



Preventable

SUSTAINABLE CARE FOR RARE TUMOUR RISK SYNDROMES

Deliverable D6.4

Project Website

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Document Control Sheet

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Date Approved by Coordinator	



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Version	Date	Author	Description of Change
1	23/01/2023	Raquel Almeida (SPI)	Creation of the project website wireframe
2	25/03/2023	Mariana Neves (SPI)	Revision of project website wireframe and content creation
3	31/03/2023	Mariana Neves (SPI)	Minor revisions

DOCUMENT REVIEW

Reviewer	Date	Reviewer Name (Short Organisation Name)
1	30/03/2023	Carla Oliveira (i3S), Sara Pereira (i3S)

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Executive Summary

The Deliverable D6.4 Project Website comprises the wireframe and content for the PREVENTABLE website and was produced under Task 6.3 – Project identity, communication channels and tools of Work Package 6 (WP6) – Dissemination, Exploitation & Communication and the main responsible for this deliverable is SPI (Sociedade Portuguesa de Inovação). The project website is a core tool for communication and dissemination activities, working as a repository for several of the project results and outputs (scientific publications, public deliverables, news on activities and RTRS-specific content).

This document aims to present the main aims of the website, the initial website wireframe and content of general sections.



1. Objectives

As a central tool for Communication, the main objectives of the PREVENTABLE website are as follow:

- **Present the project**, including informing visitors about the nature and scope of the PREVENTABLE project, its goals and mission, the consortium and all involved teams.
- **Provide information about RTRS**, including the specific conditions onto which the project focuses, and useful links for patients, families, and the general public, working as a hub for RTRS content. This information will incorporate materials produced by Task 6.3 – Outreach material for RTRS-related content by IPA.
- **Promote project results**, including events and activities, scientific and medical publications, infographics, factsheets, relevant materials for partners and stakeholders, etc.
- **Merge and market other communication channels and tools**, including social media, press releases, external events, newspaper and media articles, and newsletters.

2. Website domain

The website domain for PREVENTABLE is: <https://preventable.eu>.



3. Website Wireframe and Content

		Subscribe our newsletter!	Social Media (with “follow” option)	
Website header				
Scrollable content				
Preventable (Project’s brief description) [more] Consortium numbers (partners, countries, funding, years)				
About RTRS (Brief: What are RTRS and impact in society)				
Latest news			Upcoming Events	
Consortium (logos)				
Links (Contact us) (Privacy policy)	Subscribe our newsletter!	Recent tweets	EU emblem and disclaimer	

Blue lines refer to content that should appear in all pages (as fixed header and footer)

3.1 Main Page (by clicking on the PREVENTABLE logo = Home)

3.1.1 Website header

Logo	About	RTRS	Our Research	#KnowAboutRT RS	Media & Events	Contacts	🔍
By clicking on the logo = Home (where we have the contents listed in the table above)	<ul style="list-style-type: none"> • The PREVENTABLE project • Aim & Objectives • Why is our mission important • What drives us • Who are we • Our impact 	<ul style="list-style-type: none"> • What are RTRS? • Types of RTRS <ul style="list-style-type: none"> ○ Birt Hogg-Dubé Syndrome ○ Familial Malignant Melanoma ○ Gastrointestinal Stromal Tumours ○ Hereditary Diffuse Gastric Cancer ○ Li-Fraumeni Syndrome ○ Peutz-Jeghers Syndrome ○ PTEN Hamartoma Tumour Syndrome ○ Hereditary Leiomyomatosis and Renal Cell Cancer • Useful Links (for patients) 	<ul style="list-style-type: none"> • Project materials • Public deliverables • Scientific publications • Useful links • Preventalks 	<ul style="list-style-type: none"> • Learn & Discover (to include audiovisual materials) • Testimonials • Our stakeholders • Expert interviews 	<ul style="list-style-type: none"> • News • Press releases • Events 	<ul style="list-style-type: none"> • Contacts project coordinator • Contact form • Social media (with follow option) 	

Lists only to be seen if person clicks/places pointer above title.



3.1.2 Scrollable content

PREVENTABLE

Sustainable care for rare tumour risk syndromes

The PREVENTABLE project began in January 2023 and was created to assess the clinical, social and financial impact of applying multidisciplinary and specialized care to prevent advanced disease in families suffering from Rare tumour Risk Syndromes (RTRS). In a complex disease context such is the case of RTRS, consensus clinical guidelines and cumulative experience and knowledge of RTRS-specialized teams is essential for proper management of the diseases. [\[Learn more\]](#)



4.6

Budget
(M€)



36

Duration
(Months)



15

Partner
Institutions



8

European
Countries

About RTRS

Rare tumour risk syndromes (RTRS) are rare diseases, affecting 5 per 10.000 people or less and caused by heritable genetic variants. In RTRS, the lifetime risk to develop various cancers can be as high as 100%, and patients have a 50% chance of transmitting the disease to their offspring. [\[Learn more\]](#)



LATEST NEWS

Space for three mini news items, including one image. The content should be a summary that, when clicked on, leads to the detailed news.

Title	Title
Summary of the news (3-4 lines, max.) <i>Read the whole article here</i>	<i>Summary of the news (3-4 lines, max)Read the whole article here</i>
	ALL NEWS →

EVENTS

Space for three events, including an image and the date. Content should be just the name of the event. Clicking on it leads to detailed event.

Date	Image
Title	
Date	Image
Title	
Date	Image
Title	

Consortium

PREVENTABLE partners Logos (With links for their websites)

[\[Learn More\]](#)

FOOTER

<p>Contact info</p> <p>[Contact us here] or by preventable@i3S.up.pt</p> <p>Project coordinator Name</p> <p>Address</p> <p>Email address</p>	<p>Subscribe to our newsletter!</p> <p>(enter name)</p> <p>(enter email)</p> <p>[Subscribe botton]</p> <p>Subscribe to our newsletter to receive news and updates about the Preventable project. For more information please see our [Privacy policy]</p>	<p>Social Media (com opção de seguir)</p> <p>[LinkedIn]</p> <p>[Twitter]</p> <p>[Youtube]</p>	<p>Disclaimer</p>
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3.1.3 Privacy policy

Introduction

This Privacy Policy intends to help you understand why and how your information is collected, processed and transferred, and how you can update it and delete it. Our services, processes and communication systems are committed to ensure the highest possible degree of compliance with the applicable law: Regulation (EU) 2016/679, The General Data Protection Regulation (GDPR).

Who we are

Our website address is: <https://preventable.eu>

Data collection

While using the Preventable website, we collect data about/concerning you when: you send a message/comment through the contact form or direct email, you subscribe to the project newsletter or you visit or browse our platform.

Messages or Comments

To help spam detection, data provided in forms (name, email address, subject of the contact and the message/comment) is collected. Additionally, the visitor's IP address and browser user agent string are also collected. We store the received emails for archive purposes and later contact.

Cookies

The Preventable website uses cookies to identify information about your session use and personalisation of your browser each time you visit. A cookie is a small data file that is stored by the browser when you access the platform. These cookies do not contain any of your personal information, such as name or email. The information stored in the cookie will only identify you for this platform and are discarded when you close your browser. However, if you leave a comment on our site you may opt-in to saving your name, email address and website in cookies. These are for your convenience so that you do not have to fill in your details again when you leave another comment. These cookies will last for one year.

Embedded content from other websites

This site may include embedded content (e.g. videos, images, articles, etc.) from other websites. These websites may collect data about you, use cookies, embed additional third-party tracking, and monitor your



interaction with that embedded content. This includes tracking your activity with the embedded content if you have an account and are logged in to that website.

How we use your data

The information from the newsletter subscription process is inserted into a third-party mailing system that manages and sends e-mails. Only your name and email are used for this purpose. This programme works offline and your data is not shared.

Your information will be used for purposes directly related to the project. We shall not use this information to send you marketing for third parties, nor shall we pass the information on to third parties. Only the information provided in the subscription form shall be stored.

What rights you have over your data

Your data will only be saved if you express your consent by sending an e-mail or by submitting an online form. Your personal data will not be used for purposes other than those described in this policy without you being informed in advance or, where appropriate, your consent obtained. You can also request that we erase any personal data we hold about you. This does not include any data we are obliged to keep for administrative, legal, or security purposes.

Data retention period

Your personal data will be kept for the minimum period of time necessary for the purposes described above and/or for compliance with legal obligations. The minimum time required is the duration of the project plus an additional one year (4 years). After this period, your data will be removed from the database.

Sharing your information

Your information will be shared only on request of the police or supervisory authorities when there is suspicion that an illegal act is being committed or if this disclosure would allow an illegal act to be prevented; or as required or authorized by law.

Your rights

At any time, you can request: access to your personal data; alteration of your personal information; opposition to, cancellation or limitation in the treatment of your personal data; portability of your personal data previously provided in a structured and compatible manner and in a readable format; and for your data to be deleted and forgotten.



To exercise your rights, please contact us through the following e-mail: preventable@i3S.up.pt. Your requests will be treated with care, so that we can ensure the effectiveness of your rights. You will be asked to prove your identity, so to ensure that personal data are shared only with the owner.

Please note that, in certain cases and in accordance with applicable law, your request may not be satisfied immediately or in full. In all cases, you will be informed of the measures taken, within 30 days from the time the request is made.

Clarifications or doubts

For any questions regarding this policy or other privacy issues, or if you wish to exercise any of your rights, please contact us at: preventable@i3S.up.pt.

3.1.4 Social media links

LinkedIn: <https://www.linkedin.com/company/preventable-eu>

Twitter: https://twitter.com/Preventable_EU

Youtube: https://www.youtube.com/@preventable_eu

3.1.5 Disclaimer



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4. About Tab

4.1.1 PREVENTABLE Project

The PREVENTABLE project was created to assess the clinical, social and financial impact of applying multidisciplinary and specialized care to prevent advanced disease in families suffering from Rare tumour risk syndromes (RTRS).

PREVENTABLE started in January 2023 and is a 3-year Horizon Europe project under the call Ensuring access to innovative, sustainable and high-quality health care (HORIZON-HLTH-2022-CARE-08, Grant Agreement 101095483), funded by the European Health and Digital Executive Agency (HaDEA).

The project integrates several EU and two non-EU partners, including nine healthcare centres experts in the eight types of RTRS, from Portugal, Spain, France, the Netherlands, Norway and Germany; and Healthcare Providers of the European Reference Network on Tumour Risk Syndromes (ERN GENTURIS). The consortium is also composed of experts in the fields of health economics and behavioural science models, multidisciplinary innovation and organisational networking.

4.1.2 Aim & Objectives

In a complex disease context such is the case of RTRS, consensus clinical guidelines and cumulative experience and knowledge of RTRS-specialized teams is essential for the proper management of the diseases.

The PREVENTABLE project aims at **merging specialized clinical knowledge on RTRS pathways of care, real-life clinical data (from patients or professionals), with health economic models and social sciences approaches**. Combining this knowledge will support the evaluation of the cost-benefit of risk-reduction interventions in RTRS and the establishment of guidelines for its communication among clinical teams and RTRS patients, ultimately settling a cost-effective RTRS patient-focused care at the European level.

More specifically, the PREVENTABLE project has the following objectives:



- 1 Establish and validate RTRS-specific pathways of care and associated clinical outcomes
- 2 Find resources and develop tools for the collection of health costs
Cost-estimate RTRS-specific care pathway
Compare health costs of prevention-related with treatment-related care pathways
- 3 Use multicentric real clinical data to model disease onset and progression, clinical outcomes and health costs with RTRS patients receiving primary/secondary prevention measures and/or treatment
- 4 Conduct behavioural analysis of the uptake of pathways of care for RTRS
- 5 Increase RTRS visibility throughout the health value chain, from the general public to at-risk individuals, general practitioners, and policy-makers at a global level.

4.1.3 Why is our mission important

Intensive surveillance and the risk-reduction strategies for genetically undiagnosed or asymptomatic RTRS patients are the best way to safeguard the best interest of RTRS patients and their families, while minimizing healthcare burden associated with the treatment of RTRS patients with clinically expressed cancers.

RTRS patients have a lifetime risk of 100% of developing a cancer
50% of RTRS patients have the risk of transmitting the disease to their offspring
Hospitalization has the highest weight on advanced cancer healthcare spending

4.1.4 What drives us

The PREVENTABLE project is driven by the assumptions that:

- Implementation of cancer risk-reduction measures in asymptomatic RTRS patients will increase RTRS patient's life-expectancy and healthy aging
- It is possible to financially estimate on disease prevention in RTRS



- Risk-reduction in all asymptomatic carriers of a family is less costly than treatment of a few carriers with advanced disease
- Raising awareness about RTRS will improve recognition, diagnosis and clinical outcomes, and provide the missing tools for policy makers to promote informed risk-reduction options in healthcare systems, transnationally in EU.

4.1.5 Who are we

PREVENTABLE is a multidisciplinary consortium with professionals from the most varied fields. It is constituted by 9 full partners, 5 affiliated entities and 1 associated partner spread throughout 8 European countries.



6 EU Countries

Portugal
Spain
France
Belgium
The Netherlands
Germany

8

European
Countries

2 Non-EU Countries

The United Kingdom
Norway



15

Partner
Institutions

Fields of Action

Clinical Diagnosis, Management &
Guideline Design
Health Economics & Cost-Benefit Models
Social and Behavioural Sciences
IT and Software Applications
Hospital Management
Innovation & Organisational Networking
Media Production

The Consortium

Layout proposal: COO partner with more relevance and then shorter presentations for all other partners.



COO Partner (Country)



Brief description
1-2 lines

Project Coordinator



Name



TEAM



Name
Main role



Name
Main role



Name
Main role



Name
Main role

PARTNER NAME (Country)



Brief description
1-2 lines

TEAM



Name
Main role



Name
Main role



Name
Main role

Info to be included:

COORDINATOR

i3S – Instituto de Investigação e Inovação em Saúde (Portugal)



<https://www.i3s.up.pt/>



CHSJ – Centro Hospitalar de São João (Portugal)



SÃO JOÃO

<https://portal-chsj.min-saude.pt/>

IPATIMUP – Instituto de Patologia e Imunologia Molecular da Universidade do Porto (Portugal)



<https://www.ipatimup.pt/Site/>

ICO – Intitut Català d'Oncologia (Spain)



<https://ico.gencat.cat/ca/inici>

VHIO – The Vall d'Hebron Institute of Oncology (Spain)



<https://vhio.net/>

IDIBGI – Institut d'Investigació Biomèdica de Girona Dr. Josep Trueta (Spain)



<https://idibgi.org/>

CHU-ROUEN – Centre Hospitalier Universitaire de Rouen (France)



<https://www.chu-rouen.fr/>

CHB – Centre Regional de Lutte Contre Le Cancer Henri Becquerel Rouen (France)



<https://www.becquerel.fr/>

RADBOUDUMC – Stichting Radboud Universitair Medisch Centrum (the Netherlands)



<https://www.radboudumc.nl/en/research>

HUH – Helse Bergen HF (Norway)



<https://helse-bergen.no/en/steder/haukeland>

UKB – Universitätsklinikum Bonn (Germany)





UNIVERSITÄT **BONN**

<https://www.ukbonn.de/>

UNL – Universidade Nova de Lisboa (Portugal)



UNIVERSIDADE NOVA
DE LISBOA

<https://www.unl.pt/>

SPI – Sociedade Portuguesa de Inovação (Portugal)



Sociedade Portuguesa de Inovação

<https://www.spi.pt/en/>

EHMA – European Health Management Association (Belgium)



European Health Management Association

<https://ehma.org/>

LU – University of Lancaster (UK)



<https://www.lancaster.ac.uk/>





4.1.6 Our impact

1. Enhance RTRS healthcare management by providing new approaches and tools to estimate real health costs of prevention vs. treatment, supporting healthcare decision and policymakers.
2. Improve the clinical outcome of RTRS patients' and their high-risk relatives and decrease the costs of RTRS disease management by promoting prevention over treatment.
3. Support management of RTRS pathways of care and better opportunities for healthcare professionals and providers, optimising the use of healthcare resources with cost-effective measures.
4. Promote equal healthcare opportunities for RTRS patients regardless of their gender, social status or ethnicity, by providing guidelines for bidirectional communication between clinical teams and patients concerning prevention-related pathways of care, allowing informed decisions on preventive healthcare.
5. Promote health and encourage disease prevention, by shifting from hospital-centred to community-based, people-centred and integrated healthcare structures, successfully embedding technological innovations that meet public health needs, while patient safety and quality of services is increased.



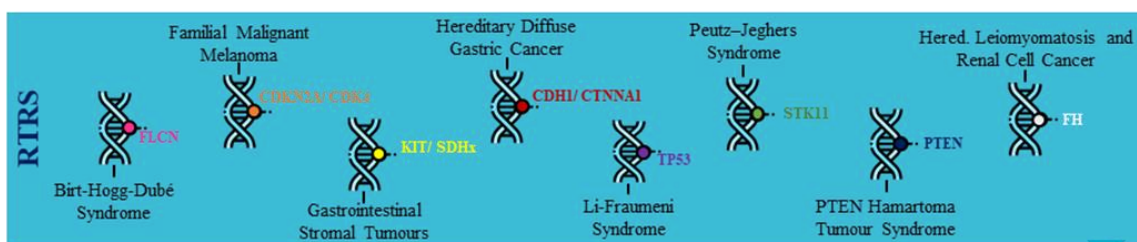
4.2 RTRS

4.2.1 What are RTRS?

RTRS are a group of rare diseases genetically determined from birth and that affect approximately 5 in 10 000 people or less worldwide. Patients suffering from RTRS have high risk for developing cancer and for transmitting the disease to their descendants. Particularly if undiagnosed (asymptomatic) or non-surveilled, RTRS patients can develop particularly aggressive cancers.

Currently, the genetic and heritable defects causing RTRS are already known for many of these syndromes. This information provides the opportunity to spot high-risk carriers before disease development and to define the conditions (target organs, age, gender cancer onset and recurrence) associated with each syndrome. Only by combining this knowledge it is possible to predict when and which cancer an asymptomatic RTRS patient will develop, establish effective disease prevention measures, and increase survival rates. Additionally, this integrative analysis allows to identify, characterize, and prospect the costs for tailor condition-specific pathways of care for each RTRS.

4.2.2 Types of RTRS



Birt Hogg-Dubé Syndrome [\[Learn More\]](#)

Familial Malignant Melanoma [\[Learn More\]](#)

Gastrointestinal Stromal Tumours [\[Learn More\]](#)

Hereditary Diffuse Gastric Cancer [\[Learn More\]](#)

Li-Fraumeni Syndrome [\[Learn More\]](#)

Peutz-Jeghers Syndrome [\[Learn More\]](#)

PTEN Hamartoma Tumour Syndrome [\[Learn More\]](#)

Hereditary Leiomyomatosis and Renal Cell Cancer [\[Learn More\]](#)

Useful Links

ERN GENTURIS

EVITA – Associação de Apoio a Portadores de Alterações nos Genes Relacionados com Cancro

Others



5. Our Research

To be populated with project results.

6. #KnowAboutRTS

Outreach Material – to be provided by IPA.

7. News and Event

To be populated with news about project activities and events.

8. Contacts

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Rua Alfredo Allen 208 4200-135 Porto, Portugal
Tel.: +351 220 408 800 Email: preventable@i3S.up.pt

Contact form – forwarded to: preventable@i3S.up.pt



Preventable

SUSTAINABLE CARE FOR RARE TUMOUR RISK SYNDROMES