# Using an Out-of-hospital Cardiac Arrest Registry to Identify Cases for an Unexpected Cardiac Death Registry in Victoria, Australia

## BRIEF BACKGROUND

Not surprisingly, medical advice regarding cardiac arrest prevention falls on deaf ears among younger age groups. Yet when SCA occurs in young people, it can have a devastating impact on the family involved. The Ambulance Victoria EMS team aimed to establish a world-first, clinical-quality registry and genetic database of individuals (ages 1-50) and at-risk family members using data captured through the Victorian Ambulance Cardiac Arrest Registry (VACAR) to identify causes. The team hypothesized that among the seemingly random events of SCA in younger persons, distinct patterns could be identified to aid the development of targeted clinical and genetic screening programs.

## STEPS TAKEN

The VACAR registry collects data on out-of-hospital cardiac arrest patients attended by Ambulance Victoria paramedics. Cases within the targeted age group were identified, and for those who survived, patients were provided with relevant opt-out information regarding the Unexpected Cardiac Death Registry (UCDR) during routine follow-up. Data for all survivors and deceased cases was provided at regular intervals to the UCDR via secure data transfer. Deceased cases are included with a waiver of consent. This data was linked to hospital records, forensic autopsy outcomes (if performed) and genetic testing of survivors and/or family members. VACAR also conducted 12-month quality of life follow-up with adult survivors. This data was also transferred to the UCDR once completed, unless patients opted out.

## CHALLENGES

This project highlighted the possibilities of an OHCA-specific registry that feeds into additional registries to better understand and prevent potentially avoidable SCA in younger patients. While it had great potential to be valuable to this project, this type of registry did not exist.

## RESULTS

The identification of cases through VACAR and linkage to hospital, forensic and genetic data provided a large prospective registry to identify patterns in circumstances and environmental risk factors for SCA in younger persons. This enabled identification of effective prevention and screening strategies along with guidelines for best clinical care.

## OUTLOOK

Once this registry is established in Victoria, the aim is to expand nationally using a similar model of case identification, linkage and follow-up procedures in other states.

## CONTACT

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