Letter of intent

File number 175.2021.041
Grant 2021/2022

Applicant

Title
The Dutch National CardioResource: powering discovery in the Inherited Cardiac Disorders

Abstract
Title: The Dutch National CardioResource: powering discovery in the Inherited Cardiac Disorders

NWO domain: ZonMW

Relevant discipline codes:
23.10.00 Pathologie, pathologische anatomie
23.20.00 Organen en orgaansystemen

Short description of the request for investment
The Dutch cardiac research community has over the last three decades emerged as a world leader in the study of inherited heart disorders that cause sudden cardiac death in young individuals. Their studies have led to the recognition of distinct clinical forms of disease, the elucidation of underlying Mendelian disease genes, insights into disease mechanisms, and the discovery and optimisation of therapies. Yet, while these previous discoveries have markedly improved patient care, significant challenges remain. Crucially, important gaps in knowledge concerning disease-modulatory factors, including genetic factors, co-morbidities, environmental factors and lifestyle factors currently hinder an accurate assessment of disease risk, prognosis and risk for severe cardiac events in the individual patient. Progress in this area critically depends on the availability of rich longitudinal clinical data obtained in large sets of patients that is coupled to other relevant datasets such as ‘omics’ data and imaging data.

The proposed investment will address this need by constructing a federated nation-wide longitudinal registry infrastructure combined with imaging data, biobanking and generation of ‘omic’ datasets for research. Investment is needed to:
(1) harmonise and combine the current patient registries at the different Dutch university medical centres by bringing them together in a nation-wide federated data infrastructure;
(2) to enrich the data collection by facilitating, in a semi-automated manner, the inclusion of new patients and the inclusion of longitudinal (prospective) data from the electronic medical record of participating hospitals;
(3) enrich the collection by generation of coupled imaging data, biobanking of biomaterial (cardiac tissue) and generation of ‘omics’ data, including whole genome sequencing data;
(4) generate a computational interface that can provide regulated access to the different datasets (clinical, imaging, ‘omic’ etc) to allow for sophisticated state-of-the-art analysis by the cardiac and general research community.

This infrastructure will be the first sustainable resource at scale for research into inherited cardiac disorders and will be critical in addressing outstanding questions in these disorders for amelioration of patient care.

Consortium members: Amsterdam UMC, Prof. dr. J. van der Velden; UM CU, Prof. Dr. P. Van Tintelen; UMC G, Prof. Dr. R. De Boer; LUMC, Dr. D. Barge-Schaapveld; ErasmusMC, Dr. M. Michels; Maastricht UMC, Prof. S. Heymans; Dutch Cardiovascular Alliance, Prof. F. Asselbergs.

Organisation responsible for the application

Confirm letter of intent
With submitting this form via ISAAC I declare to have filled in this form completely and truthfully.