

Sydney Health Partners/Monash Partners webinar, 20 June 2023

Consumer and Community Involvement in Clinical Trials Reaching people from migrant and refugee communities for clinical trials

Detailed Notes

Importance of involving CALD consumers in health care and health research

- Australia is multiculturally and linguistically diverse: 52% of the population were born overseas or have 1 parent who was born overseas; 22.5% speak a language other than English (www.abs.gov.au/statistics/people/people-and-communities/snapshot-australia/2021)
- CALD consumers bring unique perspectives that help health services and health researchers work “within diversity” rather than “with diversity”; lead to better understanding and addressing consumer needs, resulting in more positive health care experiences, better outcomes for patients, and better health care seeking behaviour in the future
- CALD communities are not a small minority; researchers need to commit to recruit people from diverse backgrounds as partners and as participants, so that CALD values, needs and preferences are heard, respected and honoured
- “If you don’t ask, I won’t tell”; researchers often make assumptions about CALD communities that are not always correct; importance of working with community members to design appropriate research and interventions
- Researchers need to change the way trials are designed and delivered to engage effectively with CALD communities, especially where English is not a first language; need to consider awareness, access and involvement in clinical trials
- Researchers collectively have a professional responsibility to advocate for system change and better resources to support diversity – not just those researchers who are working with minority communities at a point in time; we **need to do research differently, not just include different people**
- Researchers need to consider the cultural and professional lens they bring when working with diverse communities which also influences their beliefs, values and behaviours
- For many CALD communities, the final decisions by individuals will be a family decision, not an individual decision
- Researchers often frame language difficulties among CALD peoples as a barrier from their side; need to reframe this as a communication need that researchers are failing to meet; researchers and health care professionals need to take responsibility for providing linguistically and culturally appropriate resources and services to meet needs

National guidance for consumer involvement and CALD communities

- ACTA has undertaken various projects to elevate the importance of CALD community engagement in clinical trials including environmental scan, workshop report, national statement, and engagement recommendations

- MRFF principles for consumer involvement: required in all types of research, at all stages of research, in partnership with researchers, effectively, sensitively and safely, with broad diversity and equity
- Guiding principles relevant to all consumers including CALD communities
- Important that researchers involve people from all walks of life and work to remove barriers
- see ACTA and MRFF links at end of summary

Important cultural factors

- CALD peoples' experiences of health systems from their country of origin and in Australia are often not positive; even for English speaking CALD peoples; aspects of health care delivery that are not culturally and spiritually aligned with their values and beliefs, making the health system challenging; these are even more difficult for those who don't speak English well enough to communicate effectively
- Western medicine/research "leans towards survival at all costs" whereas in Islam, for example, life on earth is just a stepping stone on the journey to heaven; if you are good and patient with all that this life brings your way – good and bad – you will be rewarded; so health complications are viewed as a test from God and as a blessing, a means of cleansing one's sins
- So for CALD patients who are in a clinical situation and balancing risks and benefits of treatment or research, they may be weighing up medical, religious and cultural factors; e.g., if my body is a "vessel from God" is it permissible for me to be experimenting with it or going on a trial drug?
- Many CALD people will avoid experimental options or even conventional treatments if they believe they might interfere with God's plan for them
- So research projects that try to recruit people quickly – for example within 24 hours of hospital admission – are difficult for CALD people because they are needing to weigh up so many factors in their decision, not just their personal views
- Degree of mistrust towards researchers and research institutions among a lot of minority groups, research has a historical legacy of poor ethical practices that were done "to people" rather than collaboratively "with people", so many people influenced by these past views/experiences
- Also mistrust stems from CALD communities viewing academic institutions as elitist and not committed to the welfare of minority populations
- Mistrust also fostered by communication barriers – English proficiency, medical/research jargon, lack of sufficient information about purpose, procedures and value of the CT, complex forms and consent procedures, failing to communicate research findings back to communities,

Systemic barriers

- Systemic barriers inherent in design of clinical trials; people with no or low English literacy levels routinely excluded from CTs
- Many researchers believe the cost or burden of language translation are too great
- Some health service models – where patients might be recruited – are culturally inappropriate
- Need to engage with and actively involve community advocates in health research to help design strategies that can turn the ship around

The essential ingredient - building trust and relationships

- **“we are not hard to reach ...we find it hard to trust”**
- There are CALD people who want to be involved in clinical trials to improve access for others in their community – **“there is no lack of skills in the community; there is a lack of fair opportunities”**
- CALD consumer involvement in research helps build understanding and trust with members of that community, provides opportunity to contribute to decisions about trial direction and design, help find solutions that work for CALD members, identify ways to more effectively engage with the wider community
- More CALD involvement will also help design trials in ways that encourage more CALD community engagement
- Building trust and relationships with CALD communities is paramount to increasing engagement in clinical trials; this is an investment that takes time; should be well established before grant writing or starting a research project
- Views of religious and/or community leaders, ex football players, prominent personalities, etc. can be powerful influences
- Need to find ways to communicate with CALD people who have little or no English, to explain what clinical trials are, and why they might consider being involved in them - to help build health literacy as well as trust
- Working with representatives from CALD communities will also help ensure CTs and communication about them are culturally sensitive and culturally appropriate
- need to bring in representatives from within the communities who understand cultural and religious nuances that influence the beliefs, attitudes and behaviours of those communities

Role of interpreters/translators

- Interpreters play a critical role in helping to give equitable access to health services and health research for people who have no or limited English
- Important differences between translation and interpretation
- Conflict of interest issues can arise for interpreters working with some clients, especially in smaller communities or rural areas, etc; professional ethics for interpreters to discuss and manage these issues
- “Hard to service languages” – some efforts to help build more capacity (e.g., funding in NSW), training people from those communities to bring them into the interpreter/translator profession

HELPFUL TIPS

- Researchers often use expression of interest forms when trying to find consumers to be involved in research; this process is often too complicated: researchers should only ask for information that is really essential
- Researchers should think about how to help consumer members contribute - do they need training, background information about the project and a safe place to ask questions; is website

- and other project information easy to understand/navigate/consumer-friendly; are there multiple communication options? Limited use of medical jargon? a list of acronyms?
- If researchers are planning to have materials translated into other languages, they need to understand what “writing for translation” means; importance of simplifying complicated content
 - The “excuse” of not being able to (or afford to) access an interpreter or translate materials should be stopped
 - Need to take research to where the CALD communities are located; selection of CT sites needs to actively include locations that have higher concentrations of CALD communities (rather than avoid these sites for the same reason)
 - Need to focus not just on overall recruitment numbers but also on diversity among recruited patients
 - Include diversity among the researcher members of the team
 - Look for cultural awareness training targeted at the specific CALD groups you want to work with
 - Need to help train consumers about elements of CTs, patient numbers, risks involved, etc.
 - Create more spaces for multicultural communities to have a voice and share their views and experiences about health care and health research
 - Researchers need to be conscious of how and when they communicate with consumers/participants; often times “surges” and then nothing; need to do a better job of more regular updates, even if it is to say that there have been no major developments; better than “radio silence” which gives the sense that you don’t care and/or I don’t matter
 - Have information about CTs in public foyers of hospitals in multiple languages good place to reach lots of people about positive impact of CTs on communities
 - CALD communities in rural and regional areas across Australia more challenging to engage in research; telehealth and tele trials are helping to open more access though much work to be done for non-English speakers
 - If creating videos in other languages, have text in language at the bottom as well as audio in language; co-designing any messaging should involve community representatives and translators or interpreters; issue of literal translation vs ensuring coherent message
 - CALD communities are very broad – need to get to know your population better; start with one or two communities and then build up; don’t try to recruit everyone from across a diverse community; perhaps start with a group with high numbers or most affected by the health condition of interest; strategies and solutions that work for one community may also be relevant for engaging with other minority groups

HELPFUL LINKS/RESOURCES

National

- Inaugural National Multicultural Health Conference, November 2023 in Sydney.
<https://www.multiculturalhealthconference.org.au/>
- ACTA Clinical Trial Diversity: CALD project <https://clinicaltrialsalliance.org.au/resource/acta-clinical-trial-awareness-and-access-amongst-culturally-and-linguistically-diverse-cald-populations-environmental-scan/>

- Summary of recommendations from ACTA for CALD communities in clinical trials
https://clinicaltrialsalliance.org.au/wp-content/uploads/2023/05/20230502_ACTA_CALD-in-Clinical-Trials-Reccomendations.pdf
- MRFF Consumer involvement guidelines
<https://www.health.gov.au/resources/publications/principles-for-consumer-involvement-in-research-funded-by-the-medical-research-future-fund?language=en>

Consumer groups (national):

- Sisters Cancer Support Group <https://scsg.org.au/>
- Cancer Voices Australia <https://www.cancervoicesaustralia.org/>
- Consumers Health Forum of Australia <https://chf.org.au/consumer-and-community-organisations>

For consumer representatives (NSW/ACT)

- Health Consumers NSW <https://www.hcnsw.org.au/for-consumer-representatives/state-level-engagement/>
- Cancer Voices NSW Consumer Involvement in Research Program
<https://www.cancervoices.org.au/consumer-representatives/>
- Consumer Advocates with CanAct <https://www.canact.com.au/>
- Researchers looking for consumers: <https://www.cancercouncil.com.au/research/for-researchers/consumer-review-grant-applications/>
- SWSLHD Consumer and Community Participation Networks and Services
<https://www.swslhd.health.nsw.gov.au/ccp/network.html>
- WSLHD <https://www.wslhd.health.nsw.gov.au/consumer-partnership/get-involved/get-involved>
- SESLHD <https://www.seslhd.health.nsw.gov.au/how-to-participate-as-a-consumer-south-eastern-sydney-local-health-district>
- SLHD <https://slhd.health.nsw.gov.au/donations-support/consumer-community-participation>

Community and Consumer organisations (national/NSW):

- Arabic Council Australia <https://www.arabcouncil.org.au/>
- Arabic Welfare Inc. and or Arab Workers Network <https://www.arabicwelfare.org.au/>
- Auburn Diversity Services <http://www.adsi.org.au/>
- Australian Islamic Medication Association <https://aimamed.com.au/contact-us/>
- Bankstown Multicultural Youth Service <http://www.bmys.net.au/>
- Ethnic Communities council NSW (ECCNSW) <https://eccnsw.org.au/>
- Islamic Women's Welfare Association <https://www.iwwa.org.au/contact-us/>
- Multicultural Disability Advocacy Association NSW <https://mdaa.org.au/>
- Muslim Health Professionals Australia <https://mhpaustralia.com.au/executive-team>
- Muslim Women's Association <https://mwa.org.au/>
- Australian Muslim Women's Centre for Human Rights <https://amwchr.org.au/>
- The Multicultural Network <http://tmn.net.au/>

Language translations

Documents developed by FECCA (Federation of Ethnic Communities' Councils of Australia) and AUSIT (Australian Institute of Interpreters and Translators Inc):

- [Recommended Protocols for Translation of community communications](#) - would be most relevant for researchers to refer to when developing the English text
- [Guidelines for Community Review Panels](#) – Co-design: if we were to engage members of the community to review documents after they have been translated, there are some good tips and questions to guide the review panel.

Links to previous SHP/Monash Partners webinar recordings

Webinar 1: Involving consumers in planning, development and design

Webinar 2: Practical strategies for consumer involvement and lessons learned

Webinar 3: Empowering consumers by establishing a Consumer Advisory Panel

Webinar 4: Reaching people from migrant and refugee communities for clinical trials

Monash Partners: <https://monashpartners.org.au/webinars-home/>

Sydney Health Partners: TBC