Research in the Intensive Care Unit (ICU) Information for Patients and Families / Whanau

Wellington Regional Hospital

Capital & Coast District Health Board (CCDHB) has a strong commitment to promote and support research as a normal part of its operations. It recognises the contribution research makes to promoting health and deciding clinical treatment.

All research undertaken at CCDHB has been approved by the organisation and by one of the Health and Disability ethics committees in New Zealand. This is to ensure the patient's rights and welfare are protected.

Many of the previous studies Wellington ICU has been involved in have led to changes in how we do things in ICU. This has led to improved outcomes for our critically ill patients.

Research in the Wellington ICU may include:

- Comparing different but common treatments
- New use of existing medicines
- Clinical trials of new medicines
- Observational studies
- Asking for your view or experience on some part of your involvement with the hospital or your health problem

Many research studies depend on patients who meet the studies required criteria volunteering to take part in the study. The criteria could be if the patient has a certain condition, is at a particular stage of treatment for a condition, or are in a particular age group.

This leaflet explains what is involved in a research study.

Taking part in a study

If you meet the required criteria for being included in a study you may be approached by a researcher to discuss taking part. This discussion will include:

- · A full explanation of the study
- How you will be involved

What the benefits and risks are

Patients must give their consent to be part of any research study.

You will be given a copy of the information sheet that has been approved by a health and disability ethics committee. Please read this very carefully. If you need a translator to help you understand the information please let the researcher or your nurse know.

Do ask as many questions as you like to make sure that you fully understand what the study is about and what will be required of you. You may wish to discuss the study with your family / Whanau before you make a decision.

Your involvement in research is completely voluntary (your choice). If you do decide to take part in the study, you will need to sign a consent form stating that you understand the requirements of the study and that you agree to take part.

You can withdraw from a research study at time without needing to give a reason for withdrawing.

If you decide not to take part or withdraw from a research study, your treatment and the care you receive now or in the future will not be affected in any way.

When patients are unable to give consent

Patients in ICU are usually too unwell to consent to being involved in a research study for themselves. In these cases we often ask the patient's relative, Whanau or friend whether or not they believe the patient would wish to take part in the study if they were able to decide for themselves.

For some research study in ICU patients may be enrolled in the study before family, Whanau and friends can be spoken to. This process is approved by the ethics committee for some low risk studies.

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The study will be stopped if any harmful effects appear or if the doctor feels it is not in your relatives, Whanau or friends best interest to continue.

When your relative, Whanau or friend is able to speak to the researcher they will be asked for their consent to continue with the research study. If the research study has finished they will be asked for consent to use the information that has been collected.

Compensation

Your involvement in a research study is voluntary and there will not be any payment for taking part. Compensation for any harmful effects from research study treatment may be covered by ACC or by the research study sponsors (developers) if it is a medicine trial or new treatment. This will be explained in the information sheet given to you by the researcher. If you are not sure please ask the researcher or doctor.

Supporting the research in Intensive Care Services

If you would like to make a donation towards ongoing research in the ICU please ask the research nurse or doctor for more information. Donate to: ICU Research Department Intensive Care Services Level 3

Wellington Regional Hospital

If you have any questions or concerns about the rights of a participant in a research study, you may contact an independent health and disability advocate.

This is a free service provided under the Health and Disability Commissioner Act
Telephone (Free) 0800 555 050
Fax (Free) 0800 2787 7678 (0800 2 SUPPORT)
E-mail advocacy@hdc.org.nz

Whanau Care Services

For Maori support please contact Whanau Care Services. Monday – Friday 8am to 4.30 pm.

Phone (04) 385 5999 Ext 80948

Contact details

ICU Research Department, Intensive Care Services, Level 3, Wellington Regional Hospital, Phone: (04) 806 0446 Fax: 904) 806 0440

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