Letter of intent

File number 175.2021.011
Grant 2021/2022

Applicant

Title Novel sustainable strategy for collecting patient data in a Hereditary Cancer Registry

Abstract

NWO domain: ZonMw

Relevant research fields:
Medicine: 23.10.00 Pathology, 23.20.00 Organ and organ systems, 23.80.00 Epidemiology; Life sciences: 21.40.00 Genetics.

Brief explanation of the requested investment:
At present the Netherlands plays a leading role in research on hereditary cancer syndromes, which are rare diseases. When it comes to research in rare diseases, the resources as well as the availability of data is very limited. This unavailability of data and existing patient cohorts is a challenge for almost every research and innovation project on rare diseases. Current classic registries, if even available, are too laborious to be sustainable and often fragmented. With the proposed infrastructure we will establish a sustainable, innovative registry for hereditary cancer syndromes that is build upon patient empowerment and digitalization of health care and that is aligned with current standards such as FAIR. This strategy includes both a patient portal and professional portal for continuous data capture of patient-reported outcomes and experiences, natural history and follow-up. To establish this, funding will be requested to establish the infrastructure and start-up the registry through local data managers with in parallel efforts to enable semi-automated data exchange. The infrastructure will be developed in close collaboration with stakeholders, such as patient representatives, clinicians and researchers. The proposed novel registry strategy will be connected to the registry of the European reference on Hereditary Cancer (ERN GENTURIS) that is also led by the Radboudumc (genturis-registry.eu). Currently all UMCs have top expertise in hereditary cancer and 4 UMCs and the NKI are member of ERN GENTURIS.

Indication of the group of researchers involved: Researchers, active in the field of health sciences or molecular and translational research, who are affiliated to a Dutch academic centre and/or recognised expert centre associated with the European Reference Network Genetic Tumour Risk Syndromes (including 52 top expert centres in 24 EU Member States).

LSRI Roadmap: no alignment with LSRI Roadmap foreseen.

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.

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