

Seeking best practices for cardiac rehabilitation registries in Europe

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Cardiac rehabilitation has been established as a core component of secondary prevention in cardiovascular diseases (CVDs).¹ Its beneficial effects have long been proved by clinical trials and meta-analyses which show a clear reduction in morbidity and mortality in patients after an acute coronary event.² This worldwide accepted intervention is challenged in everyday clinical life as the demography of population changes, increasing the complexity of cardiac conditions while novel invasive and pharmacological approaches appear. In this variable medical environment it is of apparent importance that cardiac rehabilitation is being delivered effectively to all patients according to clinical practice guidelines through high quality services.³

A well accepted research instrument which helps us to evaluate cardiac rehabilitation programmes so as to improve their efficiency is national and international registries and Poffley et al. in their recent systematic review report on all available cardiac rehabilitation registries.⁴ The authors provide us with very useful insights regarding the design and execution of these registries as well as barriers, limitations and enablers of implementation. They mention that “well-designed and well-executed registries capture data that reflect ‘real-world’ clinical practice, helping us to evaluate patterns of care and disparities”. This claim immediately raises the question of how we can have a well-design and well-executed cardiac rehabilitation registry so as to gather solid and conclusive data that will help us improve cardiac rehabilitation programmes. Based on this review we may be easily disappointed by the heterogeneity of the registries, which is mainly due to differences in cardiac rehabilitation structure, legislation, funding and national guidelines. But if we take a closer look we easily find out that many registries converge to some certain points which seem to be important for all registry designs. They all, or most of them, collect data on demographics, medical history, anthropometrics, clinical and psychosocial measures, and medication. They use a web-based data-entry method which is an easy and quick way for data collection and may be further improved by technology improvements and novel ‘big data’ methods. The majority collect data at

cardiac rehabilitation enrolment and cardiac rehabilitation completion, they are governed by national cardiac rehabilitation working groups within associations and securing patients’ privacy is indisputable.

Apart from these similarities these registries show significant differences which are important and affect their quality. Service-level data and process methods were poorly reported thus affecting the use of registry results in audit and feedback. Follow-up data are missing and evaluation of cardiac rehabilitation outcomes was limited. A universal rule for collecting individual participants’ information without the need of a signed informed consent while securing patients’ privacy is needed and it would certainly increase enrolment. Incentives related to national legislation, to programme certification and reimbursement or benchmarking and auditing seem to be more effective compared with voluntary participation. Funding is crucial and seems to be a major barrier in conducting and retaining a cardiac rehabilitation registry. Securing funding from the government or research funding bodies may be preferred since industry sponsorship of cardiac rehabilitation activities is somewhat difficult.

Even if we combine all the above mentioned requirements, we still cannot guarantee a successful implementation of a registry, excellence in data quality and the translation of registry results into immediate changes in cardiac rehabilitation practices, especially when there is no interaction between registry and audit.⁵ It is also disputable whether registry reports may affect national health systems by increasing the availability of cardiac rehabilitation programmes, which remain unacceptably low in most European countries.⁶ To overcome problems and challenges in developing CVD registries in Europe, the creation of specific recommendations by

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European Associations and countries with long experience in maintaining cardiac rehabilitation registries, is an emerging need.⁷ The first efforts with the Carinex Survey⁸ and the European Cardiac Rehabilitation Inventory Survey⁹ were recently improved by the European Cardiac Rehabilitation Registry and Database (EuroCaReD),¹⁰ which is a significant proof that a multi-national cardiac rehabilitation registry in European countries is feasible. This registry has created a tool for putting together information on the clinical status of cardiac rehabilitation across Europe. Although EuroCaReD is a primary international registry it shows almost the same advantages and limitations as the rest of the registries presented by Poffley et al. It is, therefore, important to maintain the continuity of this effort because it offers to the cardiac rehabilitation community a unique opportunity to improve the quality of standardized data collection, increase motivation for participation and provide sufficient data which can be used as a benchmark throughout European countries.

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