



Preventable

SUSTAINABLE CARE FOR RARE TUMOUR RISK SYNDROMES

Deliverable D6.1

Dissemination & Exploitation Plan including communication activities and RTRS-specific content 1

March 31st 2023



Funded by the European Union



Document Control Sheet

PROJECT INFORMATION

Project Number	101095483
Project Acronym	Preventable
Project Full title	Cancer prevention vs cancer treatment: the rare tumour risk syndromes battle
Project Start Date	1 January 2023
Project Duration	36 months
Funding Instrument	Horizon Europe Funding Scheme Research and Innovation Action
Topic	HORIZON-HLTH-2022-CARE-08-04
Coordinator	i3S – Instituto de Investigação e Inovação em Saúde

DELIVERABLE INFORMATION

Deliverable No	D6.1
Deliverable Title	Dissemination & Exploitation Plan including communication activities and RTRS-specific content 1
Work-Package No	WP6
Work-Package Title	Dissemination, Exploitation & Communication
WP-Leader (Name and Short Org. Name)	Raquel Almeida (SPI)
Task No	T6.1
Task Title	Developing and updating the Dissemination & Exploitation Strategy
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Reviewers (Name and Short Org. Name)	Raquel Almeida (SPI)
Status	Draft <input type="checkbox"/> Final <input checked="" type="checkbox"/>
Deliverable Type	Report <input checked="" type="checkbox"/> Data <input type="checkbox"/> Demonstration <input type="checkbox"/> Other <input type="checkbox"/>
Dissemination Level	Public (PU) <input checked="" type="checkbox"/> Sensitive (SEN) <input type="checkbox"/> Classified <input type="checkbox"/> PU: Public, fully open SEN: Sensitive, limited under the conditions of the Grant Agreement Classified R-UE/EU-R – EU RESTRICTED under the Commission Decision No2015/444 Classified C-UE/EU-C – EU CONFIDENTIAL under the Commission Decision No2015/444 Classified S-UE/EU-S – EU SECRET under the Commission Decision No2015/444
Date Approved by Coordinator	



DOCUMENT VERSION HISTORY

Version	Date	Author	Description of Change
1	06/03/2023	Mariana Neves (SPI)	Creation of D6.1 Communication, Dissemination and Exploitation strategies
2	28/03/2023	Mariana Neves (SPI)	Minor changes after work package leader review.
3	30/03/2023	Mariana Neves (SPI)	Minor changes and preparation of the final version after Project Management Team review.

DOCUMENT REVIEW

Reviewer	Date	Reviewer Name (Short Organisation Name)
1	28/03/2023	Raquel Almeida (SPI)
2	30/03/2023	Carla Oliveira (i3S), Sara Pereira (i3S), Liliana Sousa (i3S)

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ABBREVIATIONS

Abbreviation	Definition
C&D&E	Communication & Dissemination & Exploitation
CSO	Civil Society Organisations
DNSH	Do no significant harm
EC	European Commission
EER	Expected exploitable results
ERN GENTURIS	European Reference Network Genetic Tumour Risk Syndromes
EU	European Union
GDPR	General Data Protection Regulation
HaDEA	European Health and Digital Executive Agency
HEMII	Health economics, management and insurance institutions
IP	Intellectual property
KER	Key exploitable results
KIP	Key impact pathways
KOL	Key opinion leader
KPI	Key performance indicators
MO	Main objective
NGO	Non-Governmental Organisations
R&D	Research and Development
RTRS	Rare tumour risk syndromes
S&T	Science & Technology
SO	Specific objective
TRL	Technology readiness level



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Executive Summary

The Deliverable D6.1 – Dissemination & Exploitation Plan, including communication activities and RTRS-specific content 1 was produced under Task 6.1 – Developing and updating the Dissemination and Exploitation strategy of the work package 6 (WP6) – Dissemination, Exploitation & Communication. SPI (Sociedade Portuguesa de Inovação) is the main responsible for this deliverable and the implementation of its strategy, with the core contribution from i3S (Institute for Research and Innovation in Health), IPA (Institute of Molecular Pathology and Immunology of the University of Porto) and EHMA (European Health Management Association).

This document aims to provide an overview of all communication, dissemination, and exploitation activities, setting strategies for their successful implementation. This document was produced to be a guide for all consortium members on how to efficiently engage with stakeholders. Key messages and target groups for communication are identified and characterized to ensure maximized dissemination and outreach, and expected exploitable results are proposed to highlight the impact of the project beyond its lifetime. Additionally, this deliverable also contains the first part (out of three) of RTRS-related content, produced by IPA as part of activities developed under Task 6.3 – Outreach material for RTRS-related knowledge.

This document will be supported and complemented by a set of other elements of the project:

- Deliverable D6.2 “Dissemination & Exploitation Plan, including communication activities and RTRS-specific content 2”
- Deliverable D6.3 “Dissemination & Exploitation Plan, including communication activities and RTRS-specific content 3”
- Deliverable D6.5 “Sustainability and Exploitation Strategy 1”
- Deliverable D6.6 “Sustainability and Exploitation Strategy 2”



PREVENTABLE project

Rare Tumour Risk Syndromes (RTRS) are a group of rare diseases genetically determined by birth, which predispose patients to high susceptibility to developing cancers during their whole lifetime and transmitting the disease to their offspring. PREVENTABLE was created to address the existing knowledge gap on the costs of the RTRS pathways of care, particularly when comparing prevention and therapeutical approaches. The main aim of the project is assessing the clinical, social and financial impact of applying multidisciplinary and specialized care to prevent advanced disease in families suffering from RTRS.

PREVENTABLE is focused on eight RTRS and will define and evaluate specific settings of their pathways of care, including diagnosis, prevention and therapeutic protocols, and compare the cumulative health costs of prevention versus treatment. This will allow to tailor specific pathways of care to prevent advanced disease in RTRS-carrying families, and reduce the economic burden associated with hospitalization and treatment, supporting new clinical guidelines with increased clinical benefit and cost-effectiveness.

PREVENTABLE is a 36-month Horizon Europe project under the call HORIZON-HLTH-2022-CARE-08 and 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 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.

Overall, PREVENTABLE will enable to implement cost-effective RTRS patient-centred care with long-term clinical, social and financial benefits across Europe, and a long-lasting impact on all RTRS patients and their families.

Partners:

Instituto de Investigação e Inovação em Saúde da Universidade do Porto (i3S), Portugal
Centro Hospitalar de São João EPE (CHSJ), Portugal
Instituto de Patologia e Imunologia Molecular da Universidade do Porto (IPATIMUP), Portugal
Institut Catala D'Oncologia (ICO), Spain
Fundacio Privada Institut D'Investigacio Oncologica de Vall-Hebron (VHIO), Spain
Fundacio Institut D'Investigacio Biomedica De Girona Doctor Josep Trueta (IDIBGI), Spain
Centre Hospitalier Universitaire de Rouen (CHU-ROUEN), France
Centre Regional de Lutte Contre Le Cancer Henri Becquerel Rouen (CHB), France
Stichting Radboud Universitair Medisch Centrum (RadboudUMC), the Netherlands
Helse Bergen HF (HUH), Norway
Universitätsklinikum Bonn (UKB), Germany
Universidade Nova de Lisboa (UNL), Portugal
Sociedade Portuguesa de Inovação (SPI), Portugal
European Health Management Association (EHMA), Belgium
University of Lancaster (LU), the United Kingdom



Chapter 1

Introduction



1. Introduction

The Deliverable **D6.1 “Dissemination & Exploitation Plan, including communication activities and RTRS-specific content 1”** is developed under work package 6 (WP6), which has the following objectives: 1) to design and implement a dissemination, communication and exploitation strategy; 2) to develop a clear project identity for PREVENTABLE; 3) to ensure a tailored and adequate dissemination to specific target groups identified; and 4) to ensure that the results of the project are exploited and have a lasting impact in Europe and the World.

The present document consists on the first version of the communication, dissemination & exploitation (C&D&E) strategy for PREVENTABLE, including an additional section of RTRS-related content, which will together contribute to increased outreach and impact of all the project activities, results and outcomes. The strategy in this document will be continuously monitored and updated in the deliverables **D6.2 “Dissemination & Exploitation Plan, including communication activities and RTRS-specific content 2”** and **D6.3 “Dissemination & Exploitation Plan, including communication activities and RTRS-specific content 3”**. The main responsible partner for implementing this plan is **SPI** with **core contributions from i3S, IPA and EHMA**. However, C&D&E activities are a joint effort from all the partners and, therefore, this document aims at being a guide for all consortium partners on how to effectively communicate and disseminate the key messages of the project.

PREVENTABLE was funded under the call HORIZON-HLTH-2022-CARE-08, ‘Ensuring access to innovative, sustainable and high-quality healthcare’, which is a Pre-commercial Procurement call aiming at supporting activities that can boost innovation in healthcare systems. The main goal of PREVENTABLE is the assessment of the clinical, social and financial impact of applying multidisciplinary and specialized care to prevent advanced disease in families suffering from RTRS. Thus, the C&D&E strategy in this deliverable took into consideration the expected short-term outcomes and long-term impacts of the project within the call, presented in **Table 1**.

Table 1 PREVENTABLE expected outcomes (short-term) and impacts (long-term) under the scope of HORIZON-HLTH-2022-CARE-08 Pre-commercial Procurement call¹.

Expected outcome (short-term)	<p>Decision-makers and policymakers in the field of healthcare:</p> <ul style="list-style-type: none"> • Avail of new approaches to financial planning and financing mechanisms that provide flexibility to stretched health budgets, including alternative procurement and contractual methods; • Apply cost-effective spending strategies based on the optimisation of the use of resources, while maintaining or improving health outcomes equitably;
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¹ <https://ec.europa.eu/info/funding-tenders/opportunities/portal/screen/opportunities/topic-details/horizon-hlth-2022-care-08-02>



Expected impact (long-term)

- Access tools that enable them to better remunerate, contract and incentivise healthcare professionals and providers;
- Take evidence-based and socially equitable healthcare financial decisions.
- Health and social care services and systems with improved governance mechanisms and more effective, efficient, accessible, resilient, trusted and sustainable, both fiscally and environmentally. Health promotion and disease prevention will be at their heart, by shifting from hospital-centred to community-based, people-centred and integrated healthcare structures and successfully embedding technological innovations that meet public health needs, while patient safety and quality of services are increased;
- Healthcare providers are trained and equipped with the skills and competencies suited for the future needs of healthcare systems that are modernised, digitally transformed and equipped with innovative tools, technologies and digital solutions for healthcare. They save time and resources by integrating and applying innovative technologies, which better involve patients in their own care, by reorganising workflows and redistributing tasks and responsibilities throughout the healthcare system, and by monitoring and analysing corresponding healthcare activities;
- Citizens are supported to play a key role in managing their own healthcare, informal carers (including unpaid carers) are fully supported (e.g., by preventing overburdening and economic stress) and specific needs of more vulnerable groups are recognised and addressed. They benefit from improved access to healthcare services, including financial risk protection, timely access to quality essential healthcare services, including safe, effective, and affordable essential medicines and vaccines;
- Health policy and systems adopt a holistic approach (individuals, communities, organisations, society) for the evaluation of health outcomes and the value of public health interventions, the organisation of healthcare, and decision-making.

One of the ways to ensure that the achievement and maximization of impacts and outcomes of the project, even beyond its lifetime, is by means of C&D&E. Thus, the purpose of D6.1 is to deliver a clear strategy for the C&D&E activities, defining key messages and target groups (or stakeholders), their roles and interests in the project, and providing an overview of channels, tools and activities to reach them. An initial plan will be proposed, considering the anticipated expected results and outcomes, which shall be continuously monitored and updated whenever necessary.

Thus, to support the understanding of this document, it is important to clarify the distinct nature and goals of these three concepts (**Figure 1**):

- **Communication** aims at promoting the project through its full lifespan, informing, and reaching out to society and showing the developed activities and the use and benefits that the project will have for the citizens.



- **Dissemination** aims at making the project results available for others to use, transferring knowledge by appropriate means (e.g., open sciences), other than from any protection or exploitation of the results.
- **Exploitation** aims at effectively using the project results for scientific, economic, political, or societal purposes, beyond the project scope and lifetime, turning them into concrete value for the society, via exploitation routes (e.g., marketing a new product, providing a service or standardise activities or policies).

While communication activities start once the project launches and finish at the end of the project, Dissemination and Exploitation activities start once project results are available and expand beyond the project's lifetime.

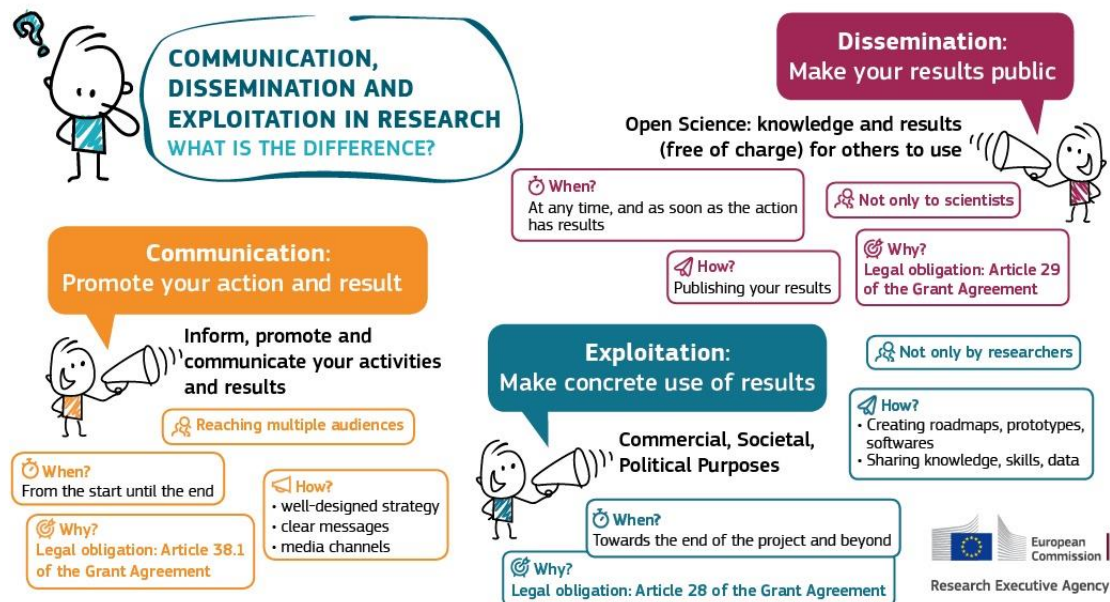


Figure 1 Differences between Communication, Dissemination and Exploitation².

Additionally, it may also be important for the reader to have insights in other relevant concepts, such as:

Stakeholder: An individual or a group of persons or organisation(s) of interest for the project or that can affect or is/are affected by the project.

Stakeholder engagement: Set of strategies or processes that aim for reaching, interacting with, and influencing the stakeholders, bi-directionally, to understand their needs, interests and perspectives.

² https://research-and-innovation.ec.europa.eu/strategy/dissemination-and-exploitation-research-results_en



Intellectual Property Rights: The legal rights given to the inventor or creator to protect his invention or creation for a certain period.

Result: A result is defined as “any tangible or intangible output of the action, such as data, knowledge and information whatever their form or nature, whether or not they can be protected, which are generated in the action as well as any attached rights, including intellectual property rights”.

Key Exploitable Results (KER): An identified main interesting result, which has been prioritized due to its high potential to be “exploited”, i.e., to make use of and derive benefits such as decreasing the value chain of a product, process or solution, or act as an important input to policy, further research or education³.

³ <https://intellectual-property-helpdesk.ec.europa.eu/system/files/2022-02/HEU%20Results%20platform.pdf>



Chapter 2

Communication Strategy and Plan



2. Communication Strategy and Plan

Communication aims to **promote the project from the moment it starts until it ends**, sharing information regarding the project's mission, results or activities. Communication activities allow for reaching multiple audiences and relevant stakeholders, allowing engagement early in the project. PREVENTABLE strategy will consider the next **three principles** as best practices for communication:

- **Avoid the 'one-size-fits-all' approach**, adopting tailored communication strategies to efficiently reach different target groups, considering language, visual content, and means of communication;
- **Respect the 'do no significant harm' (DNSH) principle⁴** – Article 17 of Regulation (EU) 2020/852 – by developing communication activities that do not compromise the environmental objective, particularly regarding printed materials.
- **Continuously monitor, evaluate, and update communication**, according to project progress and outreach performance.

The main responsible for the communication strategy is SPI. The consortium partners will be responsible for disseminating the project among relevant target groups, resorting to the available tools and channels, including offline activities and events. Partners will also be requested to provide feedback on the communication activities and propose internal and external events for project participation.

The main sections of the communication strategy will be defined as follow:

- **Why** do we communicate? – Communication objectives
- **Who** are we communicating to? – Target groups
- **What** do we communicate? – Key messages
- **Where** and how do we communicate? Tools and channels
- **When** do we communicate? – Action Plan

2.1 Why do we communicate? – Communication Objectives

The PREVENTABLE communication activities will have **3 main objectives** (MO), each one with a set of specific objectives (SO):

- **MO1: Promote the PREVENTABLE project** to multiple stakeholders
 - **SO1:** Develop the visual identity of the project;

⁴ https://knowledge4policy.ec.europa.eu/glossary-item/do-no-significant-harm_en



- **SO2:** Establish guidelines, tools and channels for the effective communication of the project;
- **SO3:** Produce useful information to populate the project communication channels, in an internally structured way according to project development.

- **MO2: Raise awareness and provide information about RTRS**
 - **SO1:** Develop targeted content to inform the general public about RTRS, using storytelling and marketing practices;
 - **SO2:** Provide useful information to RTRS patients and their families, including regarding their specific syndrome and the benefits of prevention;
 - **SO3:** Provide information on health costs associated with RTRS.

- **MO3: Support the dissemination activities in stakeholder engagement** at the national, European and international levels, promoting future collaborations
 - **SO1:** Develop tailor-made promotional materials to deliver PREVENTABLE key messages;
 - **SO2:** Implementing communication channels for establishing and supporting relevant networks between consortium partners and external stakeholders;
 - **SO3:** Support all project partners in their communication and dissemination activities amongst relevant stakeholders and multipliers.

To accomplish these goals, PREVENTABLE has defined a set of target groups, which will be key audiences to maximize project outreach and impact. The stakeholder engagement resulting from targeted communication activities will also contribute to the project development and the robust value proposition of expected exploitable results.

2.2 Who are we communicating to? – Target groups

The definition of the audiences to whom PREVENTABLE will be communicating to will be key not only for the dissemination and exploitation of the project but will also have an impact on project development itself since several activities will aim at bringing relevant stakeholders to the discussion. By defining communication target groups, it is possible to hypothesize and identify their main interests and benefits in engaging with the PREVENTABLE, as well as their value for the project and the consortium. This will then make it possible to better define the key messages, the requirements regarding messaging adaptation (language), and which will be the most useful channels and tools to reach these audiences.

Considering PREVENTABLE communication objectives, target groups were defined (**Table 2**), including potential interests (benefits for target groups) and roles (their importance for the project).



Table 2 PREVENTABLE communication target groups

Target Group	Definition	Interest & Role
Patients & their families	RTRS-diagnosed patients, either by genetic or cancer diagnosis, their relatives and informal care providers.	<ul style="list-style-type: none"> This group will be interested in learning more about RTRS, organisations or institutions working with these syndromes, networking with other patients and families, etc. This group is relevant for a better understanding of the pathways of care from the patient's perspective and will participate in activities such as the focus groups, <i>PrevenTalks</i>, and contribute to RTRS-content, by providing testimonials.
Academia	Research institutions and universities, individual researchers, postdoctoral fellows, doctoral students, graduate and undergraduate students	<ul style="list-style-type: none"> All research areas covered in PREVENTABLE will have an interest in the project results and benefit from its knowledge, including for establishing new collaborations. Research institutions, universities and researchers will be informed and actively engaged/invited to relevant project activities, such as webinars and workshops. Additionally, they will be part of the stakeholders to be consulted for the stakeholder mapping activities (T5.1);
Healthcare Professionals	General clinicians, oncologists, nurses and clinical staff, and diagnostic technicians.	<ul style="list-style-type: none"> This group will have an interest in the knowledge resulting from PREVENTABLE and in participating in discussions regarding the current pathways of care. This group will be able to provide the most informed advice and clinical decisions, ensuring patients' best interest. The project will rely on healthcare professionals for active implementation and follow-up of project activities and results. These professionals will also contribute with advice and expertise and have a crucial role in the definition of guidelines.
Medical Associations	Associations researching cancer: Portuguese Oncology Society (SPO), European Cancer Organisation (ECO), European Association for Cancer Research (EACR), European Society for Medical Oncology (ESMO), the European Reference Networks ERN, particularly ERN GENTURIS; or on rare diseases: European Union Committee of Experts on Rare Diseases (EUCERD)	<ul style="list-style-type: none"> This group will have an interest in the knowledge resulting from PREVENTABLE and in participating in discussions regarding the current pathways of care. This group will be an essential stakeholder group in the consultation process, and be actively involved in the project's activities (e.g., <i>PrevenTalks</i>, webinars and workshops), to ensure there is an interlinkage between the societal, political, and industrial impact of the project.
Healthcare Institutions and	Public and private hospitals, oncology institutions and hospitals, such as Instituto	<ul style="list-style-type: none"> These institutions will be interested in having insights regarding the most cost-effective and prognostically-positive pathways of care, either



<p>Pharmaceutical Industry</p>	<p>Português de Oncologia (IPO), Institut Catala d'Oncologia (ICO); diagnostic centres, private clinics, (palliative) care providers, pharma companies (drug and devices) and startups.</p>	<p>preventive or therapeutic, for the implementation of guidelines.</p> <ul style="list-style-type: none"> This group is involved in the care pathways, so institutions within this group will be important stakeholders in the consultation process, and be actively involved in the project's activities (e.g., <i>PrevenTalks</i>, webinars and workshops), to ensure there is an interlinkage between the societal, political, and industrial impact of the project;
<p>Health economics, management, and insurance institutions (HEMII)</p>	<p>Health management companies, health economics experts and companies, public and private hospital management officers, public and private insurance companies</p>	<ul style="list-style-type: none"> The project will produce valuable knowledge and tools (cost-model) for the field of health economics, with a consequent impact on healthcare management and health insurance planning. This group will be consulted as relevant stakeholders and invited to participate in dedicated project activities (e.g., <i>PrevenTalks</i>, webinar on how the project outcomes could impact public insurance).
<p>Civil Society Organisations (CSO) & Non-Governmental Organisations (NGOs)</p>	<p>CSO or NGOs that advocate for RTRS, hereditary cancer or rare diseases, including patients' associations and community platforms, at the EU and international levels.</p> <p>RTRS: Associação de Apoio a portadores de Alterações nos genes relacionados com Cancro Hereditário (EVITA, Portugal), Geneticancer (France), Actitud Frente al Cáncer (Spain), Facing Our Risk of Cancer Empowered (FORCE, USA)</p> <p>Rare Diseases: EU: European Organisation for Rare Diseases (EURORDIS)</p> <p>International: World Health Organization (WHO) Regional Office for Europe, NGO Committee for Rare Diseases, Rare Diseases International (RDI), International Rare Diseases Research Consortium (IRDiRC).</p>	<ul style="list-style-type: none"> This group shares common interests regarding RTRS-related and cancer-related awareness-raising and research development. CSOs and NGOs play an important influential role in civil society, with an important advocacy role for patients, families, and informal care providers. They can support links and networks between the project consortium with patients and other similar organisations, having a role as multipliers. They also can exert significant policy influence, which will be important for maximizing outreach and impact.
<p>Policymakers and Key opinion leaders (KOLs)</p>	<p>Policymakers or KOLs involved in healthcare, and health management, such as national Ministries of Health and health agencies, the European Commission (EC), the European Health Parliament, the European Observatory on Health Systems and Policies, the European Centre for Disease Prevention and Control, the European Medicines</p>	<ul style="list-style-type: none"> This group is interested in making informed decisions and negotiations, supported by scientifically and clinically accurate data. The project benefits from policymakers and KOLs to shift the approach of care to risk reduction, based on the proof that prevention is more cost-effective than treatment of (fewer) advanced disease carriers. The milestone-setting potential of



	Agency (EMA), European Health Economics Association (EuHEA)	this project requires eminent political involvement from an early stage onwards.
General Public	Civil society in general. Individuals who are not patients nor their relatives.	<ul style="list-style-type: none"> • The general public can benefit from PREVENTABLE as they may become patients themselves, and will therefore have a source of rigorous and curated information about RTRS, being empowered to take preventive actions, and influence policymaking. • The project will mainly benefit from this group as a source of multipliers in the RTRS awareness-raising, promoting the outreach to potential carriers and patients.

2.3 What do we communicate? – Key messages

After identifying the driving forces for each target stakeholder group in engaging with PREVENTABLE, the key messages to be communicated were categorized into four main themes:

1. PREVENTABLE General Key Messages:

- **To communicate project activities**, such as consortium meetings, thematic workshops, webinars, participation in national and international conferences, news in external media platforms, etc.;
- **To communicate project results and achievements**, such as scientific publications, IT tools, cost models, meetings with policymakers, organisations, or other relevant external parties.

Main target groups: All target groups.

2. Messages related to RTRS and their impact on society:

- **To raise awareness regarding RTRS**, more specifically what are RTRS, inform what are the current means for prevention and diagnosis, RTRS prevalence in the population (despite being a rare disease) and how RTRS can affect diagnosed and undiagnosed patients and their families;
- **To provide information to patients and the general public** regarding each specific RTRS condition, including their genetic causes, disease and hereditary risks, preventive care strategies, support platforms and services;
- **To promote prevention behaviour**, particularly within high-risk groups (RTRS-mutation carriers' and oncologic patients' relatives);



- **To share real-life testimonials** of RTRS patients, their families and/or informal care providers, which will be collected as part of T6.3.

Main target groups: Patients & their families, Civil Society Organisations (CSO) & Non-Governmental Organisations (NGOs), Policymakers and KOLs, Healthcare professionals, Academia, General Public.

3. Messages related to the **healthcare management of RTRS:**

- **To raise awareness of the economic burden of therapeutic and palliative care** for RTRS-related cancer patients, and its exponential impact when considering their high-risk relatives;
- **To communicate about the potential cost-benefit** of risk-reduction prevention measures versus treatment approaches and their ultimate impact on the patient's prognosis.
- **To promote the role of PREVENTABLE as a promoter of healthcare sustainable and circular economy**, by encouraging the cost-effective use of scarce and expensive resources.

Main target groups: HEMII, Policymakers and KOLs, Healthcare institutions and pharmaceutical industry, Medical Associations, and Academia.

4. Messages related to **national and EU organisations and actions on Rare Diseases & RTRS**

- **To inform patients and their families about organisations working on RTRS** and their activities at the national level (partners' countries) and European level
- **Promote collaboration, networking and outreach** between rare diseases and RTRS-related CSOs and NGOs, medical associations, sister projects and topic-related initiatives.

Main target groups: Patients and their families, Healthcare professionals, Medical Associations, Healthcare institutions and pharmaceutical industry, Civil Society Organisations (CSO) & Non-Governmental Organisations (NGOs), Academia, General public.

2.4 Where and how do we communicate? – Tools and channels

Effective communication of key messages relies on the correct language adaptation considering the target groups and using the appropriate tools and channels. For PREVENTABLE, a set of communication tools and channels was defined and is presented in **Table 3**.



Table 3 PREVENTABLE communication tools and channels.

Tools & Channels	Purpose	Target group	Message range (R) and type (T)*
Website	A central tool for active dissemination strategy. It will be a repository for all relevant information: RTRS-related content, project results, social media, publications, news, events and all other dissemination activities. Hub of information for all the relevant stakeholders.	All stakeholders	R: Wide T: Exp., Obj.
Social media	LinkedIn: Formal and informative social media channel, which will be the main channel to announce project-related events, publications, achievements, etc.	Academia, CSOs & NGOs, Healthcare professionals & Associations, Healthcare institutions and Pharma Industry, Policymakers	R: Wide T: Pers.
	Twitter: Less formal, equally informative social media channel, also allows for a swift reproduction (retweet) of other relevant events and posts.		R: Wide T: Pers.
	Youtube: will work as an archive for all video content and broadcast of virtual events.	All stakeholders	
	Instagram: More informal platforms, which will allow the outreach to a broader, less technical audience.	Patients and their families, General public	R: Wide T: Pers.
Audio-visual materials	RTRS-related content and expert interviews in the form of audios, videos and other multimedia formats.	Patients and their families, Healthcare Professionals, Policymakers	R: Wide T: Exp., Obj.
Communication materials	Informative materials, including in-paper, to be used in external events or when engaging with relevant stakeholders (contacts or meetings), including project brochures and flyer, factsheet, and roll-up. Digital materials will also be produced, such as templates, logos, and virtual backgrounds.	All stakeholders	R: Wide T: Exp., Obj.
Newsletter	In-depth look and review at all relevant research developments, outcomes and impacts, maintaining a degree of detail that is suitable for the general public.	Patients and their families, Academia, Healthcare professionals and associations, CSOs and NGOs.	R: Wide T: Exp., Obj.
Press releases and media articles	Efficient channel for promoting PREVENTABLE and communicating the results to the general public and all stakeholders.	All stakeholders	R: Wide T: Exp., Obj.

*exp – expository, obj – objective, pers – persuasive

Additionally, PREVENTABLE may take advantage of pre-existing **rare disease, RTRS and cancer online platforms and communities** as channels for communication and stakeholder engagement. These types of platforms generally aim at raising awareness, community gathering or being tools to find synergetic projects and programmes. Some of these are CORDIS (Community Research and Development



Information Service), ERA-Net for Research Programmes on Rare Diseases (E-Rare), INNOVCare, RD-Connect, European Platform for Rare Disease Registries (EPIRARE), RareConect and Orphanet.

2.4.1 Website

The PREVENTABLE website is a project deliverable (**D6.4 – Project website**) and will be launched on **M3 (March 2023)** and will be a central communication channel and tool for the project as it will:

- **Present the project** – what is PREVENTABLE, 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, in close articulation with the ERN-GENTURIS website, working as a hub for RTRS content.
- **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 (feed), press releases, external events, newspaper and media articles, and newsletters (subscribe button).

2.4.2 Social media channels

Social media will be the main communication channel with the target groups. The type of language should be adapted to each social media platform and the target groups. The language style in social media platforms should be welcoming, inclusive and persuasive. To increase the chances of being found by relevant stakeholders and enhance visibility and outreach, keywords, and hashtags should be used, according to post content and platform:

- **Keywords:** rare disease(s), RTRS, cancer syndromes, hereditary cancer, medical genetics, oncology, oncologic patients, cancer prevention, cancer surveillance, cancer treatment, pathways of care, healthcare costs, health management, health burden.
- **Hashtags:** #preventable_eu, #rarediseases, #horizoneurope, #RTRS, #KnowAboutRTRS, #cancer, #cancerprevention

Social media channels for PREVENTABLE will be initially created on **LinkedIn, Twitter and Youtube** (**Table 4**). These channels will be used to communicate about the project and disseminate project results and outcomes, such as publications, events and workshops, RTRS-related content, etc.



Table 4 PREVENTALBE Social Media platforms (at M3)

LinkedIn	Username: Preventable_EU Link: https://www.linkedin.com/company/preventable-eu/
Twitter	Username: Preventable_EU Link: https://twitter.com/Preventable_EU
Youtube	Username: Preventable_EU Link: https://www.youtube.com/@preventable_eu

At a later stage, an **Instagram** account will also be released, as it is one of the most used platforms for branding marketing, being able to target broader audiences, particularly patients and their families and the general public.

Partners will play an important role, as content engagement with third parties will be enhanced by sharing and commenting on the project's posts. Additionally, to increase visibility, other accounts can be tagged:

LinkedIn: European Commission, Research and Innovation, European Health and Digital Executive Agency (HaDEA).

Twitter: @EU_Commission, @HorizonEU, @EU_HaDEA

Additional **social media handles will be requested to the consortium partners** to include their own organisations in the social media posts whenever pertinent.

2.4.3 Audio-visual materials

A set of audio-visual materials produced by IPA will be produced for implementing campaigns to reach at-risk individuals, General Practitioners and Policymakers, in a mission to prevent cancer and promote health literacy, raising awareness on risk factors, preventive behaviour and early detection. These materials incorporate deliverable **D6.7 “Sets of audio-visual materials, specific for outreaching RTRS at-risk individuals, general practitioners, and policymakers”** to be produced under **Task 6.3 – Outreach material for RTRS-related knowledge**, and which will be further described in this document on chapter 5 “RTRS-specific content”.

2.4.4 Communication materials

Informative materials will be produced to allow a more effective communication with stakeholders during online and offline communication activities, including the main messages of the project and, whenever applicable, targeting particular stakeholder groups. The in-hand and digital materials will include 1 brochure, 1 flyer, 1 factsheet and 1 roll-up. Additionally, document templates will be produced as part of the virtual identity of the project (**section 2.7.2**).



2.4.5 Newsletter

Every 6 months, a bi-annual newsletter will be released to subscribers, to update project development, including project achievements, summarize the activities performed in the previous months, announce upcoming project events, as well as other RTRS-related content. The newsletter release plan is presented on **Table 5**.

Table 5. PREVENTABLE newsletter release plan

Volume	Tentative Release Month	Tentative Content
1	June 2023 (M6)	Presentation the aims of the project, consortium, communication channels (website, social media channels), news and upcoming events.
2	December 2023 (M12)	Summary of Year 1: results, publications, activities, news, events, etc..
3	June 2024 (M18)	Summary of 3 rd semester 1: results, publications, activities, news, events, etc..
4	December 2024 (M24)	Summary of Year 2: results, publications, activities, news, events, etc..
5	June 2025 (M30)	Summary of 5 th semester: results, publications, activities, news, events, etc..
6	December 2025 (M36)	Final summary of the project: relevant results, outcomes and impacts, future prospects

2.4.6 Press release and media articles

Press releases will be developed to cover the main achievements of the project to target technical and non-technical audiences and will be shared through the main communication channels, including the website. These press releases will be translated to the partner’s language by each partner. Whenever suitable, these materials will be provided to ERN-GENTURIS National Coordinators from countries not involved with the PREVENTABLE project, for potential translation to additional languages and further dissemination. Any other media articles produced by SPI or any other PREVENTABLE partners at the institutional or national (e.g., institutional websites, national newspapers or media channels, etc.) level fall under this category.

2.5 When do we communicate? – action plan and timeline

The action plan for the communication strategy is presented in **Figure 2** and will be generally defined by three major phases:

- **Phase 1 (M1-M3):** in this initial phase the main communication strategy will be designed, including the project identity, a general understanding of the necessary approach for the project (driving



objectives for communication and approach to stakeholders), initial stakeholder mapping and implementation of part of the communication channels (website and social media platforms).

- **Phase 2 (M4-M12):** this phase will be focused on the initial steps to raise awareness, launching other communication tools and channels (e.g., newsletter and press releases), updating communication ideas and strategy.
- **Phase 3 (M13-M36):** encouraging community engagement online and offline, with continuous update of the communication strategy considering performance reports.

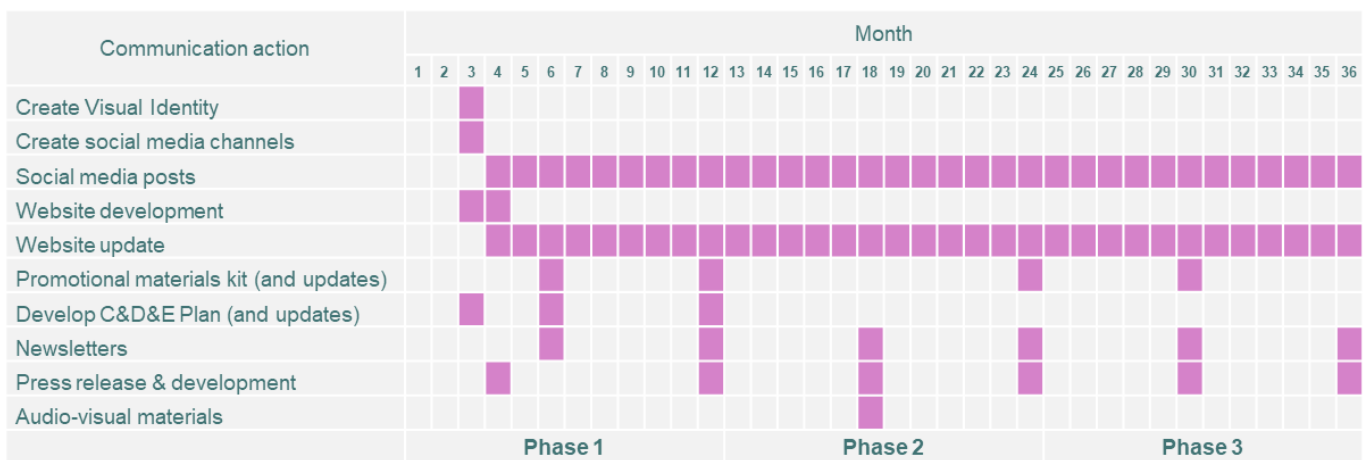


Figure 2 PREVENTABLE Communication activities calendar (status at M3)

Since the timing and consistency of communication is important for the effectiveness of stakeholder initial and continuous engagement, a set of initiatives relevant to the project were selected (Table 6) to provide support to the communication action plan, particularly regarding social media posts. These dates can be opportunities to produce and release content with pertinent timing, maximizing impact.

Table 6 Relevant dates for PREVENTABLE communication activities

January	
Month	Cervical Cancer Awareness Day (teal/white)
February	
4	World Cancer Day
11	International Day of Women and Girls in Science
15	International Childhood Cancer Day (gold)
28	Rare Disease Day (zebra print)
March	



8	International Women's Day
Month	European Colorectal Cancer Awareness Month (dark blue)
April	
7	World Health Day
May	
8	World Ovarian Cancer Day (teal)
25-31	European Week Against Cancer
Month	Skin Cancer Awareness Month (black)
Month	Bladder Cancer Awareness Month (yellow)
June	
13	Global Non-Melanoma Skin Cancer (black)
18	World Kidney Cancer Day (orange) Doctor's Day (Portugal)
July	
Month	Sarcoma Awareness Month (yellow)
September	
27	World Cancer Research Day
Month	Blood Cancer Awareness Month (burgundy)
Month	International Child Cancer Awareness Month (gold)
October	
6	European Carers Day
Month	Breast Cancer Awareness Month (pink)
Month	Liver Cancer Awareness Month (emerald)
November	
16	World Pancreatic Cancer Day (purple)
17	European Prostate Cancer Awareness Day
Month	Lung Cancer Awareness Month (white or pearl) Gastric Cancer Awareness Month (periwinkle blue) Pancreatic Cancer Awareness Month (purple)

Dates in light blue are highly relevant and directly linked to the project. Dates in pink show relevant dates which are not directly associated with the project, but which can be great opportunities to generate content and promote the project and its impact. Colours following awareness months or days correspond to the colour code typically used for the awareness ribbons of each cause, which may support the preparation of communication content.

2.6 Monitoring

Monitoring of PREVENTABLE communication plan and all communication efforts is crucial to follow-up the execution of the plan, evaluate the need for potential updates in the strategy, and to prospect future



communication opportunities. Thus, monitoring will be done by **performance measurement, key performance indicators (KPIs) and reporting.**

2.6.1 Performance measurement

Performance measurement allows to evaluate the level of outreach among relevant target groups and the general public, by assessing their level of acknowledge and engagement with PREVENTABLE. Performance measurement can be done qualitatively (e.g., social media engagement, engagement of participants in events, feedback from participants, etc.) and quantitative assessment using KPI (**section 2.6.2**), providing insights on the effectiveness of channels, tools and messaging being used. Performance measurement will allow the continuous assessment and alignment of the communication activities with the project goals and objectives (**Figure 3**).

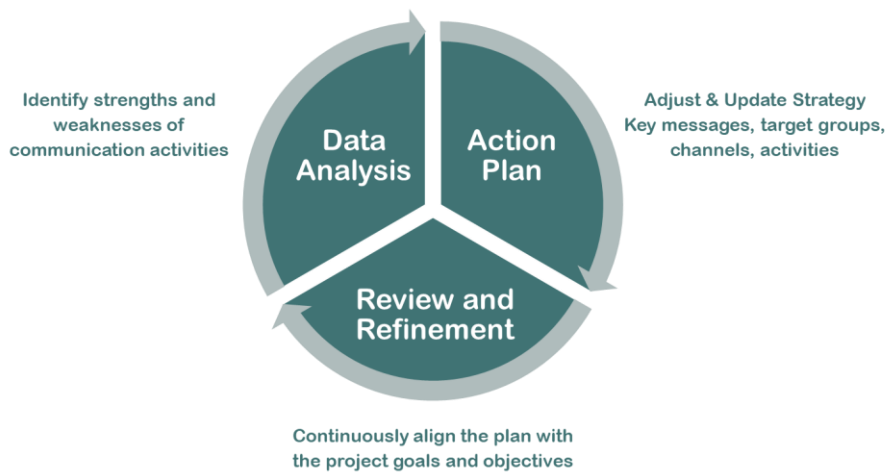


Figure 3 Performance measurement cycle

2.6.2 Key performance indicators (KPIs)

KPIs enable the quantitative assessment of performance by setting target values for communication goals. **Table 7** presents KPIs for PREVENTABLE communication activities and the means for their verification.

Table 7 PREVENTABLE communication KPIs and means of verification

Tools & Channels	KPIs	Means of verification
Website	1,000+ unique monthly visitors	Google Analytics
Social media	LinkedIn: 500 followers, 10,000+ impressions	Social media analytics
	Twitter: 500 followers, 100+ retweets	



	Youtube: 100 views	
	Instagram: 500 followers	
Audio-visual materials	(Full list disclosed in Chapter 5)	Project internal reporting
Communication materials	1 brochure, 1 flyer, 1 factsheet, 1 roll-up, document templates	Project internal reporting and website analytics
External events	9+ events	Project reporting
Newsletter	200+ subscribers	Platform analytics
Newspaper and media articles	5 press releases	Website analytics and project reporting

2.6.3 Reporting

Data on performance of communication activities will be gathered **every six months by SPI (Table 8)**, and shared with project partners.

Table 8. Reporting Plan for PREVENTABLE communication activities

Reporting no.	Month	Communication Activities Reporting Period
1	June 2023 (M6)	01/01/2023 to 30/06/2023
2	December 2023 (M12)	01/07/2023 to 31/12/2023
3	June 2024 (M18)	01/01/2024 to 30/06/2024
4	December 2024 (M24)	01/07/2024 to 31/12/2024
5	June 2025 (M30)	01/01/2025 to 30/06/2025
6	December 2025 (M36)	01/07/2025 to 31/12/2025

All additional written actions, e.g., publications, and news, must be reported to SPI using the **Preventable Communication Efforts** form (**Figure 4**, list of communication activities made by partners – which we can share on social media or used for monitoring), which will be made available in the project collaborative space.



Communication Efforts						
List of communication efforts made by partners.						
Partner(s) (Organization and Name)	Activity name and type (publication, news, etc.)	Date and place	Potential Outreach (Target groups and estimate number of participants)	Objectives (WP, KERs and impact)	Status of Dissemination (Planned/Completed)	Link / content
1						
2						
3						
4						
5						
6						
7						

Figure 4 PREVENTABLE Communication Efforts form

In this monitoring tool, partners will be asked to provide the following information:

- Partner(s) (Organisation and Name);
- Communication name and type (e.g., publication, news, etc.);
- Date and place;
- Potential Outreach (target groups reached and estimate number of participants);
- Objectives, considering WPs, KERs and impact – max 200 characters;
- Status of dissemination (if planned or completed);
- Link/content to the activity (if applicable).

2.7 Visual identity

Visual identity is pivotal to strengthening engagement and differentiating the project from others, making it more easily recognizable and rememberable. The selection of logo and colours is also a powerful tool to deliver the message regarding the scope and mission of the project. SPI developed a visual identity toolbox, comprising a series of visual elements that will support the communication and dissemination activities among the target groups. The PREVENTABLE visual toolbox includes a logo, colour palette and a series of Microsoft Word and PowerPoint templates, to be used during all communication and dissemination activities. Promotional materials, such as brochures, flyers, factsheets, and roll-up will also be produced following the visual identity of the project.

2.7.1 Logo and colour palette

A logo is a strong tool to create engagement, by differentiating the project and promoting its straightforward recognition. It is one of the first impressions reaching the target audiences and, as such, should be carefully



considered. The logo should skilfully transmit the nature of the project while the colour palette should support the association of all graphical elements with the key concepts in the message.

The PREVENTABLE logo (**Figure 5**) is composed of two main elements, a graphical representation on the left, and the name and main mission of the project ('Preventable – Sustainable care for rare tumour risk syndromes') on the right. The graphical element aims at representing the concept of 'care' with the hand in the bottom part, and two main concepts related to RTRS: the 'hereditary' component by the dot-outlined DNA helix and the 'rare disease' concept by the single pink dot among the blue ones. The colour palette (**Figure 6**) was defined considering the colours typically associated with some of the cancers caused by RTRS (pink for breast cancer and teal for ovarian cancer).



Figure 5 PREVENTABLE logo

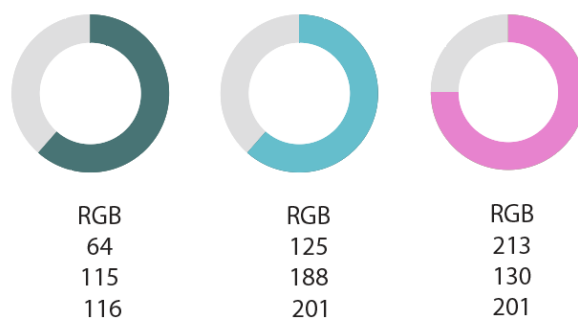


Figure 6 PREVENTABLE colour palette and corresponding RGB and Hex colour codes

2.7.2 Documentation template

As part of the visual toolbox, graphical templates for Microsoft Word (**Figure 7**) and PowerPoint (**Figure 8**) were developed. All documents produced such as reports, deliverables or meeting agendas or minutes, should use the Word template. All presentations performed within the Consortium meetings and internal or external activities or events should use the PowerPoint template. This way, it is possible to set a professional baseline level for the produced documents and presentations, providing a sustained and



strong visual identity, which is crucial, particularly in communication and dissemination activities with relevant stakeholders.

The figure displays a 3x4 grid of Microsoft Word template pages for the PREVENTABLE project. Each page includes the Preventable logo and a 'Document title here' placeholder. The pages are as follows:

- Page 1 (Top Left):** Title page featuring the Preventable logo, project name, and a 'Deliverable DX.X' section with a title and date-deadline placeholder.
- Page 2 (Top Middle-Left):** Document Control Sheet containing sections for Project Information, Deliverable Information, and other metadata.
- Page 3 (Top Middle-Right):** Document Version History and Document Review sections, each with a table for tracking changes and reviews.
- Page 4 (Middle Left):** Abbreviations section with a table for defining project acronyms.
- Page 5 (Middle Middle-Left):** Table of contents section listing various parts of the document and their page numbers.
- Page 6 (Middle Middle-Right):** Chapter page layout with a 'Chapter number' and 'Chapter Subtitle' placeholder.
- Page 7 (Bottom Left):** Content page with a '1. Title 1' section, a paragraph of dummy text, a bar chart (Figure 1), and a table (Table 1).
- Page 8 (Bottom Middle-Left):** Content page with a '1.1.1 Title 2' section, a paragraph of dummy text, and three donut charts (Figure 2).
- Page 9 (Bottom Right):** A dark green footer page with the Preventable logo and tagline.

Figure 7 PREVENTABLE Microsoft Word Template

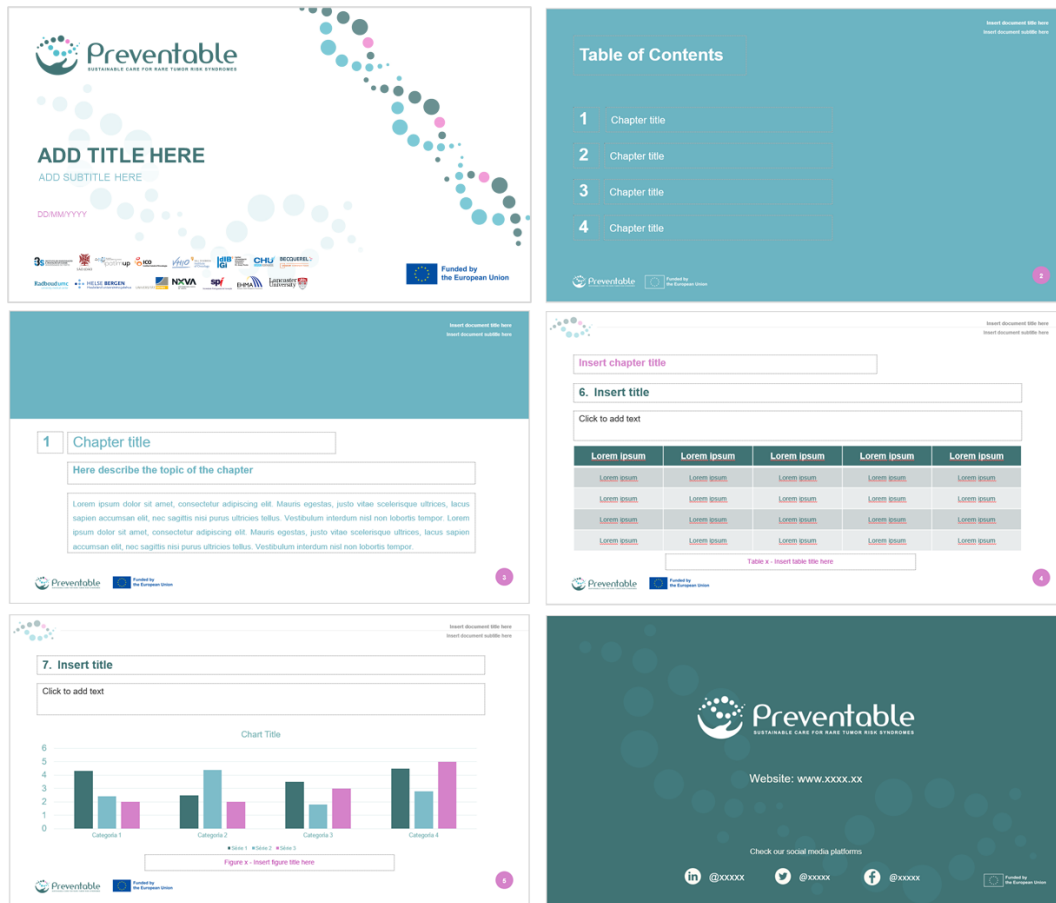


Figure 8 PREVENTABLE Microsoft PowerPoint Template

2.8 Funding statement

Acknowledgements to the EU funding are mandatory and part of the official from the European Commission for Horizon Europe beneficiaries. As such, and as foreseen in the grant agreement, this implies that in all ‘communication and dissemination activities and any infrastructure, equipment, vehicles, supplies or major result results funded by the grant’, beneficiaries must acknowledge EU support by displaying the **European flag**⁵ (Figure 9) and **funding statement**.

⁵ https://ec.europa.eu/regional_policy/information-sources/logo-download-center_en



Funded by
the European Union



Funded by
the European Union

Figure 9 Funded by the European Union (horizontal and vertical options)

The **funding statement** should be included in any publication, including project deliverables, as follows:

“Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or The Health and Digital Executive Agency (HaDEA). Neither the European Union nor the granting authority can be held responsible for them.”

Further information on the funding statement and disclaimer can be found in the Grant Agreement (**Article 17**), and information on the use of the EU emblem in the context of EU programmes is available [here](#).

2.9 European general data protection regulation (GDPR)

PREVENTABLE is committed to deploying fully privacy-compliant activities. The consortium is committed to protecting privacy rights, including personal data (information that relates to an individual who can be directly or indirectly identified), in full conformity with the new European General Data Protection Regulation (GDPR)⁶ as well as its relevant directives. This also includes the European Directive 95/46/EC on the protection of individuals with regard to the processing of personal data and on the free movement of such data, and Directive 2002/58/EC concerning the processing of personal data and the protection of privacy in the electronic communications sector. The consortium is committed to addressing those obligations with care and with a proactive approach. Further information on GDPR can be found [here](#).

In this sense, **IP addresses should be considered personal data**, since "online identifier" is also included in the definition of "personal data". Tracking the IPs of website visitors without their consent in Europe could lead to legal consequences under the rules of GDPR. The consortium is committed to addressing those obligations, legal requirements, and consequences, with a proactive approach.

Newsletters: Contact data will be collected for the distribution of newsletters, which requires a mailing list. This data collection is done by voluntary registration and users can request to be deleted from the mailing list at any time sending a request to the project official email.

Website visitor tracking: to optimize the user experience on the website, information (e.g., name, email, IP address, date and location of access) may be collected when and if the user allows cookies on the web

⁶ <http://data.europa.eu/eli/reg/2016/679/oj>



navigator. Any other information regarding user data collection and storage will be made available on the website privacy policy.

Events: Personal information is collected through registration (e.g., name, position, email, country, interests, etc.). Communications may also be sent by email to event attendees, who may request the removal of their information from the communication listings by email to the project official email.



Chapter 3

Dissemination Strategy and Plan



3. Dissemination Strategy and Plan

Dissemination main goal is to **disclose and promote project results so that others can use them**, extending the impact of the project beyond its lifetime, and activities should **start once project results are available**. Via dissemination, knowledge sharing is promoted with relevant communities and stakeholders supporting engagement and project sustainability. Similarly, it is important to correctly identify the target audience and dissemination channels. This plan should be monitored and updated accordingly and all partners should contribute with their efforts for its successful implementation.

3.1 Dissemination Objectives

This dissemination strategy has **4 main objectives (MO)**, some with specific objectives (SO):

- **MO1: Raise awareness and maximize impact by openly sharing knowledge**
 - **SO1:** Inform about RTRS and their impact in society, and show the efforts of PREVENTABLE to address issues related to RTRS healthcare management, and how patients and their families can benefit from project outcomes;
 - **SO2:** Provide information about cost-benefits of preventive RTRS pathways of care to healthcare professionals, scientific community, healthcare industries, political institutions and policymakers, general public, etc.

- **MO2: Support engagement with stakeholders** at the national, European and international levels, promoting future collaborations
 - **SO1:** Openly and transparently sharing knowledge, in a free-of-charge way (open sciences) without compromising intellectual property rights (IPR) ;
 - **SO2:** Engage with potential early adopters or end-users of project results, understanding their needs and interests, paving the way to produce robust value propositions of project results and outcomes (supportive role of exploitation)

- **MO3: Support decision and policy-making** by the different players in the field of RTRS, health, economics and politics, by providing access to project results by clinical teams, health management structures, policymakers and key opinion leaders (KOLs) that will assist the delineation of guidelines for RTRS pathways of care.

- **MO4: Pave the way for future collaborations** with research, clinical, healthcare industrial or policy-making partners, by facilitating networking between the consortium and external partners with synergistic interests.



3.2 Dissemination Target Groups

Target groups (same definition as for communication) and their roles for the dissemination strategy were identified ([Table 9](#)).

Table 9 PREVENTABLE Dissemination target groups and their roles

Role for Preventable	Patients & their families	Academia	Healthcare Professionals	Medical Associations	Healthcare Institutions and Pharm. Industry	HEMII	CSOs & NGOs	Policymakers and KOLs
Raise project visibility	x	x	x	x	x	x	x	x
Bring inputs to the research and best practices of the project	x	x	x	x	x	x	x	x
Give feedback on project results and activities	x	x	x	x	x	x	x	x
Promote project within their own networks		x	x	x	x	x	x	
Consider project results for future R&D opportunities and collaborations		x		x	x	x		
Consider project results in upcoming regulations and policies				x		x		x
Early adopt and end-use of project results			x	x	x	x		x

The identification and categorization of target audiences for dissemination activities will be further complemented by the complete stakeholder mapping, which will be developed under **WP5 – Making rare tumour risk syndromes (RTRS) visible, Task 5.1 – Stakeholder Mapping** by EHMA.



3.3 Dissemination Key Messages

Since dissemination is focused on sharing project results and outcomes, key messages to be disseminated were defined according to the expected outcomes of WP with new scientific and clinical knowledge production (WP1-4) (**Table 10**).

Table 10 Main messages to be disseminated per WP

WP1	<p>Outputs regarding condition-specific pathways of care for RTRS:</p> <ul style="list-style-type: none"> • Patient’s setting for each RTRS and list of parallel condition-specific pathways of care (T1.1) • Matrix of clinical procedures for condition-specific pathways of care (T1.2) • Prevention and treatment datasets (T1.4)
WP2	<p>Outputs regarding health costs collection and estimation:</p> <ul style="list-style-type: none"> • IT tool for costs collection and assignment of reference health costs per RTRS (T2.1 and T2.2) • Cost estimation for each condition-specific pathway of care per RTRS and for every RTRS (T2.3) • Health costs differences of preventive versus treatment approaches (T2.4)
WP3	<p>Outputs regarding RTRS outcomes and model costs:</p> <ul style="list-style-type: none"> • Literature findings regarding natural progression of RTRS-associated diseases (T3.1) • Computational model for analysing differences in outcomes and costs of primary/secondary prevention measures and/or treatment in RTRS patients (T3.4)
WP4	<p>Outputs regarding uptake of pathways of care of RTRS:</p> <ul style="list-style-type: none"> • Barriers and facilitators to the implementation of prevention-related care pathways of RTRS (T4.1 and T4.2) • Guidelines for the recommendation and communication of prevention-related pathways for RTRS using person-centered approaches (T4.3)

3.4 Dissemination Tools and Channels

The tools and channels for dissemination for PREVENTABLE, presented in **Table 11**, will support the achievement of the main objectives of dissemination and will correspondingly have specific objectives.

**Table 11 Tools and channels and corresponding dissemination objectives**

Tools & Channels	Dissemination Objective				Specific objectives of tool/channel
	MO1	MO2	MO3	MO4	
Website	x	x			Be a central element for an active dissemination strategy, highlighting project results and outcomes. Be a hub of information for patients and other relevant stakeholders.
Social media	x	x			Advertise progress, results and other dissemination activities to targeted audiences.
Scientific publications	x	x	x	x	Inform the scientific community on the results and outcomes of PREVENTABLE. Create opportunity for future collaborations.
Webinars	x	x		x	Showcase results and new knowledge generated by PREVENTABLE and create open discussions to acquire insights and foster collaborations with relevant stakeholders.
Thematic workshops and events	x	x	x	x	Showcase results and new knowledge generated by PREVENTABLE and create open discussions to acquire insights and foster collaborations with relevant stakeholders.
External events	x	x	x	x	Present key findings and conclusions of the project, increase awareness of RTRS and associated healthcare costs, and promote collaboration opportunities with relevant stakeholders. Partners should ensure coverage in their respective countries and any international area of their access.
Newsletter	x	x			Inform about PREVENTABLE progress, results, outcomes, activities and events.

It is also convenient to understand how all the different channels reach specific target groups (**Table 12**), as this will ensure the correct adjustment of messaging (language) and selection of the key messages to be delivered, according to the target group to be reached.



Table 12 Groups targeted by each dissemination tool and channel

Dissemination Tools & Channels	Target groups								
	Patients & their families	Healthcare Professionals	Healthcare Institutions and Pharmaceutical Industry	Medical Associations	Health econom., manag. and insurance institutions (HEMII)	CSOs & NGOs	Policymakers and KOLs	Academia	General Public
Website	x	x	x	x	x	x	x	x	x
Social media	x	x	x	x	x	x	x	x	x
Scientific publications		x	x	x	x	x	x	x	
Webinars		x	x	x	x	x	x	x	
Thematic workshops and events	x	x	x	x	x	x	x	x	x
External events		x	x	x	x	x	x	x	
Newsletter	x	x	x	x	x	x	x	x	x
Newspaper and media articles	x	x	x	x	x	x	x	x	x

3.5 Open sciences

It is the responsibility of PREVENTABLE beneficiaries to ensure open access of project results. The project will preferably use open access, open peer review, open methods, and open-source processes. The Grant Agreement foresees that all scientific publications will be done in open access (OA) journals, so beneficiaries must ensure that the final peer-reviewed accepted manuscript (machine-readable electronic copy) or produced data is deposited in a trusted repository for scientific publications (Zenodo and OpenAire). Sherpa Romeo tool will be used to guarantee that any forthcoming journals maintain the rights to deposit the pre-print version. Post-print articles will also be published at ResearchGate, LinkedIn or other professional/social media platform. Academic thesis produced under the PREVENTABLE will be deposited at institutional repositories and/or linked to national OA repositories. Additionally, scientific communications (either oral or poster including data, software, models, algorithms, and workflows) will also be prepared and openly disseminated and made available by the consortium. Whenever applicable, beneficiaries or authors should safeguard enough intellectual property rights without conflicting with open sciences requirements, (Grant Agreement, Article 17). **The Project Coordinator will be responsible for monitoring the open science practices.**



3.6 Monitoring

For **monitoring** all PREVENTABLE dissemination efforts tools and strategies for **performance measurement, key performance indicators (KPIs, Table 13)** and **reporting** will be established.

3.6.1 Performance measurement

Performance measurement of dissemination activities will be done based on KPIs (**section 3.6.2**) and by the number of successful collaborations extending beyond the project, as long as they have been a result of any dissemination activity.

3.6.2 Dissemination Key Performance Indicators (KPIs)

The KPIs defined for the dissemination activities are presented on **Table 13** together with their means for verification.

Table 13 PREVENTABLE communication KPIs and means of verification

Tools & Channels	KPIs	Means of verification
Scientific publications	3	Project internal reporting, Google scholar
Webinars	at least 2 per year, 300+ participants	Project internal reporting
Thematic workshops and events	At least 2 per year; 50+ participants	Project reporting
External events	9+ events	Project reporting

3.6.3 Reporting

Similar for communication activities, all partners should inform SPI about the participation or organization of a dissemination event. To do so, partners must update the PREVENTABLE Event Calendar (**Figure 10**, for partners to inform future events where the project should participate), which will be made available in the collaborative workspace.

The results of the dissemination activities will be collected **every 6 months** and reported to the partners during a yearly communications meeting with the partners, to review the results and adapt the strategies in place, if needed.



Events				
Future events where the project should participate in or where you intend to participate in representing the project				
	Partner(s) (Organization and Name)	Event name and type (meeting, conference, workshop)	Date and place	Link / content
1				
2				
3				
4				
5				
6				
7				
8				
9				
10				

Figure 10 Event Calendar for dissemination activities



Chapter 4

Exploitation Strategy and Plan



4. Exploitation Strategy and Plan

Exploitation aims at maximizing the impact of the project by **the effective use of project results or outputs, tangible or intangible, for scientific, economic, political or societal purposes and beyond the scope and lifetime of the project**. In this way, the sustainable translation of project results and outcomes is achieved, delivering solutions regardless of their nature (e.g., providing a service, standardise guidelines or policies).

All Horizon Europe beneficiaries are required to use their best efforts in developing exploitation activities to increase the mid- and long-term impact of project outcomes, up to four years after the end of the action. This includes direct exploitation or indirect exploitation by another entity, by transfer or licensing. If such efforts fail, the grant agreement also foresees that *'if, despite a beneficiary's best efforts, the results are not exploited within one year after the end of the action, the beneficiaries must (unless otherwise agreed in writing with the granting authority) use the **Horizon Results Platform to find interested parties to exploit the results**. If results are incorporated in a standard, the beneficiaries must (unless otherwise agreed with the granting authority or unless it is impossible) **ask the standardisation body to include the funding statement (see Article 17) in (information related to) the standard.**'*

Thus, setting an exploitation strategy and planning exploitation activities will be important to ensure PREVENTABLE results and outputs can be effectively exploited within the timeframe required, either for commercial, decision-making, and societal purposes.

The Grant Agreement foresees the preparation of an **Exploitation Plan (D6.5 and D6.6) in Task 6.4 – Exploitation and Project Sustainability**, under **WP6**. Thus, the exploitation strategy and plan presented herein is an initial proposal, which intends to set the basis for identifying project's expected (exploitable) results and define the methodology to identify **Key Exploitable Results (KER)** in later stages of the project.

4.1 Objectives

The main objectives of the exploitation plan of PREVENTABLE are:

1. To effectively **deliver the relevant knowledge, outcomes and results produced to the target groups** identified
2. To deliver a **measurable benefit to society** through the **valorisation of project outcomes** and its **Key Exploitable Results (KERs)**
3. To contribute to the project's sustainability in terms of **knowledge transfer** and **replicability beyond the funding period**



4.2 Key impact pathways (KIPs)

Horizon Europe relies on the idea of Key Impact Pathways (KIPs) (Figure 11) to track and increase the impact of EU-financed projects. The goal of KIPs is to promote public awareness and policymakers' understanding of the impacts that funded projects have on the economy and society. The KIPs consist of storylines that can be used to effectively communicate the project. Identifying KIPs will allow the selection of time-sensitive indicators (short, medium and long-term) to support the monitorization of project's impact. Such indicators are proposed for each KIP and can be re(de)defined for the specific purposes of the project.



Figure 11 Horizon Europe KIPs

Based on PREVENTABLE main goals, expected results and outcomes, **5 main KIPs** across the three categories are anticipated to be the most relevant pathways to maximize impact and communicate the value of the project:

- **KIP1** – Creating high-quality new knowledge
- **KIP3** – Fostering diffusion of knowledge and Open source

- **KIP4** – Addressing EU policy priorities and global challenges through research and innovation
- **KIP6** – Strengthening the uptake of research and innovation in society

- **KIP7** – Generating innovation-based growth



4.3 Expected exploitable results (EERs)

In Horizon, a result is defined as “any tangible or intangible output of the action, such as data, knowledge and information whatever their form or nature, whether or not they can be protected, which are generated in the action as well as any attached rights, including intellectual property rights”⁷. The main expected results of PREVENTABLE, as foreseen in the initial proposal are presented in **Figure 12**. Understanding how these correlate with KIPs will help evaluating the suitability and monitoring of the exploitation activities.

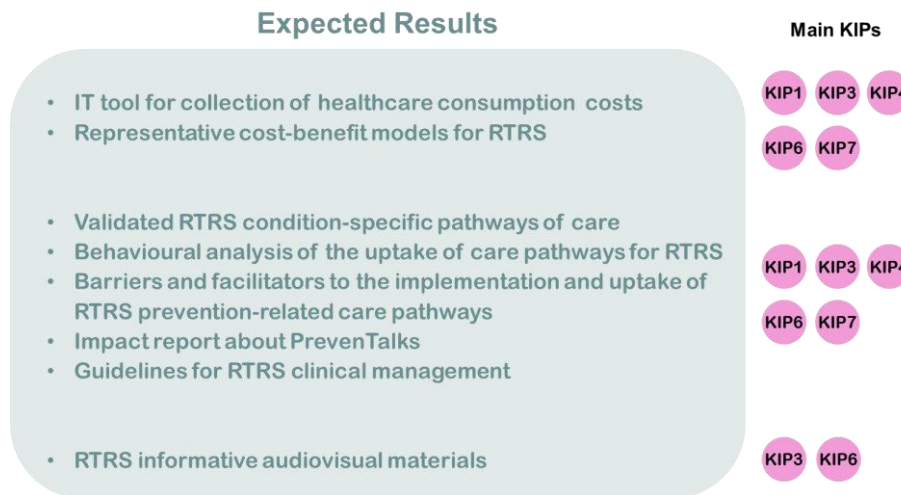


Figure 12 PREVENTABLE expected results and correlation with key impact pathways (KIPs)

However, **not all expected results are exploitable, nor every EER have enough level of innovation to be considered key exploitable results (KER)**, so internal conferencing is required to analyse the exploitability of achieved results. Even though it is easier to perceive the potential exploitation value of a particular result as the project progresses, it is important to start formulating exploitability as early as possible and engage partners in this process. To list all the potential exploitable results to be produced by the project, an **Exploitation Assessment** will be performed, to do an initial characterization of these and all other potential EERs, with the input of consortium partners based on their corresponding WP. In this initial assessment, it will be asked to WP and Task leaders to identify expected exploitable results and outcomes regarding their type (IT and Modelling Tools, Knowledge & Intellectual Property (IP), Documents & Reports, Procedures & Policies, Service, Other), delivery date, expected technology readiness level (TRL, **Figure 13**) or target stakeholders.

⁷ <https://intellectual-property-helpdesk.ec.europa.eu/system/files/2022-02/HEU%20Results%20platform.pdf>

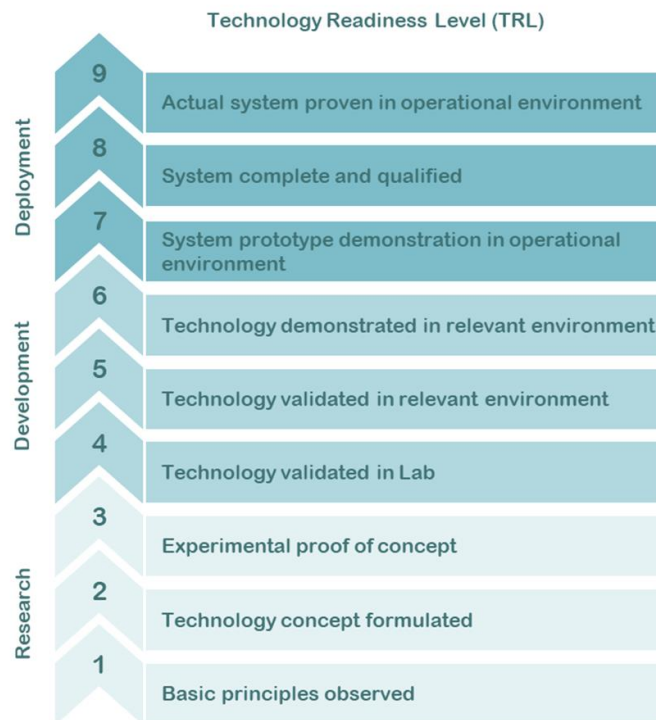


Figure 13 Technology Readiness Levels (TRLs)

This list shall be updated with time, as the project progresses, and according to project results.

4.4 Strategy to identify key exploitable results (KERs)

At a later stage, KERs will be selected from a list of EERs based on their innovation, exploitability, and impact values. The contribution from consortium partners as well as external members (e.g., external Advisory Board and other relevant stakeholders) is important for developing KERs with strong value propositions and close to societal and commercial needs.

One of the strategies to identify and select KERs will be to develop activities (surveys or workshops) to elaborate the following information for each EER:

1. What are the areas of impact or main target sectors?
2. Which problem will the project outcome solve?
3. Main project results that will be used?
4. Where will the outputs be made available during and after the project?



5. Who are the main end-users of your results?
6. How will you contact them?

Collecting this information will aid the development of a KERs list and outline exploitation routes in any relevant area of impact or target sector. **Exploitation Manager** and **KER leaders** may be assigned to support the development of KERs and ensure regular and active contribution of all partners in the exploitation strategy. KER leaders will be in charge of coordinating the description and characterization of specific KERs with all involved partners and should, under the coordination of the Exploitation Manager, clarify partner’s roles and the legal requirements for exploitation under an Intellectual Property and IPR perspective. For each KER, exploitation roadmaps should be developed, to identify milestones, timelines, and responsibilities of different partners for effective exploitation. Also, business plans, Go to Market (G2M) strategies or value proposition models should be developed for KERs with high technological readiness level (TRL).

The Project Management team should be informed of and engaged in the discussion of all activities created within the scope of the exploitation strategy. Strong engagement with stakeholders is also crucial, to understand market needs, to make sure KERs have impact for potential end-users.

4.5 Exploitation activities

Exploitation activities (**Table 14**) will start from the beginning of the project and extend beyond its completion. Being the work packages with stronger scientific and technological components, WP1-WP4 will play a crucial role in supporting these activities by providing the knowledge foundation and the development of potential KERs. During these activities, different stakeholders will be targeted to ensure the maximum outcome. The subsequent updates on the Exploitation Plan (**T6.1** and **T6.4**), will refine and complete the initial exploitation strategy.

Table 14 Exploitation Activities

Exploitation Activities and Tools	Objective(s)	Target expected results
<p>Scientific publications</p>	<ul style="list-style-type: none"> • Deliver the relevant knowledge, outcomes and results, disseminating the findings to the scientific and healthcare community. Promote collaborative research in the future. • Support decision and policymaking. 	<p>RTRS condition-specific pathways of care</p> <p>Cost of care and cost of prevention</p> <p>RTRS Health cost-benefit models</p>



<p>Participation in external events</p>	<ul style="list-style-type: none"> • Identify synergistic initiatives and engage with (new) relevant stakeholders, encouraging future collaborations and co-creations. 	
<p>Workshops and Seminars</p>	<ul style="list-style-type: none"> • Understand the sector/industry needs, by closely engaging with early adopter or end-users of project results. • Inform and disseminate the findings to multiple stakeholders. 	<p>All EERs</p>
<p>Civil society partnerships</p>	<ul style="list-style-type: none"> • Foster cooperation during and after project lifetime. • Take advantage of the advocacy power of these organisations to promote awareness on PREVENTABLE (strong multipliers). • Increase the value and exploitability of project's KERs by the involvement of these players in project development, understanding their needs and interests. • Establish links and identify joint activities to be undertaken about RTRS, fostering cooperation beyond the project's lifetime. 	<p>Guidelines for communication prevention/surveillance/treatment-related pathways of care</p>
<p>Cross-project activities</p>	<ul style="list-style-type: none"> • To reach out to the identified projects and suggest collaborative activities (e.g., a joint webinar or workshop). • To identify Horizon Europe funding opportunities and finding and building a consortium. • Target organisations interested in applying for Horizon Europe calls relevant for sustainability of PREVENTABLE. 	<p>ALL EERs</p>
<p>Deliverables for policymakers and KOLs</p>	<ul style="list-style-type: none"> • Raise greater awareness about PREVENTABLE and promote uptake of knowledge, namely regarding potential impacts of the cost-model to be developed. 	<p>Cost of care and cost of prevention RTRS Health cost-benefit models</p>
<p>Special interest / working group</p>	<ul style="list-style-type: none"> • To create opportunities for joint publications, collaborations and applications. 	<p>All EERs</p>



4.6 Potential barriers to exploitation and mitigation strategies

The following barriers to exploitation and mitigation strategies were identified:

1. RTRS patients lost for follow-up (WP1-WP3)

- **Risk:** there is a chance that RTRS patients, which have been diagnosed, either clinically or genetically, at the PREVENTABLE clinical centres, with one of the 8 syndromes of the project, will move to other hospitals to continue the remaining pathway of care. This risk could compromise the aims of the project in tasks that require large patients' datasets.
- **Mitigation measure:** to decrease the chances of losing track of a patient path, PREVENTABLE will actively engage with other clinical centres from ERN GENTURIS distributed across 23 countries in the EU, and also with clinical centres in Norway. This may require involving additional partners in the consortium, but PREVENTABLE-hired personal is expected to cover the working needs.

2. Cost-benefit studies are not possible for all the eight RTS (WP1-WP4)

- **Risk:** potential of having insufficient numbers of RTRS patients to validate the condition-specific pathways of care feeding the cost-effective models.
- **Mitigation measure:** the Coordinating centres for such RTRS will activate their national and GENTURIS-based clinical networks to enlist additional patients' aggregated data. This may require involving additional partners in the consortium, but PREVENTABLE-hired personal is expected to cover the working needs.

3. Implementation of the PREVENTABLE results will be conditioned by the nature of different health care systems across Europe (WP1-WP4)

- **Risk:** there may be differences across European countries in the pathways of care for RTRS patients, since guidelines are sometimes national and not based on European consensus. Also, calculation of actual price/cost of clinical procedures may differ across European countries, and prevent general project conclusions.
- **Mitigation measure:** the PREVENTABLE consortium will collaborate with the ERN GENTURIS to promote the creation/implementation of European consensus guidelines on the RTRS herein included. Although this may occur after project conclusion, it is anticipated that the outcomes of PREVENTABLE live beyond its termination. Regarding price/costs of clinical procedures, the project will always provide country-specific ratios between procedures used in prevention and procedures used in treatment for all RTRS, and this will be comparable across various health care systems.



4. Lack of resources available at hospitals organizations level (WP2-WP3)

- **Risk:** there's the possibility that the PREVENTABLE project demonstrates that, for each RTRS, either prevention or treatment is more cost-effective, with hospitals not being equipped with resources and personnel to address this reality.
- **Mitigation measure:** specific planning of a different set of resources and personnel (either related to preventive or treatment procedures) will be needed according to each RTRS and across European hospitals. Redirection and/or reinforcement of clinical teams may be required to support either surveillance and prevention-related activities or support targeted GENTURIS will be pivotal in taking this type of results to the field and to relevant stakeholders.



Chapter 5

RTRS-Specific content



5. RTRS-Specific content

As part of the communication & dissemination activities, the production of RTRS-related outreach materials is planned, to raise awareness regarding these rare syndromes. This is part of **Task 6.3 – Outreach material for RTRS-related knowledge** led by IPA under **WP6 – Dissemination, Exploitation & Communication**.

5.1 Objectives

This highly specific task will produce a set of novel health contents about RTRS (audio-visual format, and printable/digital documents) with the **main objectives** of:

1. Increasing the visibility of RTRS and its patients;
2. Empowering individuals at-risk in the complex decision-making process;
3. Informing on the clinical presentations of RTRS, risk criteria or guidelines, and pathways of care;
4. Aiding better management and health policies on RTRS through by different stakeholders.

To do so, an initial plan for outputs and activities is proposed in the following section.

5.2 Planned Outputs

The main challenge of this task will be to produce a set of meaningful and impactful audio-visual materials for dissemination about 8 different diseases/syndromes and for 3 different target-audiences – at-risk individuals, general practitioners, and policymakers. This complex “matrix” of specific needs and outputs will be tackled through a participatory design, with different stakeholders, and using a two-stage development: an initial pilot stage, in which 1 RTRS will be chosen to create contents and test them for impact and adequacy, preceding the second stage of audio-visual production for all RTRS.

The target audiences defined by the project, its specific aims, and outputs are:

5.2.1 At-risk Individuals

Individuals who are asymptomatic carriers of a known mutation or family members of known carriers who still don't know their mutation status or have chosen to not be tested.

Specific aims:

- Inform on disease outcomes and health consequences for carrier;
- Inform on primary and/or secondary prevention option and their efficacy, and available treatments;
- Help make better informed decisions in a complex decision-making moment



Outputs:

- 8 “Simply Rare” videos

Short and concise infographic videos on each RTRS: epidemiological data, clinical manifestations, preventive and treatment options, disease outcomes.

- 8 “*Simply Rare*” printables

The same short and concise information as previous, but in a leaflet format for printing and easy memory, for each RTRS.

- 8 “*Rare Stories*” mini-docs

8 films on patient’s life journeys with disease, on a more personal style, that reflects the main challenges and attitudes towards the disease and the complex decision-making process.

5.2.2 General Practitioners (GP) / Family Physician

1st line doctors, family physicians, who are in close contact with potential families or carriers with relevant clinical manifestations.

Specific aims:

- Increase awareness of these rare syndromes and their clinical manifestations;
- Increase knowledge on risk criteria and/or guidelines for the 8 RTRS;
- Inform on disease progression and outcomes;
- Make aware of reference networks for rare diseases.

Outputs:

- “Rare Guide” Booklet in 2 formats:
 - A digital document in easy printable format, with succinct state-of-the-art scientific information on each RTRS, including genetic background information on each syndrome, clinical manifestations, risk criteria and/or clinical guidelines, preventive options and treatments.
 - Interactive web tool, with the same objectives and information, but in a searchable interface for easy consultation and segmentation of information
- 8 disease fact-sheets



Baseline information with epidemiology data, hereditary patterns, prevention and treatment options, that can be downloaded and printed for hand-outs to carriers, patients or at-risk family members.

- ‘Case-studies’ videos:

Patients with more emblematic and clinically relevant pathways share their stories and clinical information, in the first-person, in a voluntary format with formative intent for doctors.

- “Risky talks” podcast

Experts on RTRS talk about their work and challenges, and can include doctors, researchers, patient advocates, etc., in a new podcast series with (at least) 10 episodes of around 10 min each.

5.2.3 Policymakers and decision-makers

Individuals and organisms with high responsibilities in disease management and in the definition of health policies.

Specific aims:

- To give more visibility on RTRS;
- Help better management and health policies through scientifically-sound information.

Outputs:

- “Rare but not alone” documentary

Film on the lives and challenges of RTRS patients, caregivers and health managers, that reflects the lack of public acknowledgment on these rare diseases and sheds light on its particular nature and needs.

- Project’s Results

Summary of the key-findings of the “Preventable” project, in its different vectors of research and action, in an infographic video that puts forward all the relevant information to inform better health policies and management.

5.3 Interaction with other partners and WPs

The task outputs to be produced will benefit greatly from several project’s partners and collaborators, and will interact closely with other WPs, as schematized in [Figure 14](#).

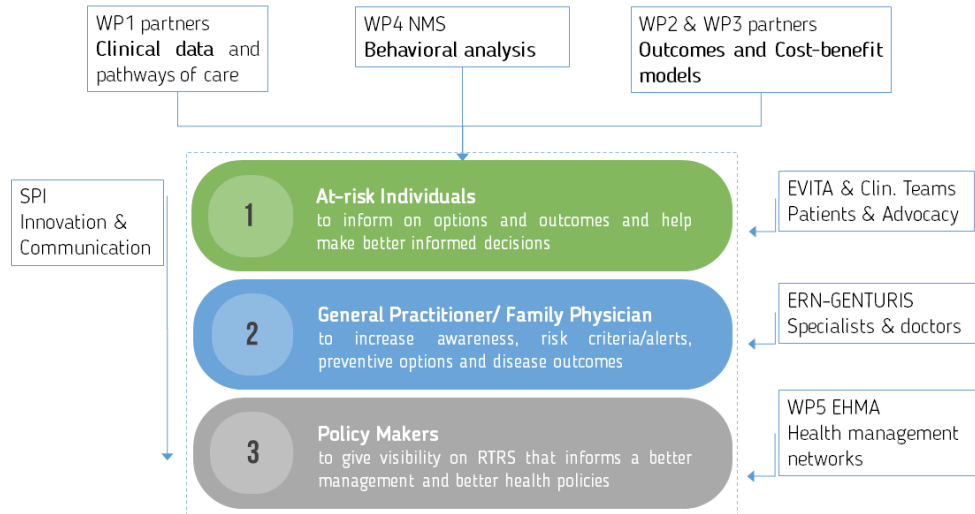


Figure 14 WP interconnection of the production of RTRS-related outreach material

Data from 3 vectors of the project - the Clinical, Behavioural Cost-benefit analysis, respectively addressed in WP1, WP4 and WP2&3 - will inform production. These will be of key importance to determine the most relevant contents of the audio-visuals, namely regarding the clinical manifestations of each syndrome, the pathways of care, perceptions and attitudes towards the different syndromes, the outcomes in terms of disease burden and the cost-benefit associated with each treatment or preventive (primary and secondary) option.

At the pre-production stage, the clinical teams from the project, EVITA patient association, GENTURIS Reference Network, and EHMA, will be crucial in establishing connections with patients, doctors, health managers and policymakers, as the needs “on the terrain” are encountered.

The final outputs and the dissemination channels and effectiveness will greatly depend on SPI expertise and leadership regarding WP6.



Chapter 6

Final Remarks



6. Final Remarks

The Deliverable 6.1 provides a guide for the PREVENTABLE partners to participate in the communication, dissemination and exploitation activities, and potentiate the impact of the project, as expected for Horizon Europe. The methodologies proposed herein have a strong interplay but very particular and distinct aims. The set of activities proposed herein and will be monitored throughout time and required updates on this initial plan will be made to safeguard effective outreach, including under the scope of deliverables **D6.2 “Dissemination & Exploitation Plan, including communication activities and RTRS-specific content 2”** (M6) and **D6.3 “Dissemination & Exploitation Plan, including communication activities and RTRS-specific content 3”** (M12). Additionally, the exploitation strategy will be further developed under **D6.5 “Sustainability and Exploitation Strategy 1”** (M6) and **D6.6 “Sustainability and Exploitation Strategy 2”** (M30).



Preventable

SUSTAINABLE CARE FOR RARE TUMOUR RISK SYNDROMES