: for example, issues associated with distribution of power, trust, and exploitation are likely to loom large, as are challenges relating to equity and benefit sharing. But such assumptions are likely to oversimplify matters if they do not draw on the perspectives and experiences of those who have lived experience of cross-cultural biobanking research.

As part of a broader study investigating the ethical issues associated with the networking activities and globalisation of Australian biobanks, we engaged with Aboriginal people whose tissue—or that of their family members—has been stored in the biobank of the National Centre for Indigenous Genomics (NCIG). Torres Strait Islander people were not interviewed in this study—hence the use of the terms Aboriginal people or peoples. NCIG contains more than 7000 blood samples from more than 35 Aboriginal communities across Australia. Most of the samples were collected between the 1960s and 1990s from communities that were under government or missionary control and, consequently, it is likely that consent was likely neither sought nor given for the storage and secondary use of samples at the time of their collection.

In order to explore the experiences of communities and individuals whose tissue had been stored in the NCIG collection, AH was engaged by NCIG to establish relationships and conduct semi-structured interviews with people from the Titjikala, Galiwinku, Tiwi Islands, Yarrabah, Fitzroy Crossing, Derby, One Arm Point, and Mulan communities over 3 years. AH's role in NCIG is to revisit the communities from which these samples were taken and ask individuals what they would like to have happen to the samples. This may include, for example, giving consent for the samples to remain in the biobank, returning them to country, or destroying them. AH is in a rare position to provide insight into Aboriginal people's perspectives on biobanking as she is a member of an Aboriginal community and has family members who have samples in the NCIG biobank. In this article, we report on 42 interviews with members of the Aboriginal communities named above, and on a structured discussion with AH.

### **Methods:**

In the first phase of this project, AH visited and established relationships with the following communities— Titjikala, Galiwinku, Tiwi Islands, Yarrabah, Fitzroy Crossing, Derby, One Arm Point, and Mullen between September 2015 and September 2018. This process of relationship building, which involved multiple visits to communities and ongoing community consultation, was critically important for building trust in communities with prior negative research experiences (for example, through researchers taking blood samples without consent, or conducting research and not reporting back to community on results). Once AH had built trusting relationships, it led to invitations to cultural ceremonies, family and community events.

The communities that AH engaged were among the more than 35 communities from which samples were collected by Professor Bob Kirk and others over several decades between the late 1950s and the 1990s.<sup>1</sup> These communities were selected because AH had family or professional connections with them, or because they had existing relationships with NCIG. The communities are remote and range in size from 200 people to 3000 people. Following a process of relationship building, AH invited community members to take part in semi-structured interviews. Forty-two participants were interviewed between September 2015 and September 2018. Some of these interviews occurred in pairs or small groups because some people felt more comfortable having these discussions in groups rather than one-on-one. As participants spoke a mixture of English and their cultural language, an interpreter was used at all times.

All participants provided written consent to be interviewed, and interviews lasted between 30 and 60 minutes. Interview questions focused on whether participants recalled having blood samples taken;

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<sup>1</sup> For an interactive map of the original collection sites, please visit <https://ncig.anu.edu.au/collection/collection-sites>.

their reaction to news of the storage of their own or a family member's blood sample in NCIG; what they would like to have happen to the sample; whether they would prefer Aboriginal people's samples to remain separate from other samples (e.g. from non-Indigenous people or Torres Strait Islander peoples); and their views towards sharing samples with international researchers. In this paper, we report on participants' perspectives towards the storage of their samples in NCIG.

In the second phase of this project, in November 2018, AH participated in a formal structured discussion with two team members (EL and MW). The purpose of this formal discussion was to draw on AH's cultural experience and embedded knowledge in relation to biobanking in indigenous settings, and to explain and further clarify community members' perspectives on participation in the NCIG biobank. Discussion questions focused on her role as Community Engagement Coordinator at NCIG; her experience working with Aboriginal communities; and the perspectives of individuals she had engaged with towards participation in the NCIG biobank collection. This process of formal discussion enabled us to introduce an element of reciprocity that was appropriate to the subject matter and faithful to the cultural environment being explored.

All interviews were digitally recorded and transcribed. Interviews (including the discussion with AH) were double coded by EL and MW, with themes, codes and categories discussed with AH and at regular team meetings. The coding procedure was informed by Charmaz's work on grounded theory and Morse's outline of the cognitive basis of qualitative research.<sup>13-14</sup> This process involved initial line-by-line coding and gerunding to encode process and action. Initial codes were then synthesised into categories and abstracted into concepts. Codes, categories and themes were refined as new codes, categories and themes emerged.

This research was approved by The University of Sydney and Australian National University Human Research Ethics Committees. In addition, AH spent a significant period of time working with community organisations, community elder groups, traditional owners, land councils, and research partners to ensure that a culturally appropriate consent process was used.

### **Results:**

Given Australia's history of colonisation, abuse and exploitation of Aboriginal and Torres Strait Islander peoples, it was expected that many of the ethical issues raised by biobanking (particularly those around consent, trust, power and exploitation) would be magnified within First Nations communities. While these interviews revealed that this was indeed the case—as one participant noted: “it has to be well protected...so other people [don't] steal or anything” **P1**—they also revealed that interview participants placed value on the NCIG collection and on biobanking more generally.

*Shared hope, empowerment and reconnection*

Interviews that we had previously conducted with the Australian general public had revealed a strong, belief that biobanks would contribute to medical progress, and a corresponding willingness to participate in biobanks.<sup>15</sup> AH reported that her interview participants appeared to be similarly hopeful that biobanking research could lead to medical breakthroughs and potential solutions to medical issues affecting their communities:

...[they are] hoping that there is going to be a better explanation about why so many people are sick and why some medications are working while other medication isn't working. And ...everybody hopes there's some sort of magical cure for diabetes and renal and MJD [Machado-Joseph Disease]. **AH**

This was reflected in several participants' comments:

It could help us to get more medicine, much more cure, more information about what's in our body, what we should eat. **P3**

You know I believe that if you don't study or do research, well how you gonna find a cure for cancer? **P4**

Many participants were particularly hopeful that the biobanking research being conducted by NCIG could benefit future generations, through the identification of genetic illnesses:

The reason why I did this was, my daughter, three years ago, died of, they call it sudden unexplained death and when they spoke to us about her death and why she died, they didn't have a ...cause. So we decided as a family to do that, because they may pick up in the blood samples not now but for the generation, for the next generation after that and they might pick up something in ours that could tell us why. **P1**

I think it very important that research is done and if it benefits my family, myself and my community, in terms of any diseases or something... I want to know if I'm, you know, I mightn't be conscious that I might be a carrier of a certain gene that can cause health problems that I can carry on to my children. **P4**

But while the perceived benefits for the general public began and ended with scientific advances, Aboriginal participants revealed a number of additional benefits for their communities. For many participants, being offered the opportunity to give consent for their samples was potentially empowering precisely because of historical disrespect and exploitation:

I feel very proud of being asked as an Aboriginal person, because we know from our grandparents, the stolen generation<sup>2</sup> history. That was very painful. You know so, that sort of thing made me feel good and you know to be treated as a human being. **P2**

That blood is from us...it is important, especially with Murri people. I think because of all the, because we been, some people having been oppressed from when they were old, older, you know like with the Stolen Wages and they did it without asking anyway. But it's just to bring back that respect back to the people. It's to honour the family...the family line. **P5**

In this context, the growing importance given to explicit consent, to community governance of biobanks, and to control over samples and data were seen to have significant restorative power:

You know back in the days, we were under the Act.<sup>3</sup> You know, we didn't get the choice of anything, but today, you can. And we've got rights, to say what happens here, what happens there. And good consent, consultation is important to our people. **P6**

I mean the government had control of everything really and we were subjected to government policies and rules, regulations. So really I don't know, even if we did object really, I don't think we had no options really, no choice. **P7**

[Re consent] I think it's really important. You can't just go and you know take something from someone, you know. Because, it's either stealing or yeah it's not right. You can't do anything these days without consent. **P8**

Support for the NCIG collection and for biobanking research in general also stemmed from the belief that it could facilitate an understanding of culture and history for future generations and had the potential to reconnect family members. In an increasingly technological age, where First Nations children and youth are turning away from traditional culture and language, the samples were viewed as a way in which future generations could learn about their family history:

Because of the kids now doing what they see in tv, television and all that. And they'll try to copy cat that...What is, them traditional culture for the people, and then, they mix it in...then one day they'll lose their identity, not their identity but their culture...They'll lose their

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<sup>2</sup> The "stolen generation" refers to children of Australian and Torres Strait Islander descent who were taken from their families by federal and state government agencies and churches under acts of their respective parliaments between 1910 and 1970. Such policies and actions were part of a broader policy of forced assimilation.

<sup>3</sup> The 1915 amendments to the Aborigines Protection Act 1909 gave the government power to forcibly remove Aboriginal children from their families.<sup>16</sup>

culture. And then they'll think "oh we're lost. What now?" And how, can maybe they can lose their language. Who knows? So that's I think, these kinds, is better to be able to restore or to be able to do like a book and keep them books <sup>4</sup> in the library? And try to get that our descendants. **P9**

AH reflected on the importance of this to many participants:

These elders know that in 40 years these kids are going to want to know who they are. So they think that having a sample there, these kids are going to be able to trace who their family is, to say "oh yes my grandmother was in this collection, she was part of this amazing thing that brought about this amazing change and I can see her tribe was this". **AH**

The samples themselves were also perceived as a type of legacy that individuals can pass on to future generations:

It's good that we can have that to be our, like, sort of a family tree...where our future kids coming up. And then, you know...they could follow up through that. And find out who is their grand, great grandfather. **P9**

...it's good that for future generations to... know where and how they fit in. **P10**

AH indicated that for participants who had few material assets, the samples appeared to be a particularly significant form of legacy:

...this is something they can leave for their kids, they don't have money, they don't have assets, there's nothing for them to be able to give their kids other than culture and language, but this is a legacy. This is their legacy. **AH**

Having a sample within the biobanking collection was also perceived as a way in which families could potentially be reconnected:

...a lot of our mob been removed from you know through government policies, past government policies and yeah so, not only myself but other families to [be able to], retrace their...family tree. **P7**

And some people are wondering, the families not knowing, from the Stolen Generation too, you know, not knowing where their country is. Some people know, but they might never met

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<sup>4</sup> NCIG has created a video that Aboriginal and Torres Strait Islander people can watch that explains the role of NCIG, the samples and DNA. It describes taking the stories from DNA and creating an online library of DNA books. See: <https://ncig.anu.edu.au/about>



their, mightn't remember their parents, you know? Just been taken away. I see for myself it may be a good thing. **P11**

*Broken trust, grief and loss*

For those individuals and communities who were hesitant about keeping their samples in the NCIG collection or wished to withdraw their samples (i.e. to dispose of them, or return samples to country), there were several reasons as to why this was the case. Some were reluctant to allow the samples to remain in the biobank collection as they had been collected without permission, as AH explained:

...it was purely the principle of the matter that their samples were taken, granted for good reasons, but given to someone without permission. And just on that pure principle they couldn't allow us to have their samples. **AH**

For others, discussing the samples brought up painful memories of family members who had since passed away. Their reluctance to allow the samples to remain in the biobank, therefore, was due in part to grief and loss:

...we've got your brother or your sister blood sample. You know that's precious to me, because that's the only thing we got left. That's part of them, you know, so I think that's really, I don't know, what's the word. Sacred, some sort of thing that's belonging to them, that's left. You want that to be treated with respect or anybody for that matter, hey. I think I'd feel, I think I'd get emotional. I think I'd be crying to know that someone's got 3ml blood sample of someone that's passed away and to me that's precious because that's all that's left of them, apart from memories... Something like that is very important. **P6**

Others spoke to the grief and loss stemming from colonisation and associated transgenerational trauma, and how this could act as a potential barrier to participation in NCIG:

A lot of people, I guess you know... through colonisation were taken away and I think you know a lot of people are affected from that transgenerational trauma stuff and so a lot of people are suffering today. Even though some of them never went through it themselves, but they stuck with that hurt and you know that loss and grief from their parents. **P8**

Because some of them they don't even know who they are, their identity. **P13**

That's true, yeah, where they come from, you know. **P8**

For some individuals, their hesitation to participate in the biobank was due to negative past experiences with researchers and an (understandable) lack of trust that their community would benefit from such research:

Because a lot of the researchers come here and do the research, and the people, Aboriginal people, they don't get a result... They just, do it, test it with us, and do then they go away and forget us. **P12**

For one community, cultural taboo around blood and concern for the spiritual afterlife was the primary reason for wanting to withdraw their samples from the biobank collection, as several participants explained, and AH further clarified:

As Aboriginal person... that blood sample, sacred sample...once its bringed back, then we might get rid of it. In proper way. Not just chuck it in the, anywhere in the ground. **P12**

Well firstly it's very sacred and it's got life in it and... to us it's very important because in blood there are lots and lots of different ceremonies that are involved. **P3**

...blood is such a taboo subject...what does this mean, does this means that their spirit hasn't moved on to the next world, does this mean that this is why we've got so much bad luck? **AH**

Importantly, however, while this community did collectively withdraw their blood samples from the biobank, they also wanted to make a final scientific contribution. Therefore, the community gave permission for NCIG to extract the DNA and sequence the genetic data from the 1200 samples, before the byproduct was returned to community for burial or disposal.<sup>517</sup>

NCIG made substantial efforts to build and maintain a genome resource for research that offers potential benefit to Aboriginal communities and consistently paid careful attention to cultural respect and safety. Perhaps due to these efforts, those who were willing to allow their samples to remain in NCIG expressed a strong preference towards keeping their samples and associated data in Australian biobanks, with research conducted by Australian researchers:

I'm an Australian person yeah...And my blood sample, my everything should be here in Australia. **P3**

## **Discussion**

This study explores the attitudes of Aboriginal people towards participation in an Australian biobank—the National Centre for Indigenous Genomics. While a minority of participants were hesitant about keeping their or their family member's sample in the NCIG collection, the majority of

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<sup>5</sup> See: <https://www.canberratimes.com.au/story/6484722/what-should-we-do-with-indigenous-dna-samples-in-university-labs/>

participants saw participation in the biobank as having numerous benefits, some of which were unique to Aboriginal communities.

Participants' accounts told of the ongoing impact of colonisation, intergenerational trauma, and of grief and loss caused by the fracturing of families and communities by the Australian government's forcible removal of First Nations children between 1910 and 1970. They also provided insight into the lived experience of unethical research practices and of researchers' frequent failure to return results to communities. This echoes findings by others that First Nations communities have often been "left in limbo" by researchers,<sup>4 p 6, 18</sup> with information gathered from communities for the benefit of researchers, with no consideration of what would benefit communities.<sup>4, 19</sup>

Despite the long history of abuse and exploitation of First Nations peoples, participants in this study were largely supportive of the activities of NCIG—as reflected by their decision to keep their or their family member's blood sample or DNA in the collection. They were hopeful that biobanking research could provide important insights into the health of their community members and identify potential treatments for diseases that disproportionately affect Aboriginal people. They were also hopeful that biobanking research could benefit future generations: that their children and grandchildren may experience improved health or avoid genetic illnesses; reconnect with family members; trace their family tree; and gain a sense of their culture, identity and belonging.

We suggest that the hope and optimism expressed by many participants towards the NCIG collection is, in part, due to efforts by NCIG to engage with communities in a way that is culturally appropriate, respectful and mindful of the safety of participants. NCIG was established in 2013 to manage historical samples and is governed by a majority First Nations board. Its primary aim is to enable First Nations people who have a sample in the collection to make a decision about whether their sample should remain in the collection, be returned to country, or destroyed. If an individual has died then, where possible, NCIG will contact their relatives.<sup>17</sup> If individuals decide to keep their sample in the biobank, then their DNA is extracted from the sample and the data added to the NCIG collection. In time, the NCIG collection will be made available to researchers, but participants will always be able to withdraw from the collection or opt out from particular projects if they so choose, (i.e. dynamic consent)<sup>17</sup> which enables participants to maintain control over how their sample is used.

Others have noted that successful research with First Nations communities requires time to establish a trusting relationship between researchers and the community;<sup>4</sup> respect for the First Nations people's culture, traditions and values;<sup>4, 18</sup> and recognition of the diversity of First Nations people's perspectives.<sup>20-21</sup> Respect can be developed through researchers paying careful attention to the cultural, social, and political structures of individual First Nations communities.<sup>4, 18</sup> As noted by

Arbour and Cook in regard to blood samples and genetic information, respect can be demonstrated by ensuring that participants are able to exercise self-determination when it comes to how their samples are used—as is the case in the NCIG collection.<sup>18</sup>

NCIG has invested significant time and resources into establishing relationships with the Titjikala, Galiwinku, Tiwi Islands, Yarrabah, Fitzroy Crossing, Derby, One Arm Point, and Mulan communities.<sup>17</sup> AH has spent 7 years thus far, visiting communities and establishing relationships with community leaders and members. Careful attention has been paid to communities' preferences for engagement with researchers and ongoing communication. Newsletters are planned to keep participants up to date and engaged with the project, and communities will be visited at least annually and provided with updates on specific projects and NCIG activities more generally. These efforts demonstrate NCIG's commitment to ongoing engagement with communities, so as to ensure that these First Nations people have an input into what happens to their sample, and that First Nations communities throughout Australia receive the benefits from biobanking research.

This study provides unique insights into the views of communities that are frequently excluded from such investigations. It does, however, have all the limitations associated with small qualitative studies—most notably that assumptions cannot be made about generalisability. This study is also somewhat unusual in that the first author is both the interviewer and herself the subject of a formal discussion. This is, however, consistent with the recognition in qualitative research that researchers inevitably bring their own perspectives to their subject matter.<sup>13</sup> It is also consistent with the ethical principles of research involving First Nations communities, which place community engagement and consultation at the centre of research ethics and view such arrangements as strengths rather than weaknesses.

## **Conclusion**

Engagement with Aboriginal communities in Australia reveals that the risks and benefits of scientific research are strongly shaped by their experiences of colonisation. As a result, restoration of control and cultural respect are key concerns for these communities and are absolutely necessary if biorepositories are to be developed, maintained and used into the future. More positively, biobanks can also be a source of shared hope, empowerment and reconnection. While this should not lead us simply to valorise biobanks, it reveals the complexity of Aboriginal people's perspectives. This research reminds us (again) of the need to engage deeply with communities in order to respond appropriately with respect for their cultural values and norms, and to develop culturally relevant policies and processes that enhance the benefits of biobank participation and minimise potential harms.

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