



**New Horizons for Cardiovascular Health  
a personalised approach to preventing the preventable  
by using digitalisation and health data**

Credit: Sara Otter

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*FH Europe Foundation*

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# CVDs in numbers - personal, familial, societal and economic impact

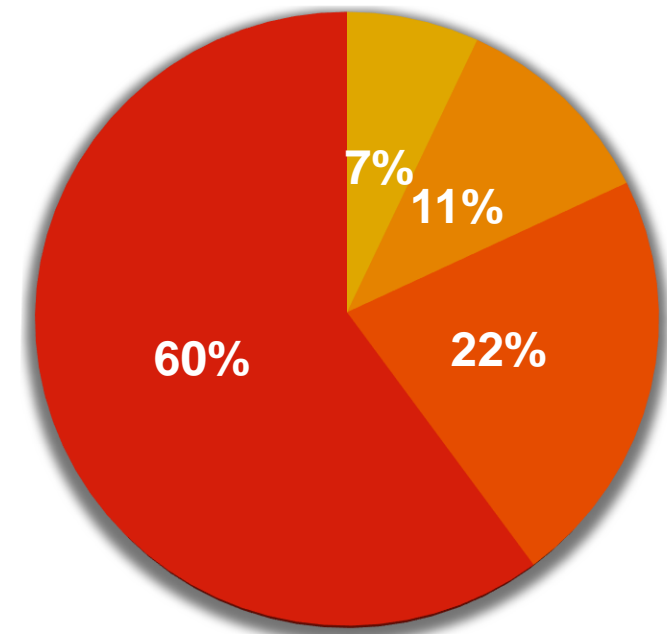
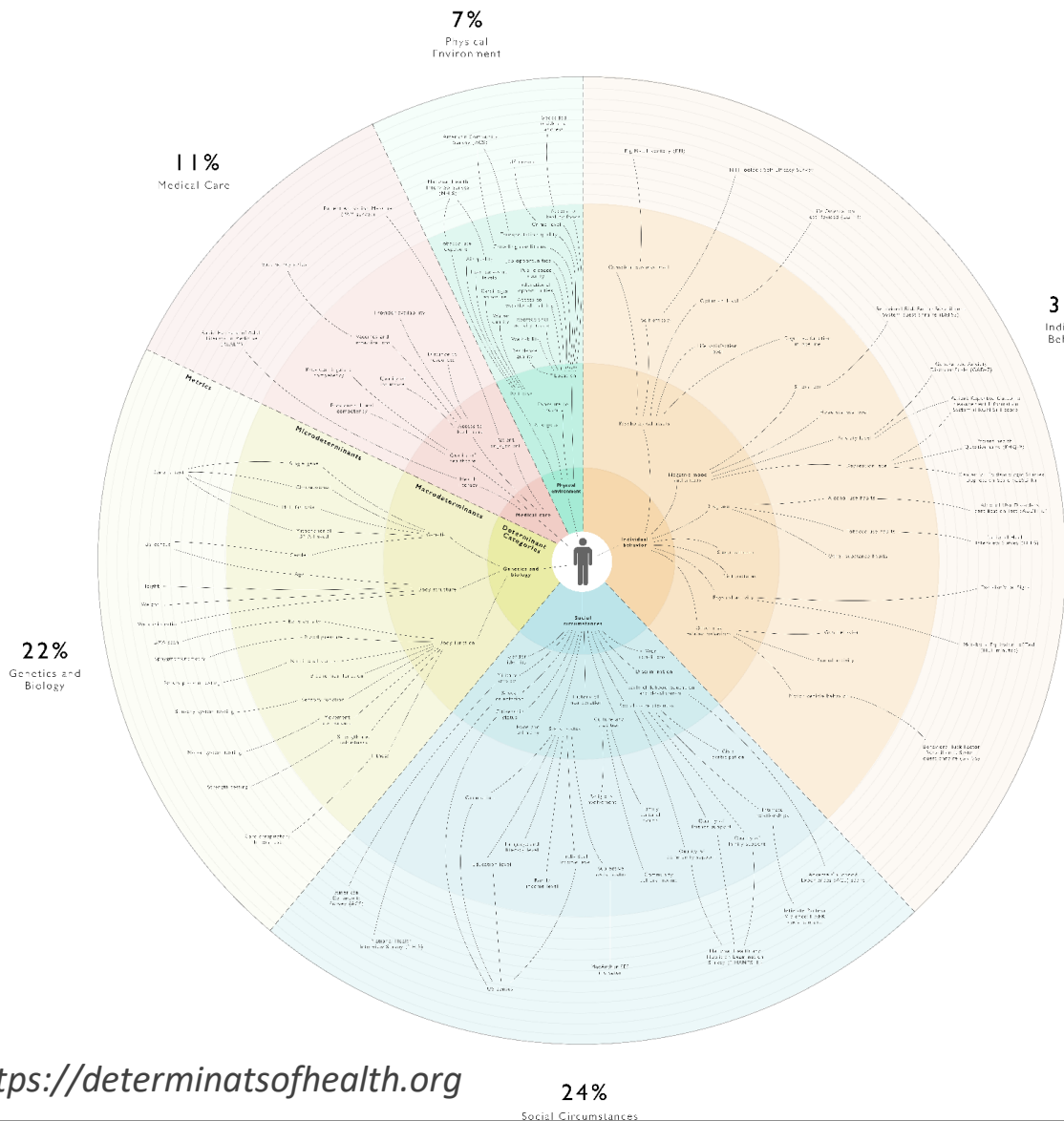
- **17.9 million** people died from CVDs in 2019 – the major cause of mortality and morbidity globally
- **85%** of death due to heart attack and stroke
- **more than 75%** deaths in LMICs
- **EUR 210 billion** per year in Europe – the cost of CVDs

# CVDs prevention, early detection and screening: insufficient and/or inefficient

- **health systems design** - hospital-centric, prioritising the diagnostic and treatment
- **misconceptions** around CVDs prevention and development (“lifestyle disease”)
- **low awareness rate** at population level on methods to promote and preserve CVH
- **low interest** of relevant stakeholders in the implementation of evidence-based screening and early detection (**FH screening, Lp(a) testing**)
- low awareness of **non-modifiable factors such as genetic** factors in CVDs pathogenesis
- **low integration** of all cardiovascular health determinants (social, economic, demographic, environmental and behavioral factors)

# Determinants of HEALTH

Model of all factors correlated with health outcomes for an individual



- Physical environment
- Health system
- Biologic, genetic factors
- Socio-Individual

Source: <https://determinatsofhealth.org>

# Familial Hypercholesterolemia

## The world's most common and non-modifiable CVD risk factor

- **Genetically determined**, dangerously high level of LDL cholesterol in the blood
- **2 forms:** heterozygous (common) and homozygous (very rare and very severe)
- Undetected and untreated/unmanaged, leads to early heart attacks, heart disease and even deaths, as early as 4 years of age (HoFH).

- **1 in 300** people have FH

- **50%** is the risk of inheriting FH from a parent with FH

- **Every minute a child with FH is born** somewhere in the world

- **Every day a child with HoFH is born** somewhere in the world

- **1 in 17** heart attacks is due to FH, which could have been prevented

- **Less than 10%** of people with FH are diagnosed and adequately treated

- **Over 30 million people worldwide** have FH, and **90% still do not know it!!!!**

# Familial Hypercholesterolemia

The world's most common and non-modifiable CVD risk factor

Therefore, a combination of **screening** methods - universal paediatric screening, (reverse) cascade screening – family screening members (parents, siblings, children) of index cases, and opportunistic screening – **is essential.**

# Digitalization and health data

## Key pillar in advocacy for CVD prevention



EU 2022 CZ



**FH Europe**  
The European FH Patient Network



**FH** DIAGNÓZA FH, z.s.



**SENÁT**  
SENÁT

### The Time is Now: Achieving FH Paediatric Screening Across Europe



**The Prague Declaration**  
6 September 2022

An accompanying event of the Slovenian Presidency of the Council of EU 2021.



si2021.eu

*Technical Meeting on*

## **Achieving Equity and Innovation in Newborn Screening and in Familial Hypercholesterolaemia Paediatric Screening across Europe.**

11th October 2021



 **FH Europe**  
The European FH Patient Network

# Role of patients in advocacy for implementation Innovation through multidisciplinary collaboration



Browse the logos of those that have already signed the Prague Declaration to the EU





# High lipoprotein (a)

## An independent CVD risk factor

- Lp(a) level is **genetically** determined
- Every person reaches the lifetime level of circulating Lp(a) already in **early childhood**
- LP(a) levels are independent of **lifestyle**
- High levels of Lp(a) affect **1 in 5 people**, this means est. **1.4 billion people globally**
- If one of the parents has elevated Lp(a), there is a greater chance of inheriting this risk factor
- **Males and females are equally** likely to have the genetic high levels of Lp(a).

# Lp(a) International Initiative



Credit: Sara Otter

# **Vision of the International Lp(a) Initiative**



**Lp(a) measurement is the norm globally, and elevated Lp(a) is managed efficiently and equitably, to contribute towards the prevention of premature cardiovascular disease and related deaths.**

# Members of the Lp(a) International Task Force



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# Goals

1

To raise awareness about Lp(a)

as an independent and a major inherited CVD risk factor and how this can be effectively managed, among policy makers, health care professionals, patients and the public.

2

To demonstrate the cost-effectiveness of CVD prevention

through the diagnosis of high levels of Lp(a) as a strategy towards CVD prevention.

3

To test personalised prevention models in health systems

focussing on implementation science in the field of Lp(a).

4

To utilise effectively digital transformation and health data

to support research and sound decision-making in the context of Lp(a).

5

To devise a forward-looking research and policy agenda in Lp(a)

anticipating trends and critical issues, in collaboration with social futurists.

In parallel, a process will be outlined to establish national task forces in the three key countries ( Canada, China and Japan) to enable implementation.

# Data and digitalization enabling PERSONALISED PREVENTION of CVD – digital screening

- Hospital information systems
- EHRs
- Registries

[Home](#) > [Advances in Therapy](#) > [Article](#)

## Familial Hypercholesterolemia Identification Algorithm in Patients with Acute Cardiovascular Events in A Large Hospital Electronic Database in Bulgaria: A Call for Implementation

Original Research | [Open Access](#) | [Published: 23 March 2021](#) | **38**, 2323–2338 (2021)

Source: Petrov, I., Postadzhyan, A., Vasilev, D. et al. Familial Hypercholesterolemia Identification Algorithm in Patients with Acute Cardiovascular Events in A Large Hospital Electronic Database in Bulgaria: A Call for Implementation. *Adv Ther* **38**, 2323–2338 (2021). <https://doi.org/10.1007/s12325-020-01608-3>

# Next BIG thing: patient's and citizen's generated data

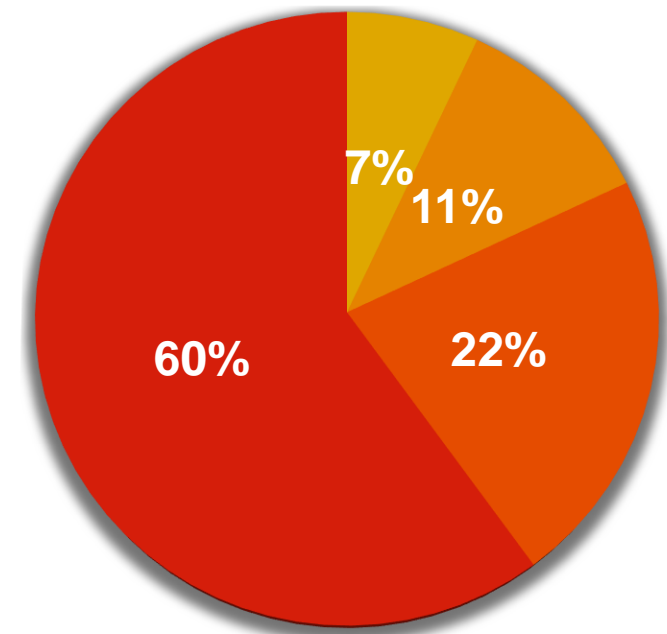
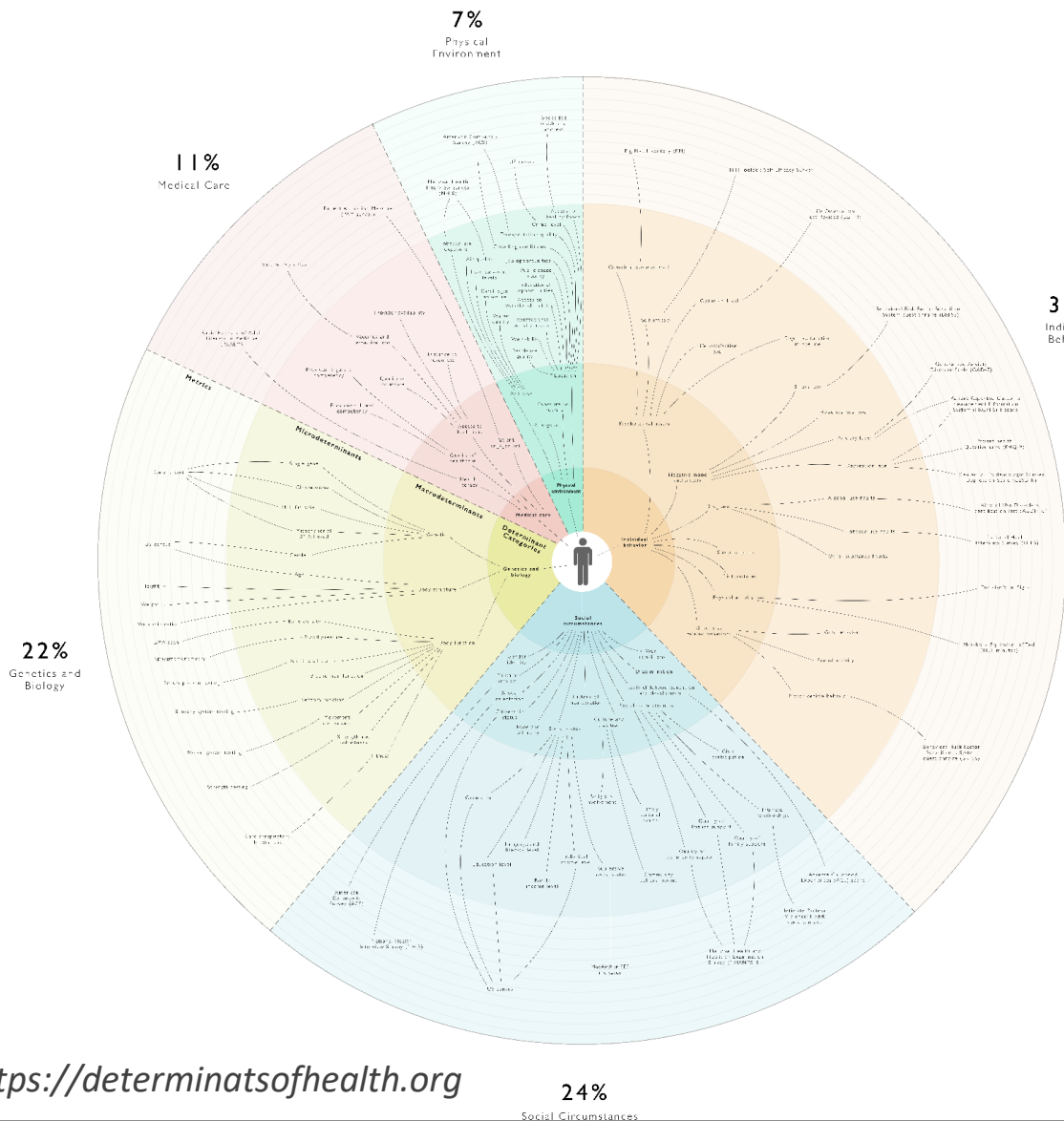
- Medical data
- Lifestyle data
- Behavioural data
- Socio-economic data
- Environmental data



## • Virtual Twin

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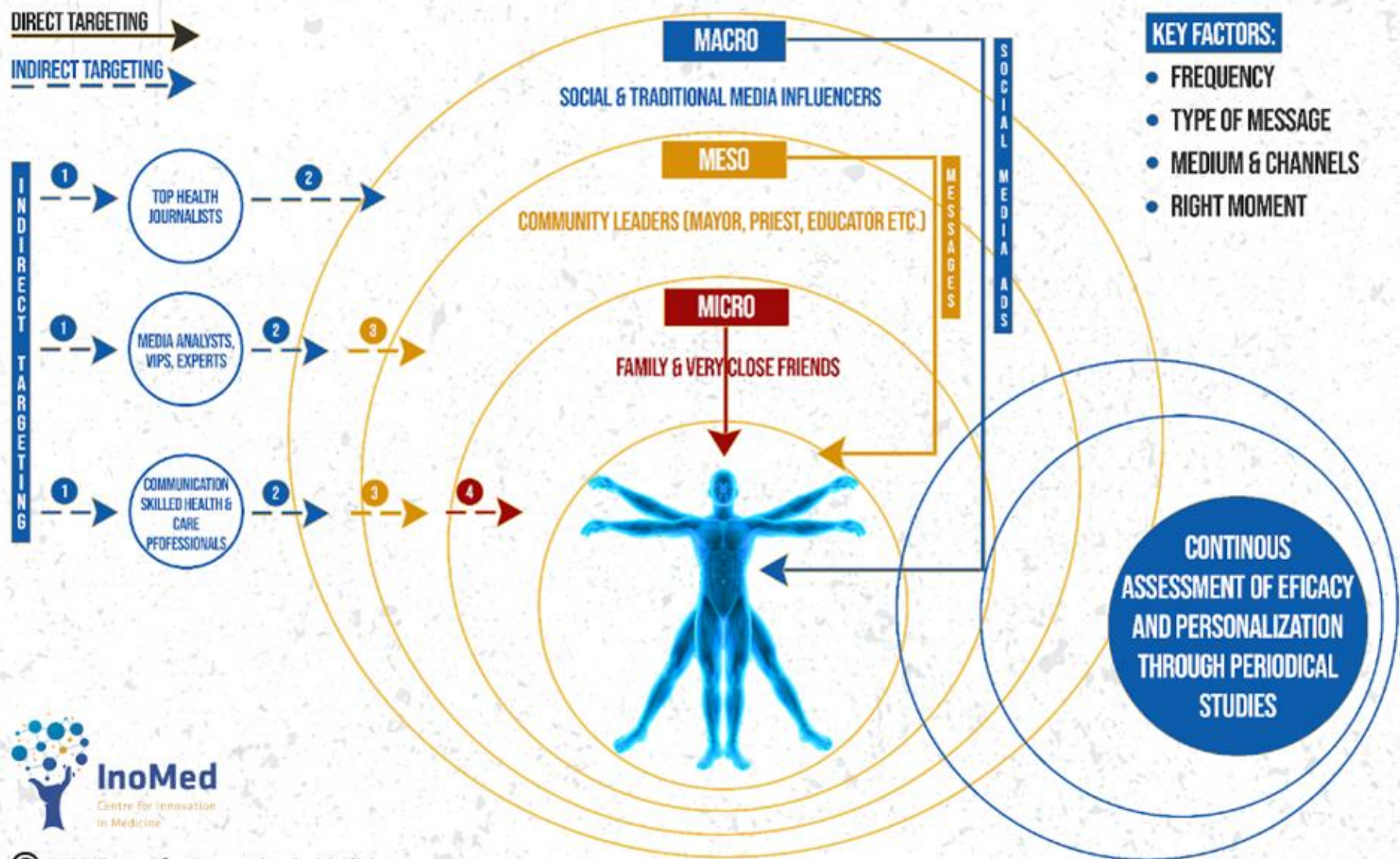


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# Personalised Communication Models Concept – Citizen Matrix based



# Towards a new model shift from CVD to CVH

- Human-centric, data-driven
- “Whole of society” approach
- Top-down and bottom-up
- Distributed leadership
- Incorporating innovations coming from biotech revolution (genomics, RNA-based therapies, gene editing, gene therapies etc)

**“The electric light did not come from the continuous improvement of candles” – (Oren Harari)**



# Call to Action: A Global Code for Cardiovascular HEALTH

- co-creation process involving key stakeholders (traditional and non-traditional)
- evidence-based recommendations to promote and to preserve CVH
- frameworks for implementation in real life settings
- policy recommendations aiming to increase the uptake of the Code for CVH



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# THANK YOU

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