Our Objectives

The PREVENTABLE project seeks to integrate specialized clinical knowledge, real-life data, health economics, and social sciences approaches to evaluate the cost-effectiveness of risk-reduction interventions in RTRS by combining these insights.

In the complex landscape of Rare Tumour Risk Syndromes (RTRS), consensus clinical guidelines and the expertise of specialized teams are crucial for effective disease management.

Our desired impacts

The impact includes:

1. **Enhanced Management**: Providing new tools to assess health costs, aiding decision-makers.
2. **Improved Outcomes:** Prioritizing prevention for better clinical results and cost savings.
3. **Optimized Care**: Supporting professionals in efficient resource use.
4. **Equal Opportunities**: Ensuring all RTRS patients receive informed, equal care.
5. **Health Promotion**: Shifting to community-based care with tech integration for better services.

Consortium

www.preventable.eu

Carla Oliveira
i3S – Institute for Research and Innovation in Health, University of Porto

T. +351 220 408 800
E. preventable@i3S.up.pt

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Preventable

SUSTAINABLE CARE FOR RARE TUMOUR RISK SYNDROMES

Sustainable care for Rare Tumour Risk Syndromes (RTRS)

Funded by the European Union

Project Overview

The PREVENTABLE project, launched in January 2023, aims to evaluate the clinical, social, and financial impacts of implementing specialised care to prevent advanced diseases in families affected by Rare Tumour Risk Syndromes (RTRS). This 3-year Horizon Europe initiative, funded by the European Health and Digital Executive Agency (HaDEA), involves collaboration among EU and non-EU partners, including nine healthcare centres specialising in RTRS across several countries, as well as experts in health economics, behavioural science, innovation, and organisational networking.

What are RTRS?

Rare Tumour Risk Syndromes (RTRS) are rare genetic diseases affecting fewer than 5 in 10,000 people globally, with high cancer and hereditary transmission risks. Understanding family health history is vital for managing these conditions, as undiagnosed patients may develop aggressive cancers. Many RTRS have identifiable genetic defects, enabling early identification of high-risk carriers and tailored preventive measures. Integrating this knowledge allows prediction of cancer development, defining associated conditions, and estimating costs for personalized care pathways.

Types of RTRS

Rare Tumour Risk Syndromes (RTRS) comprise a diverse array of genetically inherited conditions that elevate individuals' predisposition to various types of cancer. Below, PREVENTABLE outlines the research focus and the principal investigators involved:

Birt-Hogg-Dubé Syndrome (BHDS) — **FLCN**

Joan Brunet
ICO – Intitut Català d'Oncologia

Familial Malignant Melanoma (FMM) — **CDKN2A/CDK4**

Hildegunn Vetti
HUH – Helse Bergen HF

Gastrointestinal Stromal Tumours (GIST) — **KIT/SDHx**


Paula Soares & Ana Azevedo
i3S & Centro Hospitalar de São João

Hereditary Diffuse Gastric Cancer (HDGC) — **CDH1/CTNNA1**


Carla Oliveira & Ana Azevedo
i3S & Centro Hospitalar de São João

Li-Fraumeni Syndrome (LFS) — **TP53**


Claude Houdayer & Jean-Christophe Thery
CHU Rouen & CHB Rouen

Peutz-Jeghers Syndrome (PJS) — **STK11**

Prof. Dr. Stefan Aretz
UKB – Universitätsklinikum Bonn

PTEN Hamartoma Tumor Syndrome (PHTS) — **PTEN**

Janneke Schuurs-hoeijmakers
Radboud – Stichting Radboud Universitair Medisch Centrum

Hereditary Leiomyomatosis and Renal Cell Cancer (HLRCC) — **FH**

Judith Balmaña
VHIO – Vall d'Hebron Institute of Oncology

Work Packages

Establishment and Validation of parallel and condition-specific care pathway per RTRS

Development of resources and tools for collecting health costs and estimating costs for each parallel and condition-specific care pathway for RTRS

Modeling of costs and outcomes for RTRS patients.

Behavioural analysis of the uptake of care pathways for RTRS syndromes

Dissemination of PREVENTABLE's scientific evidence to stakeholders across the health value chain, including the public, at-risk individuals, general practitioners, and policymakers globally.