HEALTH POLICY PROPOSAL FROM:

Cris Kerr, Advocate for the Value of Patient Testimony

EVERYONE AGREES

yet nothing happens

In it's 'Overview', the *'Australian Atlas of Healthcare Variation' 2015*(1) reports that;

- ***'much of the variation documented in the atlas is likely to be unwarranted'***
- *'work is needed to assess the outcomes of interventions, to help identify appropriate treatment rates, and what level of variation is warranted';*
- *'inconsistent data collection methods and indicators make it difficult to draw direct comparisons', and;*
- *'the atlas should be seen as a catalyst for generating action, with the ultimate aim of improving people's care and outcomes, through improving the efficiency and effectiveness of the healthcare system'.*

Under '*Investigating and addressing unwarranted variation*', the report concedes;

- *'The atlas strengthens the case for developing and* ***adopting patient-reported outcome measures*** *as a means of monitoring and feedback on the outcomes achieved;*
- *The atlas has highlighted the* ***lack of outcome measures collected in Australia****, from either routine data or other means* ***such as patient-reported outcome measures;***
- *This restricts understanding of both the benefits and harms people experience when they have healthcare interventions, and;*
- *A better understanding of clinical outcomes would allow us to know what level of intervention benefits patients across Australia*'.

This latest report graphically **highlights the need to collect more comprehensive data** so we can better analyse the huge variations in health treatments, interventions, and outcomes, and **recommends collection of patient-reported outcomes**.

The press release for the report stated as follows:

- '*The atlas is presented alongside the first* ***national recommendations for action'.***

- "*The atlas should be seen as a catalyst for generating action, with the ultimate aim of improving people's care and outcomes, through improving the efficiency and effectiveness of the healthcare system," said Professor Duggan*.

In their response, the **Business Council of Australia** noted;

- '*Analysis such as this empowers governments to proceed with* ***sensible program redesign*** *in a careful and informed manner, which ultimately delivers* ***better outcomes for government budgets and better healthcare for all Australians***'.

In 2014, the '*Exploring Healthcare Variation in Australia*'(2) report stated:

- '*Information on the outcomes of treatment is also critical*.

- *Outcomes of care: A* ***lack of routine information on outcomes of care*** *is the key limitation of work on healthcare variation.*

- *At present there is no consistent approach between state and territory jurisdictions in the use and monitoring of healthcare interventions or pathways.*

- *For most procedures examined in this paper,* ***there is no systematic way of monitoring outcomes of care in Australia.***

- *Linking care inputs and processes with outcomes can provide information to help determine the appropriate rate for an intervention.*

- ***Patient outcomes should begin to be integrated into routine data collection processes****, and there may be advantages in a more coordinated, national, approach to tracking outcomes of care in a variety of modalities, treatments and interventions.'*

My eHealth proposal aligns in full with all recommendations.

Australia's new eHealth record system should be re-purposed for secondary research use of data.

It should incorporate **capacity for patients to self-report their health outcomes in structured ways** within their own eHealth records.

My proposal would **resolve noted health data gaps and limitations,** and enable deeper, and more **thorough analyses of health treatments, interventions and outcomes.**

Further, Australia should develop an overarching **National Health and Medical Research framework, with honourable intent**, in the best interest of all Australians.

One that is;

(i) publicly owned and operated within an environment protected from all potential 'conflicts-of-interest' (commercial or otherwise);

(ii) includes capacity for patients to self-report their health outcomes in structured ways, and;

(iii) is created with singular purpose... to enhance the short and long-term health outcomes of all Australians in the most cost-effective way.

The benefits of making a **more comprehensive set** of **de-identified health data** readily **available to all scientific disciplines** would be innumerable.

Australia would be far better-equipped to **utilise health data with meaningful purpose** to;

- support and better-prioritise Australia's health and medical research;
- speed-up our knowledge and learning in a blame-free environment;
- support faster translation of data into more effective treatments that improve outcomes, and in the process, minimize unnecessary suffering (and associated unnecessary costs);
- enhance equity across all health treatments and outcomes, and ultimately;
- ensure our public healthcare systems remain sustainable, and affordable well into our children's and grandchildren's futures.

National health, national productivity, health budgets and associated economic benefits following introduction would be innumerable and would compound year on year.

As an example of cascading benefits;

- over time, the healthcare industry would realise massive gains in productivity;
- collecting data directly from patients would dramatically raise transparency and provide unprecedented 'post marketing surveillance' insights and opportunities, and;

- research would not only enhance treatment effectiveness and efficiency, it would also provide insights for future Australian product development.

This is THE win-win health policy proposal Australia needs.

It is deserving of high profile support.

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References:

(1) Australian Commission on Safety and Quality in Health Care's report '*The Australian Atlas of Healthcare Variation*'
http://www.safetyandquality.gov.au/atlas/

(2) '*Australian Commission on Safety and Quality in Health Care and Australian Institute of Health and Welfare. Exploring Healthcare Variation in Australia: Analyses Resulting from an OECD Study.*' Sydney: ACSQHC, 2014.
http://www.safetyandquality.gov.au/wp-content/uploads/2014/05/Exploring-Healthcare-Variation-in-Australia-Analyses-Resulting-from-an-OECD-Study.pdf

(3) '*Health System Transparency Receives a Welcome Boost, Business Council of Australia*', 26 November 2015
http://www.bca.com.au/newsroom/health-system-transparency-receives-a-welcome-boost

Supporting References:

(1) *International: International Consortium for Health Outcomes Measurement (ICHOM)* http://www.ichom.org/who-we-are/

(2) *Australia - NSW: Measuring Outcomes to Benefit Patients* - The Agency for Clinical Innovation (ACI) hosted a workshop in Sydney on 28 May 2015 to mark the start of its strategic partnership with the International Consortium for Health Outcomes Measurement (ICHOM). Bringing together a select audience of health agencies, clinicians and consumers, the workshop provided an opportunity to learn more about ICHOM's approach to value based healthcare

and to consider the enablers for identifying and measuring outcomes that matter to patients in NSW. http://www.aci.health.nsw.gov.au/about-aci/newsroom/measuring-outcomes-that-matter-most-to-patients/ichom-workshop-videos

(3) Quote; ' … *"I think the take-home message is that self-reported health matters," said Christopher P. Fagundes* … ' from STUDY: *'The effect of self-reported health on latent herpesvirus reactivation and inflammation in an ethnically diverse sample'*; Kyle W. Murdock, Christopher P. Fagundes, M. Kristen Peek, Vansh Vohra, Raymond P. Stowe; Psychoneuroendocrinology Journal, July 2016 http://www.psyneuen-journal.com/article/S0306-4530(16)30187-1/abstract

Self-reported patient outcomes

are the missing link

in our health and medical data collections

and

our health and medical research frameworks and

systems.