Original Research

Use of bodily tissues in research – Pacific perspectives from Dunedin, New Zealand

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ABSTRACT

Introduction: Donation of human tissue is essential for biomedical research to improve our understanding of the causes and treatment of diseases. To facilitate this, researchers need to understand what approaches and processes make donation and storage more acceptable for various communities. This study explores the perspectives of Pacific peoples living in Dunedin, New Zealand on the use of human tissues for biomedical research.

Methods: In April 2018, four focus groups were held with members of the Pacific community in Dunedin. Each of the four groups was demographically different, with groups consisting of: elders of mixed ethnicity, university students, medical doctors and one Tongan group of mixed ages. An open-ended questioning style was used, with specific prompts about participant’s perceptions of the purpose and processes for donating tissues for research and what might make them more or less likely to donate.

Findings: A total of 18 (11 female, 7 male) individuals participated, with a variety of ethnicities (Samoan, Tongan, Cook Island, Niuean, Micronesian, Tokelauan, Papua New Guinean) and age groups (18-25 years, n = 5; 26-35 years, n = 4; 36-55 years, n = 2; 56+ years, n = 7) represented. There were a diverse range of views expressed, reflecting the diversity of participants across different ethnicities and ages. While participant responses varied widely in terms of enthusiasm or caution towards different types of donation, similar themes emerged regarding the importance of detailed informed consent, and respect and trust towards both the donors and/or their tissues. The importance of culture and religion on the attitudes or perspectives towards donation was also highlighted. Finally, it was perceived that donation is likely to be more acceptable if researchers are able to explain why their work is meaningful in a Pacific context and adapt to Pacific situations and/or concerns within the research protocols.

Conclusions: For Pacific peoples to derive the most benefit from research initiatives it is important that processes to collect human tissue are respectful of cultural protocols and expectations to support participation. This study provides useful information to support the evolution of guidelines for the use of tissue for research within the NZ context.

Key Words: Pacific, research ethics, tissue banking, tissue donation

INTRODUCTION

The collection and storage of human tissue samples, such as organ tissue, blood, hair, urine, sputum, or foetal tissue is foundational to biomedical research. The acceptability of this practice differs across communities, with indigenous and minority migrant communities being less likely to participate.1 International studies suggest that the factors that influence participation range from practical concerns, such as fear of needles or lack of appropriate communication about research processes or...
benefits, to more fundamental issues such as an absence of trust between communities and health researchers and differing perspectives about the cultural significance and appropriate handling of human tissue. Given the significant implications (both positive and negative) of this type of research for communities, dialogue about appropriate guidelines to provide protection and share benefits from research with communities is critical.5

In Aotearoa New Zealand (NZ), the use of blood samples for research (including collection, storage, use and return or disposal of donated tissue) is regulated under the Human Tissue Act 2008.6 Embedded in this is the requirement to account for the “cultural and spiritual needs, values and beliefs” of both the tissue donor and their family. Researchers in NZ have benefitted from a significant body of scholarship related to Māori (the indigenous peoples of NZ) perspectives on the collection and use of biospecimens,7-10 and research ethics more broadly.11,12

To our knowledge, the only comparable information available for Pacific communities in NZ is a summary of submissions to Human Tissue Act.13 This summary noted that Pacific peoples were less likely to donate tissues and that submitters had highlighted the need for informed consent to include full information about research processes and use of tissues, the importance of family involvement in participant decision-making, potential diversity between younger and older Pacific peoples and, for some, a desire for a body to be intact for burial.13

In the broader Pacific context there is an emerging literature base exploring perspectives from Pacific communities across the Pacific and United States about biospecimen collection.14-20 Perspectives raised include a spiritual dimension to donations, a desire to contribute for the good of community, reservations due to historic breaches of trust, and the importance of consent and respectful partnerships with Pacific communities.16-19,20 The most extensive piece of work done thus far is within the Native Hawaiian community.14 Using a series of workshops to gain views across community, a series of six ‘G.R.E.A.T.’ principles were developed to guide biobanking development. The authors note (p.576) that “GREAT Research involves the target populations in the governance, participants have the option to be re-consented with each specimen use, education is ongoing and informative, accountable researchers come from the population of focus, the process is transparent and open, and the research reflects the priorities of the people.” 14 Given the rapid growth in new technologies and treatments underpinned by biomedical research, it is timely to add to our knowledge of Pacific perspectives on tissue sampling in Aotearoa New Zealand. This study explores perspectives from Pacific peoples from a variety of ages and ethnic groups, resident in Dunedin, New Zealand.

METHODS

Ethical approval for the study was granted by the Dean’s Department, Dunedin School of Medicine, University of Otago (D18/102). The proposed project was reviewed by the Ngāi Tahu Research Consultation Committee and procedures for data collection and analysis were aligned with the University of Otago Pacific Research Protocols.21

Recruitment Process

Recruitment from the Dunedin Pacific community was supported by the University of Otago’s Division of Health Sciences Pacific Advisory Group (PAG), and the Pacific Trust Otago (PTO). This included engagement with key Pacific community members who invited a convenience sample of individuals that they believed might be interested in the topic, and who were available to meet. The sample included adults aged over 18 years who identify as Pacific and who had, at least, conversational English. One goal of the recruitment was to have a degree of diversity in the range of ethnicities and ages represented.

Focus Group procedures

A senior Pacific staff member (FS, RR) attended each focus group to open and close the meeting according to appropriate Pacific protocols and provide assistance where required. Information sheets about the study had been circulated prior, but these were summarised again at the beginning of the focus group and any questions answered. The main body of the focus groups were facilitated by two researchers (JA, TS) using predetermined general lines of questioning about experiences and understandings of donating blood/tissue for research and what
might make them more or less comfortable about this. Focus groups were run in a flexible semi-structured manner to allow for conversation to flow and interesting or novel responses to be further discussed. A gift (koha/mea'alofa) was provided for each participant. Interviews were audio recorded and transcribed for analysis. As the project was a partnership between non-Pacific Trainee Intern Medical Students and Pacific researchers, the process had features of both mainstream focus groups (non-Pacific facilitators and predetermined lines of questioning) and Talanoa (held in a Pacific space, opening and closing with prayer, conversational approach, mea'alofa and with oversight by Pacific staff). 22

**Data analysis and dissemination**

Transcripts were analysed using a thematic approach.23 The focus groups were very rich in information and perspectives so the focus of the analysis was on aspects of the transcripts which described individual’s perspectives on research involving human tissue and how researchers might most effectively work with Pacific communities to conduct this research. Three of the research team (including one Pacific staff member) read through all transcripts and independently generated themes.

As noted above, the research was aligned with the University of Otago Research protocols, meaning that the analysis was conducted within the context of principles of relationships, respect, reciprocity and utility. 21 These were then collated and synthesised into a smaller set of themes through a process of discussion and consensus. These were then circulated to the rest of the research team for further discussion and refinement before being finalised into the themes presented here.

As a further validity check of the findings, preliminary results were presented, and feedback was invited during an evening session to participants who were available to attend.

**RESULTS**

A total of 18 (11 female, 7 male) individuals participated, with a variety of ethnicities (Samoan, Tongan, Cook Island, Niuean, Micronesian, Tokelauan, Papua New Guinean) and age groups (18-25 years, n = 5; 26-35 years, n = 4; 36-55 years, n = 2; 56+ years, n = 7) represented. The four focus groups included; elders from a range of ethnic groups, Pacific university students from a range of ethnic groups, a group of medical doctors undertaking postgraduate study and a group of Tongan participants of a variety of ages.

Seven overarching themes were identified here; diversity, informed consent, communal relationships, spirituality, meaning, trust and adaptability. These themes were strongly interconnected, with multiple facets to each. These are discussed, along with illustrative quotes from participants, in more detail below.

**Diversity**

This was a theme which appeared consistently throughout the feedback, highlighting the diversity of cultures, language and experiences across different Pacific ethnicities, generations and religious affiliations. There was also a sense of evolving perspectives, with communities considering and responding to new contexts and challenges, including new experiences of health care and developing technologies in both care and research.

“Everybody’s different. So... as long as you talk to the people involved with what their preference... don’t just have a blanket idea that because it’s ok with me, it will be ok with [someone else], everybody’s got their own preference.” [FG2]

“I think for myself like being in the sciences I have a different perspective on the use of tissue so that informs how I view like, “oh yeah it’s going towards science” I think that’s okay. Perhaps generations before us were like “that’s part of who we are, that’s part of your being,” like they’d treat it differently.” [FG3]

This diversity was evident in participant reflections about what types of body tissue they would be willing to donate and under what circumstances.

“It’s weird cause when you said the hair I was automatically like no. And then blood I was like, ok yeah. But like in our culture, like your head and everything to do with hair is very like tapu.” [FG2]

“I think urine is okay, blood sure... with our cervical thing we do self-swabs, they’re fine with that... so I think it really depends... obviously the heart and the liver are really you know big organs and very taboo in a lot of ways. Especially we also use that for black magic as well so there are things we’re very suspicious with.” [FG4]
This variety of views and concerns around use of body tissues means that researchers need to be careful to check assumptions about what types of sampling may or may not be appropriate for different Pacific participants.

**Informed consent**

This issue seemed to be critical to the ethical acceptability of any research project. In reflecting on the comments, it is possible to split this into its two components: information and consent.

The ‘information’ part includes researchers being able to communicate the purpose of the research, including its longer term scientific implications and more personal, concrete applications, and give detailed information about how tissue would be collected, cared for and disposed of.

"...the word research is quite loaded to be honest, and when you say that to a lot of generations before us, they would be like... “what’s the point of that?” But when you bring it back to the everyday life context and they’re like “ohh, now I see what you mean.” [FG3]

"It is important for them to know what are you going to do with the parts when it’s done... what do the family want or what does the person want. Cause it’s important for them to know exactly what’s gonna be used for. If it’s not used, how is it going to be disposed of, or if it’s done in a manner that they agree with. So... give them the finer details. At least they are at rest, and it’s done in a proper manner, in respectful way.” [FG2]

"...researchers need to be aware of the way they communicate to Pacific people. So for example my parents they [need] a lot of translating for them cause if you tell them, “oh we’re gonna do research on diabetes”, like that’s not enough information for them to understand... you have to tell them what they’re going to [do], they’re going to put a needle to take blood out.” [FG2]

Appropriate communication of this information was also discussed, including appropriate use of translators and/or family members, the value of face-to-face discussion, and even going to participants rather than requiring them to come to a clinical setting, which may be stressful. This communication also needs to be responsive to different understandings of health and perceptions of how the body works.

"...I think it would just be like a difficult conversation... it’s just a lot of concepts that they wouldn’t have thought of at home [in the islands], it’s just completely something that wouldn’t have been in their mind like at all.” [FG3]

“We’ve been doing [traditional medicine] for centuries you know, so whatever new comes in we’re really questioning and doubting until it’s proven.” [FG4]

The second part of this was consent, with some participants noting that they would need both time to think and consult with others who would contribute to the decision on whether they could or should participate.

“I’m not too sure whether I can answer straight away, that’s my answer, I don’t know, but for me I’ll tell you to give me a week to go back home.” [FG2]

There was also hesitation about the scope of consent and the potential for coercion or manipulation, especially in the context of tissue banking (the storage of tissue for future, unspecified research), and how far initial consent would spread to future studies.

“...I guess it’s kinda like, I don’t know, I just don’t want to feel forced to do the second [study] if I did the first one but rather the option to do both of them and then just pick.” [FG2]

“I think the more information you could get maybe, I mean the better for your understanding and also in informing your “yes” or “no” whereas if it’s... vague it’s kind of like...I would personally have questions... are you masking something else that I’m saying yes to?” [FG3]

**Communal relationships**

As mentioned above, some participants noted that they would need to talk to family members before agreeing to give tissue. This was further emphasised by other participants, who described the role of extended family, elders and ministers in decision making about issues around human bodies and tissue.

“...if you’re talking with [a person about] taking a [body] part... there should be a process for [them] to discuss with researchers and his family cause that will save a hell of a lot of to-and-fro... to make sure that [his] family agreed. Cause they could just turn up on the day and say “you’re not touching his body” over a dead body.” [FG2]
"...usually you propose things to the elders and they decide what happens from there so if like a research thing was to happen you’d probably talk to them and they’d decide... if they were going to let people be a part of that, as opposed to going to each house and asking each person... it’s a community thing.” [FG3]

Again, there was diversity in these responses, with some participants noting that younger Pacific peoples may be more likely to be comfortable giving consent as an individual.

"If it was blood I wouldn’t mind doing it on my own but if it was like you said the heart or the brain or something I would like to talk to my parents" [FG3]

There was also a sense that among some younger Pacific participants that they viewed themselves as having a role in supporting and educating older family members about Western medicine and research.

"I think it’s important as well... that I open up that conversation with my grandparents and things about what like happened to me and things like that in terms of the research, maybe that could be maybe a way of educating them and being more open to research if need be." [FG3]

The central importance of upholding the strength of the family within decision-making was further emphasised when the potential negative consequences of participation were discussed. Some participants noted that the risks of making a mistake in donation of tissue to research were severe and related to potential displeasure of ancestors or disconnection of descendants.

"...we’ve seen it first hand, seen our grandparents come back [from the dead], so all these conversations about the blood and the body and it sticks into me... I might give you blood and then my grandma turns up and says, “why you doing this?”” [FG2]

"...the thing about bodies, it’s like ancestral worship, and ancestral beliefs so your body is just a continuation of that ancestral line there and should there be any interruption in the chain you’re sort of affecting your lineage down the line. So... you have to make sure that whatever's been taken returns to them." [FG4]

"...we also have... the black magic... so even cutting my hair I will have to bury it myself or hide it or not just leave it randomly. Most people can allegedly do whatever black magic with that. So we take our body parts... conservatively, we don’t really want to give it. And if we do give it, you really need to convince the patient on what’s going to be done.” [FG4]

"...to us the Bible says, “you’re supposed to go back to earth”, that’s why we believe we shouldn’t get cremated and stuff so... I’d be disappointed if I found out you burnt it and then I’d probably be in more trouble from my parents.” [FG2]

"...like the Bible say, “Jesus lost his blood to make you live,” us live. Same thing we give, to give our blood to the people, to research and make other people live too, same thing.” [FG1]

For some participants, a space for prayer within the research process was seen as important, both for their own protection and the success of the research. This may sit in parallel with currently available option of having disposal of tissue accompanied by a karakia (blessing) according to Māori tikanga (protocols).

"...my family would have to sing a karakia... it's important, you know because part of this has been taken away of our body and because it's about tapu... also sometimes we pray... that piece of whatever tissue will work for other people for this for the research, it's like blessing it so that it will be successful, whatever the research is.” [FG1]

"...it’s important, because if you’re giving part of your body to help others, you know a blessing ... a lotu would be very important in our culture for that.” [FG1]

"Doing a karakia for us wouldn’t apply because I think the way I understand it, the Māori call on
their ancestors and they call on their Gods, so deities so if you... karakia over my blood, you haven’t actually blessed my blood at all.” [FG2]

**Motivation and meaning**

The sense of contributing to family and community was a key motivating factor for people to participate.

“For me I guess... if it’s a small enough amount of blood that I don’t need it... and it’s going to contribute to you understanding Pacific people in particular because there’s not that much statistics and knowledge around Pacific people and how we are different from others.” [FG2]

“...I really can’t see an avenue on how I could like effectively convince them that they can have their tissues stored indefinitely, with each other... probably the only way is to maybe say 'we’re gonna store this tissue if there's something that may affect your children, some hereditary things maybe in the future.'” [FG4]

This reiterated the need for researchers to communicate clearly the possible implications of their research for Pacific communities.

“I always feel like... the research should always be reciprocated back to where it came from, in some ways like there’s almost this responsibility as researchers that you give back to the communities it came from or the people it came from.” [FG3]

This notion of reciprocity relates strongly to the next theme.

**Trust and respect**

Participants pointed out the importance of relationships, trust and respect within the research process. These values required, amongst other things, knowing who the researcher is, taking time to build a relationship and being comfortable that they are doing good things.

“...there’d be a point where I’d still be like just wondering "who they are," I dunno what it is, maybe it’s me personally... it’s good to know the person, character and stuff before I trust them with something.” [FG3]

“But for you to have some really good data, you have to build a good relationship with your participants and gain their respect and trust... and they’ll give you over and beyond what you ask them for.” [FG2]

“I think it’s the communication because once you lose that trust in the beginning, it ruins the whole reputation for all the health staffs presently and in the future. So... I think it’s a lot of counselling and explaining before you can take a specimen from us.” [FG4]

The importance of following cultural protocols featured strongly as well.

“...in order to be successful in anything for that manner back home, you need to follow the cultural protocols. And if you divert from that, just a little, you compromise the whole thing.” [FG4]

“...it’s all a matter of living in that society and knowing the changes and knowing whose who and so... there is no protocol... [it’s] inherent knowledge of history, of culture and tradition.” [FG4]

As well as recognising that Pacific peoples have a long history and memory of research, not all of it positive.

“...it’s hard to trick the Island people nowadays because we’ve been tricked so many times, so we have common sense to determine what’s BS [bullshit] and what’s not.” [FG4]

“It’s like showing all our cards, if we show our cards, then I don’t know what you have so why should I trust you and put my cards down first.” [FG4]

**Adaptability**

This final theme connects back to all of the other themes. As Pacific migrants to NZ have skilfully navigated the complex combination of traditional views and practices with NZ health models and service provision, researchers need to be flexible and responsive to the diverse and changing needs of Pacific participants, especially when creating research protocols to fit with Pacific cultural contexts and perspectives. This includes flexibility in communication styles, informational resources, settings for discussions, time allowed for relationship building and consent.

“I think there should be a bit of education process with both the family and the researchers, cause I guess everybody’s different, they have different views. But I think if they really understand what’s
DISCUSSION

This study found a range of themes regarding Pacific views on tissue donation, reflective of the variety of responses and perspectives among our respondents. Overall, the findings echo previous information from the NZ context, in terms of diversity of views, the importance of informed consent, the importance of family in decision making and concerns about maintaining the integrity of the body for spiritual reasons. There were also commonalities with research involving Pacific communities across the region, in particular related to the importance of trust and relationships with researchers, the spiritual dimension of donation and participant’s desire to contribute to the wellbeing of Pacific communities through research involvement.

Pacific participants in this study were open to discussing new ways to support better health for their families, while remaining vigilant to the potential cultural, physical and spiritual risks that new opportunities bring. Researchers who wish to work with Pacific communities also need to be open to discussing how ‘business as usual’ research protocols can be adapted to respond to Pacific situations and concerns. The themes identified here provides some insights that may help researchers understand the context that surrounds tissue donation for Pacific peoples. Of particular relevance and areas for future attention are how to effectively facilitate informed consent, building in time and processes for communal consultation and consent, and the need for options around storage and disposal of tissue that is safe, both biologically and spiritually. There is a need to be mindful also of previous negative experiences Pacific peoples have had with researchers.

This study was exploratory and is limited by relatively small numbers and drawing from a single geographic population. Conducting the interviews in English was a limitation as there is potential for misunderstanding with some concepts potentially being challenging to translate between English and Pacific languages. Further work is needed to extend these findings and develop frameworks or principles which can inform ongoing research. It is important to note that the scope taken for these discussions was very broad, covering a variety of scenarios for tissue collection and, implicitly, types of biomedical research. Future research would benefit from more focused discussion of each of these contexts and could usefully include a brief presentation about that particular process alongside the broader context of tissue sampling and biobanking. This would allow respondents to also discuss larger issues of governance and leadership as well as their thoughts from the perspective of an individual participant.

CONCLUSION

When engaging Pacific peoples in research initiatives that involve collecting human tissue it is important that processes are aligned with cultural protocols and expectations. The results suggest that there is still significant work to be done to ensure that researchers are confidently able to meet their obligation to account for the “cultural and spiritual needs, values and beliefs” of both the Pacific tissue donors and their families. This study provides useful information to support the development of guidelines within the NZ research context.

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