



The George Institute for Global Health

Better treatments. Better care. Healthier societies.



ROUNDTABLE REPORT

Roundtable Agenda Chaired by Professor Christine Jenkins

What we understand about sex and gender bias in research and healthcare	Dr Cheryl Carcel	The George Institute
How the sex and gender bias plays out in CVD: <ul style="list-style-type: none">•the lived experience•the health care experience•the public health response	Panel: Dr Cheryl Carcel Jen O’Neill Robert Zecchin Julie Anne Mitchell Bonney Corbin	The George Institute Consumer Advocate Western Sydney LHD, ACRA Heart Foundation Australian Women’s Health Network
How the sex and gender bias plays out more broadly in women’s health		
Discussion: <ul style="list-style-type: none">•What is the lived experience?•How does this play out for the communities•How can we ensure consumer lived experience informs this	All	
Summary and next Steps	Prof Christine Jenkins	The George Institute

EXECUTIVE SUMMARY

Organisations representing consumer groups were invited to attend the Sex & Gender Bias in Research and Healthcare Roundtable November 4 2021.

The objectives of the Roundtable were to

- Describe consumers' experience and understanding of the impact of sex and gender on health and healthcare experience;
- Identify consumer priorities for action;
- Understand what consumers/stakeholders believe is needed to achieving equity across in health, health care and research;
- Establish a process for the ongoing involvement of consumers in the work in this area.

Eleven organisations were represented and take out points included:

- Routine sex and gender data collection limited.
- Intersectionality – gender, age, cultural and socioeconomic backgrounds should be considered.
- No gender lens on generic health plans and limited funding of men's and women's health strategies and no LGBTQI+ strategy.
- Where does consumer input sit in the hierarchy? Advisory or leadership?
- Consumer engagement needs to be early and consumers need to feel safe.
- Need to disaggregate data in a way that is useful.

There was support for ongoing engagement and a formal invitation to participate in future work will be arranged.

DISCUSSION SUMMARY: Involvement and Representation

1. Involvement of consumers in research EARLY is critical, from study design and planning onwards. Involvement in setting the research questions is essential. Consumer networks can also assist researchers in reaching diverse communities.
2. Research recruitment and involvement is not representative, this is a key concern of consumers - male/female participation but also LGBTQI+ representation, age (with older women missing out on participation in research), people who are pregnant or breastfeeding, ethnicity, and other elements.
3. The level of demographic detail which would enable broader representation is not collected from participants, reported in research studies, or reflected on by researchers.

DISCUSSION SUMMARY: Raising Awareness & Education

4. Awareness building campaigns on sex and gender need to focus on consumers, clinicians and researchers (not just consumers) and ensuring these groups have the same level of understanding at the same time.
5. Education and capacity building for clinicians about sex and gender needs to start before they are in patient facing roles. This requires teaching sex and gender as core to understanding health interventions and outcomes from student level on.

Primary care also needs strategies to ensure there is greater awareness, knowledge & skills in understanding the impact of sex and gender.

DISCUSSION SUMMARY: Data Collection and Analysis

6. Education and capacity building is needed for researchers and clinicians about how to collect, analyse and report sex/gender data (as well as the other data in point 2). Tools are available like the [ABS Standard](#) for this to be done consistently across disciplines and the research sector (though currently poorly adopted).

7. Research should be required to stratify their results by sex/gender. Advocacy and interaction with funders (including NHMRC) is needed to develop Australian guidelines which require sex and gender stratification and analyses in all funded studies.

DISCUSSION SUMMARY: Breaking down silos

8. The silos and competition between diseases needs to be broken down, alliances between disease focussed organisations for pooling of messages is important. Examples are the common goals shared between CVD-heart/kidney/stroke/diabetes advocacy organisations; and men's and women's health groups. This, along with an economic argument, will assist government advocacy and change. The health economic case for sex and gender analyses is strong but at present not as well developed as it could be.

9. Need for a better understanding of the atypical features of common presentations informed initially by male presentations; and greater awareness by women of the risks of deprioritising their own health needs below that of family and other responsibilities, such as work. This is particularly relevant to cardiac rehabilitation, where under-representation of female patients was observed.

ORGANISATIONS REPRESENTED

- Australian Women's Health Network
- Healthy Male
- LGBTQI+ Health Australia
- Older Women's Network
- Heart Foundation
- Australian Breastfeeding Association
- Jean Hailes
- Australian Cardiac Rehabilitation Association
- Health Issues Centre (Vic)
- The George Institute for Global Health

FOLLOW UP MEETING CONDUCTED:

- Health Consumers NSW

Next Steps

- Report to be circulated
- Invitation for ongoing involvement in discussions around sex and gender bias in research and medicine
- Updating on progress of Centre for Research Excellence and participation.