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1 in 4 Deaths but No National Picture: Consensus on Closing the CVD Data Gap

In Australia, Cardiovascular disease (CVD) causes 1 in every 4 deaths, claiming a life every 12 minutes. Despite this burden, we lack consistent national data to understand whether our policies, programs, and treatments are delivering the best outcomes for Australians, and if they could be improved.

National CVD data is urgently needed to evaluate what works, track outcomes and benchmark care according to <u>Australia's Heart and Stroke Data Challenge</u> — <u>Recommendations from the National CVD Data Summit</u>, a new report released by the Australian Cardiovascular Alliance (ACvA).

"We can't improve what we don't measure," says ACvA President Professor Jamie Vandenberg. "Despite major investment in Australia's health data systems, there's agreement that we still don't have the depth of clinical data we need on risk factors, disease progression, treatments or patient outcomes."

In response to these sector-wide concerns, ACvA held a National Cardiovascular Data Summit, bringing together clinicians, researchers, state and territory health leaders, Federal government agencies, industry representatives, technology experts and consumers to examine the problem and recommend a path forward.

"We currently collect CVD health data in different systems such as electronic medical records or stand-alone registries, providing different information in different ways," says Professor Dominique Cadilhac (Monash University, and co-director ACvA Big data Flagship) who chaired the Data Summit Advisory Committee, and is the Executive Director of the Australian Stroke Clinical Registry.

"This fragmented data landscape makes it difficult to see the big picture. We also have a complex health system divided across state, territory and federal responsibilities. Nationally, this means we're missing key opportunities to monitor and benchmark care, improve care quality, target research where it's most needed, track impact and ultimately, reduce disability and save lives from CVD."

A solution is achievable and this national CVD data gap is a sharp contrast to cancer, where mandatory reporting of every diagnosis has supported a national database operating since 1982. That rich dataset has helped drive Australia's world-leading cancer survival rates and continual improvements in evidence-based care.

The Report provides five recommendations that are foundational for a solution:

- 1. Establish a national CVD data leadership body
- 2. Develop a National CVD Minimum Dataset
- 3. Address System Integration Problems
- 4. Use Al and emerging technologies to unlock data
- 5. Secure sustainable long-term funding

"Genuine consensus across an entire sector is rare, and when it emerges on both the problem and the solution, it signals a critical moment for action," says Professor Vandenberg. "The sector's unified recommendations outline a clear path forward, giving us the opportunity to build the national data foundation required to tackle Australia's number one killer."



The next steps, commencing in 2026, will focus on collaboration with governments, registries, and key stakeholders to advance the first two recommendations of the Report.

You can download the complete report HERE.

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The Australian Cardiovascular Alliance

The <u>Australian Cardiovascular Alliance</u> (ACvA) is the peak leadership body for the advancement of cardiovascular research in Australia. ACvA advocates for a collaborative and thriving cardiovascular research sector that is data-driven to deliver better health outcomes for patients and tangible economic benefits.

ACvA brings together national expertise to identify research priorities and works with health systems through the health leadership research forum (HLRF) government engagement platform. This platform connects health leaders from all jurisdictions to use data and evidence to identify care variations and address disparities where research can provide solutions.

ACvA represents the country's leading cardiovascular research bodies, scientific societies, individual researchers, industry partners, and non-government organisations.