Kaupapa Māori Research Protocols Information Sheet

Multi-Ethnic New Zealand Study of Acute Coronary Syndromes (MENZACS Study)

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Locality: The University of Auckland (Auckland City Hospital and Middlemore Hospital) and Christchurch Heart Institute

The purpose of this information sheet is to describe the kaupapa Māori research protocols that have been included in this study. Body fluids and tissue are a tāonga (treasure) and appropriate tikanga (Māori custom) processes have been put in place to ensure that your blood sample, given in this study, is treated with care and respect. The MENZACS study has a Māori Governance Group, as well as a Māori co-investigator on the research team. These protocols have been developed by the Māori Governance Group in consultation with various Māori representatives, both academic and community-based. You do not have to be of Māori descent to have these processes in place for your blood sample.

Thank you for reading this

WHAT TIKANGA PROCESSES ARE IN PLACE?
The research team acknowledges that there are cultural considerations in this type of research. The Māori Governance Group has oversight of tikanga processes as well as kaitiaki (guardianship) over the project on behalf of Māori participants and whānau. The tikanga processes currently in place are described within this information sheet. If you would like to request a specific process that is not included here, please feel free to talk with the research team.

Participants who would like to perform a karakia (blessing) at the time of blood collection are encouraged to do so. Once your blood has been collected, it is sent for storage and the tikanga processes are dependent on the storage location, which are described below.

WHERE IS MY BLOOD STORED?
In Auckland, your blood will be stored at the Auckland Regional Biobank.
In Christchurch, your blood will be stored at the Christchurch Medical School Biobank.
In Waikato, your blood will be sent to and stored at the Auckland Regional Biobank.³

WHAT HAPPENS TO LEFTOVER BLOOD?
Leftover blood will either be destroyed, or kept in storage for potential use in other research in the future. There is a section of the consent form where you can choose to be part of future research or not. For this

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study, if you choose to have your sample destroyed after it has been used for the purposes outlined in the main Participant Information Sheet, then you can choose standard disposal or disposal with karakia.

In Auckland, our sample processing and storage facilities have been blessed by kaumatua representing faculty and mana whenua. Samples that are identified for disposal with karakia, at the time of consent, are noted in our sample tracking software which manages our storage process. At the time of sample disposal your sample will be retrieved and added to the annual ceremony for samples leaving the University of Auckland. Our faculty kaumatua bless the samples and they are then disposed of using the universities standard biohazardous material management protocol.

In Christchurch, samples which are to be disposed of with karakia are identified using a distinctive label. Bishop John Gray wrote a karakia for the disposal process, which was first performed by the Māori Chaplains in the Christchurch Hospital Chapel on the 6 September 2005, and is now conducted approximately every six months.

**WHAT HAPPENS IF MY BLOOD IS SENT OVERSEAS?**

Some samples may need to be sent overseas for analysis by collaborating investigators or through industry contracts developing similar genetic or circulating biomarker tests. Any blood samples sent to sites outside New Zealand will be labelled with a coded number only. A karakia will be performed before samples leave the storage facility for transport overseas. A memorandum of understanding between the research team here in New Zealand and the overseas laboratory will be drawn up at the time that there are enough people in the study to send samples away for analysis. The Memorandum of Understanding will outline our expectation for the care of your sample based on the principle that it is a tāonga (disposal by karakia will not be available at overseas facilities). Only the necessary amount would be sent overseas for specific testing, so it unlikely that there would be any sample left over. You will find a section in the consent form where you can decide if you want your sample to only be used in NZ or if you are happy for it to be sent overseas.

**WHO DO I CONTACT FOR MORE INFORMATION OR IF I HAVE CONCERNS?**

If you have any questions, concerns or complaints about the study at any stage, you can contact the Principal Investigator, Associate Professor Malcolm Legget on 09-923 6713

If you want to talk to someone who isn’t involved with the study, you can contact an independent health and disability advocate on:

- **Phone:** 0800 555 050
- **Fax:** 0800 2 SUPPORT (0800 2787 7678)
- **Email:** advocacy@hdc.org.nz

For Māori Health Support or to discuss any concerns or issues regarding research, please contact:

**Auckland Hospital:** If you require Māori cultural support, talk to your whānau in the first instance. Alternatively you may contact the administrator for He Kamaka Waiora (Māori Health Team) by telephoning 09 3074949 ext 29200

**Christchurch Hospital:** Kathy Simmons
Ngā Ratonga Hauora Māori
Phone 03 364 0640 Extension: 86160 Fax: 364 6018

You can also contact the health and disability ethics committee (HDEC) that approved this study on:

- **Phone:** 0800 4 ETHICS
- **Email:** hdecs@moh.govt.nz