A FRAMEWORK FOR PERFORMANCE REPORTING AND DRIVING WELLBEING OUTCOMES IN NSW

Organisation: Centre for Health Economics Research and Evaluation (University of Technology Sydney)

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Submission to Public Accounts Committee inquiry into a framework for performance reporting and driving wellbeing outcomes in NSW

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Dear Public Accounts Committee,

We welcome the opportunity to submit to the Public Accounts Committee inquiry into an effective framework for reporting on the performance of NSW Government services and driving wellbeing outcomes for NSW residents.

We are writing this submission as members of the Centre for Health Economics Research and Evaluation (CHERE) at the University of Technology Sydney (UTS). One of CHERE's key research strengths is into the measurement and valuation of quality of life (QoL) and wellbeing, and use of the data collected to inform decision making.

We raise the following points to inform the development of a framework for performance reporting and driving wellbeing outcomes.

1. Where to measure outcomes

As part of the framework, quality of life and wellbeing outcomes should be measured routinely in population surveys, government services and also in hospital and other health care settings. This should be done across the state to ensure that all socio economic and cultural groups are represented. Conducting routine assessment using validated tools (see Section 2) allows for the wellbeing and QoL of NSW residents to be tracked over time, and changes to be directly linked to the services provided across different groups in the population, and allows us to refine our understanding of the relationships between social determinants of QoL and wellbeing, and outcomes of importance to the NSW population.

2. What outcomes to measure and how to measure them

Given that wellbeing and quality of life have numerous and competing definitions, a key starting point would be to define these terms in the context of the framework. These definitions can then be used to inform what should be measured to ensure that the framework measures what matters to all NSW residents. This should include clarifying the constitutes of wellbeing and QoL for the population. For example, defining whether wellbeing and QoL include health, social, economic

and environmental aspects. This could be done using a mixed methods approach including literature review, and a consensus process amongst stakeholders to identify a core set of outcomes to collect to ensure standardisation whilst minimising the burden of reporting and assessment.

It is important that what is measured is culturally appropriate for all NSW residents. This is challenging, as perceptions of quality of life and wellbeing are influenced by cultural background. Therefore, the standardisation of assessment tools is important, but different toolkits may be needed in different population groups. For example, for Australia's Aboriginal and Torres Strait Islander people, tools like the What Matters to Adults (WM2A) measure assess wellbeing from their values and perspectives. This tool was developed by a broad collaboration including CHERE researchers (Howard et al 2023). A key priority of the Department of Health and Aged Care's National Aboriginal and Torres Strait Islander Health Plan 2021–2031 is to develop a culturally informed evidence base to support the development, implementation and assessment of policies and programs.

It is also important that appropriate and psychometrically validated instruments and measurement tools are used, and this information can be gained from reviewing the existing evidence relating to the tools.   There are many types of tools available, including those focused on different constructs of QoL, including generic and condition specific health focused QoL measures, and also broader QoL measures covering a wider range of constructs (hence the need to define what will be measured). These include such instruments with CHERE involvement such as the generic EQ-5D (Viney et al 2013, Norman et al 2014), SF-6Dv2 (Brazier et al 2021; Mulhern et al 2021) and EuroQol Health and Wellbeing (EQ-HWB, Brazier et al 2022; Peasgood et al 2022; Carlton et al 2022), and condition specific measures in, for example, cancer (King et al 2018). Other measures already used in NSW such as the PROMIS-29 (Hays et al 2018) are also available. The final choice may be a core set of instruments covering a broad range of wellbeing and QoL outcomes, and this can be informed by existing work exploring the relationship between broad measures, some of which has been conducted by CHERE (e.g. Heijdra Suasnabar et al 2024)

While generic instruments are suitable for comparing QoL across different settings, and for broad assessments and health policy planning, focused instruments provide more detailed and relevant information about specific conditions. This makes them valuable for clinical settings and outcome monitoring. It is important to choose the most reliable and valid instrument for the NSW population and to validate it within this population.

We would recommend a review and consultation process with experts in wellbeing and QoL measurement to identify possible instruments, and assess the available validation evidence to finalise the choice. Key areas of validation include face, content and construct validity, and reliability. These are qualitative and quantitative approaches to establish whether instruments measure what they were developed to measure, whether they cover the whole construct, and how accurately they do this. Another key indicator is responsiveness to change over time, which is a property for measures included in the framework to demonstrate given the need to accurately monitor outcomes over time.

It is also important to establish a framework about who should provide the data. Self-reported completion is optimal, but there are populations (e.g. children, the elderly, and people with severe health conditions) where proxy report is preferable and comparable (Bahrampour et al 2024; Ratcliffe et al 2023).

3. How to value these outcomes

Alongside the measurement of QoL and wellbeing, it is also possible to assign weights to the outcomes measured to understand what elements of QoL and wellbeing are most valued by the population. This ensures that programs and policy developments can focus on improving what matters most to the NSW population.

There are a number of methods to do this that are widely used in a variety of policy areas to understand population preferences, including health, transport and the environment. These include Discrete Choice Experiments and Best Worst Scaling, which are ways of asking the population to 'trade off' different elements of, for example, QoL, with the resulting data modelled to estimate scoring weights that tell us which wellbeing elements the population most values in wellbeing across health and other domains. These weights can be used alongside the data collected from the population to report on performance, inform policy decisions and program development. CHERE has been extensively involved in using choice experiment methods to develop these weights for use in decision making (e.g. Viney et al 2013; Norman et al 2013; 2014; Mulhern et al 2019; 2021; Norman et al 2023).

4. How to use the data collected in decision making

It is also important that the framework includes clear guidance about how the data collected is used to report on service performance, and inform programs and policy to improve wellbeing. For example, as mentioned elsewhere, scores and outcomes can be monitored over time, and improvements or worsening in scores linked to external indicators relevant to the context, and

different demographic groups. This could include, for example, service characteristics or health indicators, and support understanding of the underlying mechanisms driving systematic differences in outcomes across different domains including health, social, economic, geographic and environmental.

As described in Section 3, wellbeing and QoL preference weights to understand which outcomes are of most importance to the NSW population can be assessed to inform performance monitoring, program development and policy decisions. These data should be used alongside cost information to inform better performance in the health system (to assess cost-effectiveness). From a wellbeing perspective, this can inform where the best investments are across a range of domains of government policy (e.g. housing, environment, infrastructure to improve wellbeing, health care, education and aged care) (Torbica, Mulhern and Norman, 2024)

Data gained may help us better identify which areas -- as highlighted by the Commonwealth 'Measuring What Matters' national wellbeing framework -- will benefit from upstream or midstream approaches to address conditions that contribute to poor health and QoL. This allows resources to be optimally allocated to either moderating individual-level social needs or addressing community-level root causes of health inequities.

It is also important that the data availability is considered as part of the framework, as it would provide a valuable resource to various stakeholders, including academics, policy and decision makers, clinicians, and those in other health and clinical settings.

Thank you again for the opportunity to submit to the inquiry. To discuss any matters raised please contact Brendan Mulhern, Associate Professor of Health Economics (█████████████████████, or via phone at ███████████████)

Signed

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