The Economist INTELLIGENCE UNIT

EXECUTIVE SUMMARY

DATA AND DIGITAL TECHNOLOGIES TO IMPROVE CLINICAL OUTCOMES FOR HIGH-RISK CARDIOVASCULAR PATIENTS IN AUSTRALIA

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INTRODUCTION

Cardiovascular diseases (CVD) account for around one quarter of deaths in Australia.[1] The Economist Intelligence Unit estimates that the annual direct and indirect costs of CVD in Australia totals US$12.3bn.[2] There are numerous modifiable risk factors for CVD, but the most important include hypertension (high blood pressure), high cholesterol, tobacco use, diabetes and obesity.[3] While much of the recent focus has been on primary prevention through lifestyle modification, those high-risk patients with existing CVD—such as peripheral artery disease or a previous heart attack or stroke—require particular attention to avoid further morbidity and mortality.

The improved use of data and digital health tools has the potential to enable more coordinated and patient-centred models of care. The Digital Health CRC takes this further in saying "research and innovation in digital health offers Australia significant economic and business development opportunities, as well as great promise for the better health of our community".[4]

On 27 May 2020, The Economist Intelligence Unit—supported by the Australian Cardiovascular Alliance (ACvA) and Digital Health CRC and with sponsorship from Amgen—convened a virtual roundtable discussion with 25 representatives from across the Australian cardiovascular healthcare landscape.

Co-hosted by the Economist Intelligence Unit with **Dr Gemma Figtree**, president of ACvA and professor in medicine at University of Sydney & Royal North Shore Hospital, and **Dr Tim Shaw**, director of research and workforce capacity at Digital Health CRC, the roundtable aimed to identify barriers, challenges and opportunities to improve outcomes for high-risk CVD patients by improving the use of data and digital technologies.

[1] Australian Institute of Health and Welfare. Cardiovascular disease. In: Welfare AIoHa, editor. Canberra 2019.
[2] Economist Intelligence Unit. "The cost of silence: Cardiovascular disease in Asia", 2019
[3] Centers for Disease Control and Prevention. "Know your risk for heart diseases". Available from: https://www.cdc.gov/heartdisease/risk_factors.htm (Accessed Jun 2020).
[4] Digital Health CRC. "About us". Available from: https://www.digitalhealthcrc.com/about-us/ (Accesed Jun 2020).

PARTICIPANTS

Meeting participants were drawn from a wide range of expertise in clinical medicine, healthcare delivery and infrastructure. Organisations represented included: Australian Digital Health Agency, NSW Health, Agency for Clinical Innovation, Central Coast Local Health District, Western Sydney Primary Health Network, Western NSW Primary Health Network, University of Sydney, Victorian Heart Hospital, Royal North Shore Hospital, Sydney Medical School, The George Institute for Global Health, National Heart Foundation, SCvA, Digital Health CRC, MedicalDirector, Cerner, Alcidion, Cardihab and FRED IT.

MAPPING THE HIGH-RISK CVD DATA CHALLENGE

The challenges in managing high-risk CVD patients are numerous, even in Australia's advanced health system. The participants noted that ineffective transition of care remains a key challenge, compounded by discontinuity in individual patient health information shared between care providers. Furthermore, the use of data and digital tools represent their own challenges for healthcare professionals.

The appropriate data being made available at the point-of-care to inform clinical decision making is a key challenge. Physicians may have access to vast quantities of an individual patient's data, but with no practical and time-effective way to easily digest, prioritise or share it. Ensuring the right information is shared at the right time, is a key priority that participants identified.

Sharing of data is not straightforward, and barriers to effectively doing so include ethical and privacy concerns, healthcare IT system complexity and operational stability during data extracts, interoperability of systems, legislative frameworks and a lack of consistency in definitions and standards. Participants noted many of the technical challenges to improve data linkage and interoperability can be solved—and in many cases have been by using the Fast Healthcare Interoperability Resources (FHIR) standard—but that data custodial issues remains a key challenge sharing of health data between different elements of the healthcare system.

OVERCOMING BARRIERS: DATA-SHARING SUCCESS IN PRIMARY HEALTH

The Western Sydney Primary Health Network has a joint data-set between primary care, community care and acute care, with data-sharing agreements in place with close to 70% of GPs, either at practice- or physician-level. The agreements allow for customisation so individual physicians or patients can opt out.

Meanwhile, Western NSW Primary Health Network and South Western Sydney (SWS) Primary Health Network are embarking on a pilot to improve interoperability based on a successful programme at SWS Primary Health Network that used integrated real-time active-data (iRAD) to share critical patient data between hospitals, general practice and other connected healthcare professionals.

NSW Health are moving forward with two key pieces to support such efforts: a state-wide patient reported measures programme and IT system; and building agreed data sets into the electronic medical records. Both of these elements include clinical decision support and dashboard functions with data available in clos to real-time.

Scoping work or pilots are also planned in Queensland, South Australia, Victoria and Western Australia.

"There's very little in the medical curriculum around interactions with digital platforms, let alone data quality, coding or standardised terminology. We have a whole cohort of people graduating that are focussed on clinical care, but not [...] curation and maintenance of high quality data and not understanding how data will be used downstream when the patient moves to other parts of the health system."

Governmental representative

Clinician awareness and education—at all levels of medical training from undergraduate through to continuing education—was highlighted as an opportunity to ensure the improved collection and use of patient medical data. Work in this area is already being led by the Australian Digital Health Agency.

The wider use of digital tools in healthcare also requires further cross-functional collaboration and education. Finally, targeted education around data and digital health for the general public is required to ensure the patient community is informed of how their data is collected, used and what clinical benefits they will ultimately realise from the systems.

"There are cases where discharge summaries are incomplete and general practitioners have nothing; on the flip side it's not helpful for them to receive 55 pages of investigations without giving the key bits of information. At the end of the day, [the GP] wants to know, what happened, what did they do, and why did they do it. It's about providing the right context for the data."

Cardiologist representative

IDENTIFYING DATA AND DIGITAL OPPORTUNITIES FOR HIGH-RISK CVD PATIENTS

While significant work has been conducted in building a robust digital health foundation, for instance the 10-year *eHealth Strategy for NSW Health 2016-2026* the discussion uncovered several opportunities to refine and prioritise this space for high-risk CVD patients.

Firstly, a standardised minimum set of functional data requirements for high risk CVD patients would be beneficial This data specification needs to be informed by physicians and based on the way they generate and use data in clinical practice, and their perspectives on the optimum 'technology-agnostic' data requirements. Four use cases were proposed: information a clinician needs during a consultation; information that shared care teams require to effectively manage patients (particularly relevant in Australia's healthcare systems with jurisdictional divisions between federally funded primary care and state funded hospitals); aggregated information for research or clinical audits, and; information needed by the patient. A standardised approach will ultimately address issues around data interoperability and tensions and facilitate the development of appropriate digital tools that meet clinical needs.

Secondly, improved use of existing data—recognising distinct use cases such as patient-communication or in clinical research—is an area of priority. One key area to address is the real-time data sharing to enable continuity of patient care between providers. While the participants highlighted success of using the FHIR standard to facilitate data sharing between hospital departments and into the primary care network, broader challenges remain in ensuring that the right data is captured in a way that facilitates sharing and informs patient care. The interplay between data systems designed for clinical versus research use is another priority area to be addressed.

Thirdly, there remains a significant opportunity to combine existing and new complex patient datasets to improve care and self-management. This includes access and integration of new biologic information such as genomic and proteomic data, as well as from internet-connected devices and applications. Real-time utilization of live data sets has the potential to be transformative, for example in the identification of early indications of acute events. Once risk has been identified, it can be further used to drive consumer-focused digital interventions.

The human capital required for large-scale data extraction from electronic medical records, and concerns around the underlying stability of such systems when being accessed, are continuing challenges to progressing research. Again, pilots are underway to address this, with a NSW project developing technology to extract data from health record systems without negatively impacting underlying essential clinical performance. Maybe most importantly for patient care, the prioritisation of data extracted and packaged to provide timely feedback to physicians on the quality of care they are providing must be considered. This may have the added bonus of being a useful tool for clinical audit.

Furthermore, the better use of comprehensively-linked health data provides an opportunity to pinpoint inequitable access to optimal and value-based care. Data-driven classification of heterogeneity in the treatment landscape allows for exploration of the underlying causes and provides the evidence required to drive reform.

Finally, supporting the creation of solid business cases—that enable funding to be secured for efforts to improve data linkage and use to improve patient outcomes—is needed to further capitalise on the health data opportunity. Business cases must be linked to improved outcomes that represent cost- or resource-saving. Examples of such models are being piloted in primary health networks, involving shared-benefit or blended funding models where funds are paid out if a hospitalisation is avoided, which can then be re-invested in the system. The design of these business cases is another area requiring cross-functional collaboration and government investment.

"Audit and care quality are important for physicians, but the reimbursement system is now forcing safety as a financial drive. The challenge is [less around] interoperability and [technological restrictions] of getting real-time access to data, but around demonstrating the return on investment for jurisdictions, and creating a business case."

Health informatics platform representative

KEY TAKEAWAYS: PRIORITISING ACTION AND IMMEDIATE NEXT STEPS

Notwithstanding the challenges the discussion highlighted the significant investments made to date in enabling the improved use of data and digital tools. The panellists also identified several near-term priorities and opportunities to build on the existing foundation for the use of data and digital tools in high risk CVD. These range from further clarifying needs through to standardising approaches, but collectively share a challenge in requiring extensive cross-functional collaboration and political commitment to proceed:

- **Defining the functional data requirements for healthcare professionals managing high-risk CVD patients:** The identification of a technology-agnostic functional specification for data required by cardiologists, primary care specialists and allied health workers should be the foundation of any further efforts to use data and digital tools. This specification should be designed to meet four core use-cases: the information a clinician needs during a consultation; information shared care teams require; aggregated information for research or clinical audit, and; information needed by the patient. The specification would provide the underlying clinical objectives to drive the delivery of optimal high value care, rather than just supplement existing models of care with incremental technical advances.

- **Creating a business case for the use of data within healthcare settings:** As many of the challenges around adopting digital solutions and data linkage are commercial or data-custodial—as opposed to purely technical—the need for clear guidance or a framework for building a business case to secure financial investment is warranted. This must be coupled with collaboration at the various government levels to resolve data-custodial issues.

- **Improved standardisation of data sets for predictive analytics and artificial intelligence:** There was a view among stakeholders of the need to nationally standardise data sets and ensure they are readable by artificial intelligence and to support machine learning. This was a solution considered to address the significant workforce challenges experienced in healthcare currently and into the future.

- **Building broader data linkage and interoperability across the health system:** Moving into the mid-term, the logical next step is to ensure the required data are efficiently and effectively stored, shared and retrieved in a way that is conducive to the four core data use-cases included in the functional specification and contributes to achieving improved outcomes for high-risk CVD patients. The opportunity of improved longitudinal and linked datasets cannot be understated in its capability to provide real-time quality of care assurance, and provide the evidence required to drive improvement in service delivery relevant to all elements of the healthcare system. Once coordinated in shared care and consumer facing models, this data presents the opportunity of personalized clinician decision support, and the potential to trigger interventions at appropriate times to proactively mitigate the risk of acute events and optimise outcomes.

- **Educating target groups on the opportunities for data and digital:** Ensuring all stakeholders—including physicians, patients, and the general public—are informed and recognise the potential for optimal creation and use of health data to improve CVD outcomes in the healthcare system is a vital step to achieve buy-in and ongoing commitment. For physicians this may include specific education on the opportunity of data to improve patient care, and for patients better understanding of what they need to know to be empowered is important. This advocacy on the opportunities for improved data utilization to healthcare outcomes would also involve reassurance and education on data security and governance to ensure appropriate use.

CONCLUSION

While many of these challenges identified by participants will not be easy to progress, it was acknowledged that there is a significant amount of work underway and systematic processes to identify opportunities to ensure Australia capitalising on the digital health revolution are highly valuable.