# Best care, any place, every time.

Palliative Care Clinical Studies Collaborative (PaCCSC) is a research collaborative at the University of Technology Sydney (UTS).

We are part of the Improving Palliative, Aged and Chronic Care through Clinical Research and Translation (IMPACCT) research centre.

We research clinical options that improve the wellbeing of people living with life-limiting illnesses.

# **IMPACCT**

### A UTS Health Research Centre

Improving Palliative, Aged and Chronic Care through Clinical Research and Translation (IMPACCT) is a research centre dedicated to improving the care, and quality of life of people with chronic conditions and palliative care needs.

Find out more at www.uts.edu.au/IMPACCT

# Palliative Care Clinical Studies Collaborative

# Information for clinical trial participants

Questions and answers for people with lifelimiting illnesses who are thinking about a clinical trial.

### Contact us

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UTS CRICOS PROVIDER CODE: 00099F

### What is palliative care?

Palliative care is person- and family-centred care provided to people with life-limiting illnesses. The aim of palliative care is to improve the quality of life for patients, families and caregivers by addressing individual needs that may be physical, emotional, social, cultural or spiritual.

# How do I find out about Paccsc clinical trials?

You can find information on our website about our current clinical trials including trial locations and criteria for participating in each trial. You can email us to request more information about our trials.

# How do I get involved in a PaCCSC clinical trial?

It is important that you meet the eligibility criteria for any clinical trial. Talk to your doctor about your suitability for a clinical trial. You or your doctor can contact us or your nearest participating trial site for further information.

### Is it safe to participate?

Trials may include potential risks to participants, which we would discuss with you before you decide to participate. Each clinical trial is approved by a Human Research Ethics Committee (HREC), whose role it is to protect research participants. Participant safety is our highest priority and we always put participants and their families' wellbeing first.

# What are the benefits of participating?

We can't guarantee any personal benefits to individual trial participants. Your participation will contribute to building knowledge about how and if medications or other treatments are effective in improving the quality of life for patients with life-limiting illnesses.

### How much time will it take?

This will vary between clinical trials and depends on the type of trial. Some trials will involve hospital visits, and some may take place in your home. A trial might include trying a new medication or it could be answering a series of questionnaires.

# Will participating affect my current care?

No. You will continue to receive care from your current doctor or other treating health professionals. We will keep your doctor informed of the clinical trial progress and outcomes.



# Will my personal details be kept private?

Yes. Clinical trial participants' personal details are confidential. Publications using clinical trial research findings do not refer to names or identifying details of individual participants.

# If I decide to participate, can I change my mind?

Yes. You can opt out at any time and you don't have to give a reason. However, if you give a reason this may help us with designing future clinical trials as participant experience is important to us.

# I have more questions. How can I find out more?

You can talk to your doctor, go to our website or contact us by email. You can also read more about clinical trials in Australia. See the Further information section, below.

### Further information

The National Health and Medical Research Council (NHMRC) Australian Clinical Trials website includes lots of information for the general public about clinical trials, how they work, and how to take part.

www.australianclinical trials.gov.au