Submission to the

Draft
National Health and Research Strategy Consultation

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1. Introduction

World Wellness Group Ltd (WWG) is an independent multicultural health social enterprise working to reduce health inequity. Established in 2011, we deliver services within the health system whilst simultaneously working on systemic issues that create and often unknowingly perpetuate entrenched inequity for multicultural population groups. Our work is underpinned by a human rights framework on the basis that health is a human right and the principle of universal access to health care regardless of background, affordability, or visa status. The health status of all people is impacted by the social, cultural, political, environmental and economic determinants of health. These determinants frame our work in health service delivery and advocacy. A focus on the social determinants is critical to reducing the unfair and unjust conditions of living that cause poor health and mental health.

Delivery of our purpose occurs via four strategic priority areas:

1. **General Practice & Primary Care Clinic:** Delivery of culturally responsive and accessible primary care general practice and allied health wrap around care that provide tailored physical and mental health clinical care in Brisbane and a state-wide telehealth service called the Multicultural Connect Line.

2. **Multicultural Lived Experience Voices**: Engaging people of multicultural background with lived/living experience of migration, settlement and acculturation and the healthcare system within our models of care via a substantial multicultural peer support workforce whilst also grounding our engagement of bicultural lived experience voices both in the co-design of our health service models of care and advocacy efforts focused on improving health care access, equity and just outcomes for the multicultural communities we serve.

3. **Contributions through Partnering:** Galvanising corporate, industry and government partners to contribute towards resourcing, design, and delivery of a more accessible and equitable healthcare system for people of multicultural backgrounds.

4. **Knowledge Hub**: Building evidence and data about access and equity barriers for multicultural communities, health status and health outcomes including best practice evidence-based approaches to enable delivery of culturally responsive and accessible physical and mental health services with the appropriate level of funding resources and capacity building around cross-cultural clinical frameworks.

WWG was engaged to provide a report to the Australian Government Department of Health and Aged Care on options to address the health navigation needs of multicultural communities, to be developed in consultation with Primary Health Networks. Two Think Pieces were developed as part of the stakeholder engagement and consultation process in preparation for a workshop held in June 2023 to stimulate discussion and thinking with Primary Health Networks to inform development of the report:
(1) PHN Needs Assessments : *Capturing multicultural health data and engagement with multicultural communities to pursue health equity*
(2) Commissioning: *Co-designed commissioning lens focused on multicultural health*.

Our service delivery and advocacy are informed by research to which we also contribute.

2. Focus of this Submission

The focus of this submission is on long-standing and systemic exclusion (either overt or inadvertent) of multicultural health (including mental health) on the national research agenda. People from multicultural backgrounds:

- continue to form a significant proportion of the Australian population

  The 2021 Census reported that 27.6 per cent of Australians were born overseas and almost half of Australians had at least one parent born overseas (48.2 per cent). In terms of language, 5.6 million people or 22 per cent, reported using a language other than English at home (an increase from 4.8 million people or 20.6 per cent in 2016). 3.4 per cent of the population spoke English not well or not at all.

- experience a high burden of health inequalities as reported by many studies and by the Australian Institute of Health and Welfare (AIHW) over many years, particularly through the *Australia's Health* series and other publications including a spotlight report for the National Mental Health Commission focused on multicultural mental health.

Our submission is informed by our service delivery and learnings from:

- the lived/living experience of the people who access and deliver our services
- our capacity to engage and consult meaningfully with individuals and communities both locally and nation-wide
- our relationships with other multicultural health and social care services, with Primary Health Networks (PHNs), and overseas organisations such as the UK National Health Service Race Health Observatory
- our preparation and delivery of nationally significant issues such as Mental Health in Multicultural Australia (MHIMA), now the Embrace program of Mental Health Australia, amongst others.
- lack of consistent and meaningful national data about multicultural health
- the initial and ongoing impact of COVID-19 on multicultural communities
- our promotion of research to and support of prospective participants

3. General Comments

We welcome progress towards establishing a National Health and Medical Research Strategy and are generally supportive of the concepts established in the Draft.

We particularly endorse the clear focus on 'equity' in the Goals (page 9) and the Values (page 10) and how equity is subsequently interwoven and addressed within each Focus Area and Enabler.

We note that multicultural communities are explicitly listed as one of several 'priority' populations (page 14) but are concerned that there is no reference to or acknowledgement of intersectionality. These groupings often overlap and people from multicultural backgrounds may also form part of other named priority populations – they may also identify as LGBTIQ+, living with a disability, with mental health conditions, in low socioeconomic groups and living in regional, rural or remote areas

We completely understand and support the substantial focus on Aboriginal and Torres Strait Islanders but note that the document provides little detailed information on initiatives to address equity issues for the other priority populations.

The concept of a National Health and Research Strategy is an opportunity to provide effective and high-level guidance to the sector on the importance of addressing the inequities outlined below which exclude multicultural Australia and supporting the stated focus on equity.

We suggest that the draft falls short in this respect. **While naming CALD as a priority population, the term appears only three times in the entire document:** on page 16 as an element of the defined priority populations; on page 48 under *Definitions*; and on page 52 as Reference 29.

Addressing multicultural inequities does not appear at all on page 6 (themes from the Phase 1 Consultations: What the National Strategy should aspire to). Any engagement of multicultural individuals, communities and researchers in this consultation seems conspicuously absent, or if there was representation, it does not appear to have been captured.

We would also suggest that the use of the term CALD (Culturally and Linguistically Diverse) is itself potentially problematic.

The term is often used within Australian government, the private sector, and in research and academic institutions to describe populations other than the Anglo-Celtic majority. There is increasing academic and community debate about the usefulness of the term CALD. [i]

Many commentators in the sector view the term as increasingly questionable and note that is does not include consideration of biogenetic factors which are regarded as impacting significantly on health and other inequalities. It is also suggested that the term is not readily understood or actively used by the individuals or communities which are defined by it. They may instead refer to themselves as from 'migrant or refugee backgrounds' or by terms such as 'Chinese-Australian', 'Lebanese- Australian' etc... The acronym is also considered disrespectful – by contrast, it should be noted that it is accepted practice to use the term Aboriginal and Torres Strait Islander rather than the acronym ATSI.

For these and other reasons there is an increasing preference for the term "multicultural". Examples include: organisations such as the Multicultural Youth Advocacy Network, Multicultural Centre for Women's Health, Australian Multicultural Community Services, Multicultural Australia to name a few.

Government increasingly uses the term, for example, the Multicultural Framework Review. There is also currently a Federal Minister for Multicultural Affairs at Cabinet level.

WWG prefers to use the term ‘multicultural’ and rather than CALD.

4. Some examples of multicultural exclusion

4.1. Dementia

In October 2019, a paper [ii] by academics from Sydney University and the National Ageing Research Institute (NARI) in the Medical Journal of Australia suggested that Australian dementia research is not sufficiently inclusive of Australians from ‘CALD’ backgrounds and that, as a consequence, they may be receiving inequitable or inappropriate dementia care.

42 of the 94 then registered active dementia clinical trials in Australia excluded patients not fluent in English. Australians from multicultural backgrounds were also excluded from epidemiological research on dementia. Of 16 studies identified, all collected data exclusively in English, and six excluded participants who were not fluent in English.

4.2. Older People

In 2015 the Federation of Ethnic Communities’ Councils of Australia (FECCA) commissioned a Review of Australian Research on Older People from CALD Backgrounds.[iii] The review identified research gaps in the evidence base on older multicultural Australians, including research about: particular groups, including new and emerging communities; older people from refugee backgrounds; those who arrive in Australia at an older age; people from smaller population groups; or those who live in regional, rural or remote areas.

Further gaps were identified in particular topic areas including: treatment and care options for older people from ‘CALD’ backgrounds once a health diagnosis has been made; communications between ‘CALD’ residents in aged care facilities and care workers; and the increasing proportion of people from ‘CALD’ backgrounds in the aged care workforce.

The same review identified a number of items in the literature which highlighted the difficulty of including and retaining ‘CALD’ participants in research, and the need for appropriate strategies to address this, including the provision of relevant language services.

4.3. Oncology

In 2019, at the Clinical Oncology Society of Australia Annual Scientific Meeting, Cancer Council Victoria hosted a breakfast symposium to explore the underrepresentation of ‘CALD’ people in cancer clinical trials due to various barriers including challenges with communication, opportunity and awareness, and cultural issues.

An analysis of 20,000 cancer patients in South West Sydney[iv] suggested limited access to clinical trials as being most significant for ‘CALD’ people whose preferred language is not English, with recruitment of these patients as low as 3.9% compared to 8.4% for ‘non-CALD’ patients and 7.7% of ‘CALD’ patients who were proficient in English.

4.4. Clinical Trials

People from multicultural backgrounds are routinely excluded from clinical trials with 'lack of English languages proficiency' frequently cited as an exclusion criterion.[v] One in five registered clinical trials in Australia documented exclusion of participants with low English proficiency. The proportion is, in practice, probably higher, as trials may exclude participants with low English proficiency during the informed consent process, even when English proficiency was not included in the exclusion criteria. [vi]

Barriers to participation include:

- language, literacy (including health literacy and research literacy)
- cultural factors
- lack of researcher capacity to engage, recruit and retain
- other exclusion criteria.

We commend and contributed to the 2023 Australian Clinical Trials Alliance recommendations contained in *Advancing clinical trial engagement, involvement, and participation for people from culturally and linguistically diverse backgrounds* but have yet to see widespread uptake of the recommendations in the sector.

A 2025 paper similarly proposed strategies to improve participation of culturally and linguistically diverse participations in clinical trials. [vii]

4.5. Journal Publications

A 2010 review[viii] determined that of **4,146** articles published in three major Australian health journals in the period January 1996-August 2008, only **2.2%** had a primary focus on health issues among people from multicultural backgrounds.

Professor Helen Skouteris (Monash Warwick Professor in Health and Social Care Improvement) led a repeat of this study to look at period September 2008-January 2023 and established that in those fifteen years – there had been a sharp decline to **1.1%**.

In an astonishing but not unexpected irony, this paper was submitted to but not accepted by several journals and remains unpublished.

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5. Suggestions for further consideration

5.1. Ethics

The research sector is rightly guided by a strong commitment to ethics and there are clear national guidelines (such as the NHMRC National Statement on Ethical Conduct in Human Research) and Human Research Ethics Committees (HRECs) review research proposals.

We do, however, wonder what is ethical about frequent:

- use of 'lack of English language proficiency' as an exclusion criterion for participation in research, particularly in clinical trials
- overt or inadvertent systemic racism
- consequent perpetuation of health inequities and inconsistencies
- compromising the generalisability of research findings and results of clinical trials if the sample is not representative of the population.

We note that this is often justified as follows:

- poor English language proficiency 'complicates' the consent process
- 'additional expenses' in language services provision
- "They" don't engage, are hard-to-reach and take up too much time.

The Draft Strategy contains only 5 references to ethics:

- Page 5 (Themes which emerged during Phase 1 consultations) which called for streamlining of processes (including ethics).
- Page 22 (Clinical Trials) – roll out of the Human Research Ethics Committee Quality Standard and Accreditation Scheme
- Page 23 (Consumer and Community Involvement) – diagram illustrating factors impacting trust in and perceived effectiveness of the Health and Human Research Sector
- Pages 61 and 62 (References).

The NHMRC has recently issued a Summary of Changes to the NHMRC National Statement on Ethical Conduct in Human Research 2025 (which currently are planned to be effective from early 2026).

The Summary announces "major thematic changes in Section 4 – Ethical considerations specific to participants" (page 4). There remains, however, no chapter relating to multicultural issues.

The Revised Statement will therefore continue to be silent on ethics relating to:

- specific research on multicultural individuals and communities
- inclusion in population-based studies to ensure samples are representative of the population as a whole and that, in translation and implementation, the generalisabity of findings is not compromised.

It has frequently been suggested that the Statement should, given the demonstrated inequities, include a chapter on multicultural populations, similar to Chapter 4.7 Research with Aboriginal and Torres Strait Islander people and communities. The Summary of

Changes document states that this revised Chapter includes “strengthened guidance responsive to input from key stakeholders”.

Again, while completely supportive of efforts to respond to the inequities and particular issues experienced by Aboriginal and Torres Strait Islanders, we suggest that, given the demographics, the Statement will be neither comprehensive nor inclusive without specific attention to multicultural issues.

It is hard to see how the Vision and Goals of the Draft Strategy which include “equity” can be achieved without attention to this matter.

5.2. Funding

We suggest that the equity goal will not be achieved as long as funding allocation and decisions perpetuate the exclusion of people from multicultural backgrounds.

We therefore welcome the reference (page 40) “Targeted investment in health research that addresses disparities and supports Australia’s diverse communities will advance equity and improve population health”.

We believe that, particularly when research relevant to the whole population is funded by public monies, there should be clear **mandated** requirements on applicants to demonstrate

- how the proposal will be inclusive of multicultural participants and, if not, the reasons for that exclusion
- proposed data collection
- proposed engagement, recruitment and retention strategies
- multicultural representation on any advisory groups
- budgetary allocation for the provision of language services

A relevant model is provided in the United States. The National Institutes of Health (NIH) Revitalisation Act of 1993 and NIH policy amended in 2001 require that NIH funded research must include ‘minority ethnic’ groups or provide sound scientific arguments for their exclusion.

5.3. Data

Access to and the generation of comprehensive, consistent and reliable data is a central and essential component of health and medical research.

There are, however long standing and identified deficits in the collection and reporting of data relating to Australia’s culture, language and ethnicity diversity. These are particularly evident in health and in research.

Data challenges (highlighted in the response to COVID-19) include:

- inconsistent definitions – the often-used term CALD can be defined in multiple ways (e.g. country of birth, ancestry, language and religion)
- inadequate data collection – many health and research data collections lack consistent variables to identify multicultural people

- poor implementation of Standards – even the relevant 1999 ABS core standards are not widely or consistently implemented in national health data sets.

The 2020 FECCA Issues Paper *If we don't count it…it doesn't count!* Identified and proposed responses to deficits in national data collection and reporting on cultural, ethnic and linguistic diversity, particularly in administrative, survey and research data.

As mentioned above, the core variables proposed in the relevant 1999 ABS Standard are not routinely and consistently collected. The most commonly applied variables remain:

- Country of birth – excluding the so-called Main English-speaking Countries (MESCs)
- Language spoken at home or preferred language

Country of birth is an inadequate indicator on its own and does not account for cultural or ethnic background. For example, a person born in Singapore could be of Chinese, Malay, Indian and many other backgrounds. Significant numbers of people who may have been born in Australia, who may have English language proficiency, or who continue to identify strongly with a particular cultural or religious group are often excluded from CALD data sets. In addition, the exclusion of people from diverse cultural or ethnic backgrounds who were born in the MESCs, including UK, Ireland, Canada, United States, New Zealand and South Africa, the populations of which are increasingly diverse, means that Australian data may underrepresent CALD populations. These measures excluded approximately 1.4 million persons who have English as their spoken language but were born in Australia and have one or both parents born in a non-MESC identified in the 2016 Census.

The FECCA Issues Paper proposed a way forward including key decision points and suggested the formation of a high-level National Working Group, involving relevant stakeholders and expertise, to develop recommendations as to how national and jurisdictional data collection could be more consistent, complete and useful.

It also suggested that mechanisms should be developed to mandate data collection, including requirements for:

- the collection of defined data on cultural, ethnic and linguistic diversity in administrative data sets.
- the inclusion of participants from culturally, ethic and linguistically diverse backgrounds in relevant national surveys.
- the inclusion of such participants in social, health and medical, and other research (including clinical trials), particularly when such research purports to be representative of the Australian population as a whole.

There are overseas examples of mandatory diversity data collection and reporting, particularly in health services and research:

- United Kingdom – the 2010 Equality Act and the 2012 Health and Social Care Act
- United States – the 2010 Patient Protection and Affordable Care Act required federally funded health programs to collect data on race, ethnicity and primary language.

The lack of consistent data collection was particularly evident in relation to COVID-19. At the outset the only demographic variable within the National Notifiable Diseases Surveillance System were age, sex and Aboriginal and Torres Strait Islander status. As a result of community advocacy, amendments required the addition of country of birth and a language indicator. This was intended to monitor vaccine uptake in multicultural communities, but the incapacity of the Australian Immunisation Register to incorporate these data highlighted the issue of the critical lack of interoperability between data systems.

The absence of consistently applied variables has resulted in a dependence in the research sector on data integration projects, such as the Person-Level Integrated Data Asset (PLIDA). Whilst useful in some instances, these processes are complex, time-consuming and expensive. National agreement on core multicultural variables to be collected consistently across all jurisdictions and national health data sets is essential.

In 2022, the then Minister for Multicultural Affairs, Andrew Giles, announced a comprehensive review of current multicultural data. There has, however, been little progress to date.

We believe that is insufficient for the Draft Strategy to state (page 18) that "we must also take advantage of **available data**, emerging technologies and modernised practices" without acknowledging current data deficits

We suggest that the Draft Strategy could play an important high-level role in highlighting and supporting the need to improve data relating to Australia's multicultural diversity in health and medical research.

5.4. Genomics

For multicultural individuals, the increasing focus on genomics and pharmacogenomics is yet another potential cause of inequity:

- There is a lack of culturally appropriate participant information and explanatory material in languages other than English.
- Genomic data bases are not representative of diverse communities.
- This impacts on personalised medicine and could determine appropriate treatment levels (for example, in oncology where chemotherapy doses are most often predicated on the predominant Ango/Celtic majority and may be too high or potentially harmful for some ethnicities).

We note the ongoing work of the Centre for Population Genomics (a partnership between the Garvan Institute and the Murdoch Children's Research Institute, in collaboration with multicultural community organisations to develop promotional material and encourage targeted communities to provide samples. Some work in this regard has been progressed by the NHS Race Health Observatory. See: Genomics and Precision Medicine - NHS – Race and Health Observatory

5.5. Workforce

We welcome the focus of the Draft Strategy on a diverse research workforce and the development of an Australian Health and Medical Workforce Plan:

- (Page 4) Ensure equity, access and workforce development through inclusive policies, broad participation and sustained investment in a diverse, skilled research community.
- (Page 6) Build diversity and equity across the research workforce particularly at senior levels
- (Page 38) Diversity and lived experience enrich workforce capability, and initiatives to improve gender balance {*we would suggest the inclusion of culture and language diversity here*} and integrate consumer perspectives into research teams deepen the impact and relevance of research
- (Page 38) Improve data capture to monitor workforce demographics over time to inform future intervention

We note that there is no current data on the multicultural health and medical researchers, but the number is likely to be significant as in the general health and mental health, pharmacy, aged care and disability services workforces. We are aware of frequent reporting of individualised or systemic racism, and barriers to career progression.

We suggest that multicultural researchers can clearly play an important role in engaging, recruiting and supporting multicultural participants.

The workforce could also be augmented through community based multicultural research navigators working within multicultural community organisations and services.

5.6. National Strategy Advisory Council

We welcome the proposed Advisory Council and that is necessary to ensure strategic oversight, coordination, accountability and responsiveness. This is essential because, as pointed out, the research sector is complex and multifaceted.

It is, however, not explicitly stated in the Draft Strategy to whom or to which entity the Advisory Council will provide such advice, who the decision-makers are, and who will be responsible for implementation, monitoring and reporting.

We suggest that the central concept of equity articulated throughout the Draft Strategy should also apply to the appointment of members of the Advisory Council.

We would therefore expect multicultural representation on this body.

We consider it likely that the Advisory Council would need to be supported and informed by a range of sub-groups and would advise multicultural representation on all relevant of these groups. We would also advocate for the establishment of a specific group to focus on multicultural issues across the Strategy.

6. Recommendations

A. Document structure

1. Australia's population demographics and the systemic exclusion of people from multicultural backgrounds from health and medical research, require the Strategy to articulate a greater and more explicit focus on multicultural research.

2. The term 'multicultural' should be used in preference to 'culturally and linguistically diverse' (CALD)

B. Towards Equity

To achieve the stated goal of equity and not perpetuate inequity, the Strategy should highlight the following needs …

3. Address current exclusion of multicultural people from clinical trials for reasons considered unethical. Reference and promote *Advancing clinical trial engagement, involvement, and participation for people from culturally and linguistically diverse backgrounds* (Australian Clinical Trials Alliance, 2023)

4. Inclusion in a future revision of the National Statement on Ethical Conduct in Research of a chapter on Research with Multicultural People and Communities (c.f. current Chapter 4.7 Research with Aboriginal and Torres Strait Islander people and communities.

5. Applicants for research funded by public monies to demonstrate how, unless there are valid scientific reasons, the proposal will be inclusive of multicultural participants (including: proposed data collection; engagement, recruitment and retention strategies; representation on advisory groups; and budgetary allocation for language services. (Consideration to be given to mandating this requirement).

6. Consistent core data about multicultural participants to be collected at source in health and medical research. (Consideration to be given to mandating this requirement).

7. Increase multicultural representation in genomic data bases

8. Require capture in the proposed Australian Health and Medical Workforce Plan consistent data about the research workforce, including multicultural indicators.

9. Appropriate multicultural representation on the proposed Advisory Council and in any other sub-groups.

10. A specific multicultural advisory group.

7. References

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