MONASH University

EXPLANATORY STATEMENT

Project ID: 51066

Project title: Pan Cancer Initiative: Core Outcomes Set PRMs | Implementation Considerations and Tools

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You are invited to take part in this study. Please read this Explanatory Statement in full before deciding whether or not to participate in this research. If you would like further information regarding any aspect of this project, you are encouraged to contact the researchers via the email addresses listed above.

What does the research involve?

The Australian Real World Cancer Evidence Network (Pan Cancer) is a five-year initiative jointly funded by Movember and the Australian Government (Cancer Australia and Department of Health, Disability and Ageing). It aims to advance the goals of the Australian Cancer Plan by improving the collection and use of real-world data on the outcomes and experiences of Australians affected by cancer. The initiative includes defining a core outcomes set (COS) for use across all cancer types, together with a recommended list of patient-reported measures (PRMs), comprising patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs).

The purpose of this study is to understand how organisations across Australia currently collect patient-reported data in cancer care. This information will help researchers identify common approaches, gaps in measurement, and practical considerations for aligning data collection with a national cancer outcome framework.

If you agree to participate, you will be asked to complete a short online survey (maximum 8 questions). The survey will ask whether your organisation is using any PROMs and/or PREMs and, if so, which instruments are used.

The survey will take approximately 3–5 minutes to complete. We will not be collecting any personal information or data.

Why were you invited for this research?

You have been invited because you are based in Australia and involved in a service, registry, research program, or organisation relevant to cancer care, quality measurement, or patient-reported measures.

Source of funding

This research has been funded by the Movember.

Consenting to participate in the project and withdrawing from the research

B clicking the link provided in the invitation email, you indicate your consent to participate in this research project.

Your participation is voluntary.

Possible benefits and risks to participants

There is no direct personal benefit to you. However, your participation will contribute to improving national guidance for measuring patient outcomes and experiences in cancer care.

There are no anticipated risks beyond those encountered in normal professional activities.

Storage of data

The data will be stored for at least 5 years on secure Monash University servers accessible only to members of the research team (current and future).

Data collected during this study will be transferred to the Movember and archived securely for an indefinite period for research validation and, where applicable, re-use in accordance with ethical guidelines

Use of data for other purposes

Following data sharing guidelines, data may be made available for use by other researchers. This data will be held on secure public repositories and may be a requirement of some journals before publication.

Results

A summary of the results will be available following project completion.

Complaints

If you have a complaint concerning how this research (Project ID: 51066) is conducted, please contact:

For projects conducted in Australia
Executive Officer Monash University Human Research Ethics Committee (MUHREC) Office of Research Ethics and Integrity Room 116, Administration Building B (3D) 26 Sports Walk, Clayton Campus Monash University VIC 3800 Tel: +61 3 9905 2052   Email: muhrec@monash.edu

Clicking on the survey link indicates that you consent to participate in this research project.