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A National Adult Congenital Heart Disease Registry in Greece: A Big Challenge

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Survival prospects of patients with congenital heart disease (CHD) have significantly improved since surgical repair became available almost four decades ago. Nowadays, over 85% of infants born with CHD are expected to reach adulthood and cardiologists have to face this new growing population in their routine clinical practice. It is estimated that every year ~1000 babies with CHD are born in Greece, while there are 40,000-50,000 adolescents and adults with various types of congenital heart lesions in the country.

Data on the exact prevalence and long-term outcome of adult CHD patients is lacking because of the lack of national registries. The term "clinical registry" is defined as an observational database of a clinical condition, procedure, therapy, or population in which there are often no registry-mandated approaches to therapy and relatively few inclusion or exclusion criteria.[1] Clinical registries provide important mechanisms for evaluating patterns of care, and assessing the safety and effectiveness of a healthcare system, with the ultimate aim being to improve clinical outcomes. Clinical registries capture data that reflect "real-world" clinical practice in large patient populations. Cardiac societies worldwide have a longstanding willingness to support the innovative and effective use of these initiatives. It is noteworthy that during the previous Congress of the European Society of Cardiology the number of submitted abstracts dealing with registry studies surprised the organisers, and prompted the President of the Society to name this year's meeting the "Year of the Registries".

The Hellenic Cardiological Society has recognised the recent increase in the number of adult patients with CHD in our country and has therefore launched an electronic-based registry, named CHALLENGE (Adult Congenital Heart Disease Registry. A Registry from the Hellenic Cardiological Society). The aims of the CHALLENGE registry are to facilitate the investigation of the prevalence and long-term outcomes of specific congenital heart defects and their treatment, in order to develop an efficient organisational structure for the improvement of healthcare concerning patients with CHD. In addition, this project will facilitate the cooperation between general cardiologists who are non-experts in CHD and their colleagues in tertiary referral centers and centrally based CHD units.[2]

This follows the good example set by other national cardiology societies that have already launched similar projects. For example, in 2000, the Interuniversity Cardiology Institute of Netherlands, and the Netherlands Heart Foundation took the initiative to develop a national registry and DNA-bank of patients with CHD in the Netherlands, named CONCOR (http://concor.net). So far, 107 hospitals have participated in this successful initiative and almost 13,500 patients with CHD have been included.

The development of a clinical registry of CHD patients in Greece will result in a "public good" that has the potential to improve patients' lives. Government policy makers have a unique role to play in fostering such an initiative. This support may take the form of funding to develop and sustain such a registry and financial incentives for providers to participate in important clinical registries.

References

1. Bufalino VJ, Masoudi FA, Stranne SK, et al; American Heart

Association Advocacy Coordinating Committee. The American Heart Association's recommendations for expanding the applications of existing and future clinical registries: a policy statement from the American Heart Association. Circulation. 2011; 123: 2167-2179.
2. Parcharidis G. Adult congenital heart disease in Greece: need for a step forward. Hellenic J Cardiol. 2011; 52: 193-194.