

Monitoring anaphylaxis in Australia: a case in point informed by worldwide experience, driven by partnerships and collaborations

There is strong evidence that rates of anaphylaxis are rising worldwide¹; however, discrepancies in how and where anaphylaxis cases are counted, and a lack of detail on key drivers of anaphylaxis, limit our understanding of the true burden of the disease. In response to this, stand-alone anaphylaxis registries have been developed (variously purposed with better understanding epidemiology, clinical characteristics of anaphylaxis, and deaths) to inform policy and health care. Our scoping review in this issue of *JBIM Evidence Synthesis*² provides a detailed examination of anaphylaxis registries that exist globally, and considers their value in improving knowledge and care of people experiencing anaphylaxis. The scoping review methodology was well suited to concurrently answer multiple questions and to map registry features, including scope, operation, and impact, to inform future efforts to establish a comprehensive anaphylaxis registry for national or global application.

This review identified 19 anaphylaxis registries operating in 28 countries, including Europe, the United Kingdom, Canada, the United States, Korea, and Australia.² While they are all different, these registries exist to collect clinical and/or population-level data for research, provide clinical support tools to improve patient care, and operate as allergen surveillance systems to protect those in the wider community with allergies. Information synthesized in this review highlights lessons learned from registries as well as current gaps, which can inform the implementation of future anaphylaxis registries.¹

Collecting standardized clinical data on severe reactions, and incorporating feedback mechanisms to take timely action to remove products and report unsafe food practices, is an important goal of an anaphylaxis registry. The Victorian Anaphylaxis Notification System (VANS), in operation in Australia since 2018, collects mandatory data on all anaphylaxis presentations to hospital emergency departments (EDs), with immediate reporting to health authorities required by law if the cause is suspected to be a packaged food.³ Data recently published from VANS have already shown the value

of systematically collecting jurisdiction-wide ED anaphylaxis data to determine incidence, cause, and hospital outcomes.⁴

Additionally, evidence regarding fatal anaphylaxis is crucial. Currently, only 3 registries globally report fatal anaphylaxis, with varying ability to comprehensively capture every event.² Despite this, we have learned valuable lessons, particularly from the long-standing UK Anaphylaxis Fatality Registry, about tragic and potentially preventable deaths, and this has informed management and international guidelines.⁵ Given the limitations with reporting anaphylaxis in national morbidity and mortality statistics, capturing standardized information on every near miss and death within a registry is essential. Critically, future systems must include timely reporting to protect patient safety.

A key limitation of many registries is their restriction to certain settings. For example, VANS only captures patients accessing care in the ED,³ while the European Anaphylaxis Registry predominately captures patients accessing care in specialist clinics.⁶ Registries also differ in the data they include, such as severity of reaction and allergen type.⁷ As anaphylaxis can occur in any setting, it is important to facilitate standardized reporting of reactions across the health system (including primary care), with the potential for consumer input.

Incorporating key concepts and accessibility features in anaphylaxis registry design addresses these limitations. Planning for registry linkage with other secondary health data (such as administrative, medication, and biobank datasets) provides a unique opportunity to monitor anaphylaxis in the population; identify predictors for outcomes, comorbidities, and diagnostic clues; and reveal novel targets for prevention. Furthermore, registries provide an infrastructure and resource to conduct quality research. Evidence from established anaphylaxis registries have characterized the changing allergen and patient profile and informed practice.⁴⁻⁸

An Australian bipartisan Parliamentary Inquiry into Allergies and Anaphylaxis was conducted in 2019.⁹ The Inquiry identified that Australia

currently lacks a consistent approach to allergy and anaphylaxis management, with missed opportunities for diagnosis, and suboptimal treatment and management. The associated report, *Walking the Allergy Tightrope*,¹⁰ made 24 recommendations to address the critical need for a national plan of action. One of the key recommendations was to develop an Australian anaphylaxis registry.

Our scoping review identified that establishing and maintaining registries require a substantial resource commitment with strong stakeholder support and collaboration. Australia has strong partnerships in the allergy sector as evidenced by the 2014 partnership between the Australasian Society of Clinical Immunology and Allergy, and Allergy & Anaphylaxis Australia to develop a national allergy strategy.¹¹ In August 2022, the Australian Government Department of Health announced AUD\$26.9 million funding jointly to the National Allergy Council (NAC; formerly the National Allergy Strategy) and Australia's peak allergy research body, the National Allergy Centre of Excellence (NACE). In a world-first, the NAC and the NACE will work together to deliver an allergy and anaphylaxis evidence base, and efficiently translate findings to practice. A united goal of these organizations is to develop and implement an Australian anaphylaxis registry, initially tasked to capture real-time data on food-related allergic reactions to packaged food. Ensuring that the registry captures data consistent with the Australian Acute Anaphylaxis Clinical Care Standard¹² will enable monitoring of patient care and outcomes. Integrating knowledge gained from current registries through this scoping review, as well as engaging with key stakeholders, will inform the development of a future-proofed anaphylaxis registry for Australia, with potential global application.

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