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Preventing the Preventable

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Bridging the Equity Gap

Community-Based Health Mediation for Early Paediatric Screening of Familial Hypercholesterolaemia in Europe

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Background

Familial hypercholesterolaemia (FH) is a common inherited genetic condition characterised by elevated low-density lipoprotein cholesterol (LDL-C) from birth, leading to an increased risk of premature cardiovascular disease. Early identification through paediatric screening enables timely intervention and can significantly improve long-term health outcomes. However, access to screening and preventive care remains unequal, particularly among underserved and socially disadvantaged populations. Socioeconomic, cultural, linguistic and structural barriers may contribute to delayed diagnosis and missed opportunities for prevention.

Objectives

To assess barriers to equitable paediatric FH screening and explore how community-based health mediation could help overcome these challenges. Particular attention was given to Roma communities in Romania and migrant populations in Cyprus, two populations that may experience additional barriers to accessing preventive healthcare. The assessment aimed to identify opportunities for culturally appropriate, inclusive and person-centred approaches to improve awareness, trust, participation in screening and access to follow-up care.

Methodology

Desk research and a structured review of available evidence were conducted as part of the Work Package 4 (WP4) Health Mediation Assessment Report. The Dahlgren–Whitehead model of the social determinants of health was used as an analytical framework to identify and categorise barriers at individual, community, socioeconomic and healthcare-system levels. Particular attention was given to health literacy, language, cultural considerations, trust in healthcare services and structural inequalities. The assessment also explored opportunities for community-based health mediation to facilitate communication, strengthen engagement with underserved populations and support more equitable access to paediatric FH screening.

Results: Disparities in screening and care

Diagnosis

In **high-income countries** **92.4%**

In **non-high-income countries** **48%**

of children had a genetic diagnosis

Dharmayat, K. V.-V.-S. (2024). Familial hypercholesterolaemia in children and adolescents from 48 countries: a cross-sectional study. *The Lancet*, 403(10421), 55-66.

4 Years

Reported average **diagnostic delay** of FH for **women** compared to men

Balla, S. E. (2020). Women living with familial hypercholesterolemia: challenges and considerations surrounding their care. *Current atherosclerosis reports*, 22, 1-13.

Literacy

1 in 5
people with FH have **inadequate health literacy**

Those from lower income and education categories report the lowest levels

Hagger, M. S. (2018). Health literacy in familial hypercholesterolemia: A cross-national study. *European journal of preventive cardiology,* 25(9), 936-943.

Trials

92%
of children enrolled in **paediatric statin trials where white** indicating disparities in research representation

Belay, B. R. (2009). Underrepresentation of non-White children in trials of statins in children with heterozygous familial hypercholesterolemia. *Ethnicity & Disease*, 19(2), 166-171.

Barriers

- **Low awareness and health literacy**
- **Underrepresentation in research**
- **Lack of trust**
- **Language/cultural barriers**
- **Administrative/financial obstacles**

FH mediation Framework: Nine building blocks organised into **three** connected pillars

REACHING PEOPLE
- FH literacy and education
- Community-rooted mediators
- Promoting prevention & screening

SUPPORTING ACCESS
- Mediation/ healthcare integration
- Patient-provider mediation
- Navigating barriers

SUSTAINING EQUITY
- Equity monitoring
- Addressing social determinants
- Community empowerment

Conclusion

Community-based health mediation offers a promising approach to making paediatric FH screening more equitable, accessible and inclusive. By strengthening trust, addressing cultural and linguistic barriers, and supporting families throughout the screening and care pathway, it could help reach underserved populations.
Insights from the PERFECTO pilots in Romania and Cyprus may inform scalable, person-centred screening strategies and contribute to more equitable cardiovascular prevention across Europe.

Contact

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