

PERFECTO, preventing the preventable.

An innovative FH paediatric screening project, has just kicked off!

31 January 2024, Amsterdam, The Netherlands

We are delighted to share that the PERFECTO project, co-funded by the European Union, has officially been launched with a kicked-off meeting of the consortium partners. The project was successfully selected in response to a call for proposals on prevention of NCDs - cardiovascular diseases, diabetes and other NCDs from September 2022.

PERFECTO stands for **“Preventing thE PReventable – Familial HypErCholesterolaemia paediatric screening for cardiOvascular health”**. It is a landmark initiative for personalized prevention, tackling an often overlooked genetic/hereditary cause of cardiovascular disease through the lens of social innovation. And its mission is to generate evidence for the implementation of FH Paediatric Screening across Europe which presents an unquestionable opportunity to make a significant positive impact for affected individuals, their relatives, and the wider society as well as healthcare systems which are facing a critical point post-pandemic.

The project concept was developed by a consortium based on a well-balanced mix of partners that comprises patient and citizen perspectives screening expertise of models implemented in health care systems and screening associated HTA expertise and uptake of new innovation, social sciences in interdisciplinary research; addressing the public health needs of citizens in volatile and scarce resource circumstances; advocacy, knowledge sharing and training for public health. The consortium partners include FH Europe Foundation with Magdalena Daccord as the Consortium’s Coordinator, EuroScan with Dr Inaki Gutierrez Ibarluzea, Cyprus University of Technology with Assoc. Prof. Andrie

The launch meeting, which took place between 29 and 30 January in Warsaw, Poland, was attended by all the partners and expert advisors, experienced with successful implementation of FH screening programmes, as well as representatives of the European Commission with Yvette Azzopardi from DG Sante and Hulya Okuyan, the Project Officer from HaDEA.

“Together with FH patients, advocates and Ambassadors, clinicians, scientists, policymakers and health systems experts, we embark on this journey to bring innovative solutions to the forefront of CVD prevention. This multidisciplinary collaboration underscores our commitment to empowering communities and ensuring a healthier future for generations to come.” – said Magdalena Daccord, CEO of FH Europe Foundation and the Consortium’s Coordinator.

Familial Hypercholesterolaemia (FH) is the world’s most common monogenic disorder, affecting 1 in 300 people. This means 2.5 million Europeans, with 2 million adults and 500,000 children have FH. Yet, to date only est. 10% are diagnosed and treated causing a huge burden of CVD, which is preventable. FH is marked by high levels of low-density lipoprotein (LDL), commonly known as the ‘bad’ cholesterol, from a young age. This compound accumulates in the arteries from birth and poses a very high risk of developing increasing atherosclerotic

cardiovascular disease (ASCVD) risk at an early age. In fact, compared to the general population between the ages of 20 and 40, these individuals are twenty times more likely to develop significant cardiac complications, such as angina or myocardial infarction (commonly now as a heart attack).

Early screening, detection and personalised prevention which means appropriate treatment combined with healthy lifestyle habits, is key to a “normal and a CVD-free” life.

At the core of PERFECTO is to move forward the implementation of FH Paediatric Screening across Europe by creating a more enabling and supporting environment, focussing especially on countries where CVD burden is the highest and FH awareness is lower among wider stakeholders. PERFECTO, based on the FH Europe Network experiences and current activities of awareness, recognizes that there is an unmet need in relation to a better insight in the understanding of the attitudes and decision-making processes of stakeholders necessary to moving forward with implementation of FH Paediatric Screening. PERFECTO will use a bottom-up, citizen-led approach to develop and fine-tune a personalised communication model that could be generalised beyond FH and could be used/replicated for other condition with risk factors that are common for the majority of NCDs such as cancer and metabolic disorders. PERFECTO will build on advocacy efforts at the European level on the topic of FH Paediatric Screening but also aim to reach the entire population, not only diagnosed patients, as this is an essentially undiagnosed disease, to empower parents to seek and accept information and relevant screening. Special focus will be on populations that are typically not included in health policy design, in this case the Roma population in Romania, and their perceptions, barriers and knowledge base addressed in the proposed Personalised Communications Model (PCM). The project aims to transcend barriers (physical, cognitive, cultural, language) with the use of open and innovative practices in a digital era through the development of an integrated digital PCM to improve the scope and content (knowledge/literacy, skills/competences, self-efficacy/empowerment) and provide an alternative model/complementary learning environment orientated towards real needs and concerns to enable the uptake of FH Paediatric Screening with a framework adaptable to other EU countries to improve both health literacy and policy advocacy potentially for all countries within the consortium’s coverage (EU-wide and beyond). By doing so, PERFECTO will have a true patient and citizen driven approach with a strong capacity building element for multiplication, specifically in countries among population groups in need. It will address the knowledge gaps referred to earlier, adding relevant evidence to the state-of-the-art, with substantial impact envisaged in FH Paediatric Screening implementation, and, ultimately contributing to the reduction of CVD burden and health inequity.

PERFECTO is funded by the European Union. Views and opinions expressed are however those of the authors only and do not necessarily reflect those of the European Union or HaDEA. Neither the European Union nor the granting authority can be held responsible for them.

The project comes to life at an important time, when the European CVD community actively advocates for a joint response to the CVD as the public health burden. FH Europe Foundation

is a Partner of the European Alliance for Cardiovascular Health (EACH), advocating for a European Cardiovascular Health Plan. PERFECTO is launched 3 weeks following the launch of PerMed FH, a precision medicine project for FH. With the Joint Action on Cardiovascular Diseases and Diabetes launch later in 2024, also co-funded by the EU4Health Programme, PERFECTO will seek to identify and amplify any synergies on the mission to minimise the burden of CVD and diabetes in Europe.

More information on the project, the work packages and the progress will be communicated through a dedicated webpage. Please follow #PERFECTO, #FHchildscreening, #FindFH and #EU4Health #HealthUnion #CVD #CVH #NCD #personalisedprevention for additional information. And register to our newsletter to receive regular updates, if you have not done so yet.

About the Partners

Stichting FH Europe Foundation (FH Europe) (NL) www.fhef.org : The Foundation's main focus is advocacy and patient support, it drives public health policy improvements and collaborates progressively with leading European and the EU institutions – like the European Commission, the European Parliament and many other EU stakeholders. FH Europe Foundation is the next stage in the evolution of FH Europe (fheurope.org), the European Network of FH patient organisations. FH Europe and its Network has a leading place in the European public health policy space responding to the unmet needs of patients and people affected with inherited lipid conditions. FH Europe Foundation member patient organisation in Bulgaria will play an active role in testing/ validating materials and outputs from WP3. FH Europe is aware that the Bulgarian health system has implemented cholesterol screening at age 16. Building on this, Bulgaria aspires to implement a fully-fledged FH Paediatric Screening Programme, which could leverage the results and learnings from PERFECTO.

EuroScan (DE) <https://www.i-hts.org/> : The network acquired legal status in 2017, becoming EuroScan International Network e. V., a not-for-profit scientific association registered in Germany connecting public agencies, scientific organisations and individuals across all continents. EuroScan has been and aims to remain the main global forum for sharing and developing of methods for early identification and pre-assessment of emerging, new, and obsolete health technologies. EuroScan membership comprises several organisations around the world including members in four continents but mainly based in Europe (NIHR UK, Agenas IT, Osteba SP, AETSA SP, NIPHNO NO, Inca FR) and Asia Pacific (MaHTAs Ma, NECA SK, Singapore HTA, CDN TW; Australia and New Zealand). EuroScan holds a MoU with several organisations including WHO, HTAi; INAHTA, HTAsiaLink and REDETS. EuroScan has been collaborating in several EU funded projects among those it can be mentioned the active Horizon 2020 SAFENMEDTECH (<https://safenmt.com/>) and the IMI EU-PEARL (<https://eu-pearl.eu/>).

Cyprus University of Technology (CUT) (CY) <https://www.cut.ac.cy/> : CUT is the second largest and one of the leading research Universities in Cyprus, that has high values regarding its academic character and its emphasis on high quality research in major branches of science and technology. It has a staff of approximately 300 academics, approximately 400 Researchers and Special Scientists, and 219 administrative employees supporting all aspects of teaching and research. Research emphasis at CUT is reflected in the substantial funding provided to academics for the establishment of research centres and laboratories, the support it provides for collaborations with world renowned Universities and Institutions, and the participation of its faculty in several national and European research projects.

The University is pioneering in the production of applied research and achieving excellence in the international research area. In order to meet the challenges of society and industry, the results of the research produced at the University are transferred as know-how to society, industry and productive organisations to create innovative solutions with significant economic, social and environmental benefits. In the context of research, innovation and entrepreneurship activities, new jobs and opportunities are created for young scientists in cutting-edge sectors.

Centre for Innovation in Medicine (InoMed) (RO) <https://ino-med.ro> : InoMed is a non-governmental organisation based in Bucharest, with a focus on innovation in healthcare. It aims to shorten the time between the emergence of innovations in the medical sector and their application for patients' benefit in Romania and elsewhere. The Center develops programs to educate, inform and engage all audiences about innovation in medicine to create a friendly environment for early adoption of innovative technologies, ideas, products and services. InoMed also serves as an independent platform for informed dialogue between stakeholders in the field of omics medicine, personalised (precision) medicine, digital health, data oncology, immune-oncology, cancer research, biotechnology, systems biology and other hot scientific topics. InoMed is active in dedicated communication, education, advocacy and policy channels but also research activities.

European Public Health Alliance (EPHA) (BE) <https://epha.org> : A member-led organisation made up of public health NGOs, patient groups, health professionals and disease groups, we work to improve health and strengthen the voice of public health in Europe. EPHA has a solid network of 80 members dedicated to providing better health for all across the EU, through umbrella organisations and national members. Together with them, EPHA advocates for public health solutions leading to better health for all based on its values of equity, solidarity, sustainability, universality, diversity and good governance. Through its Roma Health Network, EPHA is also one of the leading NGO alliances for the voice in Roma health.

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