

PARTICIPANT INFORMATION SHEET

UTS HREC REF NO. ETH21-6506

Healthcare professionals' perspectives on the barriers and enablers of cancer clinical trial participation in the Australian Arabic-speaking community

WHO IS CONDUCTING THIS RESEARCH?

My name is Dr Rayan Saleh Moussa and I am an academic at the University of Technology Sydney (UTS), leading a [diverse team of researchers](#) on behalf of the Cancer Symptom Trials (CST) collaborative within the IMPACCT Centre (Faculty of Health, UTS). The CST collaborative was established in 2017 to address the unmet symptom management needs of Australians living with cancer through clinical trials. Through our clinical trials, we research options for improved management of symptoms that can occur due to a cancer diagnosis and related treatments. Our goal is to ensure the best quality of life possible for people with cancer. We have designed this study to understand how we may improve cancer clinical trial participation in the Australian Arabic-speaking community.

WHAT IS THE RESEARCH ABOUT?

It is well established that people from culturally and linguistically diverse (CALD) communities experience poorer healthcare access and healthcare outcomes. This is compounded by lack of representation and/or eligibility for potentially life-saving clinical trials. The CST collaborative at UTS is keen to advance the involvement of CALD community members at all stages of its clinical research program, with the goal of increasing CALD patient participation in its cancer clinical trials. The CST collaborative has chosen to commence its program of engagement with the Australian Arabic-speaking community. Arabic is the third most spoken language in Australia following English and Mandarin.

In this study, CST seeks to engage through a series of focus groups with **healthcare professionals** who work with **adults with cancer** from the **Australian Arabic-speaking community**, to understand the barriers and enablers of Australian Arabic-speaking patient participation in cancer clinical trials.

WHY HAVE I BEEN INVITED?

You have been invited to participate in this study because you are a healthcare professional who has experience working with **adults with cancer** from the **Australian Arabic-speaking community**. You have either received this email as a member of a health professional mailing list or you have responded to a social media post about the study.

FUNDING

The Cancer Symptom Trials collaborative receives infrastructure funding from Cancer Australia and some of these funds have been allocated for this study.

WHAT DOES MY PARTICIPATION INVOLVE?

If you decide to participate in the study, you will be invited to take part in a single focus group discussion led by a member of the research team. The focus group will be held via a video-conference meeting using the secure UTS Zoom Platform. The focus group session will be conducted with a maximum of 10

participants (plus facilitators) and take up to 90 minutes. There are no costs associated with participating in this research project, nor will you be paid for your time. If you are not available to take part in one of the allocated focus group sessions, there is the option of participating in an individual interview at a mutually convenient time.

Consent and registration: If you decide to participate in the study, you will need to provide your consent by ticking a box on the Humanitix registration page, acknowledging that you have read this Participant Information Sheet.

Once you have consented to the study, you will then proceed through the study registration process via Humanitix and be asked to select your preference for one of three focus group sessions available or an interview if you are not available to attend the scheduled focus group sessions. The interview will follow the same consent process as for the focus groups, will be conducted by a member of the research team using the UTS Zoom platform, at a mutually convenient time and will cover the same topics as the focus groups.

Information collected: By consenting to this study, we will also collect some demographic details about yourself via the Humanitix registration process including: your gender; ethnicity; language capable of speaking or understanding; which state in Australia you are located; your type of work setting; your occupation; years of experience in your occupation; any experience in clinical research and how you heard about this study. This data will be treated confidentially and is being collected for the purpose of reporting our research findings in a de-identified format.

Registration confirmation: Once you have completed the study registration via Humanitix, a confirmation email with your consent response, and a copy of this Participant Information Sheet will be sent to you confirming your registration.

A Zoom meeting link for your preferred focus group session will be emailed to you in the week prior to the focus group. Please do not share this link. If your colleagues or others wish to attend, please invite them to register by sharing the original invitation email/social media post with them. If you have selected to take part in an interview, you will be contacted by a member of the research team to arrange for a mutually convenient time to conduct the interview.

Zoom Platform: Zoom is a free video-conferencing platform that you will need to have downloaded to your device before the focus group or the interview. Please click this link to download Zoom: <https://zoom.us/>. We will be using the secure UTS Zoom platform to ensure your privacy.

The focus group (or interview) discussion will cover the following topics:

- your understanding of clinical trials;
- your experience as a healthcare professional working with adults with cancer from the Australian Arabic-speaking community and their participation in cancer clinical trials;
- your perspectives of any barriers or enabling factors contributing to cancer clinical trial participation in the Australian Arabic-speaking community; and
- any recommendations or suggestions you may have to improve cancer clinical trial participation with people from the Australian Arabic-speaking community.

By consenting to participate, you are also consenting to the audio and video recording of the focus group (or interview) session, which will help to ensure accuracy of data collection for analysis purposes. The recorded focus group (or interview) will be transcribed verbatim (word for word). Your name will be replaced with a code, so your responses will not be associated with your name. The recordings will be permanently deleted once analysis is complete.

ARE THERE ANY RISKS/INCONVENIENCE?

The content of the focus groups (or interviews) are not anticipated to cause any physical, psychological or emotional harm, as they are focused on seeking opinions from you as the healthcare professional.

The biggest impost is on your time. The focus group is expected to take up to 90 minutes. We have tried to ease this inconvenience by conducting the focus groups via Zoom and offering different session times for you to choose from. If you are unable to take part in the scheduled focus group, we are providing the option for an interview at a mutually convenient time.

We will also be collecting some demographic details from you at registration for the purpose of reporting our research findings. These questions will take approximately 5 minutes to complete. All data collected and reported will be treated confidentially by replacing your name with a code, and securely stored in a de-identified format as explained in the section *“What will happen to information about me?”* below.

DO I HAVE TO TAKE PART IN THIS RESEARCH PROJECT?

Participation in this study is voluntary. It is completely up to you whether you decide to take part. If you decide not to participate, or to withdraw from the study, it will not affect your relationship with the researchers, UTS, nor will it impact your memberships with the professional health networks.

WHAT IF I WITHDRAW FROM THIS RESEARCH PROJECT?

If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason, by contacting CST (CST@uts.edu.au). If you decide to leave the study, the researchers will not collect additional personal information from you, although personal information already collected will be retained to ensure that the results can be measured properly and to comply with law. You should be aware that data collected up to the time you withdraw will form part of the study results. If you do not want your data to be included, you must tell the researchers when you withdraw from the study.

WHAT WILL HAPPEN TO INFORMATION ABOUT ME?

By agreeing to participate in this study, you consent to the research team collecting and using demographic details about you for reporting the findings of this study. Any information obtained in connection with this study that can identify you will remain confidential.

All demographic details collected will be de-identified and treated confidentially by replacing your name with a code. The data will be securely stored in a de-identified format on a controlled-access folder on the UTS server for five years, and access will be limited to the project research team and administrators.

By attending the focus group you will be asked to respect other participants and keep the discussion private to ensure the confidentiality of others. The focus groups (or interview where applicable) will be conducted via video-conferencing and will be recorded. Once transcribed, your name and any identifying information will be removed. Transcripts will be labelled with a study code. All recordings, transcripts,

information and analysed data will be stored on a controlled-access folder on the UTS server for five years, and access will be limited to the project research team and administrators. Once recordings have been analysed, they will be permanently deleted to further ensure your privacy. After five years all data will be securely disposed of.

The data gathered from this study will be used to inform future CST studies and may be used for future research purposes with appropriate ethical approval. It is anticipated that the findings of this study will be published and/or presented in a variety of forums for example at conferences and in peer review journal publication(s). In any publication and/or presentation, the research findings will be provided in such a way that you cannot be identified.

In accordance with relevant Australian and NSW Privacy laws, you have the right to request access to the information about you that is collected and stored by the research team. You also have the right to request that any information with which you disagree be corrected. Please inform CST via the email provided at the end of this document if you would like to access your information.

WHAT IF I HAVE ANY QUERIES OR CONCERNS?

If you have queries or concerns about the study, please feel free to contact us on CST@uts.edu.au.

You may download a copy of this Participant Information Sheet for your records.

NOTE:

This study has been approved in line with the University of Technology Sydney Human Research Ethics Committee [UTS HREC] guidelines. If you have any concerns or complaints about any aspect of the conduct of this research that you wish to raise independently of the research team, please contact the Ethics Secretariat on ph.: +61 2 9514 2478 or email: Research.Ethics@uts.edu.au] and quote the UTS HREC reference number. Any matter raised will be treated confidentially, investigated and you will be informed of the outcome.