

The FAIRVASC project

Findable, accessible, exchangeable and reusable data.

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<FRAME> The name FAIRVASC consists of two parts where VASC stands for vasculitis. The FAIR part of the name relates to the FAIR principles for describing, storing and publishing scientific data, defined in 2014. The acronym FAIR indicates that the collected data must meet the following criteria: Findable, Accessible, Interoperable and Reusable. Or in proper Dutch: Vindbaar, Toegankelijk, Uitwisselbaar en Herbruikbaar. <END FRAMEWORK>

An important European research project called FAIRVASC has started on the 1st June of this year. The project aims to bring the data in a number of European vasculitis databases together in a structured way in order to better research vasculitis. In addition to a number of university hospitals, the Vasculitis Foundation and the patient organizations of Ireland and the United Kingdom are also participating in this project. They do this through the recently founded Vasculitis International.

Researching vasculitis requires large amounts of data to draw well-founded conclusions about treatments and outcomes. The problem with rare diseases such as vasculitis is that there are by definition few patients that you can involve in such research. Certainly when, as is often the case now, this happens separately in each European country.

It is therefore essential to combine the patient databases or "registries" as the specialists call them, from the individual European countries. That way you can build a dataset large enough to enable meaningful research. However, in order to be able to combine them, the relevant data must be recorded in the same way, which is certainly not the case.

FAIRASC therefore uses state-of-the-art technologies and a framework to link the various European databases. In this way a merged European database is created that offers possibilities for new research with regard to these challenging syndromes.

A serious challenge in sharing international data is dealing with the legal and ethical aspects. That subject will therefore have a high priority. A dedicated team of lawyers will ensure that all activities are carried out in accordance with GDPR (General Data Protection Regulation) and other

important regulations. The patient organizations will help to ensure that this is done carefully, both at national and European level.

Once the FAIRVASC database is in place, after analyzing the data, an attempt will be made to identify characteristics (genetic markers, physical characteristics, etc.) that can better predict how the patient's disease will develop and what their main health risks are. In turn, such markers can evolve into new tests that can help physicians choose the best treatment method for the individual patient. Patient organizations will also contribute in this area, for example by indicating where their priorities lie.

Patient organizations also play a role in this project when it comes to the structure of the database, the preparation of training materials, the public dissemination of the results of the project and promoting the expansion of the number of linked databases.

FAIRVASC is a research project started by researchers and medical specialists from the European research organization EUVAS and RITA, the European Reference Network for diseases resulting from a malfunctioning immune system. From the start of the project application, this group has been working closely with patient organizations in Ireland, the United Kingdom and our own Vasculitis Foundation. This project brings together leading scientists, doctors and patient organizations.