

Dear Participant,

You are invited to participate in a project, **'Assessing the quality of consumer entered data - Direct comparison of patient entered data on CART-WHEEL (rare tumour database) and clinician entered data (PMCC sarcoma database).**

In Australia, rare tumours such as sarcoma make up to 20% of all cancer diagnoses, yet they only receive about 5% of research funding and attention. The CART-WHEEL rare tumour website aims to address this issue. It collects information directly from people such as yourself who have been diagnosed with a rare tumour to increase our understanding of such cancers. The site is available on the internet, accessible internationally, to collect information from as many people as possible. More information regarding this website can be found on the provided pamphlet and on-line (www.cart-wheel.org).

This study will compare the information entered by people with rare tumours on CART-WHEEL to doctor collected information on the sarcoma database at the Peter MacCallum Cancer Centre. This will enable us to examine any differences between the two sources of data and to determine the usefulness of CART-WHEEL information for future research.

You have been selected to be a part of this study as you have a diagnosis of sarcoma and data on the Peter MaCallum sarcoma database.

If you would like to participate in this study please log on to www.cart-wheel.org and follow the prompts provided on the website. You have control over any data you enter onto the CART-WHEEL website as you determine what you want your information is used for. Different levels of consent range from storage of your de-identified data to consent to be contacted for participation in a relevant clinical trial.

LEVEL ONE consent is required in order for this study participation. However, please read all the options carefully and feel free to agree to more levels of consent depending on what you think is best for you.

If you require further information or if you have any problems concerning this project, you can contact the BioGrid Australia Office or the principal researchers:

Dr Susie Bae
Dr Jayesh Desai
A/Prof Clare Scott

Telephone: +61-3-9342 3126
Telephone: +61-3-9342 7695
Telephone: +61-3-9345 2498

If you have any complaints about any aspect of the project, you may contact:

Name: Relevant PMCC HREC personnel
Peter MacCallum Human Research Ethics Committee
Telephone: +61-3-9656 1699

The CART-WHEEL database is carried out according to the *National Statement on Ethical Conduct in Human Research* (2007) produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies.

We appreciate your time to help us better understand sarcoma and other rare tumours.

Yours sincerely,

A handwritten signature in black ink, appearing to be 'Jayesh Desai'.

Dr Jayesh Desai, Sarcoma Medical Oncologist, Peter MacCallum Cancer

Esther Yeoman (Sarcoma Nurse Coordinator, Peter MacCallum Cancer Centre)

Associated Investigators: A.Prof Clare Scott (Medical Oncologist, Royal Melbourne Hospital), Dr Susie Bae (BioGrid Clinical Research Fellow), Dr Suzanne Kosmider (Medical Oncologist, Royal Melbourne Hospital)