SUBMISSION

CONSULTATION ON THE ROLE AND FUNCTIONS OF AN AUSTRALIAN CENTRE FOR DISEASE CONTROL

PRIORITIES OF THE AUSTRALASIAN INSTITUTE OF DIGITAL HEALTH

The Australasian Institute of Digital Health (AIDH) is pleased to provide input to the Australian Government Department of Health and Aged Care's consultation on the role and functions of an Australian Centre for Disease Control. The AIDH will have more to say about the establishment, role, and functions of an Australian CDC in the coming months.

The AIDH represents a community of over 30,000 people working across all aspects of the healthcare sector. The Institute has more than 250 distinguished Fellows who are experts or pioneers in the field of digital health and boasts a membership of more than 2,000 professionals comprised of clinicians, health informaticians, health executives, administrators, researchers, educators, and health technology business leaders.

The AIDH provides objective, non-partisan, and independent advice on the use of digital health and health informatics to enable the health sector to improve health outcomes and to solve our healthcare system's most pressing challenges. A holistic and systemic approach to data and digital is key to health transformation and will be critical to the success of an Australian CDC as part of a national health sector.

The AIDH's unique composition and reach brings together an extraordinary network of Australia's leading digital health experts across the private, public and community sectors to advance our transition to a digital health future.

Principles and Priorities for an Australian Centre for Disease Control

Public health informatics has called for many years for a central, co-ordinated response to pandemics and other significant outbreaks of disease, as evidenced by the global experience with COVID-19.

The Australasian Institute of Digital Health (AIDH/the Institute) believes that such co-ordinated responses are possible through a single national authority like an Australian CDC, provided the design, and the role and functions of such an authority is guided by the following priorities and principles.

1. The CDC should be independent of political views, always acting purely in public health interests.

2. CDC personnel should be experts in public health, and health informatics. Expertise and experience in public health informatics[1] at all levels within the CDC is needed.

3. CDC personnel need to have appropriate authority to act as required. While keeping government abreast of issues, the CDC should be legally enabled to act independently of the government of the day.

4. Data and the digital enablement of health and public health will be critical to the success of the CDC. This will require a systemic and holistic approach to the design of the CDC – from what it's purpose will be, what it will be empowered to do, and how it will work with other existing public and private organisations. Given this, the AIDH strongly urges the government to revisit the National Digital Health Strategy, the National Interoperability Strategy (both owned by the Australian Digital Heath Agency) and the National Health Data Strategy (AIHW was running national consultations on this pre-COVID-19) to ensure a consistent and comprehensive approach to data management, use and governance that best serves the health and public health goals and needs of the Australian people.

5. The CDC should have a fluid structure of expert personnel engagement. This would allow personnel with specific fields of expertise to step up and play leading roles in responding to specific public health demands.

6. In supporting national coordination of the public health sector, a CDC will need to develop key affiliates in all aspects of public health, PHN's, educational institutions, health professional associations and consumer groups. However – given the integral role private hospitals played in Australia's and most notably, Victoria's public response to the COVID-19 pandemic, this network of key affiliates must also include the private sector.

7. A key lesson from the COVID-19 pandemic was the need for consistent data collection that is not too onerous and not constantly changing in terms of content and frequency. We have elaborated more on this in the next section of our submission.

8. With the scale and magnitude of data collection across various government departments and agencies both at the federal and state levels, a CDC that is well connected with existing departments and agencies (AIHW, ACSQHC, etc) is foundational to a 'whole of government' approach to addressing prevention, promotion, and the protection of Australians.

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[1] Centers for Disease Control and Prevention (CDC). Introduction to Public Health. In: Public Health 101 Series. Atlanta, GA: U.S. Department of Health and Human Services, CDC; 2014. Available at: https://www.cdc.gov/training/publichealth101/informatics.html

9. An Australian CDC must incorporate state-based data and advice but maintain its independence in decision making and in the provision of advice and guidance.

10. Secure networks and platforms with an ability to link data from multiple sources and systems. An appropriate amount of data to identify age, sex, ethnicity, comorbidities, recent travel, exposure, risks, etc., that allows the CDC timely data access to assess all potentially contributing factors when a new 'event/disease/public health risk' is emerging.

11. Advances in machine learning and artificial intelligence will, over time, influence how the CDC will access and work with data models. The CDC will need to maintain knowledge currency in these advances and ensure appropriate clinical, ethical and data governance standards can be applied in its build and application of advanced data models.

12. Governance models to ensure that certain groups/communities are not pinpointed and exposed as a response to an outbreak/risk. The responsible sharing of data to allow a measured and consistent response is key in this regard.

13. For the CDC to have the technical capability to analyse data and develop timely guidance, it must consult broadly, work with organisations such as the AIDH, collaborate with educational institutions, public health agencies and existing relevant international bodies.

14. For the CDC to establish itself as a leading and trusted national body that provides guidance to governments, public health organisations and the general public, this guidance must be based on the best available evidence. Expertise in infodemic management and communications in the age of disinformation and misinformation will be required. The 'old rules' of public health communication prior to the age of social media have proven to be ineffective and thus the CDC will need to give due consideration to evidence, transparency and communication strategies that give it the best opportunity to establish and retain its reputation as a national trusted body.

15. The CDC should lead health promotion, communication, and outreach activities to the extent that it can act as a central repository for the promotion of communication and outreach activities already being undertaken by other government (and non-government) organisations to avoid duplication and strategically fill gaps of relevance to the work of the CDC.

16. To ensure that our public health workforce is prepared for future emergencies, both in Australia and abroad, the CDC could consider maintaining a register of people capable and willing to respond and move to the area of greatest need. This would need to extend across all disciplines and ancillary staff that support these services. Ability to second specialist staff and expertise as required. Such a database would need to be continually maintained and updated.

17. The CDC should support and retain the public health workforce in reducing the burden of non-communicable disease by working closely with health peak bodies on prevention programs.

18. The CDC will be an attractive employer to public health professionals and public health informaticians. There is inadequate current supply of people with the required skills and experience, so planning will be needed to ensure existing organisations aren't drained of staff who want to change employers to the CDC.

19. Given workforce shortages, it will be necessary to rethink what public health and public health informatics expertise is required by all clinicians and non-clinicians who work in the health

sector. It is likely that all health professionals and those who support health delivery in data and digital roles will be required to have some expertise in public health and public health informatics.

20. Addressing health illiteracy and gaps in public knowledge of risks and preventions, the ability to quickly link and trace data through a single unique identifier, are gaps in Australia's preparedness and response capabilities which a CDC should address in cohort with a national health data strategy.

21. Available, clear, concise and most importantly – consistent messaging across jurisdictions are necessary in the CDC having a holistic approach across public health including the domains of health protection and promotion and disease prevention and control.

22. An Australian CDC should include vital clinical data such as clinician preferences, prescribing and dispensary practices in Australia and its variation across the country. The inclusion of state based regulatory differences and rationale for the noticeable differences (if any) ought to be listed and discussed via a 6 -12 monthly audit to ensure that there is a standardised Australian recommended clinical practice in the future with minimal variation across the nation

23. An Australian CDC should work closely with researchers and research organisations. There are opportunities to enhance research participation via secure, shareable and accessible health data upon approved request via partnering research organisations/entities; and to fund or support in other ways research that is of a priority to the Australian CDC.

Data systems to ensure maximal preparedness, effectiveness, and impact.

The digital delivery of healthcare gained tremendous momentum during the COVID-19 pandemic. With increased demand amongst consumers and an enduring expectation that digital health will play a role in enabling preventative health and the provision of health service delivery, health data collection has reached a historical high in Australia.

Our experience from the pandemic, however, clearly demonstrates that there is a lack of consistency in data storage and capability in data linkage amongst and between pathology services, primary health providers, hospitals and public health professionals, highlighting the indisputable need for a central, co-ordinated response to health crises or other significant outbreaks of disease.

The current challenges and systemic issues facing the collection, collation, and analysis of health data at the national level include:

- Inconsistency in data collection (much of which is still manual and not digital)
- Consistent proliferation of data silos
- A lack of understanding by those collecting health data of its value and potential use outside of direct clinical care purposes
- A lack of cross jurisdictional standards for adoption of digital solutions and data sharing abilities
- Fragmentation of specialist health data
- Variability in open data standards use between states and health providers
- Lack of standardised systems and data exchange models
- Unidirectional data transfer, i.e., one-way from a clinical setting to a registry but cannot be shared back

The clinical knowledge domain is large, and can be messy, complex, and ever evolving. In the absence of a national health data strategy and widespread appreciation for the value of this data, we intuitively build clinical systems and data sets to match local requirements, to ensure that we can achieve our immediate end goal with the data we collect. However, the result is a myriad of health data silos, making that data difficult or impossible to use to advance public health priorities through data exchange, aggregation and analysis, knowledge-related activities and research.

Often, health data analysts are confronted with a need to patch between systems and manipulate data using transformations or mappings. This comes with an inherent risk to data integrity and potential data loss. In times of health crises, this risk could result in deleterious consequences on the model of intervention, and ultimately, the Australian population.

As clinical systems grow more complex, the silo problem is amplified, and the interminable patching or data manipulation becomes progressively unsustainable. As the volume of hugely valuable, fragmented and divergent health data continues to grow, we need to change our approach to health data design – one in which health data is decoupled from specific applications and projects, but intentionally and strategically designed as a coherent health data ecosystem that is independent of any single vendor, organisation, project or clinical use case.

The CDC cannot afford, or risk becoming, another data silo. Instead, an Australian CDC should form part of, or become the driving force behind efforts to standardise atomic health data within Australia.

Work programs such as the CSIRO/Australian eHealth Research Centre's Primary Care Data Quality Foundations (PCDQF)[2] approach is intentionally working towards breaking down silos due to establishment of a shared data dictionary which is used to support exchange and interoperability across and between primary care vendors, extending laterally to other domains such as aged care and indigenous health, and potentially vertically to organisations using this data for reporting, such as AIHW, and My Health Record.

This and other global approaches can serve as the basis for a national approach to health data collection and governance that delivers the best possible outcome for all Australians. Clinical information captured as part of point-of-care documentation can, with appropriate authorisation and consent, potentially be directly integrated into a public health surveillance/registry context and ensure data coherence across various surveillance programs and registries[3]

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The AIDH would like to acknowledge the following individuals for their contributors to this submission:

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[2] https://confluence.csiro.au/display/PCDQFPhase2/Primary+Care+Data+Quality+Foundations+-+Phase+2
[3] Similarly, in 2021, the National Surveillance Unit of the Ministry of Health and Wellness in Jamaica commissioned a data standardisation program for Class 1 Notifiable Diseases in anticipation of deployment to a new national clinical data repository and to kickstart the establishment of a national, vendor-neutral, open standards-based, health data dictionary. Much of the content covered in the PCDQF work is replicated in these public health disease/event surveillance data sets. To date, Adult and Paediatric HIV, Tuberculosis, Fever and rash, and Maternal mortality data sets - https://ckm.openehr.org/ckm/incubators/1013.30.113 - have been standardised and harmonised, with further standardisation and harmonisation across other Class 1 disease and event notifications planned to continue into 2023.