Response to Consultation Paper

Role and Functions of an Australian Centre for Disease Control

December 2022

Australian Multicultural Health Collaborative

OUR CULTURES OUR LANGUAGES OUR HEALTH

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16 December 2022

Re: Response to Consultation Paper:
Role and Functions of an Australian Centre for Disease Control

Dear Planning Team,

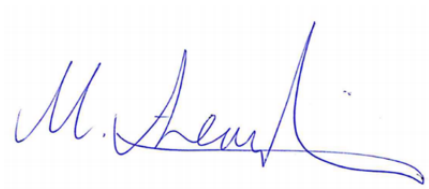
Please find below the response of the Australian Multicultural Health Collaborative to the Consultation Paper.

We sincerely appreciated the invitation to send two representatives to the recent round of consultation workshops, and for inviting us to make a submission to this consultation.

This was for us a clear indication that appropriate and inclusive responses to the particular needs of our multicultural communities were considered important in the development of the Consultation Paper and the evolution of the ACDC.

We would welcome further opportunities to engage with and support the establishment of the ACDC and its responsiveness to Australia's culture and language diversity.

Yours sincerely,



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FECCA
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World Wellness Group

1. Background - the Australian Multicultural Health Collaborative

- The Australian Multicultural Health Collaborative (the Collaborative) was launched on 17 June 2022 at the FECCA 2022 National Conference with the Hon. Ged Kearny MP, Assistant Minister for Health and Aged Care attending. A number of key organisations and partners contributed to the development of a concept document which went out for broad consultation between September and December 2021.

- The main objective of the Collaborative is to provide a national voice, leadership and advice on policy, research, data and practice to improve access and equity, address systemic racism, and achieve better health and wellbeing outcomes for Australians from multicultural backgrounds.

- The provision of informed, evidence-based and reliable advice to the Department of Health and Aged Care and participation in national policy development processes is fundamental to achieving this objective.

- The Collaborative is representative, and membership based. Members include: consumers; health services and wellbeing/social care services; practitioners; and researchers. The Collaborative also welcomes as affiliates national health peak organisations. As of November 2022, the following peaks had become affiliates: Heart Foundation, Advance Care Planning Australia, Arthritis Australia, Australian Federation of AIDS Organisations (AFAO), Dementia Australia, Mental Health Australia, National Ethnic Disability Alliance (NEDA), National Rural Health Alliance, and Palliative Care Australia

- The Collaborative is an initiative of the Federation of Ethnic Communities' Councils of Australia (FECCA) and is led by an Interim Coordination Group reflective of the membership. The Group is co-chaired by Ms. Marina Chand, Director and co-founder of World Wellness Group, and Mr. Mohammad Al –Khafaji, FECCA CEO. The Collaborative is auspiced by FECCA which provides administrative and secretariat support, policy coordination and strategic communications.

2. Focus of this Submission

- This submission makes some general comments in response to the Consultation Paper but is focussed specifically on issues relating to Australia's **culture and language diversity** which we believe should be considered in the development, establishment and operation of the proposed ACDC.

- Australia has never been more culturally and linguistically diverse. The most recent Census showed that almost most half of Australians have at least one parent born overseas (48.2 per cent) and the population continues to be drawn from around the world, with 27.6 per cent reporting a birthplace overseas.[1]

- Our submission is grounded in experience and based on learnings drawn from:
  - shortcomings in the initial response to COVID-19;
  - significant national deficits in the collection and reporting of data relating to culture and language diversity;
  - expertise from consumers, practitioners and researchers participating in the Collaborative; and
  - previous advocacy led by FECCA aimed at ensuring that these issues are appropriately considered in the development of national health strategies, plans, programs and initiatives.

3. General Comments

- We welcome the proposed establishment of the Australian Centre for Disease Control (ACDC) and are generally supportive of the Consultation Document.

- We note and endorse the focus on:

  - collaboration and communication, including consistent and clear national public health advice;
  - a broader range of public health issues beyond communicable diseases, to include non-communicable diseases, environmental health, preventive health and health promotion, and disaster preparedness and response; and
  - improving national data systems and management.

[1] https://www.abs.gov.au/media-centre/media-releases/2021-census-nearly-half-australians-have-parent-born-overseas

- In terms of the **structure** of the ACDC we believe:
    - It is essential to establish an independent and authoritative national body to coordinate responses to public health challenges across multiple jurisdictions.
    - A coordinated national response in a federal system can prove challenging, as evidenced by the response to COVID-19.
    - Rather than creating one large central bureaucracy, consideration should be given to a 'hub and spoke' model with a central office, supported by local State/Territory offices. This has the potential to capitalise on the strengths and capacities of the jurisdictions, and secure more positive engagement from them.
    - An important function of the central office would be to mediate between Australian national responses and regional/global responses through the World Health Organization and other partnerships.
    - Regardless of the final structure, it is important that the ACDC guard against diverting precious resources to the creation and maintenance of a large central bureaucracy.

- In terms of the **operation** of the ACDC we believe:
    - Non-communicable diseases need to be an explicit focus and must be resourced appropriately in proportion to their potential impact on the population.
    - A strong theoretical framework should guide the ACDC that incorporates recent advances in epidemiology and public health, particularly in acknowledging and responding to the social and cultural factors which influence health and illness. In this context we suggest that the ACDC should adopt accepted international terminology and refer to the 'social and cultural' determinants, in preference to the term 'wider' determinants used in the Consultation Paper.
    - Demonstrated independence from political and commercial interests will be crucial to achieving and maintaining credibility.
    - The ACDC should not duplicate the work of other government agencies, such as Cancer Australia, the Therapeutic Goods Administration, the Australian Digital Health Agency and others.
    - Advice on particular issues should be sought from non-government stakeholders making significant and meaningful contributions in their field of expertise.

4. Key suggestion: Establish a standing advisory mechanism to the ACDC to ensure comprehensive consideration of and responses to Australia's cultural and linguistic diversity (relates to Consultation Paper, Question 24)

- The ACDC has an ethical responsibility to recognise and respond to Australia's culture and language diversity in both its initiatives targeting the public and with respect to its workforce.
- We draw attention to a December 2022 *Lancet* Series titled "Racism, xenophobia, discrimination, and the determination of health."[2]
    - The Series notes that: *racism, xenophobia, and discrimination exist in every modern society causing avoidable disease and premature death among groups who are often already disadvantaged. It examines how the historic systems and structures of power and oppression, and discriminatory ideologies have shaped policy and practice today, and are root causes of racial health inequities. Furthermore, by applying a global lens and intersectional framework, overlapping forms of oppression such as age, gender, and socioeconomic status and their impact on discrimination are analysed. Interventions to address the spectrum of drivers of adverse health outcomes with a focus on the structural, societal, legal, human rights, institutional and system level are reviewed. Research recommendations and key approaches for moving forward are proposed.*
- The National Preventive Health Strategy[3] identified CALD people as one of many groups with greater health needs and who may experience greater and avoidable burden of disease.
- In 2018, the AIHW highlighted [4] that CALD people often face increased risk of negative outcomes in key public health areas such as smoking and alcohol use, obesity, food and nutrition, mental health, exercise and physical activity, chronic conditions and communicable diseases, and immunisation.

[2] https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(22)01972-9/fulltext
[3] https://www.health.gov.au/resources/publications/national-preventive-health-strategy-2021-2030
[4] https://www.aihw.gov.au/getmedia/f3ba8e92-afb3-46d6-b64c-ebfc9c1f945d/aihw-aus-221-chapter-5-3.pdf.aspx

- Other factors that would support the creation of a CALD Advisory Group to the ACDC include:
    - relatively low levels of health literacy
    - difficulties in navigating the health system
    - culture or language barriers to participation in prevention initiatives
    - lack of culturally appropriate health translations and communications
    - insufficient consideration of CALD issues in other national health strategies
    - deficits in national collection and reporting of CALD health data.

- The impact of COVID-19 has highlighted these and other disparities with significantly higher mortality rates for overseas-born Australians from non-English speaking countries.

- FECCA took a leading advocacy role in relation to the COVID-19 response. As a result, the Department of Health and Aged Care established the national Culturally and Linguistically Diverse Communities COVID-19 Health Advisory Group which, through its subgroups, has achieved significantly improved communications and engagement, data and vaccine uptake.

- This group has now evolved beyond a focus on COVID-19 to have an advisory function across the Department of Health and Aged Care and has transitioned to a more broadly focused Culturally and Linguistically Diverse Communities Health Advisory Group.

We suggest that the ACDC should set up a similar standing advisory mechanism, including consumers, practitioners and researchers, particularly if it is established as a separate entity from the Department of Health and Aged Care. Regardless, membership of this group could be more specifically focused on the remit of the ACDC, rather than the more broadly focused Departmental mechanism.

5. Responses to Consultation Paper Questions relevant to culture and language diversity

- **Question 6 (Data)**

  - The 2020 FECCA issues paper "*If we don't count it … it doesn't count*" [5] addresses significant national deficits and inconsistencies in the collection and reporting of data relating to Australia's culture and language diversity in all domains, not only in health.

  - These deficits are evident in:
    - administrative data (which most commonly captures only 'country of birth', which is not useful as a sole indicator);
    - survey data (for which sampling methodologies often do not reflect the diversity of the Australian population); and
    - social, health/medical research and clinical trials (in which people from culturally and linguistically diverse backgrounds are often underrepresented or not represented, mainly due to language issues).

  - A key recommendation of this paper called for the Australian Government to establish a high-level National Working Group, involving relevant stakeholders and expertise to develop recommendations as to how national and jurisdictional data collection and reporting on cultural, ethnic and linguistic diversity can be more consistent, complete and useful. This would involve recommending the most appropriate indicators.

  - At the FECCA 2022 National Conference, the new Minister for Immigration, Citizenship and Multicultural Affairs committed the Government to such a process.

  - We believe strongly that, potentially through a Data Advisory Group, the ACDC could play an important role in this process which will involve challenging discussions:
    - Why do we need these data and what do we do with them?
    - What would a minimum multicultural health data set look like?
    - What do we mean by 'ethnicity' and 'ancestry' (an issue largely unaddressed in Australia and about which there is some confusion)?
    - Why do so many national health data sets contain little or no information on culture and language diversity, with the exception of Aboriginal and Torres Strait Islander status?
    - Given the association between ethnicity and some diseases, how will we respond to the emerging field of genomics?

[5] https://fecca.org.au/wp-content/uploads/2020/10/CALD-DATA-ISSUES-PAPER-FINAL2.pdf

    - With the increasing focus on data linkage, particularly through the Australian Bureau of Statistics led Multi-Agency Data Integration Project (MADIP), what are the ethical considerations around linking and publishing data for culturally and linguistically diverse people? MADIP processes are often opaque, and should greater consideration be given to collecting consistent data at source, in the MBS and PBS for example?
    - Should the collection and reporting of agreed indicators, depending on the context, be mandated in reporting by Government Departments, in funding agreements and accreditation processes?
    - As is the case in the US, should publicly funded research require applicants to demonstrate how the proposed research will be inclusive of culture and language diversity?

- These conversations must include our communities, who need to understand the benefits to them of collecting such data and participating in research.

- We welcome the focus on interoperability of jurisdictional data systems. COVID-19 again provided a clear example of why this is necessary.
    - During peak COVID-19, the National Notifiable Disease Surveillance System was amended to include, in addition to Aboriginal and Torres Strait Islander status, two new indicators: 'country of birth' and a language indicator.
    - After some delay these new indicators were included in the on-line vaccination consent forms. The Australian Immunisation Register was, however, not able to accept these fields.

- In addition, the Australian Digital Health Agency has worked in partnership with FECCA since 2020 towards increasing the uptake of My Health Record in multicultural communities. My Health Record now provides the capacity for consumers to voluntarily add 'country of birth' and their preferred language to their profile.

- We again suggest that the ACDC could play an important role in much needed reform in national data.

- **Questions 12 (Health Promotion) and 22 (National Preventive Health Strategy)**

  - The ACDC could play an important role in ensuring that people working in these domains understand the importance of ensuring that initiatives are inclusive of culture and language diversity, are accessible, culturally resonant, and where necessary, specifically targeted.

  - This could be encouraged by the development of appropriate guidelines.

  - The frequent use of images of black and brown people in health promotion campaigns alone, without any substantive and meaningful content, is mere tokenism, ineffective and unacceptable.

- **Question 15 (Public Health Workforce)**

  - The ACDC must acknowledge that the public health workforce is itself culturally and linguistically diverse and, in its own workforce, reflect that diversity, including in management and senior executive roles.

  - We have been invited to be part of targeted consultation in the current analysis of the public health workforce being conducted by the Department of Health and Aged Care.

  - The ACDC must demonstrate cultural inclusion and actively encourage the diverse workforce to be able to bring their own cultural lens and lived experience to the work of the ACDC, particularly in terms of engagement with multicultural communities.

  - As evidenced by COVID-19, a 'one size fits all' approach to public health does not work. The richness provided by a culturally and linguistically diverse workforce should contribute to informing public health methodologies and approaches that are led by and respect these perspectives.

  - Following the example of the US CDC, the ACDC should facilitate and engage in targeted training and support in applied epidemiology for people from under-served and under-represented communities, including mentoring them into such programs, for example, the Master of Applied Epidemiology at ANU which is a field epidemiologist program based on the US model. This will have particular relevance in responding to new and emerging conditions.

- The ACDC should consider active engagement with multicultural professional organisations (such as the Australian Chinese Medical Association, the Australian Islamic Medical Association, the Indian Medical Association and others).
  The Collaborative can facilitate these engagements.

- **Question 25 (information provision to CALD communities)**

  - With respect to engaging with and providing public health information to consumers from culturally and linguistically diverse backgrounds, the ACDC should implement the lessons learned through the input of the communications subgroup of the Culturally and Linguistically Diverse Communities COVID-19 Health Advisory Group,

  - Translated materials should follow the guidelines established in the National Protocols for the Translation of Community Information.[6]
    This includes:
    - Ensuring the source material is drafted in simple English.
    - Avoidance of technical language whenever possible.
      When necessary, the English expression should be used followed by a simple in-language or pictorial explanation.
    - Engaging local NAATI certified translators for the original translation and a subsequent comprehensive revision by a second NAATI certified translator. The use of overseas-based translators is to be discouraged as they may not have the required knowledge and experience of the Australian context.
    - Linking to existing infrastructure such as the NSW Multicultural Health Communication Service, and Health Translations [7] (based in Victoria, but used nationally).
    - Testing of the translated materials with target communities to ensure that the material delivers the required message in a way that is understandable and culturally resonant (noting that some topics may be culturally sensitive in some communities). This is an important, but often overlooked step.

  - For distribution and engagement, partner with existing trusted community-based networks (including, but not limited to, FECCA, the Australian Multicultural Health Collaborative, the Refugee Health Network of Australia, front-line multicultural health and social care services), and with state government multicultural services (such as the South Western Sydney Local Health District Multicultural Partnership).

[6] https://ausit.org/wp-content/uploads/2022/12/AUSIT-FECCA-RECOMMENDED-PROTOCOLS-FOR-THE-TRANSLATION-OF-COMMUNITY-COMMUNICATIONS-.pdf
[7] https://www.healthtranslations.vic.gov.au/health-translations-homepage

- Other traditional mechanisms include ethno-specific media (including print, radio and television). Social media may often be useful, but some communities prefer to use ethno-specific platforms, rather than Facebook, WhatsApp and others.

- Innovative mechanisms include the COVID-19 Small Grants Program and the resulting CALD Community Health Leaders Network.

    - FECCA, through the then national Culturally and Linguistically Diverse Communities COVID-19 Health Advisory Group, administers a Small Grants Program to fund community groups to deliver COVID-19 and vaccination information in ways that were most appropriate for their communities. Over 300 communities across the country have been supported to deliver culturally appropriate, language specific messaging and outreach activities.
    - Through this process, a CALD Community Health Leaders Network was launched recently with the Minister and Assistant Minister for Health and Aged Care, and the Minister for Immigration, Citizenship and Multicultural Affairs in attendance.
    - This network has the potential to ensure multicultural communities are informed about health issues by trusted and well supported community leaders. The aim is to continue to expand the network across the country.

6. The importance of words

- We strongly suggest that the ACDC should ensure that any discourse relating to culturally and linguistically diverse communities must avoid a focus on deficits.

    - It is not acceptable to use terms such as 'vulnerable', 'vulnerabilities' and 'at-risk' in relation to multicultural communities.
    - It is not culture and language diversity itself that makes some community members 'vulnerable'.
    - Rather, the system itself causes suboptimal outcomes for them.
    - As evidenced by improvements in the national COVID-19 response and the work of front-line services, when appropriately resourced, engaged and listened to, our multicultural communities proved demonstrably resilient.

- We suggest that the use of the term 'populations', deriving from the concept of 'population health', whilst readily understood by the sector and by researchers, does not resonate well for the general public. We suggest that 'communities' would be preferable.