**Research Involving Maori Guidelines for Disposal or Retention of Samples and Specimens**

**Definition:**
*Sample* – any body part, tissue sample, or specimen of bodily fluid collected from the research participant.

**Rationale:**
Various ethnic groups, in our community have specific views regarding the handling and disposal of human samples collected for clinical testing and for research. To encourage all ethnic groups particularly Maori, to participate in research conducted by researchers of the CDHB, the following guidelines have been developed for researchers to ensure consistency with cultural practices:

- The Treaty of Waitangi principles of partnership, participation, protection and good faith will be actively addressed from the outset of the research project and during the project itself.
- Researchers must address how the research will benefit Māori, including how information will be shared with Māori.
- Before research is initiated, consent may be required from iwi/Māori groups, particularly if the research may potentially breach tikanga or involve sensitive issues. This is over and above individual consent requirements.
- Some issues may also require consent from iwi and/or hapū especially where ownership may belong to collective stakeholders.

If the research involves collection of whole body parts (limbs or whole organs e.g. tonsils, placenta) the offer to return the body part should be made to the research participant/whanau.

**For the collection of any samples:**
1. **Written approval** from the Regional or Multi-Region Ethics Committee must be obtained before collecting samples from any members of the public.
2. **Explicit signed consent** must be obtained from the individual (or authorised family/whanau).
3. The consent form for the project should contain the following phrases:
   - I consent to the researchers storing a specimen of my blood (or other tissue) for its later use as a part of this study or other research approved by the Regional Ethics Committee. YES/NO
   - I consent to any remaining samples being disposed of using standard disposal methods at the end of the study. YES/NO
   - I would like any remaining samples to be disposed of at the end of the study (please tick one):
     - Using standard disposal methods
     - Disposed with appropriate karakia

*(If applicable)*
I wish to have my donated body part returned to me at the end of the study

YES/NO

4. The Information Sheets for the project should contain the following:

- Clearly explain the number and type of samples to be taken.
- Explain why the tests or procedures are necessary.
- Explain what will happen to samples after the study is concluded.
- Explain the nature of standard disposal methods (disposal in accordance with NZS 4304:2002 'Healthcare Waste Management').
- Explain that there are two methods of disposal and participants may choose to have their remaining samples disposed of using standard disposal methods or disposed of with appropriate karakia, at the end of the study.
- Inform the participants that they have the option of having their body part returned at the end of the study (if applicable).

5. Samples to be disposed of with appropriate karakia (blessing):

all tubes or containers holding these samples should be identified at the time of collection with a special identification sticker using the following design (this design may be copied from this document and pasted into a file for printing tube labels or the gif file for the design can be downloaded from: http://whakaahua.maori.org.nz/kowhai.htm or contact the Research Office).

(By courtesy of Maori.org.nz)

*The Principal Investigator of each research project will be responsible for identifying and tracking body parts for subsequent return, if requested.

6. For disposal of identified Maori samples (i.e. samples taken from research participants who have requested to have 'remaining samples disposed with appropriate karakia' on the consent form).

At the end of the study the samples will be retained for the ceremony with appropriate karakia, and then be disposed of immediately thereafter.

7. For any subsequent dissemination of Maori samples (e.g. to other labs participating in the study), those samples should also be identified with the appropriate sticker. The lab in receipt of the samples must be informed that any remaining sample material should be returned to the disseminating lab after testing is completed, or by a certain date, which ever comes first.

8. At the end of the study, the Principal Investigator named on the Ethics Approval must ensure that all remaining sample(s) identified as requiring disposal with appropriate karakia are forwarded to the ????????????????????? to be stored for the next ceremony. Please notify the ?????????????? before forwarding any samples to allow arrangements to be made for storage (-20º freezer, ????????????? has the key).

Note: If researchers have any queries about these guidelines, please contact the Chairperson of Te Komiti Whakarite ext 88797 or Office Administrator ext 86160.