Response to the European Commission Consultation on Cardiovascular Health Checks

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The European Public Health Alliance (EPHA) is the leading European public health CSO with over 40 members across Europe. Cardiovascular disease (CVD) remains the leading cause of mortality and morbidity in Europe, with substantial societal and economic costs. CVD encompasses cardiac and vascular conditions affecting the heart, arteries, and circulatory system.

Cardiovascular health could benefit from integrating evidence-based, life-course, family-based, and equity-focused approaches into CVD prevention strategies. Current approaches to CVD screening rightly focus on prevention and major CVD risk factors, as outlined in the recommendations of the Task Force on defining a cardiovascular-renal-metabolic health check comprising organisations representing the cardiovascular, renal, diabetes, and obesity community. However, inherited conditions such as Familial Hypercholesterolaemia (FH), elevated Lipoprotein(a) (Lp(a)), Homozygous Familial Hypercholesterolaemia (HoFH), and Familial Chylomicronaemia Syndrome (FCS) are underrecognised drivers of premature CVD. FH, for example, remains underdiagnosed, with fewer than 10% of cases identified in many settings.

This extends beyond lipid disorders; collaboration with diabetes communities in Europe highlights the potential for linking lipid screening and early CVD risk detection with broader preventive screening pathways, e.g. type 1 diabetes. Vascular diseases also warrant greater attention in prevention and early detection strategies, including approaches such as ankle-brachial index (ABI) for peripheral arterial disease (PAD) risk assessment, and ultrasound screening for abdominal aortic aneurysm (AAA), which has demonstrated reductions in disease-specific mortality in targeted populations. Given the close interrelationship between cardiovascular and respiratory health, targeted respiratory function assessment for higher-risk populations, e.g. smokers, people with dyspnoea, obesity/metabolic disease, may support earlier detection of multimorbidity, improve cardiovascular risk stratification, and strengthen integrated prevention pathways.

PERFECTO highlighted persistent differences in access to lipid screening, genetic testing, diagnosis, and care (also detailed in the attached brief), shaped by social determinants. Women, underserved communities, and lower-income groups face greater barriers in FH diagnosis and treatment pathways. PERFECTO suggests a community-based mediation framework to improve equitable participation in screening. This may improve diagnosis, engagement, access to care by addressing access barriers (further detail in the attached brief).

These interventions may generate broader societal return on investment. Earlier identification and treatment of inherited lipid disorders can reduce future cardiovascular events, avoid costly complications, support long-term productivity, and strengthen health system sustainability. Many FH screening strategies are cost-effective compared with no screening and can be cost-saving in some settings depending on implementation context (Ademi et al., 2024).

Based on this evidence, the Recommendation should encourage Member States to adopt integrated, life-course CVD screening approaches that include:

- systematic integration of lipid screening into cardiovascular health checks;
- early detection pathways for inherited lipid disorders, like paediatric/cascade screening;
- vascular screening as a relevant part of the prevention process;
- targeted respiratory function assessment for higher-risk populations;
- community-based outreach strategies to empower underserved populations;
- collection of disaggregated data to monitor inequities in screening;
- stronger integration between CVD screening and broader NCD prevention pathways, including diabetes and respiratory health.

The attached brief includes evidence on FH disparities, a resource list, and an FH mediation model.

FH paediatric screening and health equity

This brief is based on findings from **Work Package 4 (WP4)** of the PERFECTO project (*Preventing the preventable: Familial Hypercholesterolaemia paediatric screening for cardiovascular health*). WP4 focused on **health equity in FH paediatric screening**, examining how social, economic, and structural factors affect access to diagnosis and care.

Drawing on research, case studies from our target countries, namely Romania and Cyprus, and existing international evidence, it identifies the **main disparities in FH** and explores how we can start addressing these today through community-based health mediation.

A particular focus was placed on marginalised and vulnerable populations, including **Roma communities** and **migrant groups**, to understand how structural barriers play out in practice, while ensuring that the lessons learned are applicable to improving access to FH screening more broadly.

Understanding the social determinants of health

To explore disparities in FH screening, we frame our analysis using the **Dahlgren-Whitehead mode**l, a widely recognised approach for understanding how health is shaped not only by biology, but also by social, economic, and environmental factors. This model highlights that inequalities in health arise across multiple levels, from individual behaviours to the design of societal systems. This means that improving FH screening is not only a clinical challenge, but also a question of how health systems reach – *or fail to reach* – different populations.

Our interpretation of the Dahlgren-Whitehead layers:

- **General socioeconomic, cultural and environmental conditions** – How systems are designed and which populations they prioritise.
- **Living and working conditions** – Practical barriers to accessing services such as healthcare, employment, and education.
- **Social and community networks** – The presence and role of family, community, or peer networks that shape awareness, trust, and engagement with care.
- **Individual lifestyle factors** – Personal health behaviours and attitudes shaped by broader determinants.
- **Age, sex, and hereditary factors** – Biological traits which may interact with systemic biases, influencing diagnosis and treatment.

Using this framework, we can better understand where and why disparities in FH screening arise across different layers of society. In this project, this framework was applied to real-world experiences of marginalised and vulnerable groups – particularly Roma in Romania and migrants and refugees in Cyprus – helping to translate abstract inequalities into practical entry points for action.

Key disparities in Familial Hypercholesterolaemia (FH)

Research shows that differences in FH diagnosis, treatment, and outcomes are **not only medical**. They are strongly shaped by **social, economic, and systemic factors**. Across these layers, several key disparities emerge:

- **Unequal access to FH diagnosis and treatment**
  People who are **white, male, higher-income, and more educated** are more likely to be diagnosed and receive treatment.
- **Underrepresentation in research and data**
  Clinical trials and FH registries often **underrepresent minority and low-income populations**, limiting accurate diagnosis and tailored care.
- **Barriers to genetic testing and screening**
  Access is reduced by **costs, location, language barriers, and mistrust** in how genetic data is used, lowering **participation in screening and cascade testing**.
- **Low health literacy**
  Around **1 in 5 people with FH** struggle to understand health information, with those from **lower income** and **education categories** reporting the lowest levels.
- **Lower participation in cascade screening**
  Families from disadvantaged backgrounds are **less likely to inform relatives or engage in follow-up testing**, limiting early detection.
- **Geographical and income-based inequalities**
  People in **lower-income countries** are less likely to receive genetic diagnosis or treatment and have **higher cardiovascular risk and complications**.
- **Gender inequalities in care**
  Women are often **diagnosed later**, treated less aggressively, and more likely to experience **treatment gaps linked to reproductive health**.
- **Higher burden of risk factors in underserved groups**
  Some populations face higher rates of **smoking, diabetes, and hypertension**, compounding FH-related risks.
- **Mistrust and limited outreach**
  Negative past experiences and lack of culturally appropriate communication lead to **lower trust in healthcare systems** and reduced engagement.

Addressing FH disparities through community-based health mediation

In response to these disparities, community-based health mediation offers a practical way to reach underserved populations, strengthen trust, and support people in navigating healthcare systems that can otherwise be difficult to access. In simple terms, it works through trained mediators from within communities who help bridge the gap between individuals and health services. While it cannot resolve all structural inequalities, it provides clear entry points to improve participation in screening, enable earlier diagnosis, and support long-term care. Unlike system-level reforms that take time to implement, health mediation offers an immediate, community-based approach

to reach populations underserved by existing screening models. This approach was explored in the context of Roma communities and migrant populations in Romania and Cyprus, where barriers to screening are often most visible.

Building on a review of health mediation approaches across Europe – including specific experiences from Romania and Cyprus, particularly among Roma and migrant communities, alongside examples from other countries – PERFECTO translated these insights into a set of concrete FH mediation building blocks to support more equitable screening across different populations.

But what do these FH mediation building blocks look like in practice?

- **Community-rooted FH mediators:** Trained mediators from within communities build trust and support early engagement with FH screening, particularly among underserved groups.
- **FH-focused health literacy and education:** Clear, culturally adapted information improves understanding of FH, genetic risk, and screening pathways, supporting informed participation.
- **Structured patient–provider mediation in FH screening and care:** Mediators facilitate communication with healthcare professionals, helping families navigate testing, counselling, and long-term treatment.
- **Navigation of barriers to FH screening and care pathways:** Practical support addresses administrative, financial, linguistic, and logistical barriers that limit access to screening and follow-up.
- **Promoting health prevention and FH screening:** Active outreach encourages participation in paediatric and cascade screening, moving beyond one-off campaigns towards sustained engagement.
- **FH equity monitoring and community-level data collection:** Mediation identifies gaps in access and participation, informing more equitable planning and delivery of screening programmes.
- **Integration of FH mediation with primary care and public health systems:** Activities are coordinated with healthcare providers and authorities to ensure referral pathways and continuity of care.
- **Addressing social determinants affecting FH care:** Mediation links individuals to social and support services, recognising that access to care is shaped by broader socio-economic conditions.
- **Community empowerment and long-term engagement on FH:** By building knowledge and trust, mediation strengthens communities' ability to engage independently with screening and care over time.

Conclusions and next steps: putting FH mediation into practice

With the FH mediation building blocks we can translate these principles into a structured framework for action. Combining these with the other PERFECTO tools – the

Personalised Communication Model (PCM) for tailored engagement, and the societal return on investment (sROI) framework for capturing wider social impact – equitable FH paediatric screening can be conducted immediately.

To do so, these are our key recommendations:

1. **Pilot FH mediation models** – Implement the full mediation pathway in national or regional settings, testing outreach, screening navigation, and follow-up support for families. Romania and Cyprus are priority contexts.
2. **Embed mediation in primary care pathways** – Integrate mediators into existing primary care and public health structures, with structured referral mechanisms and training for healthcare professionals in culturally competent engagement based on personalised communication models.
3. **Strengthen FH health literacy and community engagement** – Use culturally adapted education, community ambassadors, and peer-to-peer awareness activities to promote cascade screening and sustain long-term engagement.
4. **Monitor equity outcomes** – Collect age- and sex-disaggregated data on FH screening, diagnosis, and treatment, integrating mediator-generated community insights with national and primary care systems to inform targeted policy actions.
5. **Support mediator training and professional development** – Provide structured training in FH genetics, cardiovascular risk, communication, and navigation of healthcare and social systems.
6. **Align with broader preventive health initiatives** – Embed FH mediation within ongoing Safe Hearts Plan early detection and patient-centred care activities to support equitable cardiovascular health.
7. **Evaluate societal impact** – Use societal Return on Investment frameworks to capture broader benefits of mediation, including increased trust, social inclusion, and long-term engagement with preventive health services.

Taken together, these recommendations provide a roadmap for translating evidence into action. Although informed by targeted work with Roma and migrant communities in Romania and Cyprus, the proposed approach is intended to strengthen equitable FH screening more broadly. **The next step** is to pilot this model in real-world settings to generate evidence on what works, for whom, and under which conditions, and to refine and adapt FH screening to national contexts. *This moves the approach from concept to a tested, scalable model to reduce disparities in FH screening across Europe*.

Body of resources

Curious about research on FH disparities? The resources below provide an overview of the most relevant articles collected for the work of PERFECTO:

- 2009 – **Underrepresentation of non-white children in trials of statins in children with heterozygous familial hypercholesterolaemia** (Belay, B., Racine, A.D., & Belamarich, P. F)
    - Link: ethndis.org/archive/files/ethn-19-02-166.pdf
    - Scope: Global (AT, CA, FI, GR, NL, NO, ZA, US)
    - Content: Non-white children are severely underrepresented in paediatric statin trials for HeFH; 92% of study participants were white
- 2013 – **The Need to Build Trust: A Perspective on Disparities in Genetic Testing** (Saulsberry, K., & Terry, S.F)
    - Link: pmc.ncbi.nlm.nih.gov/articles/PMC3761437/pdf/gtmb.2013.1548.pdf
    - Scope: United States
    - Content: Minority groups have lower uptake of genetic testing due to location, socioeconomic barriers, lack of awareness, and distrust; highlights need for direct engagement by clinicians and researchers
- 2015 – **Challenges in the care of familial hypercholesterolemia: a community care perspective** (Brett, T., Watts, G.F., Arnold-Reed, D.E., Bell, D.A., Garton-Smith, J., Vickery, A.W., Ryan, J.D.M., and Pan, J.)
    - Link: researchonline.nd.edu.au/cgi/viewcontent.cgi?article=1700&context=med_article
    - Scope: Australia
    - Content: Community-based methods improve establishment of an index for contact tracing and cascade testing
- 2018 – **Health Literacy in Familial Hypercholesterolemia: A Cross-National Study** (Hagger, M.S., Hardcastle, S.J., Hu, M., Kwok, S., Lin, J., Nawawi, H.M., Pang, J., Santos, R.D., Soran, H., Su, T.C. and Tomlinson, B.)
    - Link: academic.oup.com/eurjpc/article/25/9/936/5926484
    - Scope: Global (AU, BR, CN, HK, MY, TW, UK)
    - Content: Lower income and education are linked to inadequate health literacy, leading to access barriers, lower treatment adherence, and reduced participation in cascade screening
- 2020 – **Women Living with Familial Hypercholesterolemia: Challenges and Considerations Surrounding their Care** (Balla, S., Ekpo, E.P., Wilemon, K.A., Knowles, J.W. and Rodriguez, F.)
    - Link: pmc.ncbi.nlm.nih.gov/articles/PMC7508565/pdf/nihms-1625830.pdf
    - Scope: United States, United Kingdom

    - Content: Women with FH face disparities: less likely to be on statins, more likely to discontinue treatment, and less likely to achieve LDL-C targets
- 2021 – **Addressing Gaps in Racial/Ethnic Representation in Familial Hypercholesterolemia Registries** (Mszar, R., Santos, R.D. and Nasir, K.)
    - Link: ahajournals.org/doi/pdf/10.1161/CIRCOUTCOMES.120.007306
    - Scope: United States
    - Content: FH registries lack diversity; improvements can be made via population thresholds, revising diagnostic criteria, and engaging underserved communities with targeted research and interventions
- 2021 – **Racial Disparities in Modifiable Risk Factors and Statin Usage in Black Patients With Familial Hypercholesterolemia** (Agarwala, A., Bekele, N., Deych, E., Rich, M.W., Hussain, A., Jones, L.K., Sturm, A.C., Aspry, K., Nowak, E., Ahmad, Z. and Ballantyne, C.M.)
    - Link: ahajournals.org/doi/pdf/10.1161/JAHA.121.020890
    - Scope: United States
    - Content: Black FH patients have higher cardiovascular risk burdens and are less likely to receive lipid-lowering therapy, highlighting a need for targeted prevention
- 2022 – **Familial Hypercholesterolemia Prevalence Among Ethnicities—Systematic Review and Meta-Analysis** (Toft-Nielsen, F., Emanuelsson, F. and Benn, M.)
    - Link: frontiersin.org/journals/genetics/articles/10.3389/fgene.2022.840797/full
    - Scope: Global (BR, CN, DK, GE, JP, KR, MY, SA, US)
    - Content: High FH prevalence among Black populations, influenced by bias in screening, access barriers, and underrepresentation in clinical data; suggests increased targeted screening
- 2022 – **Using Healthcare Claims Data and Machine Learning to Identify Health Disparities for Individuals With Diagnosed and Undiagnosed Familial Hypercholesterolemia** (Ahmad, Z., Xing, C., Khera, A., Huang, C.Y., Brandt, E., MacDougall, D., Ahmed, C.D., McGowan, M.P., Wilemon, K.A. and Myers, K.)
    - Link: medrxiv.org/content/10.1101/2024.07.26.24311087v1.full.pdf
    - Scope: United States
    - Content: Lipid-lowering therapy more often prescribed to white, high-income, and highly educated FH patients, revealing clear disparities
- 2023 – **LDL cholesterol targets rarely achieved in familial hypercholesterolemia patients: A sex and gender-specific analysis** (Schreuder, M.M., Hamkour, S., Siegers, K.E., Holven, K.B., Johansen, A.K., Van

De Ree, M.A., Imholz, B., Boersma, E., Louters, L., Bogsrud, M.P. and Retterstøl, K.)
    - Link: www.sciencedirect.com/science/article/pii/S0021915023001399
    - Scope: The Netherlands and Norway
    - Content: Women with FH are less likely than men to reach LDL-C targets and to be on high-intensity statins.
- 2024 – **Familial hypercholesterolaemia in children and adolescents from 48 countries: a cross-sectional study** (Dharmayat, K.I., Vallejo-Vaz, A.J., Stevens, C.A., Brandts, J.M., Lyons, A.R., Groselj, U., Abifadel, M., Aguilar-Salinas, C.A., Alhabib, K., Alkhnifsawi, M. and Almahmeed, W.)
    - Link: thelancet.com/pdfs/journals/lancet/PIIS0140-6736(23)01842-1.pdf
    - Scope: Global
    - Content: Genetic diagnosis and likelihood of being on lipid-lowering medication are lower in non-high-income countries; cardiovascular risk factors and disease rates are higher
- 2024 – **Sex Differences in Diagnosis, Treatment, and Cardiovascular Outcomes in Homozygous Familial Hypercholesterolemia** (Mulder, J.W., Tromp, T.R., Al-Khnifsawi, M., Blom, D.J., Chlebus, K., Cuchel, M., D'Erasmo, L., Gallo, A., Hovingh, G.K., Kim, N.T. and Long, J.)
    - Link: jamanetwork.com/journals/jamacardiology/fullarticle/2814835
    - Scope: Global
    - Content: No large sex disparities in HoFH; men have higher incidence of myocardial infarction and coronary interventions