Professor Christobel Saunders AO
James Stewart Chair of Surgery and
Director of Research Melbourne Medical School
155 Barry Street,
Carlton, Victoria 3053

We are kindly inviting your organisation to participate in a research study that we are conducting titled:

An exploration on the cancer care pathway in Australia: perspectives of patients, survivors and carers on diagnosis, treatment, recovery and beyond - the All.Can Patient Experience Survey.

The aim of this retrospective cross-sectional study is to obtain qualitative data on the experiences of patients and carers who have been directly impacted by cancer with the current processes of diagnosis, treatment and post-cancer care across Australia.

This 4-section survey comprises 40 (forty) questions which address patients and carers' perspectives on cancer diagnosis, treatment and post-cancer care and support in Australia. The survey will be accessible via a digital link or QR code.

We invite you to disseminate the attached project plain language statement, along with the QR code and hyperlink to your members to invite them to participate.

Participation is completely voluntary and participants may withdraw from the study at any time by exiting the digital survey. The study is completely anonymous, therefore, participants will not be required to provide any identifying information. We will conduct the distribution and analysis of the survey in line with the local regulations and The National Statement on Ethical Conduct in Human Research, and the project has been approved by the University of Melbourne Ethics Committee prior to commencement.

Thank you for your time and consideration. Please do not hesitate to contact me should you require further details.

Kind regards,

Professor Christobel Saunders
Tel: +61 3 8344 5491
Email: christobel.saunders@unimelb.edu.au

Plain Language Statement

Department of Surgery, Melbourne Medical School, University of Melbourne

An exploration on the cancer care pathway in Australia: perspectives of patients, survivors and carers on diagnosis, treatment, recovery and beyond - the All.Can Patient Experience Survey

Project Supervisor: Professor Christobel Saunders
Tel: +61 3 8344 5491 Email: christobel.saunders@unimelb.edu.au

Additional Researchers:
Dr Hannah Truong Email: hannah.truong.1@unimelb.edu.au
Tracey-Anne Dickens Email: tracey.dickens@unimelb.edu.au
Dr Sussanah Morris Email: susannah. morris@unimelb.edu.au

Introduction

Thank you for your interest in participating in this research project. The following pages will provide you with information about the project, to help you decide if you would like to take part in this research.

Please take the time to read this information carefully. You may ask questions about anything you don't understand or want to know more about.

Your participation is voluntary. If you don't wish to take part, you don't have to. If you begin participating, you can also stop at any time.

What is this research about?

This research aims to collect data on the experiences of patients and carers who have been directly impacted by cancer, including the processes of diagnosis, treatment and post-cancer care across Australia, by inviting you to complete a questionnaire.
We hope our research will help identify gaps in current care in Australia and help us to improve our care models.

What will I be asked to do?

Should you agree to participate we invite you to complete an online questionnaire comprising of 40 questions about your experiences of cancer care. This should take approximately 20 mins. The questionnaire is anonymous, so no identifying information will be collected. You will be required to scan a QR code or enter a web-address to access the questionnaire.

What are the possible benefits?

This study will help identify gaps within our current cancer care models and will inform cancer practice and policy development in Australia.
We plan to collect data from both carers and patients/survivors, so hopefully we will be able to assess what aspects of cancer care are important to each group, e.g. what emotional/psychological support systems do carers need, and how this may differ to the patients.
The results may also help in developing more effective and efficient allocation of health resources to help bridge any identified gaps in the patient/carer experience to ensure that cancer care in Australia is comprehensive and integrated.

What are the possible risks?

Because we are asking questions about your care and treatment experience of a cancer diagnosis as a carer or patient, the questions in the survey may cause some distress and discomfort, anxiety and short term pain. Our researchers contact details and helpline support organisations are detailed at the end of the survey to provide help in such circumstances.

Do I have to take part?

No. Participation is completely voluntary. You are able to withdraw at any time, but as the questionnaire is anonymous once you complete the questionnaire the data cannot be retrieved. During the questionnaire you can leave immediately by exiting the digital tab.

Will I hear about the results of this project?

Summary results will be provided to the supporting organisations that invited you to take part, and they will provide these details to you. We may also publish our findings in peer reviewed journals and at conferences. Please be assured that there will be no information that will identify you.

What will happen to information about me?

As the data collected is completely anonymous and there are no identifying questions, patient confidentiality is assured. The questionnaires are stored securely via a password-protected account with the University of Melbourne which only the research team have access to. All study data will be destroyed 5 years after publication.

Where can I get further information?

If you have questions or would like more information about the project, please contact;

Professor Christobel Saunders
Tel: +61 3 8344 5491 Email: christobel.saunders@unimelb.edu.au

Who can I contact if I have any concerns about the project?

This project has human research ethics approval from The University of Melbourne [Project ID 32576]. If you have any concerns or complaints about the conduct of this research project, which you do not wish to discuss with the research team, you should contact the Research Integrity Administrator, Office of Research Ethics and Integrity, University of Melbourne, VIC 3010. Tel: +61 3 8344 1376 or Email: research-integrity@unimelb.edu.au. All complaints will be treated confidentially. In any correspondence, please provide the name of the research team and/or the name or ethics ID number of the research project.

Link to Survey: https://redcap.unimelb.edu.au/surveys/?s=AK3X498RJXNPRX8Y