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Editorial The value of resuscitation registries



EUROPEAN

RESUSCITATION COUNCIL

As the most time-critical and the most catastrophic disease, outof-hospital cardiac arrest (OHCA) is uniquely challenging to treat and to study.¹ The unpredictable onset and time-sensitive nature of OHCA means that traditional methods used to study cardiovascular disease, such as prospective cohort studies and randomised controlled trials, are difficult to implement in the usual manner.²

For one, many patients with OHCA never make it alive to the hospital and are therefore impossible to recruit for a prospective study in the usual sense. However, it is precisely this group of patients that we have a tremendous impetus to discover knowledge about the care that they receive. This is because interventions in the early phase of the disease, such as bystander cardiopulmonary resuscitation, and activation of the Emergency Medical Services, have a considerably larger influence on survival compared to treatments received subsequently.³ The lack of data on cardiac arrest patients in the pre-hospital setting impedes our ability to formulate strategies to improve care processes where it matters most.

Secondly, the resultant selection bias from potentially only capturing data on patients presenting to hospitals means that we often lack the complete data needed to describe epidemiology and disease burden. Incidence (e.g. how many cases occur per 100,000 population) cannot be properly estimated and compared, with different studies often using different numerators.^{4,5} Further, without knowing the number of patients who died without being resuscitated, the true disease burden of OHCA remains grossly underestimated.⁶ Being unable to size up the full extent of the problem that OHCA brings to our societies, it becomes difficult to demonstrate its impact relative to other diseases (e.g. cancer), and justify the proportionate level of public attention, policy priority and research funding that our patients urgently need.

Innovative, population-based approaches are therefore required to provide vital epidemiological information for use by global communities for the purposes of quality improvement, research and formulation of effective programs and policies. Born out of this need, a number of resuscitation registries have sprung up either independently, or in collaboration with more established registries. Some of them have successfully coalesced into wider epistry networks representing larger geographical catchments.^{7–11} There are also recent efforts to upgrade these alliances from regional to global efforts. In this special issue of *Resuscitation Plus*, we are pleased to invite champions from these efforts to showcase their work. These groups

have consistently demonstrated great value through ground-breaking achievements in areas such as continuous quality improvement and research. As registries mature and gain sophistication in developing approaches to overcome inherent challenges, there is yet much more potential in what can be achieved. We invite review articles, in which we hear from these registries on their journeys, objectives, current state and future aspirations. We want to celebrate their achievements, share lessons and gain inspiration to collectively improve outcomes for our patients. We also invite original research that showcase research findings and quality improvement made possible by cardiac arrest registries.

A number of challenges for the field still exist. One, is the need for consistent definitions, such that data from global efforts become clear, and therefore comparable within and between communities.¹² Second is the adherence of registries and their users to these definitions. Third is the urgent need to encourage and empower lesserserved communities to participate in data collection efforts such that they too can be equipped with this powerful tool and share in the rewards. Fourth, to be effective in achieving their respective objectives, many registries need to increase case capture rates such that they provide a representative picture. We hope to learn from the different registries on their strategies to tackle these challenges.

Resuscitation registries address the problem of a shortage of high-quality data on OHCA, which is a uniquely difficult disease to study. Learning from the success and challenges of these diverse registries, representing a spectrum of maturity, resourcing, and format, is a vital step for us to propel clinical outcomes for our patients.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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