

Dr Shayam Mutaramalingam [@shyamrith](#)

Asked delegates - **how many of you feed back results to your participants?** I gave literal blood and sweat & never heard anything back. You have a responsibility'

'Build trust at the speed of relationships, not at the speed of your product cycle' [#ARCSAus](#)

On the ConViCTioN project, [@JanelleBowden](#)

explaining project purpose & process - key to success was time spent in planning, relationship building, **setting out ways of working**, consumers determined terms of reference & shared purpose, then everyone was *ready* to deliver





Straight up Shayam Mutaramalingam [@shyamrith](#)

Diversity is a fact in Australia. Why is inclusion a choice?

(1/4 people in Aus were born overseas, 1/2 people have parents who were born overseas, we speak >200 languages)

3. What does Australia look like?

SWSLHD Multicultural Services Implementation Plan 2021-2024

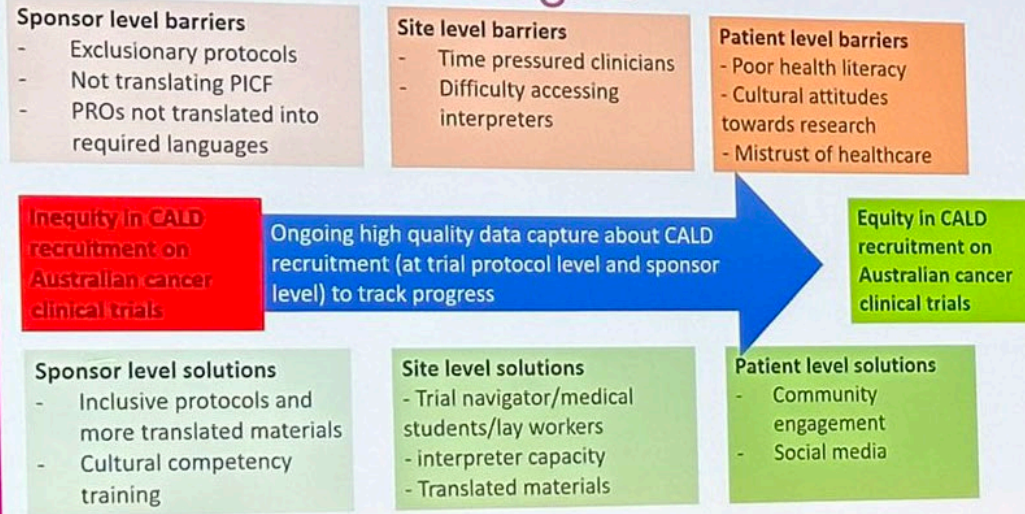
Language	Bankstown	Camden	Campbelltown	Fairfield	Liverpool	Wingecarribee	Wollondilly	SWSLHD
English	34.1%	81.1%	83.6%	24.8%	41.4%	88.3%	89.1%	46.3%
Arabic	17.2%	1.4%	3.4%	7.9%	11.4%	0.1%	0.6%	0.7%
Vietnamese	7.2%	0.3%	0.7%	20.4%	4.9%	0.1%	0.1%	7.1%
Mandarin	5.0%	0.6%	1.1%	2.5%	1.3%	0.5%	0.2%	2.5%
Cantonese	3.9%	0.5%	0.7%	4.3%	1.3%	0.2%	0.2%	2.5%
Greek	5.4%	0.5%	0.6%	0.5%	1.5%	0.4%	0.3%	2.2%
Spanish	0.9%	1.3%	1.7%	3.1%	2.5%	0.3%	0.4%	1.7%
Italian	1.7%	1.3%	0.5%	2.6%	2.2%	0.6%	0.7%	1.7%
Assyrian Neo-Aramaic	0.1%	0.3%	0.1%	6.7%	1.7%	0.0%	0.0%	1.6%
Hindi	0.8%	0.9%	2.4%	0.7%	4.0%	0.1%	0.0%	1.5%
Bengali	2.5%	0.1%	3.0%	0.0%	0.5%	0.0%	0.0%	1.3%
Urdu	1.9%	0.3%	0.9%	0.2%	1.0%	0.0%	0.0%	1.0%
Serbian	0.2%	0.5%	0.2%	1.9%	2.4%	9.1%	9.2%	0.9%
Khmer	0.1%	0.1%	0.4%	3.6%	1.0%	0.0%	0.0%	0.9%
Samoan	0.4%	0.3%	2.2%	1.0%	1.0%	0.0%	0.0%	0.8%
Tagalog	0.7%	0.3%	1.5%	0.7%	1.2%	0.1%	0.1%	0.8%
Chaldean Neo-Aramaic	0.0%	0.1%	0.0%	3.3%	0.7%	0.0%	0.0%	0.8%
Macedonian	1.0%	0.2%	0.2%	0.6%	1.0%	0.1%	0.1%	0.7%
Croatian	0.3%	0.5%	0.4%	1.3%	0.8%	0.1%	0.3%	0.6%
Indonesian	1.2%	0.1%	0.4%	0.2%	0.4%	0.0%	0.0%	0.6%
Nepali	0.9%	0.1%	0.8%	0.0%	0.3%	0.3%	0.0%	0.5%
Korean	1.2%	0.1%	0.1%	0.1%	0.1%	0.1%	0.0%	0.4%
Leo	0.0%	0.1%	0.6%	1.0%	0.7%	0.0%	0.0%	0.4%
Turkish	0.4%	0.1%	0.1%	0.8%	0.8%	0.0%	0.1%	0.4%
Filipino	0.3%	0.2%	0.7%	0.3%	0.5%	0.1%	0.1%	0.4%
Portuguese	0.8%	0.1%	0.2%	0.1%	0.3%	0.1%	0.0%	0.4%
Punjabi	0.4%	0.3%	0.7%	0.1%	0.5%	0.1%	0.0%	0.3%
Tongan	0.4%	0.1%	0.5%	0.4%	0.2%	0.0%	0.0%	0.3%
Thai	0.3%	0.2%	0.3%	0.5%	0.3%	0.1%	0.1%	0.3%
Min Nan	0.1%	0.0%	0.1%	1.2%	0.1%	0.0%	0.0%	0.3%
Polish	0.2%	0.2%	0.3%	0.5%	0.4%	0.1%	0.1%	0.3%
Other	3.6%	2.1%	4.1%	3.1%	4.5%	1.5%	1.2%	3.4%
Not stated	5.8%	4.4%	5.8%	4.4%	6.7%	6.1%	5.2%	5.6%
Total	100%	100%	100%	100%	100%	100%	100%	100%

#ARCSAus



On making change so that clinical trial populations are representative - [@DrAbhiPal](#) insisting we can't keep homogenising everyone who isn't white, middle-class...! Must use data to properly describe people. Eg measure ethnicity & English proficiency separately [#ARCSAus](#)

5. Australian data on current barriers, solutions and strategies



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Summary: We're in an inequity state

Needed:

- Ongoing high quality data capture re CALD recruitment (trial protocol & and sponsor level) - that describes people properly - is needed.
- Meaningful community engagement, investing in strategies that work essential [#ARCSAus](#)

Concepts to cover in clinic appointment

1. Break the bad news that
2. Address patient and care expectancy
3. Explain the limitations of why some patients consid
4. Explain clinical research (
5. Address common miscon (e.g. guinea pig, industry
6. Uncertainty involved in re toxicity and benefit
7. Explain greater time com investigations
8. Explain randomisation an
9. Provide the PIS and advise him to discuss with family and friends

All done via a face to face interpreter (or video) – at least double the length of a consultation for a patient who speaks English

Known intersectionality with other barriers (e.g. travel, money, time, mistrust)

Explaining the complexity of the initial conversation about a clinical trial [@DrAbhiPal](#) - overlaid then with the complexity of using interpreter and then also thinking about the intersectionality with other barriers like transport & cost of appointments [#ARCSAus](#)

LGBTQ+ people and cancer clinical trials

METHODS

- 764 cancer RCTs addressing a therapeutic intervention (1991-2017)
- 462,449 patients
- Reviewed to sexual and gender minority (SGM) reporting
- 2 independent reviewers

RESULTS

- No trials reported SGM status, LGBTQ+ status or patients with non-binary gender
- Only 2 patients were listed as having gender “not reported” or “unknown”
- 1 erectile dysfunction trial used exclusionary language – penile-vaginal intercourse

Source: Ludmir et al. Reporting and exclusion of sexual and gender minorities in cancer clinical trials. *International Journal of Cancer*. 2020.



SEXUAL ORIENTATION	INTERSEX STATUS
<p>How do you describe your sexual orientation?</p> <ul style="list-style-type: none"> <input type="checkbox"/> Straight (heterosexual) <input type="checkbox"/> Gay or lesbian <input type="checkbox"/> Bisexual <input type="checkbox"/> I use a different term (please specify) <input type="checkbox"/> Don't know <input type="checkbox"/> Prefer not to answer <p><small>* Researchers may include additional sexualities when appropriate. In these cases, people may identify as multiple identities (such as bisexual and queer), so allowing for multiple selections should be considered.</small></p>	<p>Were you born with a variation of sex characteristics (sometimes called 'intersex')?</p> <ul style="list-style-type: none"> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know <input type="checkbox"/> Prefer not to answer <p><small>* Researchers conducting research with people born with a variation of sex characteristics should consult intersex-led organisations such as Intersex Human Rights Australia.</small></p>
GENDER	
<p>How do you describe your gender?</p> <ul style="list-style-type: none"> <input type="checkbox"/> Man or male <input type="checkbox"/> Woman or female <input type="checkbox"/> Non-binary <input type="checkbox"/> I use a different term (please specify) <input type="checkbox"/> Prefer not to answer <p><small>* Research that is exclusively for trans populations may include additional gender variables when appropriate. In these cases, research participants may select more than one gender variable, so allowing for multiple selections should be considered. For indicators that are specific to trans research, visit the Researchers page on ACON's TransHub.</small></p>	<p>At birth, you were recorded as:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Another term (please specify) <input type="checkbox"/> Prefer not to answer (inclusion optional)



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#2023ARCS

Health Care Professional Positions



Source: Ussher et al. LGBTQI Inclusive Cancer Care: A Discourse Analytic Study of Health Care Professional, Patient and Carer Perspectives. *Frontiers Oncology*. 2022.



Inclusive Practitioner

I am proactive in being LGBTQI inclusive, open and reassuring. I create a place of cultural safety.

Most [LGBTQ people] come out because they're correcting a misassumption. But it shouldn't be up to them to have to be in that vulnerable situation and then be brave enough to speak up not knowing what the response is going to be.



Egalitarian Practitioner

I am accepting of all patients. If LGBTQI+ status is important the patient will tell me. However, cancer is not any different for LGBTQI+ patients.

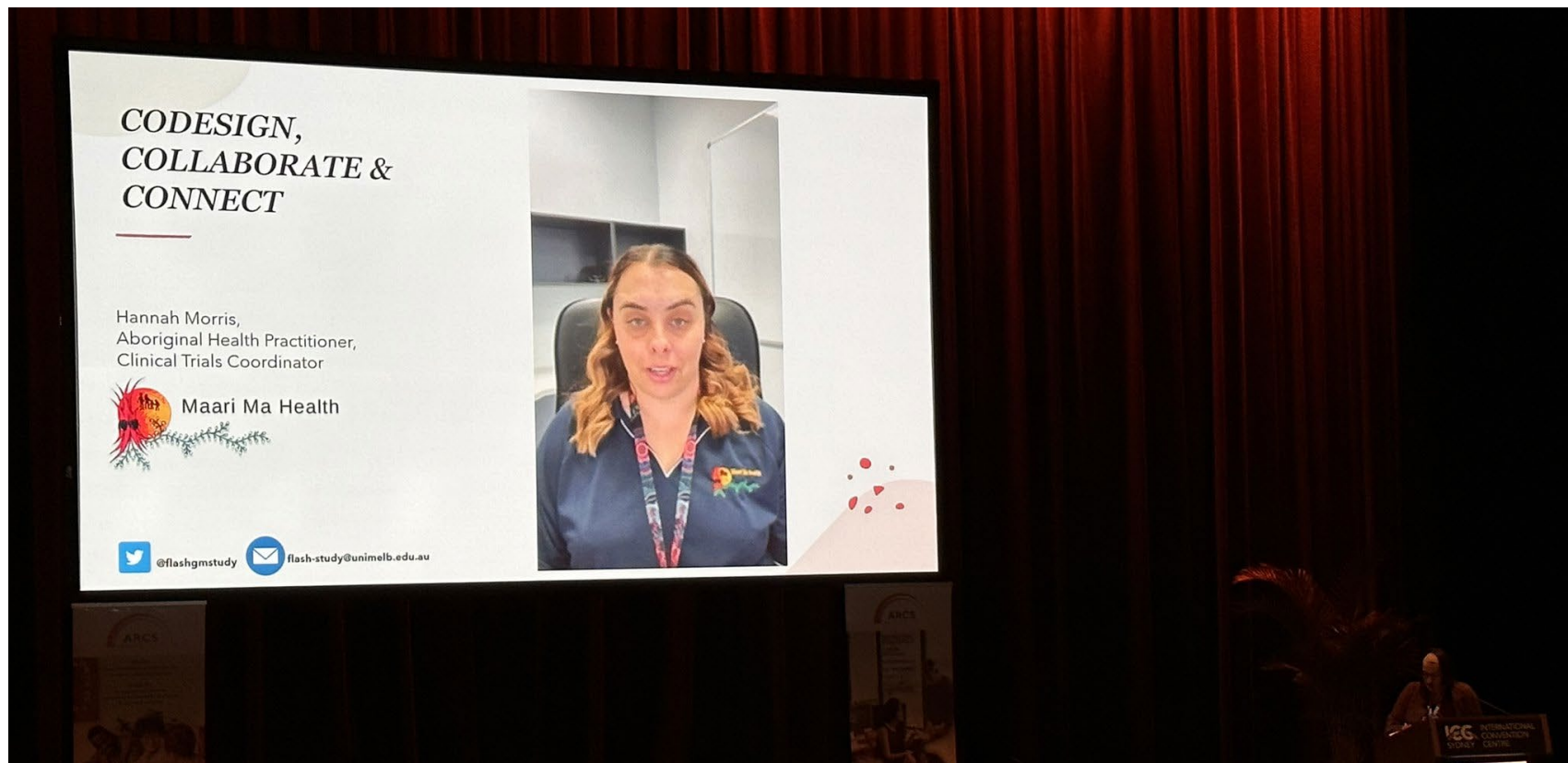
"I don't really understand the concept of "LGBTI friendly". We are "friendly" to everyone, I'm not sure why you want to single out a particular population. Surely we are well past that."



Anti-inclusive Practitioner

I don't want to know or hear about LGBTQI status or issues.

"I don't see why everyone has to **force their sexual orientation on others**. Heterosexual people don't go around talking about their sexual orientation. I am now forced into hearing about and watching **abnormal behaviour** on TV and more advertisement of non heterosexuals."



Belinda Moore, Rumbalara Aboriginal Cooperative & [@UniMelb](#) clinical trials manager [@FlashgmStudy](#)
Local Aboriginal staff at sites nationally, has **co-designed multimedia info & consent**. Benefits & joy of 'leading from the back' - building capacity in others who are integrated in communities at sites to lead this research.

Hannah Morris, coordinator at Broken Hill insists co-design & trust are key. Culturally adaptive governance, & regular study visits, 'power hours' to share learnings & celebrate successes.

Sharon, [@FlashgmStudy](#) research participant: *As a person working in research, try understanding that the priorities of mainstream Australians often don't align with the priorities of some Indigenous people. Whether you understand it or not, doesn't matter, just accept it.*

When I say “liberatory access,” I mean access that is more than simply having a ramp or being scent free or providing captions. Access for the sake of access or inclusion is not necessarily liberatory, but access done in the service of love, justice, connection and community *is* liberatory and has the power to transform.

 @miamingus

<https://leavingevidence.wordpress.com/2011/02/12/changing-the-framework-disability-justice/>