

Improved Understanding of Research Participation by Culturally & Linguistically Diverse (CALD) People Affected by Cancer

Flagship Program This Case Study is Attributed to
Policy & Practice (T2/T3)

Translational Pipeline Focus
T2/T3

Type of Cancer(s)
~Not Site-Specific Cancer

Location(s) Where Research is Based
South West Sydney Local Health District

Summary

Clinical trials play a critical role in advancing cancer care, but few patients participate in trials, particularly those from culturally and linguistically diverse (CALD) backgrounds. This contributes to health inequalities, as trial results may not apply to CALD patients, who also miss out on state-of-the-art care provided via trials. Trial participation by CALD patients is a highly relevant issue in South West Sydney (SWS), where 48% of the population speaks a language other than English at home.

While international research has found language and cultural barriers affect trial participation by CALD patients, this paper suggests language barriers are particularly problematic for CALD cancer patients in SWS. Our analysis of ~20,000 SWSLHD cancer patient records from 2006 - 2016 showed significant differences in trial participation rates according to preferred language. CALD patients whose preferred language was not English were half as likely to participate in a trial than both CALD patients whose preferred language was English and non-CALD patients. This research provides the foundation for developing targeted strategies to overcome language barriers, such as simplified and translated multimedia trial information materials, to increase trial participation by CALD patients in SWS and NSW more broadly. This will improve outcomes for this population through improved access to state-of-the-art care and more generalisable trial results.

The Contribution, Impact or Benefit to Community

This research was championed by CONCERT Translational Research Fellow & Deputy Director, Dr Ben Smith, who is a pivotal member of CONCERT's Psycho-Oncology Program.

This research was the first investigation of cancer research participation rates and correlates among CALD patients in Australia, which is one of the most culturally diverse countries worldwide. While international research has found language and cultural barriers affect trial participation by CALD patients, our research suggests

that lack of English proficiency more specifically is a significant barrier to trial participation by CALD cancer patients in SWS. The importance of this research was highlighted in the editorial for the February 2018 issue of the *Asia-Pacific Journal of Clinical Oncology*, in which the work was published: *“Overall, this study by Smith et al. is important as it highlights that language remains as a major barrier that challenges us to search for innovative solutions...more needs to be done to understand how the clinical trial enrolment can be optimized in increasingly multicultural societies, and Smith et al. have done well to bring this continuing challenge to the forefront of our minds again.”*

This work lays the foundation for endeavours to improve clinical trial participation by CALD cancer patients. It suggests that efforts to improve CALD cancer patient trial participation should focus on increasing opportunities to participate in trials by making them more accessible to people with limited English (and sometimes health) literacy. Our findings are a call to action for funding bodies, pharmaceutical companies, ethics committees, clinical staff and administrators to work together to improve trial participation by CALD cancer patients by:

- 1) ensuring that CALD communities are engaged in the trial development process;
- 2) investing additional resources in recruitment of CALD participants; and
- 3) exploring alternative methods of consenting CALD patients to trials such as audio/video consent.

We are currently exploring ways to increase the opportunities for CALD patients to take part in cancer trials by making it easier for clinicians to explain trials to CALD patients (e.g. through training of both clinicians and interpreters) and for patients to understand trials (e.g. through provision of simplified and translated multimedia trial information). We are also conducting a follow-up study of CALD cancer patients' knowledge and attitudes regarding trials to guide information provision.

This research will benefit CALD people affected by cancer. Improving CALD cancer patients' participation in trials, which provide state-of-the-art care and ensure that new cancer treatments are safe and effective, is likely to help address the poorer outcomes experienced by CALD cancer patients. Making trials more accessible to CALD patients who constitute a large proportion of the population of SWS and NSW more generally will also build research capacity by increasing the local feasibility of studies, leading to more trials benefitting CALD patients.

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