CULTURALLY RESPONSIVE BIOBANKING in NEW ZEALAND

Curator: Helen Morrin
Cancer Society Tissue Bank Christchurch, New Zealand.
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Title: Curator
Disclaimer

• Perspectives and examples from presenters personal experience from the past 17 years as curator, Cancer Society Tissue Bank Christchurch(CSTB), New Zealand.

• Our biobank has engaged with Māori as an important group as part of our biobanking community not for a specific study targeting Māori health.

• Kaupapa Māori Methodology is used for specific projects.

Setting the Scene....

# 8 BIOBANKING
- majority contain human tissues.

1. Population
2. Disease

23 March 2009
Human Tissue Act 2008 definition of Human Tissue includes all or part of body, human cells, blood, hair, nails, mucus, sputum or urine. All are regulated for collection, storage and use.
The Cancer Society Tissue Bank (CSTB) 1996

Is a **central resource** of human cancer tissues, consented for “future unspecified research purposes”…

**Canterbury Tissue Bank Board**

Māori advisors
WHY have a tissue bank?

NZ population 4.7M
Regional 600,000

Cancer Society Tissue Bank
Cancer Society Tissue Bank

1. Consent → Pre surgical bloods
2. Theatre
3. Duty Pathologist → Tumour Normal
4. CSTB Long Term storage
5. Ethics Committee approval
6. Tissue Bank Board approval
7. Tissue Release

Fresh snap frozen tissue
Serum
Plasma
DNA
Cytology slides
Paraffin blocks
Tissue micro-arrays
Ethnic Group as a Percentage of the Total Population

<table>
<thead>
<tr>
<th>Ethnic Group</th>
<th>2006</th>
<th>2013</th>
</tr>
</thead>
<tbody>
<tr>
<td>European</td>
<td>74%</td>
<td></td>
</tr>
<tr>
<td>Māori</td>
<td>15%</td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>11.8%</td>
<td></td>
</tr>
<tr>
<td>Pacific peoples</td>
<td>7.4%</td>
<td></td>
</tr>
<tr>
<td>Other (including MELAA)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other (including New Zealander)</td>
<td></td>
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</tr>
</tbody>
</table>

Definition: The group(s) you most strongly identify with
Measure of cultural affiliation
Not basis of ancestry, race, nationality or citizenship

2013 census
Percentage of Māori per region
Census 2013

Māori 8.1%
New Zealand population age structure 2013

Non-Māori
18.0% ≤15 years
15.7% ≥65 years

Māori
33.7% ≤15 years
5.2% ≥65 years

Tatau Kahukura: Māori Health Chart Book 2015

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Mortality: Māori >65 years

Figure 4.11: Major causes of death among Māori aged 65 years and over, 2000–2004

- Circulatory system
- Cancer
- Respiratory diseases
- Diabetes mellitus
- Digestive system diseases

Age-sex-standardised rate per 100,000

Hāuora 2007

Māori
European
What does being culturally responsive mean?

What are our donors expectations and understanding of research and governance?

Are they the same as academics?

How can we be more responsive to meet those needs and become more inclusive of all communities?
2014: 9 Key Principles

- PRIORITIES:
- INVOLVEMENT:
- PARTNERSHIP: mutual trust
- RESPECT: for knowledge & custodianship of knowledge
- COMMUNICATION.
- RECIPROCITY: deliver tangible benefits to Aboriginal communities.
- OWNERSHIP:
- CONTROL: Researchers must ensure the respectful and culturally appropriate management of all biological research materials.
- KNOWLEDGE TRANSLATION:
He Tangata Kei Tua
Guidelines for Biobanking with Māori 2016

Hudson et al.

Governance

Kawa – Respect for Māori principles at every decision point, comfort, control, integrity

Purpose – values and mission, intended outcome, make up of the team

Benefit- Equity and justice throughout process

Kaitiakitanga - form of guardianship for tissue, data, processes

Taonga – precious resources

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San Code of Research Ethics 2017

RESPECT: Individuals, community, culture, privacy, acknowledgement

HONESTY: Open and clear communication, transparency, ongoing relationship

JUSTICE AND FAIRNESS: Meaningful involvement in research, including learning about possible benefits and what form they might take.

CARE: Aligning process with care of both individuals and communities in relationships, excellence in research, be culturally responsive and research that improves the lives of the San.
Clearly these communities are asking for much more from researchers.

Expectation is to build a long term ongoing relationship

• to maintain trust
• integrity
• acknowledgment
• respect
• involvement in our CSTB processes.
Engaging with our community: circa 2000


No roadmaps for biobanking!

**Aim:** incorporate cultural values into our biobank to be inclusive of Māori in research.

**Consultation & involvement with Māori:**
- Biobank registration
- Ethical review - biobank & sample use
- Donor support & advocacy
- Standard Operating Procedures
- Governance board – access & use
- Scientific meetings & workshops
- Data/Results?

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Elizabeth Cunningham – University of Otago

Annette Finlay – Governance board

Our biobank’s Māori Advisors

Teoti Jardine – Kaumātau/ advocate

Tahu Stirling & Eru Waiti - Hospital
Consultation with Māori:

Ngāi Tahu legally identified as our Treaty partners in 1990 with a MOU with the University and incorporate all Māori living in the area within Te Wai Pounamu.

“All health research in Aotearoa New Zealand benefits the Hauroa (health and wellbeing) of tangata whenua.”

• University Research Manager – Maori
  Elizabeth Cunningham
  Ngāi Tahu/Ngāti Mutunga –iwi (tribe)

• Karen Keelan Ngāti Porou 2010.

• Manage & increase responsiveness of UOC research to meet the needs & aspirations of Māori.
University of Otago, Christchurch.

Ngāi Tahu
54,000 people
Section 14 - Consultation with Māori

- Māori should be consulted in the design and conduct of research that is of relevance to them.

- 14.1 Describe whether and how your study may benefit Māori, and identify the main cultural issues that may arise for Māori who may participate in your study, and explain how these issues will be managed.[<200 words]
• 14.3 The University of Otago has a Policy for Research Consultation with Māori. Have you already completed, or do you propose to undertake Māori consultation?

http://www.otago.ac.nz/research/maoriconsultation/index.html

• ☐ yes - indicate below whether Research Consultation with Māori has been undertaken or is proposed for this study:

• ☐ no - If no, provide a brief outline of reasons why not
• 9.2 Could participation in the study, or reporting of the findings, risk stigmatising individuals or population groups, or punishment/ harassment for participation?
  • □ yes □ no
  • If yes, how this risk will be minimised and managed.

Report Form
Dissemination
• Have the findings of the study been reported back to the Ngāi Tahu Research Consultation Committee?
  • If no, what is the justification for not reporting back?
Patient participation

Highlight cultural concerns………

“You may hold beliefs about a sacred and shared value of any tissue removed or stored and wish to discuss your tissue donation further with your family, whānau or iwi as this is your whakapapa.

Some research may involve analysing the genes (DNA) in your tissue to look for a gene or gene pattern associated with your condition and treatment options. Parts of this biological code (DNA) are passed from generation to generation so that research results may not be just about you but could also be about your blood relatives…. H.MORRIN ANHRC 2017
Inform donors ........

“Consultation with Māori locally and regionally has taken place and is ongoing, along with representation at governance level.”

Offer choice ........

- I consent to my tissue(s) being used for the analysis of genes (DNA) associated with my condition. Yes □ No □

- I consent to my tissue(s) and information being sent overseas for study. Yes □ No □

- I request that any remaining tissue sample(s) at the end of a study be disposed of with karakia (blessing). Yes □ No □

Offered CSTB PICF since 2003
Contact persons:

Oncology Service Christchurch Hospital:
Dr Bridget Robinson, Tissue Bank Director,
Helen Morrin, Tissue Bank Curator

Phone (03) 364 0020

Gynaecology Oncology, Christchurch Women’s Hospital.
Dr Peter Sykes,
Dr Bryony Simcock,
Dianne Harker, Research nurse

Phone (03) 364 4624

Haematology Department, Christchurch Hospital
Dr Peter Ganly,
Dr Sean Macpherson.

Phone (03) 364 0300

Children’s Haematology Oncology Service (CHOC)
Dr Siobhan Cross,
Dr Amanda Lyver,

Phone (03) 364 0740

Surgery Department, Christchurch Hospital
Dr Birgit Dijkstra
Dr Tim Eglinton

Phone (03) 364 1682

Neurosurgery Department, Christchurch Hospital
Dr Ronald Boet,
Dr Simon John.

Phone (03) 364 1217

Your rights:
If you want to talk to someone who is not involved in Tissue Banking, you can contact an independent health and disability advocate.

Telephone: 0800 555 050
Email: advocacy@hdc.org.nz

For Māori health support please contact;
Canterbury Tissue Bank Board Māori advisor
Annette Finlay

Phone (03) 375 4141

Canterbury District Health Board Māori Health Team support
Eru Waiti Team Leader

Phone (03) 364 0640 ext.88797.
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Cancer Care Co-ordinators
Māori consultation requests ethnicity data

CSTB uses self declared ethnicity and collect as raw uncoded data

107 different donor categories and combinations from 10,000 donors
Donor responses

Percentages of donors consenting to options for tissue use

<table>
<thead>
<tr>
<th>CONSENT OPTIONS</th>
<th>% Consented</th>
<th>% Consented Māori</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tissue sent overseas to research collaborators</td>
<td>99.3</td>
<td>98.4</td>
</tr>
<tr>
<td>Analysis of genes(DNA)</td>
<td>100.0</td>
<td>100.0</td>
</tr>
</tbody>
</table>
Incorporating cultural values into biobanking.

Level of comfort
• respecting Tikanga (protocols).
• Te Reo Māori, kia ora
• Hauora Manawa/Heart Health Project
  A/Prof Suzanne Pitama,(MIHI)
  Prof Vicky Cameron, et al.
Sample Tikanga: Culturally appropriate tissue handling

Food and bodily tissue should not be in contact. Replace with obviously non-food container.

Small changes increase the level of comfort of participation in biobanking and are respectful of cultural values.

- Separate disposal bins for samples that require disposal with karakia.
- Blood is tissue also.
- All staff trained in respectful handling of tissue.
Sample disposal with karakia (blessing)

Offering sample disposal with karakia is being both respectful and acknowledging donors’ cultural and spiritual beliefs.

www.otago.ac.nz/christchurch/otago014331.pdf

• Guidelines developed in 2004 by the Māori Research Development Komiti.

• Ensure tissue handling consistent with cultural practices.

• To encourage all ethnic groups and in particular Māori, to participate in research.
Memorial Service For the disposal of Human Specimens

• Ceremony conducted in Māori and English.

• Karakia ceremony - request for samples to be disposed of respectfully.

• Occasion to acknowledge all research donors.

Karakia given by Bishop John Kuru Gray specifically for this service.

Korowai covering samples.
Donors requesting sample disposal with Karakia (>10,000 donations)

<table>
<thead>
<tr>
<th>CONSENT OPTION RECORDED</th>
<th>% Requested</th>
</tr>
</thead>
<tbody>
<tr>
<td>Requested sample disposal with Karakia</td>
<td>45*</td>
</tr>
<tr>
<td>- Ever Māori</td>
<td>59</td>
</tr>
<tr>
<td>- Sole Māori</td>
<td>66</td>
</tr>
<tr>
<td>- Other Ethnicities</td>
<td>41</td>
</tr>
</tbody>
</table>

Clearly meets a need Māori and non-Māori
Governance Board Sample Use

• Donor choices recorded on database.
• Curator consults with Māori Advisor.
• Approving high quality science is respectful.
• Māori Advisors: link to Māori community for further consultation when required.

“Ngāi Tahu who are the mana whenua (the people of the land), do not support genetic research or biobanking” 2014

“I am happy to support this kaupapa ”(biobank initiative) Eru Waiti 2016
Return of Samples *

- Cultural significance to return to earth.
- Request clinical return also comfortable to biobank.
- Governance best practice to return in fixed format for health & safety issues for donor.
- Responsibility in relationship
  ➢ Correct handling
  ➢ Guidelines for burial
- Look at alternatives to sample return.

Excerpt from Formalin Handling Information

If you choose to bury tissue
Tissue must be disposed of/buried with regard for public safety, contact your local council for guidelines.
You can contact a funeral director for assistance with burying or cremating your tissue.

Guidelines for burial of tissue

- Allow sufficient soil depth (suggested at least 50cm) to:
  - prevent access by animals.
  - avoid a public health hazard or unintended disturbance
  - avoid contamination of surface soil. The preserving agent formalin will kill plants if not buried deeply enough.

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Guardianship/Governance of Research Results

• This is not “interfering” in result interpretation but an important part of the ongoing relationship.

• Results that are associated directly with Māori ethnicity need to be interpreted in context to avoid misrepresentation. Example: 2006 “warrior gene” associated with antisocial behaviour in Māori.

• Broad data sharing can result in loss of data guardianship therefore informing donors to allow culturally informed consent is vital.
Broad data (secondary repository) sharing.

- Collective consent includes cultural oversight for duration of research.
- Potential for re-identification increased due to small unique population.

CSTB:
- Māori accept anonymised data into public database for scientific publication.
- Not into secondary repository for datamining.
- Clinical trials, individual choice for access to new drugs.
- Codes of conduct.
Dissemination: It’s not just about publications and posters!

- Research conference ABNA 2014 – Guardianship.

- Institutional Open Days for public.

- Student Laboratory visits for encouraging Māori youth into biomedical research.

- Sponsoring & mentoring Māori researchers and Kaupapa Māori (Māori grants).

- Leaflet or newsletter.

- Community talks – lots! – even just 5-10 minutes in lay language.
OUTREACH

Onuku marae and UOC MOU

Rehua marae in the city
Does being culturally responsive encourage Māori to donate samples?

<table>
<thead>
<tr>
<th>Recorded Ethnicity</th>
<th>% Donors since 2003</th>
<th>% Regional Census 2013*</th>
</tr>
</thead>
<tbody>
<tr>
<td>NZ European</td>
<td>76.8</td>
<td>86.9</td>
</tr>
<tr>
<td>Māori</td>
<td>4.8</td>
<td>8.1</td>
</tr>
<tr>
<td>Pacific Island</td>
<td>0.8</td>
<td>2.5</td>
</tr>
<tr>
<td>Asian</td>
<td>2.2</td>
<td>6.9</td>
</tr>
<tr>
<td>Other</td>
<td>15.4</td>
<td>2.0</td>
</tr>
</tbody>
</table>

Annually ~10 patients decline to become donors including 1 of Māori ethnicity.

*Does not add up to 100%
Doors of Integrity

“... asked researchers to come through the door, not the window.
The door stands for the San processes.”

Me hoki rangatira mai mā te upoko, ehara mā te rārā. One should return through the front door, not the side door.

He Tangata Kei Tua: Guidelines for Biobanking with Māori Pg 18.
Acknowledgements
Cancer Society Canterbury West Coast Division

all our Donors.

• Prof Bridget Robinson (Director)
• Lucia Sinclair CSTB
• Pre admission clinic staff
• Mackenzie Cancer Research Group
• Elizabeth Cunningham
• Annette Finlay
• Surgeons, theatre staff
• Consultant Pathologists
• Registrars
• Histology team
• Māori Research Development Komiti
• Karen Keelan

The Robert McClelland Trust