

Supporting Information

Supplementary methods and results

This appendix was part of the submitted manuscript and has been peer reviewed. It is posted as supplied by the authors.

Appendix to: Carcel C, Vassallo A, Hallam L, et al. Policies on the collection, analysis, and reporting of sex and gender in Australian health and medical research: a mixed methods study. *Med J Aust* 2024; doi: 10.5694/mja2.52435.

 Table 1. Policies and practices on the collection, analysis and reporting of sex and gender data in health and medical research: survey questions

 [following pages]



A) POLICY EXISTENCE AND CONTENT

1. MANDATORY QUESTION Does your organisation have a **policy**, **procedure**, **statement or guideline** in place for defining, collecting, analysing and/or reporting sex and gender data in health and medical research? YES/NO

(This might include a specific dedicated document, or may be a section within another document such as a research code of conduct or guideline for ethical research conduct. Please note there is no expectation for all organisations to have their own policy. If your organisation does not have a policy, or is not actively conducting research, we are still interested in your views on the role these policies may play in promoting equitable research practice, funding, standards in training and/or clinical guidelines and care)

If YES -> go to question 2 If NO -> go to question 9

- 2. When was it first established?
 - In the last 2 years
 - 3-5 years ago
 - More than 5 years ago
 - $\circ ~~\text{I don't know}$

3. Why was the policy, procedure, statement or guideline established? (tick all that apply)

- It was the right thing to do
- It makes for better science
- It facilitates equal health outcomes
- To follow international progress
- It was an organisational led priority
- It was driven by an internal champion
- To be seen as a national/international leader in this field
- o Involvement in the George Institute for Global Health's previous call to action on this topic
- o Not sure
- Other, please state ______
- 4. Is your policy, procedure, statement or guideline publicly accessible? YES/NO Please share the link_____



If YES -> go to question 8 If NO -> go to question 5

5. If your policy, procedure, statement or guideline is not available on a website, are you able to share a copy with us for the purposes of this research only YES/NO

Please share your document by dropping it here:

(If your file is larger than 4.5MB please email <u>AVassallo@georgeinstitute.org.au</u>) including your organisation name. Your email address will not be stored, and your email will be deleted once the document has been saved)

If YES -> go to question 8 If NO -> go to question 6

- 6. What is the title of the document?
- 7. Does your policy, procedure, statement or guideline contain the following elements?:



Does your policy, procedure, statement or guideline contain:

| Funder | Y/N | Research | Y/N | Journal | Y/N | User of research | Y/N | Society/peak group | Y/ |
|--|-----|--|-----|--|-----|--|-----|--|----|
| | | creators/trainer | | | | | | | Ν |
| Definition for sex? | | Definition for sex? | | Definition for sex? | | Definition for sex? | | Definition for sex? | |
| Please provide the definition | | Please provide the definition | | Please provide the definition | | Please provide the definition | | Please provide the definition | |
| Definition for gender? | | Definition for gender? | | Definition for gender? | | Definition for gender? | | Definition for gender? | |
| Please provide the definition | | Please provide the definition | | Please provide the definition | | Please provide the definition | | Please provide the definition | |
| Recognition of trans and gender diverse people | | Recognition of trans and gender diverse people | | Recognition of trans and gender diverse people | | Recognition of trans and gender diverse people | | Recognition of trans and gender diverse people | |
| Recognition of people with intersex variations/differences of sex development | | Recognition of people with intersex variations/differences of sex development | | Recognition of people with intersex variations/differences of sex development | | Recognition of people with intersex variations/differences of sex development | | Recognition of people with intersex variations/differences of sex development | |
| References to other social and | | References to other social and | | References to other social and | | References to other social and | | References to other social and | |
| demographic factors which may contribute to differences in | | demographic factors which may contribute to differences in | | demographic factors which may contribute to differences in | | demographic factors which may contribute to differences in | | demographic factors which may contribute to differences in | |
| disease outcomes (for example income, education, ethnicity) | | disease outcomes (for example income, education, ethnicity) | | disease outcomes (for example income, education, ethnicity) | | disease outcomes (for example income, education, ethnicity) | | disease outcomes (for example income, education, ethnicity) | |



| Requirement or | Requirement or | Requirement or | Requirement or | Requirement or |
|----------------------------|-----------------------------|----------------------------|-------------------------------|-----------------------------|
| recommendation to | recommendation to | recommendation to | recommendation to | recommendation to |
| consider sex and/or | consider sex and/or | consider sex and/or | consider sex and/or | consider sex and/or |
| gender at the research | gender at the | gender at the | gender at the | gender at the research |
| design stage? | research design | research design | research design | design stage? |
| | stage? | stage? | stage? | |
| Requirement or | Requirement or | Requirement or | Requirement or | Requirement or |
| recommendation to | recommendation to | recommendation to | recommendation to | recommendation to |
| consider sex and/or | consider sex and/or | consider sex and/or | consider sex and/or | consider sex and/or |
| gender at the research | gender at the | gender at the | gender at the | gender at the research |
| reporting stage? | research reporting | research reporting | research reporting | reporting stage? |
| | stage? | stage? | stage? | |
| Is there a requirement | Is there a requirement | Is there a | Is there a | Is there a requirement |
| to justify the lack of | to justify the lack of | requirement to justify | requirement to justify | to justify the lack of |
| sex and/or gender | sex and/or gender | the lack of sex and/or | the lack of sex and/or | sex and/or gender |
| considerations, if such | considerations, if such | gender | gender | considerations, if such |
| consideration has not | consideration has not | considerations, if such | considerations, if | consideration has not |
| been included? | been included? | consideration has not | such consideration | been included? |
| | | been included? | has not been | |
| | | | included? | |
| How do you seek to obtain | As an organisation how do | How do you seek to | How do you seek to review | How do you seek to advocate |
| grant applications that | you seek to conduct resear | ch obtain/publish research | and assess research data in a | for research that considers |
| consider sex and/or gender | ? that considers sex and/or | manuscripts that consider | way that considers sex | sex and/or gender? Please |
| Please tick one | gender? Please tick one | sex and/or gender? Please | and/or gender? Please tick | tick one |
| | | tick one | one | |



| _By requiring they consider | _By requiring the | _By requiring they consider | _By requiring the | _By requiring the |
|-----------------------------|-----------------------------|-----------------------------|-----------------------------|-----------------------------|
| and/or assess the inclusion | consideration of sex and/or | the inclusion of sex and/or | consideration of sex and/or | consideration of sex and/or |
| of sex and/or gender | gender | gender | gender | gender |
| _By encouraging the |
| consideration and/or | consideration of sex and/or | consideration of sex and/or | consideration of sex and/or | consideration of sex and/or |
| assessment of sex and/or | gender | gender | gender | gender |
| gender | _In some other way. Please |
| _In some other way. Please | state | state | state | state |
| state | Not at all | Not at all | Not at all | Not at all |
| _Not at all | | | | |
| How are grant reviewers | | How are manuscript | | |
| advised to consider and/or | | reviewers advised to | | |
| assess the inclusion of sex | | consider and/or assess the | | |
| and/or gender | | inclusion of sex and/or | | |
| considerations in research | | gender considerations in | | |
| proposals? Please tick one | | submitted manuscripts. | | |
| | | Please tick one | | |
| By requiring this | | | | |
| By encouraging this | | _By requiring they consider | | |
| In some other way. Please | | the inclusion of sex and/or | | |
| state | | gender | | |
| Not at all | | _By encouraging the | | |
| | | consideration of sex and/or | | |
| | | gender | | |
| | | _In some other way. Please | | |
| | | state | | |
| | | _Not at all | | |

Survey continues below

8. Is there anything else you would like to tell us about your policy, procedure, statement or guideline/s? _____

OPTION TO ADD ANOTHER POLICY DOCUMENT IF NEEDED

GO TO SECTION B

9. Does your organisation have any plans to develop a policy, procedure, statement or guideline for defining, collecting, analysing and/or reporting sex and gender data in health and medical research in the near future? YES/NO

If YES -> go to question 10 If NO -> got to question 11

- 10. When do you expect to develop and/or implement a policy, procedure, statement or guideline for your organisation? In the next:
 - o 3 months,
 - o 6 months,
 - \circ 12 month,
 - o 18 month,
 - o 24 month or more

GO TO SECTION B

- 11. What is the reason for **not** developing such a policy, procedure, statement or guideline? (please tick all that apply, some options ask for further information, lease provide them in the comment section)

 - A dedicated document is not needed as other external guidelines exist instead Please provide more information, or link to documents:
 - The statistical power required to perform detailed disaggregated analysis
 - \circ \quad We do not have the internal capacity to develop one
 - We are currently planning and discussing this issue
 - \circ \quad We do not believe sex and gender should be looked at in isolation
 - \circ \quad This is not considered an important issue for our organisation

GO TO SECTION B

B) TRANSLATING POLICIES INTO ACTION

12. Does your organisation promote or recommend any external resources to support support inclusion of sex and/or gender considerations in your area of work? Y/N/Unsure

(Click for more info - For example the "<u>How to integrate sex and gender into research</u>" resources from the Canadian Institute of Health Research)

If yes, please include relevant links or details of the external resources here:

13. Does your organisation provide, list, endorse or support any training or training materials (in house or external) about sex and gender in health and medical research practice? Y/N/Unsure

(click for more info - For example, training on inclusion delivered by HR departments or training on how to conduct a sex-disaggregated analysis)

If yes please tick all that apply

- HR training
- Medical research practice training (eg sex-disaggregated statistical analysis training)
- Sex and gender concepts training
- \circ Other

Please provide more details:

- 14. At an organisation level is any training about sex and/or gender **recommended** for: (if your organisation has no relevant people please tick N/A)
 - People internal to your organisation Y/N/NA
 - People external to your organisation who interact with you Y/N/NA
- 15. At an organisation level is any training about sex and/or gender **required** for: (if your organisation has no relevant people please tick N/A)
 - People internal to your organisation Y/N/NA
 - People external to your organisation who interact with you Y/N/NA

FUNDERS ONLY

- 16. Are grant applications to your funding schemes given weight (or marked) in relation to the consideration of sex and gender and the proposed inclusion of sex and/or gender analyses? Y/N
- 17. Does your organisation evaluate or collect data on the **number and proportion** of grant applications that include sex and/or gender analyses? Y/N
- 18. Do you evaluate or collect data on the number and proportion of **peer-reviewed publications arising from your grants** that incorporate sex and/or gender analysis?

JOURNALS ONLY

18. Does your journal evaluate or collect data on **the number and proportion** of manuscripts you publish that include sex and/or gender analysis? Y/N

ALL PARTICIPANTS CONTINUE FROM HERE

FOR THOSE WHO ANSWERED **NO** TO QUESTION 1 (THEY **DO NOT HAVE** A POLICY, PROCEDURE, STATEMENT OR GUIDELINE IN PLACE)

- 19. MANDATORY QUESTION Which of the following are **barriers** to the development and implementation of a sex and gender policy, procedure or guideline in your organisation, or in an organisation similar to yours? (tick all that apply):
 - These policies are not relevant to our research content area, or we are not convinced this is an issue for our research
 - Our work is limited by the research evidence that is collected by others, so this is not relevant
 - Lack of expertise in policy development
 - Lack of content expertise in definitions, mechanisms, design, analysis and reporting of sex and gender
 - Increased cost for conducting disaggregated analysis as larger studies are needed
 - Lack of local examples of successful policies
 - These policies are thought to be too prescriptive
 - Thee policies promote an approach that is not hypothesis driven
 - We do not want to promote the consideration of sex and gender in isolation
 - External guidelines already exist (such as ICMJE guidelines) so additional ones are not required
 - Lack of leadership and institutional buy in
 - Informatics and/or other system adaptations are required to implement these policies
 - Linguistic and definitional challenges associated with sex and gender
 - Conflicting frameworks across disciplines
 - Complexity of the field and related fear of doing the wrong thing
 - Lack of up to date evidence of why this is important



- Gender bias
- Limitations of current research methods (recruitment, small sample sizes, extrapolating effectiveness from efficacy)
- None of the above
- Others_____

Please explain any of your answers

- 20. MANDATORY QUESTION which if the following may **facilitate** the development and implementation of a sex and gender policy, procedure, statement or guidelines in your organisation, or an organisation similar to yours (tick all that apply)
 - Training and support in policy development and evaluation
 - Training and support in definitions, mechanisms, design, analysis and reporting of sex and gender
 - Greater awareness or understanding of the rationale for sex and gender incorporation
 - Provision of additional funding to increase study sample sizes
 - Awards, recognition or other incentives
 - Significant Australian organisations leading by example
 - Significant international organisations leading by example
 - Integrating the analysis of sex and gender with other issues, such as ethnicity
 - Local individual champions
 - Supporting cultural shift in research practice
 - Development and use of standards and consistent tools (such as ABS Standard for sex and gender)
 - Regulation or enforcement of policy requirements
 - Supporting infrastructure changes
 - None of the above
 - Other

Please explain any of your answers

FOR THOSE WHO ANSWERED **YES** TO QUESTION 1 (THEY **HAVE** A POLICY, PROCEDURE, STATEMENT OR GUIDELINE IN PLACE)

- 21. MANDATORY QUESTION which of the following **facilitated or enabled** the development and implementation of your sex and gender policy, procedure, statement or guidelines in your organisation (tick as many as apply):
 - Training and support in policy development and evaluation
 - Training and support in definitions, mechanisms, design, analysis and reporting of sex and gender
 - Greater awareness or understanding of the rationale for sex and gender incorporation
 - Provision of additional funding to increase study sample sizes
 - Awards, recognition or other incentives
 - Significant Australian organisations leading by example



- Significant international organisations leading by example
- Integrating the analysis of sex and gender with other issues, such as ethnicity
- Local individual champions
- Supporting cultural shift in research practice
- Development and use of standards and consistent tools (such as ABS Standard for sex and gender)
- Regulation or enforcement of policy requirements
- Supporting infrastructure changes
- Other____

Please explain any of your answers

- 22. MANDATORY QUESTION Which of the following were **barriers** to the development and implementation of your sex and gender policy, procedure or guideline? (tick all that apply):
 - These policies are not relevant to our research content area, or we are not convinced this is an issue for our research
 - Our work is limited by the research evidence that is collected by others, so this is not relevant
 - Lack of expertise in policy development
 - Lack of content expertise in definitions, mechanisms, design, analysis and reporting of sex and gender
 - Increased cost for conducting disaggregated analysis as larger studies are needed
 - Lack of local examples of successful policies
 - These policies are thought to be too prescriptive
 - These policies promote an approach that is not hypothesis driven
 - We do not want to promote the consideration of sex and gender in isolation
 - External guidelines already exist (such as ICMJE guidelines) so additional ones are not required
 - Lack of leadership and institutional buy in
 - Informatics and/or other system adaptations are required to implement these policies
 - Linguistic and definitional challenges associated with sex and gender
 - Conflicting frameworks across disciplines
 - Complexity of the field and related fear of doing the wrong thing
 - Lack of up to date evidence of why this is important
 - Gender bias
 - Limitations of current research methods (recruitment, small sample sizes, extrapolating effectiveness from efficacy)
 - None of the above
 - Others_____

Please explain any of your answers

END

| Research Funders | Peer-reviewed Journals | Researcher creators and educators | Evidence synthesisers | Research advocates, peak bodies and societies | |
|---|---|--|--|--|--|
| National Health and Medical Research Council (NHMRC) | Journal of Gastroenterology and Hepatology | University of Melbourne | NPS MedicineWise | Australian Society for Medical Research (ASMR) | |
| National Heart Foundation | Medical Journal of Australia (MJA) | Australian National University | Sax Institute | Association of Australian Medical Research Institutes (AAMRI) | |
| Cancer Council (NSW) | Clinical and Experimental Pharmacology and Physiology | The University of Sydney | EviQ, Cancer Institute NSW | Public Health Association of Australia (PHAA) | |
| Medical Research Future Fund (MRFF) | Immunology and Cell Biology | The University of Queensland | Health Resourcing at Department of Health | Research Australia | |
| Office for Health and Medical Research, NSW Government | Australian and New Zealand Journal of Psychiatry | The University of Western Australia | Australian Institute of Health and Welfare (AIHW) | Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) | |
| Department of Health, Victorian Government | Journal of Paediatrics and Child Health | The University of Adelaide | Therapeutic Goods Administration (TGA) | Australian Healthcare and Hospitals Association (AHHA) | |
| Diabetes Australia | Australian and New Zealand Journal of Public Health | Monash University | JBI (Joanna Briggs Institute) | Australian Medical Association (AMA) | |
| Leukaemia Foundation | Respirology | UNSW Sydney | Cochrane Australia | Royal Australasian College of Physicians (RACP) | |
| Australian Research Council | ANZ Journal of Surgery | Walter and Eliza Hall Institute of Medical Research (WEHI) | Grattan Institute | Royal Australian College of General Practitioners (RACGP) | |
| Cancer Australia | Clinical and Experimental Ophthalmology | The George Institute for Global Health Australia | Australian Commission on Safety and Quality in Healthcare (ACSQHC) | Royal Australasian College of Surgeons (RACS) | |
| | | QIMR Berghofer | | Australian Medical Students' Association (AMSA) | |
| | | Lowitja Institute | | Allied Health Professions Australia (AHPA) | |
| | | Medtronic | | Australian College of Nursing | |
| | | Sanofi | | LGBTIQ+ Health Australia | |
| | | Eli Lilly | | Women's Health Victoria | |
| | | | | Jean Hailes | |
| | | | | Australian Clinical Trials Alliance (ACTA) | |
| | | | | Consumers Health Forum of Australia | |
| | | | | Medicines Australia | |
| | | | | ACON | |

Table 2. Stakeholder organisations identified during the planning phase

| Resource referenced by Australian organisation | Local or international | Link |
|---|------------------------|---|
| ABS Standard for Sex, Gender, Variations of Sex | Local | https://www.abs.gov.au/statistics/standards/standard- |
| Characteristics and Sexual Orientation (3 | | sex-gender-variations-sex-characteristics-and-sexual- |
| organisations) | | orientation-variables/latest-release |
| PROGRESS-Plus | International | https://methods.cochrane.org/equity/projects/evidence- |
| | | equity/progress-plus |
| WHO Handbook for Guideline Development: Chapter | International | https://www.who.int/gender-equity- |
| 5. Incorporating equity, human rights, gender & social determinants into guidelines | | rights/understanding/grc-chapter5.pdf |
| ARRIVE guidelines (Animal Research: Reporting of In Vivo Experiments) | International | https://arriveguidelines.org/ |
| Science in Australia Gender Equity (SAGE) | Local | https://www.sciencegenderequity.org.au/ |
| Canadian Institutes of Health Research Sex and Gender in Health Research | International | https://cihr-irsc.gc.ca/e/50833.html |
| | | |
| Gendered Innovations | International | https://genderedinnovations.stanford.edu/ |
| National Institutes of Health Sex and Gender webpage | International | https://orwh.od.nih.gov/sex-gender |
| Charite Institute of Gender in Medicine | International | https://gender.charite.de/en/ |
| Australian Government Guidelines on the Recognition | Local | https://www.ag.gov.au/rights-and- |
| of Sex and Gender | | protections/publications/australian-government- |
| | | guidelines-recognition-sex-and-gender |
| Nursing Leadership in Diversity and Inclusion - | Local | https://www.acn.edu.au/wp-content/uploads/guiding- |
| Guiding Principles | | principles-nursing-leadership-in-diversity-and- |
| | | inclusion.pdf |
| Transhub resources for researchers | Local | https://www.transhub.org.au/allies/researchers |
| ACON discussion paper effective and meaningful | Local | https://www.acon.org.au/wp- |
| inclusion of trans and gender diverse people | | content/uploads/2017/12/Policy-Discussion-Paper- |
| | | Trans-and-Gender-Diverse-Inclusion_V2a.pdf |
| Consumer Involvement and Engagement Toolkit | Local | https://involvementtoolkit.clinicaltrialsalliance.org.au/ |

Table 3. Resources about sex and gender used by Australian health and medical research organisations