

Hellenic Vascular Registry (HEVAR): structure, perspectives and scopes

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INTRODUCTION

The term registry although it is widely used in medical literature, it is not well defined. The MeSH (Medical Subject Headings), defines registries as the “systems and processes involved in the establishment, support, management, and operation of registers [sic], e.g., disease registers.”¹

Many developed countries have regional and national clinical registries. Clinical registries are organized systems that use observational study methods to collect uniform data to evaluate specified outcomes for a population defined by a particular disease or clinical condition. In many cases, researchers and physicians attempting to assess a group of patients, search a “registry” of these patients. A PubMed search for the term “registry” in June 2019 returns almost 21.717 title hits, the oldest citation in 1936, revealing the timeless definitive role of registries in clinical practice and research.

The scope of the registries is to analyze the epidemiology, to improve the health outcomes of patients diagnosed with particular diseases and also to monitor the quality of care. The recent published guidelines from European Society for Vascular and Endovascular Surgery on the Management of Abdominal Aorto-iliac Artery Aneurysms, emphasize the importance of quality control in vascular surgery.² The guidelines recommend that centers performing aortic surgery should enter cases in a validated prospective registry to allow for monitoring of changes in practice and outcomes.²

ESTABLISHMENT AND STRUCTURE OF THE HEVAR

The creation of the Vascular Surgery Registry (HEVAR - The Hellenic Vascular Registry) has been a desire of the Hellenic Vascular Surgery community almost from its foundation. Several times, elected members of the Hellenic Vascular Surgery tried to achieve this goal but the result was disappointing.

Hopefully, the Hellenic Vascular Registry (HEVAR, <https://vascularregistry.gr>) was established in March 2019. HEVAR

runs under the auspices of the Hellenic Society of Vascular and Endovascular Surgery (HSVES, <https://www.vascularsociety.gr>). HSVES is the leading scientific organization in Greece committed to support scientists and clinicians in Vascular Medicine and Vascular Surgery. HSVES, in an effort to evaluate and register the occurrence of vascular diseases and also to analyze the clinical outcome and care of patient treated in Greece, created a governing committee appointed to two members of the Board of the society with the task to organize this project for the duration of 3 years.

In April 2019, HEVAR became a full member of the Vascunet (<https://vascunet.org>). Vascunet is a collaboration of vascular registries, administered and partly funded by the European Society of Vascular Surgery (ESVS). It was established to improve the quality, safety and effectiveness of vascular healthcare in Europe and Australasia. Currently, Vascunet connects the national vascular registries of 23 different countries in Europe and Australasia.

SCOPE OF HEVAR

The primary scope of HEVAR is the collection of information regarding the total spectrum of vascular diseases throughout Greece. It aims to analyze the data deriving from treatment of vascular diseases over time and to create an objective evaluation assembly of treatment effectiveness that will shape the quality of healthcare service for vascular diseases in Greece. As part of the Vascunet, HEVAR will collaborate with international registries to increase its knowledge and understanding of vascular disease, and to promote excellence in vascular surgery, by means of international vascular audit and collaboration.

Finally, HEVAR will invite physicians-users to participate in future national and international clinical research projects. HEVAR may lead to research projects and suggestions that are also welcomed by institution participants. The governing committee will evaluate with transparency, objectivity and no exclusions research projects from all departments and institutions participating in HEVAR, guarantying the confidentiality and accuracy of data and the ethics.

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Figure 1. The official webpage of the Hellenic Vascular Registry (HEVAR, VascularRegistry.gr)

HOW THE REGISTRY IS SET UP?

Specialized board certified physicians working in public and private Greek hospitals, involved in vascular diseases treatment, can apply in the electronic platform to become members of HEVAR (Figure 1). The governing committee evaluates the application and activates the registration if the member fulfills the above-mentioned criteria. The electronic consists of a data entry system which currently comprises of 3 modules:

The Aortic aneurysm disease module, in which patients with aneurysm disease of the thoracic, abdominal or thoraco-abdominal aorta can be registered. Furthermore another type of diseases regarding aorta can be recorded in this modules, such as aortic graft infection and aortoenteric fistula, acute aortic syndrome (dissection, intramural hematoma, atherosclerotic ulcer) and open conversion after endovascular aortic repair. Personal patient's data, details regarding comorbidities, aneurysm anatomy, type of treatment (endovascular or open), postoperative complications, outcome and follow-up information have to be provided for each patient. (please add an image of the registry how it looks on the computer)

The Carotid artery disease module, in which patients with carotid disease are registered. Acute carotid dissection, carotid aneurysms and carotid body tumors can be also recorded in this module. In the same manner with the aortic module, personal patient's data, comorbidities, neurological symptoms if present, type of treatment [endovascular stenting (CAS) or carotid endarterectomy (CEA)], postoperative complications, outcome and follow-up information are recorded.

The Lower limb Ischemia module, in which patients with chronic and acute limb ischemia are registered. Additionally, patients suffering by lower limb aneurysmal disease (popliteal, femoral), Buerger's disease, and vascular trauma of lower limbs can be included. Similarly to the previous modules, patient's and disease's data can be recorded.

Intention of the HEVAR governing committee is to add more modules in the electronic platform so as the total spectrum of vascular procedures to be finally included.

CONFIDENTIALITY, DISCRETION AND DATA PROTECTION

Patients' data are highly confidential. Improper disclosure of these data could result in emotional or psychological harm to patients and their families. Therefore, one of the most important responsibilities of HEVAR registry governing committee was to ensure and protect the confidentiality of patient's information. All institutions and hospitals participating in this registry have to receive an Institutional Review Board (IRB) and Ethics committee approval. In order to protect the rights and keep confidential the personal data an electronic system of registration has been generated compliant with the General Data Protection regulations (GDPR) requirements. Individuals are asked to give consent and provide information about their disease on a voluntary basis and are permitted to withdraw at any time they want. In order to protect data privacy, each participating physician can have access (view and edit) only on his personal patients' data. Data are highly confidential and no access to the registry data is permitted to the members of the registry. Data of the electronic database are highly encrypted this ensured and certified by Secure Sockets Layer (SSL) technology.

HEVAR SPONSORING AND OWNING OF REGISTRY DATA

HEVAR is exclusively sponsored by the Hellenic Society of Vascular and Endovascular Surgery. In order to enhance its credibility and extend its activity, HEVAR in future will apply for grants, sponsorship and donations.

The data collected belong to the Hellenic Society of Vascular and Endovascular Surgery. A statistical analysis of data will be performed and a detailed report will be shared with the physicians, participants and their families if they ask, and approved health care professionals and researchers. Personal, identifying information will be kept private. Currently, the HEVAR governing committee is responsible for providing data upon request. A dedicated Patients Data Management Committee will be created. This committee will be responsible for sharing data outside HEVAR

COMMUNICATION WITH HEVAR AND ANNUAL REPORT

An official webpage has been created - <https://vascularregistry.gr>- which informs physicians, participants, health care professionals, researchers and web users about the establishment and scope of the Registry. All participant Departments, Units and institutions are described in detail. HEVAR is also registered in popular mobile messaging applications and a periodical newsletter is provided electronically in all members.

An annual report emphasizing into the outcomes from different treatments in aortic aneurysmal disease, carotid artery disease and peripheral occlusive disease with epidemiological data around Greece will be presented and discussed in a spe-

cial section in the annual Vascular Meetings of the Hellenic Society of Vascular and Endovascular Surgery.

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