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## Victoria, Australia – Data Collection

# Measuring the quality of life of OHCA survivors after discharge from hospital

The Victorian Ambulance Cardiac Arrest Registry (VACAR), Victoria, Australia is a clinical quality registry which collects data for all out-of-hospital cardiac arrests (OHCA) attended by emergency medical services (EMS) in Victoria, Australia. Victoria has a population of more than 6 million people, over 4 million of whom reside in the capital city of Melbourne. VACAR commenced in 1999 in alignment with the Utstein template and to date, over 90,000 records have been recorded. The registry is used to measure/monitor OHCA outcomes, drive clinical improvement within the statewide ambulance service (Ambulance Victoria), and also supports a comprehensive research program which is recognised internationally.

## PROBLEM TO BE SOLVED/BACKGROUND

The 2015 update to the Utstein template recommended the use of validated measurements tools to assess health-related quality of life post-OHCA. Additionally, the American Heart Association recommends that future cardiac arrest clinical trials focus on assessing neurocognitive impairment and the quality of life of survivors. However, few OHCA registries internationally routinely measure the long-term quality of life of survivors. Currently, the most commonly reported outcome measures include survival to hospital discharge or 30-day survival.

## DESCRIPTION OF PROJECT/PROGRAM

Acknowledging the importance of understanding the quality of life of OHCA survivors after discharge from hospital, the VACAR commenced 12-month patient follow-up. For OHCA survivors arresting since 2010, the VACAR has conducted quality of life telephone interviews 12 months post-arrest. Responders answer questions related to residential and work status, respond to two generic health-related quality of life tools (12 Item Short Form Health Survey [SF-12] and EuroQol-5D [EQ-5D]), and also respond to a functional recovery measurement instrument (Glasgow Outcome Scale-Extended [GOSE]).

## RESULTS

In 2014, the VACAR group published the 12-month outcomes of patients arresting between 2010 and 2012. With 697 responders, this was the largest study at the time to assess the quality of life of OHCA survivors. Most (55.6%) respondents reported a good functional recovery according to the GOSE, and patients reported similar results to the standard Australian population in terms of the SF-12 mental component. As at June 2017, a total of 1,624 OHCA survivors had responded to the 12-month follow-up since commencement, a response rate of 83%. The proportion of responders reporting a good functional recovery had risen to 62.2%, and the median EQ-5D index score was 0.85 (IQR 0.73-1).

Importantly however, a recent study by the VACAR group assessed the validity and measurement properties of these three generic tools in the OHCA population. The study demonstrated that, whilst the SF-12 and GOSE may be useful in OHCA survivors, the EQ-5D demonstrated high ceiling effects and more work is needed to assess its interpretability.

## CHALLENGES

Loss-to-follow-up and compliance rates are a challenge for all studies involving patient follow-up. VACAR tries to mitigate this by accessing contact information from numerous sources, including the ambulance patient care record, hospitals and patient accounts. The state death registry is also searched. Participation rates are increased by sending a letter detailing the call in the weeks prior to phone contact. A maximum of five attempts are made to contact patients.

## ADDITIONAL PLANS

The VACAR plans to collaborate with experts in neuropsychology to understand the aspects of health that are most important to OHCA survivors during the trajectory of their recovery. In a planned study, patients and their partners or loved-ones will be asked to complete a series of psychological assessments at three and six months post-arrest. The aim of this study will be to assess the neurocognitive and psychological outcomes of survivors, as well as the psychosocial needs of their partners, following OHCA.



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