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Dear Peter

Re: Draft ACT Public Health Data Strategy 2021-29

Thank you for the opportunity for Health Care Consumers' Association (HCCA) to provide comment on the Draft ACT Public Health Data Strategy 2021-29. We understand that Darlene Cox, Executive Director at HCCA, has provided comments separately.

High-quality data is a vital part of any health system committed to quality and safety. We have considered the draft strategy based on our experience. We have not been able to consult more widely with consumers to frame our response as there was insufficient time provided to do so.

We know that when used appropriately, high quality data can identify gaps, highlight areas of safety concern and service gaps and indicate areas in need of further investment. This strategy is a step towards achieving this, however we suggest a few areas that need further consideration. Our key concerns with the Draft ACT Public Health Data Strategy relate to:

1. Data Analysis
2. Data Security
3. Data and Public Performance Reporting

We have provided more detailed comments on each of these areas below.

1. Data Analysis

Our main concern around data analysis is that the focus on 'data management' in the strategy doesn't seem to emphasise the need for the kind of data analysis and interrogation that provides an evidence base for driving continuous quality improvement in our health system. The importance of this work is recognized throughout the Australian Commission on Safety and Quality in Health Care's (ACSQHC) *National Safety and Quality Health Service Standards*¹.

Undertaking this kind of analysis requires particular skills and training, including:

- Ability to blend qualitative and quantitative data to get a more accurate picture.
- Being able to determine which data is important and why, and to be flexible in changing data sources/combinations when new information comes to light.
- Recognising data bias that can be created by services, where these services are not provided in the ACT.
- Understanding the difference between correlation vs causality, that is not always clear in data.
- Taking care to avoid machine bias and algorithmic prejudice, such as those seen in the US justice systemⁱⁱ. This is particularly important when looking at predictive and prescriptive analytics.

The introduction of the ACT Digital Health Record (DHR) alone will not provide these skills in data analysis. Our understanding is that it can provide a shorthand to common queries and reporting needs but, deep analysis and interrogation of data will require staff highly skilled in data literacy.

In addition, p23 of the Strategy states the definition: “Data: 'Raw' data, collected as a discrete, objective fact or observation without interpretation”. We are concerned that this definition demonstrates a lack of understanding about data and data bias - data is not objective and without interpretation. We all make decisions when we decide *what* data is collected and *what* is deemed to be important. All of these decisions have embedded beliefs, values and assumptions. We suggest that this definition may need review.

2. Data Security

We know that consumers are concerned about the security of their data in the health sector. This has been reflected in much of the dialogue from consumers around the national introduction of My Health Record, for example. These concerns around data security include:

- Data needs to be clearly marked as not for private sale – and any private integrations need to be done carefully so we don't end up with a situation like the US has experienced with Google receiving non-anonymised medical data from a private insurer.
- Suitable anonymising processes – allowing for anonymising but also unique identifiers so people can remove their data e.g. if a consumer decides that they no longer give permission for their data to be used for research.
- Statements in the strategy to make clear that data will not be used to prejudice treatment or access to treatment for consumers.

3. Data and Public Performance Reporting

HCCA is concerned that the *Proactive Release of Data (Open Data) Policy 2015* is only referenced (at Appendix 3) in the strategy, but is not mentioned otherwise. We suggest this is a key document and is critically important when looking at the use of data and in public performance reporting. The draft strategy highlighted the need to increase trust and accountability; leveraging the principles in the Open Data Policy is an important aspect of this work. The accuracy of our health data is important to consumers and is essential for ACT performance reporting at the national level, along with benchmarking alongside other jurisdictions.

Consumers also want to see timely, clear data and reporting as part of the evidence base for providing informed consent in health care. Publicly available data on the safety and quality of our health services can form part of consumers' individual assessments in making decisions about health care. At a community or public health level, effective use of data and public performance reporting can help us all in decision-making throughout our health care system.

Other Comments - Document Design

- Page 9: the design is visually hard to parse. There is a need to be clear that the 'Foundational management' and 'Lifecycle management' are both data management functions.
- Page 13: Layering of the graphic appears to be on top of the text.
- Page 15 & 17: Colours need to be put through a colour-blindness test if they are being used to indicate paths, as depending on a person's vision ability some of the colours look the same, making it difficult to distinguish between them.

We are happy to discuss our submission further. Please contact us if you have any questions or require clarification.

Kathryn Briant

Policy Officer

Health Care Consumers' Association

28 May 2021

Anna Tito

Policy and Research Officer

ⁱ Australian Commission on Safety and Quality in Health Care's *National Safety and Quality Health Service Standards (2nd ed.)* https://www.safetyandquality.gov.au/sites/default/files/2021-05/national_safety_and_quality_health_service_nsqhs_standards_second_edition_-_updated_may_2021.pdf

ⁱⁱ For example, see: <https://www.propublica.org/article/machine-bias-risk-assessments-in-criminal-sentencing>