

## **VCCC Alliance organisational wide response to Cancer Australia's National Cancer Data Framework public consultation.**

This submission is a result of consultation with multiple stakeholders, including clinician / academics with the following expertise: Aboriginal and Torres Strait Islander Health; primary care; cancer nursing; rural/regional health service delivery; consumers; and data management professionals.

### **Q4: Do you have any comments or feedback on strategic objective 1: A mature performance reporting system?**

#### **Key themes identified by all included:**

- Indigenous co-design is critical to implementation
  - o 1.1 p14-15 There is no reference to building the scholarship of Indigenous Data Sovereignty (ID-SOV), which has vitally important implications of enacting validity and supporting the reader to source additional information
  - o 1.1.1 p15 This should not be solely about 'informing First Nations peoples' It requires working with First Nations people. Informing is not inclusive practice. Engagement with consumers and communities, particularly First Nations people, is about engaging and partnering with people with lived experience to prioritise areas of interest and use of data. Meaningful and effective engagement should be across the entire continuum, from design, implementation and evaluation, including the development and governance of a National Data Framework
- Primary Care data capture and sources missing. Primary care data is key as part of the cancer experience
- Diagnostic data missing including symptom presentation and symptom mapping. It is vital to be able to interrogate time to diagnosis. The diagnostic odyssey and interval to diagnosis is of immense importance to patients. Incomplete pre-diagnostic data, or lack of comprehensive data collection, will lead to inaccurate reporting.

#### **The following additional feedback was provided:**

- p3 Summary states that a mature performance reporting system will enhance patient care. It will also improve patient outcomes, provided the performance reporting framework prioritises an equity lens
- 1.2 Opportunity for the public trust section to align with broader national government developments including building capability, e.g., Victorian Data Sharing Act, the Data Availability and Transparency Act
- 1.3 Benchmarking is essential in driving optimal care – the gap in benchmark indicators specifically for health equity in cancer care should be developed, where the building blocks are the capture of high-quality data for all priority groups based on agreed national datasets
- Standardisation of data points, data collection methods and reporting indicators are imperative across all jurisdictions and institutions; robust, complete (no missing populations, e.g., private health outcomes) and uniform data. Incorporating determinants of health will ensure outcomes are trusted
- Data regarding research participation is critical to add to the eco-system.

**Consumer feedback also focussed on the following:**

- If appropriately managed and applied, data-linkage across cancer services (public and private) has the benefit for patients in reducing the number of tests, reducing the trauma of repeating details of experience, symptoms and treatment side effects, and increasing efficiency with hospital discharge and connectedness with primary care
- 1.2.5 Key performance indicators across jurisdictions – are these designed to help patients make informed decisions about their treatment? What information provided makes a difference for patients? Is this an aspect to increase personalised care?
- 1.3.1 states to establish a technical and clinical working group to define core indicators and data requirements – where is the expertise of a lived experience incorporated into these decisions?
- Having accessible materials available does not correlate to increased data health literacy. The Framework, as a foundation, should have broad multipronged approaches to improve general health and data health literacy

**Q5: Do you have any comments or feedback on strategic objective 2: A sustainable and fit- for-purpose data system?**

- Ensure a strong focus on capturing data across the entire Optimal Care Pathway, including data generated within the **private healthcare sector** (health services, pathology). Substantial data gaps have been identified in the past at the pre-diagnostic and diagnostic stage, particularly if patients enter the public system after a diagnosis by a private specialist
- Data on pre-diagnostic pathway is missing. The majority of cancers are not screen detected, therefore it is imperative to ensure data is captured and integrated from primary care. There is no discussion in the Framework regarding sources of primary care data. There is inadequate recognition of diagnostic steps and diagnostic datasets
- Incorporation of data re performance status/fitness is an important determinant of outcomes
- Resourcing of data collection is critical to consider
- There is increasing utility in genomic data – for purposes of identification of inherited predisposition, diagnosis and treatment. Imperative for the Framework to embed and integrate genomic data sources
- 2.5 & 2.6 There is a gap in CALD data collection where a national standardised dataset to identify and relevant for CALD population should be developed and implemented. VCCC Alliance has done work in this area. This dataset should be extended to and be collected across the continuum including in primary care. Knowing what data is missing, or not adequately collected, will then enable barriers to be assessed. Interventions can then be developed, tested and implemented to address the data gaps thereby improving data integrity.

**Consumer feedback also focussed on the following:**

- 2.5.1 Who determines or prioritises the core indicators?
- 2.5.5 Refer to PROMS and PREMS measures and collection approaches in First Nations peoples and for other priority populations. This has not been optimised for the general population and is currently underutilised with inconsistent data collection. How will the added level of complexity collecting patient experience and outcome data for people who speak a language other than English be addressed?

**Q6: Do you have any comments or feedback on strategic objective 3: User-centred, integrated and accessible data?**

- 3.1 p24 The wording for the first sentence should be ‘... **aspirations and respects Indigenous Data Sovereignty (ID-SOV).**’ The concept of ‘their data sovereignty’ dismisses the developments of the efforts in ID-SOV, and makes an implicit assertion that it is relevant to some and not all.  
NOTE: There are currently no references in the Indigenous Data Sovereignty in practice section p7-8. It should include at least the Kukutai and Taylor reference. Specific to ID-SOV in cancer in Australia the following chapter has been published: Griffiths, K. (2024). Considerations in Operationalizing Indigenous Data Sovereignty in Cancer Reporting. In: Garvey, G. (eds) Indigenous and Tribal Peoples and Cancer. Springer, Cham. [https://doi.org/10.1007/978-3-031-56806-0\\_9](https://doi.org/10.1007/978-3-031-56806-0_9) . It is important that Indigenous scholarship is recognised within these documents, and it also assists the reader in where to source further information.
- For PROMs and PREMs to be clinically meaningful, considerable investment in health service resources is required to ensure timely response to data directly provided by patients, i.e., a clinical response may be required in real time, at point of care. Clarity regarding the plan for investment to achieve these important initiatives is lacking.
- Real-time reporting capability is vital
- 3. Patient centred care as one of the guiding principles and is an important tenet to improve equitable outcomes for priority populations including CALD.

**Consumer feedback also focussed on the following:**

- Will access to the reports be equitable? For public reporting, what is the intent and who is the audience? A step in the right direction to have national data-linkage, but what does this mean for the patient experience? What is the expectation on how patients will use the data?
- What compensation will be made for people who do not speak English or who have low health literacy?
- The reporting may be perceived as an economic, efficiency and population-based exercise. How will the reports or data be used to inform personal treatment choices?

**Q7: Do you have any comments or feedback on the draft implementation roadmap?**

- **Data Accessibility for Patients and Public Engagement:** Whilst public trust is addressed, there is limited focus on making data accessible and understandable to patients, caregivers, and the general public. A user-friendly public interface may improve transparency and empower individuals to make informed health decisions
- **Integration with Broader Health Data and Social Determinants:** The framework acknowledges the need to link cancer data with social determinants but lacks specifics on integration, e.g., housing, employment, and education data, which will enhance understanding of inequities in outcomes
- **Longitudinal Tracking and Survivorship Data:** While cancer registries and clinical quality data are included, a more robust plan for longitudinal data collection that tracks patients beyond treatment, especially to capture survivorship outcomes, late effects, and quality of life over time would be beneficial

- **Clear Metrics for Equity and Priority Populations:** While there is significant emphasis on Indigenous data governance, there is less detail on metrics that can consistently assess health outcomes across other priority groups
- **Health Literacy:** It is imperative to not only understand the current level of data health literacy, but to also make a concerted effort to educate and improve the health literacy of consumers, particularly in priority populations e.g., CALD. The use of AI to improve health literacy should be given cautious consideration
- **Standardisation of Datasets:** Collection of priority populations e.g., CALD should be prioritised. The Australian Cancer Data Alliance could lead in development of a standardised national dataset to identify CALD patients.

**Q8: Are there any other comments you would like to make regarding the National Cancer Data Framework?**

1. Whilst the framework identified a number of challenges (*pg 9* fragmentation, interoperability, data gaps, data linkages and access, underutilisation of research data and limited reporting), enablers and facilitators to overcome are not adequately addressed in the implementation plan
2. There are glaring gaps in the ecosystem figure. It is not an adequate representation of what is happening nationally. VCCC Alliance member contributions include (not exhaustive, however, willing to provide a more comprehensive list):
  - UOM
    - Data Connect <https://vccc Alliance.org.au/research/data-connect/>, including PATRON (primary care data)
    - PC4 <https://pc4tg.com.au/>
    - Melbourne School of Population and Global Health, [Cancer Health Services Research](#), including PRIMCAT
  - WEHI
    - Gibb's Lab Cancer Registries and Cancer Registry Clinical Trials <https://www.wehi.edu.au/laboratory/gibbs-lab/>
3. AI is only mentioned in the Framework for use as a technical tool e.g., gleaning data from pathology reports and processing data. Further consideration should be given to the growing use of AI in educating the health literacy of patients e.g., AI could be used in translating patient information sheets, or when an interpreter is unavailable to be present or when there is need to communicate in dialects.
4. Consumer feedback also focused on the following:
  - There appears to be an apparent lack of lived experience input into framework as perceived from the language use, and outline of approaches that makes a clear distinction between roles within the roadmap. Success requires integration of consumer, community, technical, clinical, and researcher expertise in all steps of the implementation roadmap.
  - Evaluation is missing in the implementation plan. How will areas of improvement be measured? From a consumer perspective, how do you measure a change in trust or usability of the reports?
  - Without inclusion of an accompanying evaluation framework and clear measures of success, the implementation plan appears overly ambitious.
  - Ensure that consumers, communities and priority populations are represented in governance.