



Preventable

SUSTAINABLE CARE FOR RARE TUMOUR RISK SYNDROMES

Deliverable D6.2

Dissemination & Exploitation Plan including communication activities and RTRS-specific content 2

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Document Control Sheet

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1	22/05/2023	Mariana Neves	Creation of document: updating Deliverable D6.1. Major changes were made to communication and dissemination tools, including the addition of detailed information about the project website and promotional materials (digital backgrounds), the categorisation of target groups and key messages considering the feedback gathered during the PREVENTABLE Stakeholder Workshop.
2	26/06/2023	Mariana Neves	Major revision. Update to project promotional materials (flyers) and the new guide for PREVENTABLE partners. Update the exploitation section to include an overview of the methodological approach of the strategy, which is detailed in D6.5.
3	30/06/2023	Mariana Neves	Minor corrections.

DOCUMENT REVIEW

Reviewer	Date	Reviewer Name (Short Organisation Name)
1	16/06/2023	Raquel Almeida (SPI)
2	26/06/2023	Raquel Almeida (SPI)
3	29/06/2023	Sara Pereira (i3S) and Carla Oliveira (i3S)

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ABBREVIATIONS

Abbreviation	Definition
C&D&E	Communication & Dissemination & Exploitation
CSO	Civil Society Organisations
EC	European Commission
ERN GENTURIS	European Reference Network Genetic Tumour Risk Syndromes
EU	European Union
GDPR	General Data Protection Regulation
HaDEA	European Health and Digital Executive Agency
IPR	Intellectual property rights
KOL	Key opinion leader
KPI	Key performance indicators
MO	Main objective
NGO	Non-Governmental Organisations
RTRS	Rare tumour risk syndromes
SO	Specific objective



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Executive Summary

The **Deliverable D6.2 – Dissemination & Exploitation Plan, including communication activities and RTRS-specific content 2** was produced under Task 6.1 – Developing and updating the Dissemination and Exploitation strategy of the work package 6 (WP6) – Dissemination, Exploitation & Communication. The purpose of this document is to update the strategy and action plan defined previously in **Deliverable 6.1 – Dissemination & Exploitation Plan, including communication activities and RTRS-specific content 1**, with the aim to maximise the overall project reach and visibility. This includes refinement of dissemination and communication methods and tools, according to the evolving needs of the project and the consortium. This document was produced to be a guide for all consortium members and will continue to be the basis to ensure an effective implementation of the dissemination and communication strategy of PREVENTABLE to reach its different stakeholder groups.

This document is prepared as a result of the flexible and living outreach strategy, which will be subjected to relevant content-related updates as the project progresses. The consortium will actively contribute to the enhancement of the impacts created by the measures outlined by this plan. All dissemination and communication actions/activities will be ruled and take into consideration Intellectual Property rights (IPR), ownership of data, background data limitations (as stated in the Consortium Agreement), and the GDPR, as well as any other pertinent ethical issue. Additionally, this deliverable also contains the second 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.

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

- Deliverable D6.3 “Dissemination & Exploitation Plan, including communication activities and RTRS-specific content 3”;
- Deliverable D6.4 “Project Website”;
- 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

1.1 Scope of the document

The Deliverable **D6.2 “Dissemination & Exploitation Plan, including communication activities and RTRS-specific content 2”** 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 second version of the communication, dissemination & exploitation (C&D&E) strategy for PREVENTABLE, comprising the relevant updates of what has been established in **D6.1 “Dissemination & Exploitation Plan, including communication activities and RTRS-specific content 1”**. The strategy in this document will be continuously monitored and updated in the deliverable **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.

1.2 Objectives

As the second version of the dissemination and exploitation strategy, **D6.2** has the following specific objectives:

- Present the current status of dissemination and exploitation measures, including communication support actions and concrete activities implemented throughout PREVENTABLE to ensure the wide reach of project results;
- Use the findings of the first period of implementation and complement the measures with specific actions to maximise the impact of project outcomes;
- Develop a set of recommendations that the partners can apply to for the dissemination and communication of project results.

1.3 Structure of the document

The Dissemination and Exploitation Plan 2 has been structured into the following sections:

- **Chapter 1 – Introduction**, which briefly addresses the objective and structure of the document, and the methodology used to develop the plan;



- **Chapter 2 – Updates to the Communication and Dissemination Strategy and Plan**, which includes an updated overview of the project tools and channels, its current status and the development of the new communication guide for partners;
- **Chapter 3 – Updates to the Exploitation Strategy and Plan**, which includes an updated summary of the approach which is being developed for Sustainability and Exploitation under **D6.5 – Sustainability and Exploitation strategy 1**.
- **Chapter 4 – Final remarks**, which provides the general overview of the document.

1.4 Methodology

The updated plan is aimed to be a practical tool for all project partners to efficiently continue implementing their individual and collective activities with the intent to contribute to the overall dissemination of PREVENTABLE, maximising the reach and visibility of the project and of the target diseases.

This document builds on the analysis of the first period of project implementation and incorporates inputs of the partners. SPI led the development of this deliverable while taking into careful account the contributions provided by the consortium at different stages. A comprehensive methodology comprising the following main tasks was implemented to update the strategy:

1.4.1 Task 1. Co-creation activity on envisioning the refinement of target audiences

A PREVENTABLE Stakeholder Online Workshop (March 30th 2023) was jointly organized by SPI and EHMA to identify, categorise, and analyse relevant stakeholders for the PREVENTABLE project. The workshop was open to all consortium partners and comprised a set of three activities:

1. Stakeholder identification and clustering – addressing the question: *What stakeholder is needed for each PREVENTABLE WP and task?*
2. Stakeholder analysis – addressing the question: *How influent is this stakeholder? On whom or in which sector does the stakeholder exercise its power? What is their stake on the issue?*
3. Relations among stakeholders – addressing the question: *What type of relationship does exist among stakeholders?*

These activities were all performed by three different working groups, focusing on different work packages and participants were asked to identify and categorise stakeholders according to a quadruple helix divided into: Academia/Research, Public Sector, Private Sector/Industry and Civil Society and to define the influence/power and interest of each stakeholder group.



At the end of the workshop, participants on the working group comprising WP6 were also asked to provide their insights on the key messages to be delivered by PREVENTABLE.

1.4.2 Task 2. Update of target audiences and key messages

Considering the results of the PREVENTABLE Stakeholder Workshop, an update on the target audience was performed. Such changes were introduced on **section 2.1** and **2.2**.

1.4.3 Task 3. Develop a guide for communication for PREVENTABLE partners

Once the main channels and tools for communication were established, a document containing guidelines for communication was developed to support PREVENTABLE partners in their communication and dissemination activities. This document was made available to all PREVENTABLE partners in the project collaborative space, together with C&D monitoring tools established in **D6.1** (Social Media Handles, Events Calendar and Communication Efforts).



Chapter 2

Updates to the Communication & Dissemination Strategy and Plan



2. Updates to Communication & Dissemination Strategy and Plan

The communication strategy of the PREVENTABLE project aims to promote and share project information throughout its duration, engaging diverse audiences and stakeholders. It follows three key principles: adopting tailored communication strategies to effectively reach different target groups; upholding the "do no significant harm" principle, particularly in relation to printed materials; and continuously monitoring, evaluating, and updating communication efforts based on project progress and outreach performance. SPI is primarily responsible for the communication strategy, while consortium partners will disseminate project information using various tools and channels.

They will also provide feedback and propose events for project participation.

2.1 Update to Target groups

The definition of the audiences to whom PREVENTABLE will be communicating to will be key 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.

Considering PREVENTABLE communication objectives, an initial set of 10 target groups was defined in deliverable **D6.1**. After the first PREVENTABLE Stakeholder Workshop, a new distribution of stakeholders into 7 target groups for communication was defined (**Table 1**) taking into consideration the input and feedback retrieved from all the participating partners. The new distribution simplifies the definition of strategic guidelines by decreasing the partition of stakeholders into less groups, aggregating stakeholders with the same (benefits for target groups), roles (their importance for the project) and communication requirements (messaging type and language), into the same group, being them individual or collective.

Table 1 Update on PREVENTABLE communication target groups

Target Group	Definition & Examples	Interest & Role
Patients and their families	<p>Individuals: RTRS-diagnosed patients, either by genetic or cancer diagnosis, their relatives and informal care providers.</p> <p>Patients Associations: including community platforms, at the EU and international levels. RTRS: Associação de Apoio a portadores de Alterações nos genes relacionados com Cancro Hereditário (EVITA, Portugal), ACREDITAR – Associação de Pais e Amigos de Crianças com Cancro (Portugal), Geneticancer (France), Actitud Frente al Cáncer (Spain)</p>	<p>Interest:</p> <p>This group will be interested in learning more about RTRS, where to look for assistance (organisations or institutions working with these syndromes), research on RTRS, networking with other patients and families, etc.</p> <p>Influence:</p> <p>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.</p>



<p>Research Community</p>	<p>Research institutions or individuals: universities, research institutes individual researchers, postdoctoral fellows, doctoral students, graduate and undergraduate students, working on RTRS, cancer, health management, health economics or health policy.</p> <p>Research associations: Portuguese Oncology Society (SPO), Associação Portuguesa de Investigação em Cancro (ASPIC), European Cancer Organisation (ECO), European Association for Cancer Research (EACR), European Society for Medical Oncology (ESMO).</p>	<p>Interest:</p> <p>This group will be interested in the project results and benefit from its knowledge.</p> <p>Influence:</p> <p>This group is relevant as it leads research on RTRS, healthcare economic models and cancer research, being advocates for research in this field and comprising expertise and insights which could be valuable for PREVENTABLE.</p>
<p>Healthcare Professionals, Associations and Networks</p>	<p>Clinical teams: general clinicians, oncologists, nurses and clinical staff, and diagnostic technicians.</p> <p>Associations and Networks: European Society for Medical Oncology (ESMO), the European Reference Networks ERN, particularly ERN GENTURIS; European Union Committee of Experts on Rare Diseases (EUCERD), Portuguese Association for Palliative Care (Associação Portuguesa de Cuidados Paliativos)</p>	<p>Interest:</p> <p>This group will have an interest in the knowledge resulting from PREVENTABLE, and in participating in discussions regarding the current pathways of care, which will provide them the opportunity to have an active voice on the future RTRS healthcare management and communication.</p> <p>Influence:</p> <p>The project will rely on healthcare professionals for active implementation and follow-up of project activities and results. This group will be able to provide the most informed advice and clinical decisions, ensuring patients' best interest. These professionals will also contribute with advice and expertise and have a crucial role in the definition of guidelines.</p>
<p>Healthcare Institutions and Management</p>	<p>Institutions: Public and private hospitals and clinics, oncology institutions and hospitals (Instituto Português de Oncologia – IPO, Institut Catala d'Oncologia – ICO).</p> <p>Management: Management offices and teams, health management and economics associations (Portuguese association of Hospital managers – APAH) and companies.</p>	<p>Interest:</p> <p>These institutions will be interested in having insights regarding the most cost-effective and prognostically-positive pathways of care, either preventive or therapeutic. They will be interested in participating in the project activities as an opportunity to have an active voice on the future RTRS healthcare management.</p> <p>Influence:</p> <p>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>



<p>Healthcare Industry and Services</p>	<p>Industry: Pharmaceutical companies (drug development and commercialization), screening devices and technology.</p> <p>Services: public and private insurance companies, diagnostic centres and clinics (genetic labs, screening and surveillance services), palliative care providers.</p>	<p>Interest:</p> <p>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.</p> <p>Influence:</p> <p>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>
<p>Policymakers and Key opinion leaders (KOLs)</p>	<p>Policymakers, decision-makers or individuals/organisations with high influence in healthcare management and health financing, disease prevention and management advocacy.</p> <p>EU-Level: 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 Agency (EMA), European Health Economics Association (EuHEA).</p> <p>National level: Ministries of Health, Health agencies (Portugal: Direção Geral de Saúde – DGS), Regional Health Authorities (Portugal: Administração Regional de Saúde, ARS Norte, ARS Centro, ARS Lisboa, ARS Alentejo, ARS Algarve), the Netherlands: National Institute for Public Health and the Environment – RIVM.</p> <p>Others: Alliance for Health Policy and System Research (Geneva, WHO Partner).</p> <p>CSOs and NGOS working on Rare Diseases:</p> <p>EU-level: 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>	<p>Interest:</p> <p>This group is interested in making informed decisions and negotiations, supported by scientifically and clinically accurate data.</p> <p>Influence:</p> <p>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 this project requires eminent political involvement from an early stage onwards.</p> <p>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>
<p>General Public</p>	<p>Civil society in general. Individuals who are not patients nor their relatives.</p>	<p>Interest:</p> <p>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</p>



		<p>empowered to take preventive actions, and influence policymaking.</p> <p>Influence:</p> <p>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.</p>
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2.2 Update to Key messages

In **D6.1**, the main key messages to be communicated in PREVENTABLE were categorized into four main themes: 1) PREVENTABLE General Key Messages, 2) Messages related to RTRS and their impact on society, 3) Healthcare management of RTRS and, 4) Messages related to national and EU organisations and actions on Rare Diseases & RTRS. Additionally, during the PREVENTABLE Stakeholder Online Workshop, partners were asked to brainstorm about key messages (**Table 2**).

Table 2 Key messages provided from partners in a brainstorm exercise at the PREVENTABLE Stakeholder Online Workshop.

- PREVENTABLE will generate opportunities for the prevention and treatment of rare diseases, which are usually overlooked because they affect a minority of people.
- High costs of rare diseases should be addressed and PREVENTABLE will provide valuable insights on what are the costs of prevention versus treatment.
- PREVENTABLE is addressing conditions which are rare but that will lead to the development of not only one but several cancers per patient.
- PREVENTABLE will promote awareness on RTRS and preventive behaviour, leading patients to get diagnosis earlier and before the onset of the disease.
- Even though RTRS are rare conditions, they lead to the onset of several cancers which prevalent in the overall population. Thus, the PREVENTABLE is paving the way to understand the cost-benefit of preventive measures in other oncologic patients.
- PREVENTABLE is harnessing information which is already available, but is otherwise spread and loose, to bring new insights and solutions to a problem with deep societal and economic impact.

2.3 Update to Tools and channels

The set of communication tools and channels for PREVENTABLE was defined in **D6.1**. **Table 3** presents the current status of this tools and channels.



Table 3 PREVENTABLE communication tools and channels.

Tools & Channels	Purpose	Status
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.	The website was launched on M4 (April 2023), and will be continuously updated to include new features and content. https://preventable.eu/
Social media	LinkedIn: Formal and informative social media channel, which will be the main channel to announce project-related events, publications, achievements, etc.	Launched. Username: Preventable_EU Link: https://www.linkedin.com/company/preventable-eu/
	Twitter: Less formal, equally informative social media channel, also allows for a swift reproduction (retweet) of other relevant events and posts.	Launched. Username: Preventable_EU Link: https://twitter.com/Preventable_EU
	Youtube: will work as an archive for all video content and broadcast of virtual events.	Launched Username: Preventable_EU Link: https://www.youtube.com/@preventable_eu
	Instagram: More informal platforms, which will allow the outreach to a broader, less technical audience.	To be launched on M9 (September 2023)
Audio-visual materials	RTRS-related content and expert interviews in the form of audios, videos and other multimedia formats.	To be developed under Task 6.3, which started on M6 (June 2023).
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.	Logo, templates and digital backgrounds already produced. The first flyers of the project are under development.
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.	To be released on M9 (September 2023)
Press releases and media articles	Efficient channel for promoting PREVENTABLE and communicating the results to the general public and all stakeholders.	News published regarding the project kick-off meeting.



2.3.1 Website

The PREVENTABLE website (<https://preventable.eu/>) is a project deliverable (**D6.4 – Project website, submitted on M4**). The website was launched on **M4 (April 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).

The website uses the visual identity of the project and presents an overview of the project in the homepage (**Figure 1**) and is structured into 6 main menus: About, RTRS, Our Research, #KnowAboutRTRS, News and Events, and Contacts. The overall structure of the website is presented in **Figure 2**.

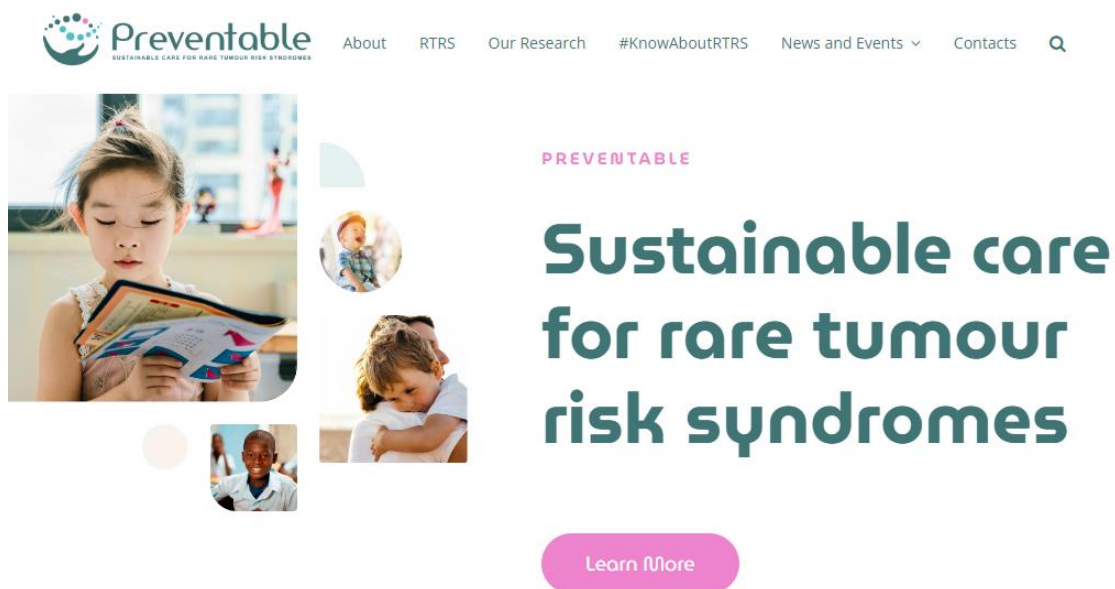


Figure 1 Homepage of PREVENTABLE website

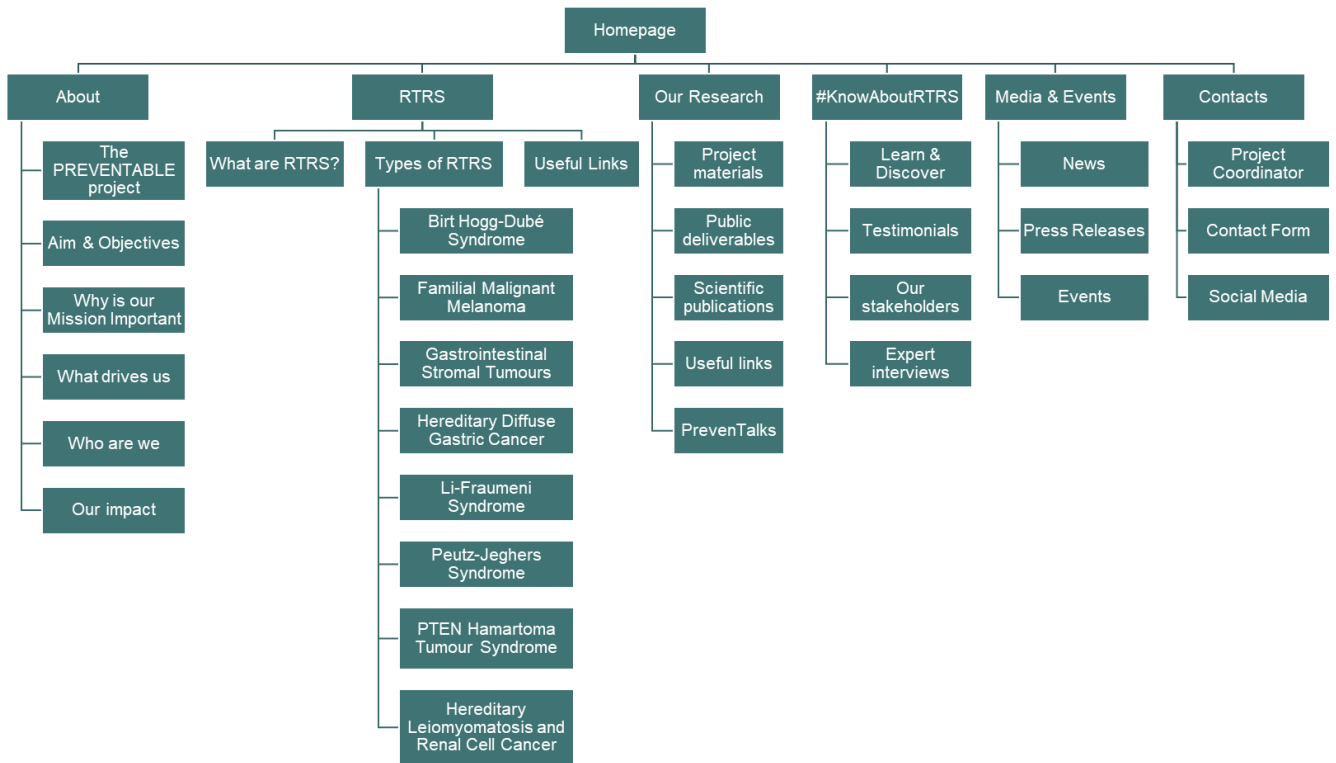


Figure 2 PREVENTABLE website wireframe

The website will be continuously monitored and updated according to the development of the project. More detailed information regarding the website and its content can be found on deliverable **D6.4 - Project Website**.

2.3.2 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 main keywords and hashtags for social media posts were defined in **D6.1**, to improve the chances of being found by relevant stakeholders and enhance visibility and outreach. Social media channels for PREVENTABLE were created on **LinkedIn, Twitter** and **Youtube** (Table 4, Figure 3).

Table 4 PREVENTALBE Social Media platforms (at M6)

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



Figure 3 PREVENTABLE Social media pages on LinkedIn, Twitter, and YouTube.

At M9 (September 2023), an **Instagram** account will also be released, as it is one of the most used platforms for branding marketing, and a powerful channel to target broader audiences, particularly patients and their families and the general public.

Partners 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. **Social media handles were requested to the consortium partners** using a document available in project collaborative space, so that partner organisations and members can be tagged in the social media posts whenever pertinent.

2.3.3 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 is described in **D6.1, Chapter 5 “RTRS-specific content”**.



2.3.4 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 were produced as part of the virtual identity of the project (**Deliverable D6.1**), including templates for Deliverables, Meeting Agendas, Meeting Minutes and Presentations.

2.3.4.1 Digital Backgrounds

Digital backgrounds are a complementary tool to brand the project, minimizing distractions while setting a professional baseline, being particularly important when meeting with external partners or stakeholders. For this reason, a light and dark version of PREVENTABLE digital backgrounds was produced, to be used during online meetings.



Figure 4 PREVENTABLE digital light (left) and dark (right) backgrounds

2.3.4.2 Flyers

The first project flyers are being developed to engage with several stakeholder groups during the activities developed under WP5 Making Rare Tumour Syndromes (RTRS) visible. The set of flyers will include a general flyer comprising information about the project, the aim, overview (duration, consortium and budget), objectives and work plan. Different versions of the flyers were also produced targeting 4 major groups: Policymakers and Health Authorities (comprising Policymakers and KOLs), Healthcare Providers and Researchers (comprising Research Community, Healthcare Professionals, Associations and Networks, Healthcare Institutions and Management), Patients (comprising also their families) and Industry (Healthcare Industry and Services).

2.3.5 Newsletter

Newsletters will be released twice a year in February (Rare Disease Day is always commemorated on the last day of the month) and September, 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 first newsletter will be published in September 2023 and the release plan is presented on **Table 5**.

Table 5. Update to PREVENTABLE newsletter release plan

Volume	Tentative Release Month	Tentative Content
1	September 2023 (M9)	Welcome message from the Project Coordinator, presentation of the aims of the project, consortium, communication channels (website, social media channels), news and upcoming events.
2	February 2024 (M14)	Summary of Year 1: results, publications, activities, news, events, etc.. Commemoration of Rare Disease Day.
3	September 2024 (M21)	Summary of 3 rd semester 1: results, publications, activities, news, events, etc..
4	February 2025 (M26)	Summary of Year 2: results, publications, activities, news, events, etc.. Commemoration of Rare Disease Day.
5	September 2025 (M33)	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

2.3.6 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. **Figure 5** and **Figure 6** present examples of news developed by SPI and UNL.



Figure 5 News on PREVENTABLE Kick-off meeting published at SPI website

(available in English and Portuguese at <https://www.spi.pt/en/spi-was-at-the-first-consortium-meeting-of-the-horizon-europe-project-preventable-at-i3s-in-porto/>)

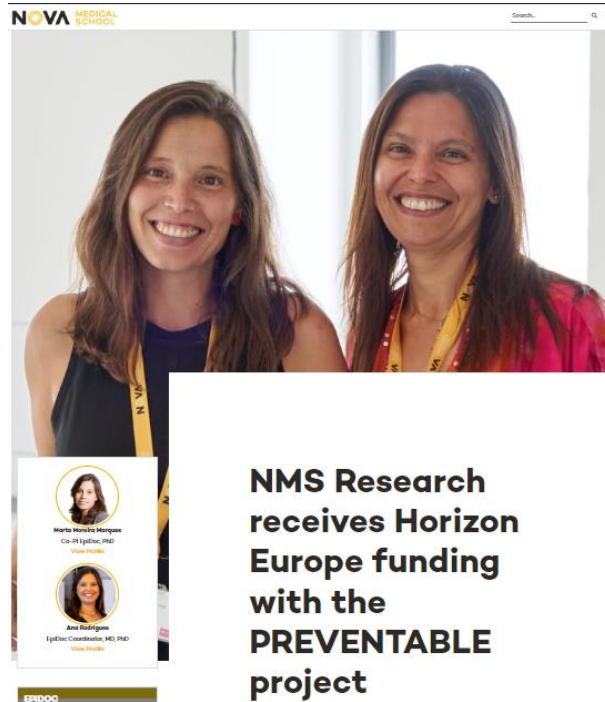
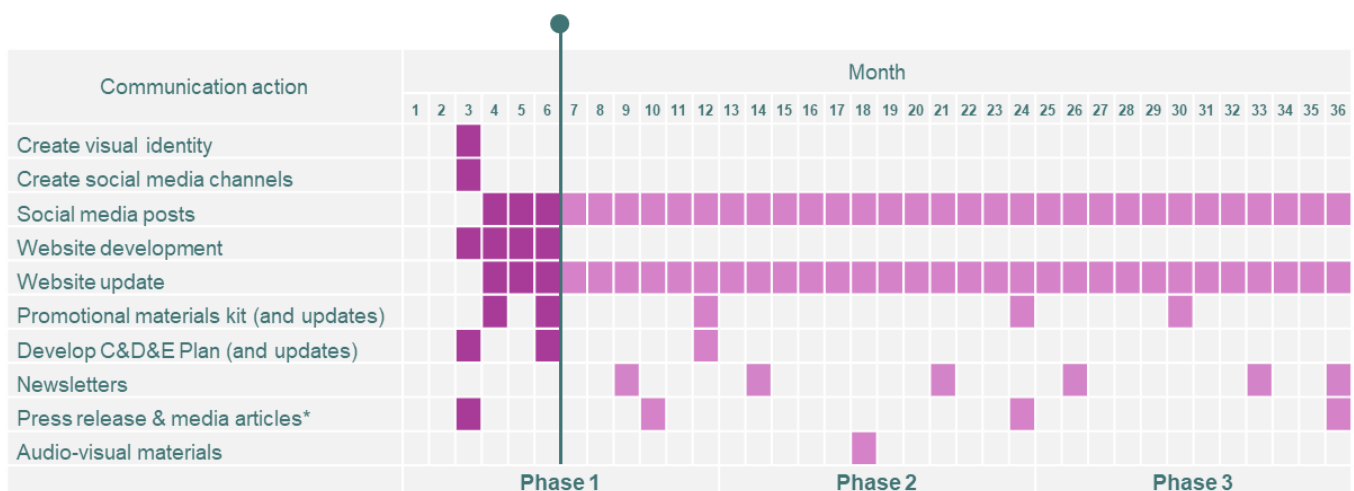


Figure 6 News on UNL participation in PREVENTABLE published at UNL website

(available in English at <https://www.nms.unl.pt/en-us/nms/news-and-events/awards-and-honours/detail/awardid/7200>)

2.4 Updates to action plan and timeline

The action plan initially proposed in D6.1 was updated (Figure 7) to better suit the project development and to indicate actions already completed or ongoing (dark pink).



* to be developed whenever major achievements occur (e.g., organisation of events, the establishment of new PREVENTABLE partnerships)

Figure 7 Update to PREVENTABLE communication activities calendar (status at M6)



2.5 Updates on 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** (more details available in **D6.1**). The current status of communication tools and channels was assessed and is shown on **Table 6**.

Table 6 PREVENTABLE communication KPIs and means of verification including current status

Tools & Channels	KPIs	Means of verification	Current Status
Website	1,000+ unique monthly visitors	Google Analytics	Data not yet available.
Social media	LinkedIn: 500 followers, 10,000+ impressions	Social media analytics	110 followers, 263 impressions
	Twitter: 500 followers, 100+ retweets		27 followers, 84 impressions
	Youtube: 100 views		Account created, still no content.
	Instagram: 500 followers		Only to be established on M9 (September 2023).
Audio-visual materials	(Full list disclosed in D6.1 , Chapter 5)	Project internal reporting	To be developed under T6.3 (initiating on M6, June 2023)
Communication materials	1 brochure, 1 flyer, 1 factsheet, 1 roll-up, document templates	Project internal reporting and website analytics	2 digital backgrounds (dark and light version) and flyer toolbox is being prepared: general flyer + targeted flyers in English and Portuguese.
External events	9+ events	Project reporting	-
Newsletter	200+ subscribers	Platform analytics	First Newsletter to be release in M9 (September 2023).
Newspaper and media articles	5 press releases or media articles	Website analytics and project reporting	7 (4 before start of the project and 3 after).

Additionally, reports on communication will be done every 6 months (**Table 7**), being the 1st report on July 2023, comprising the communication activities performed until the end of June 2023 (M6).



Table 7. Update to the Reporting Plan for PREVENTABLE communication activities

Reporting no.	Month	Communication Activities Reporting Period
1	July 2023 (M7)	01/01/2023 to 30/06/2023
2	January 2024 (M13)	01/07/2023 to 31/12/2023
3	July 2024 (M19)	01/01/2024 to 30/06/2024
4	January 2025 (M25)	01/07/2024 to 31/12/2024
5	July 2025 (M31)	01/01/2025 to 30/06/2025
6	December 2025 (M36)	01/07/2025 to 31/12/2025

2.6 Communication Guidelines for PREVENTABLE Partners

To support all PREVENTABLE partners on how to effectively develop and contribute to communication and dissemination activities, SPI developed a guide entitled “Communication Guidelines for PREVENTABLE Partners” (Figure 8). This document was sent to all project partners and is available on the project collaborative space and includes useful information, such as:

- Links for PREVENTABLE online tools and channels (website and social media pages)
- Main contact details for C&D activities;
- General rules, including how to use logos, funding statements, disclaimers, and acknowledgements;
- Procedures on how to contribute to PREVENTABLE outreach on social media platforms;
- Procedures required when participating in external events;
- Procedures required when organising PREVENTABLE events.

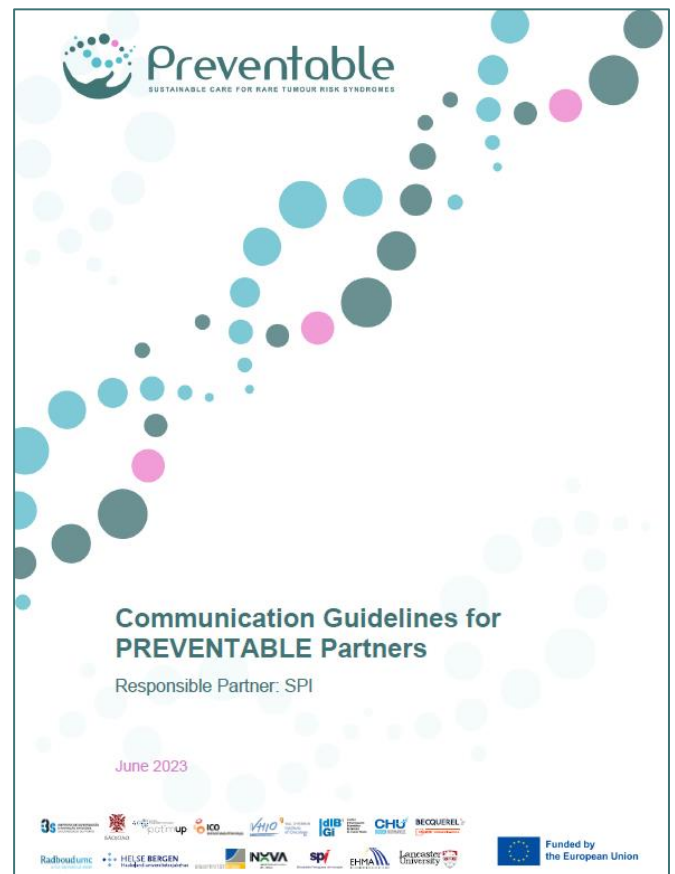


Figure 8 PREVENTABLE Communication Guide

This guide is available together with the set of monitoring documents (*Social Media Handles, Communication Efforts and Events Calendar*).



2.7 Participation in External Events

External events, such as conferences, meetings or workshops, allow to increase project visibility and exposure of the project and its results to relevant audiences. Participation in these events will allow PREVENTABLE partners to discuss their work with other experts, including researchers, clinical practitioners, and policymakers, and with patients' networks, promoting knowledge sharing and providing feedback and validation on the project approaches and strategies. Additionally, external events foment opportunities for new collaborations and networking. In this sense, a list of external events which can be relevant for PREVENTABLE partners has been done (Table 8) and will be continuously updated by all partners throughout the project lifetime.

Table 8 External events relevant for PREVENTABLE

Event Name	Date and Place	Link
EHMA 2023 Annual Conference	5-7 June 2023 Rome, Italy	https://ehmaconference.org/
Conferência Infarmed: Utilização de Dados em Saúde (PT)	25 September 2023 Lisbon, Portugal	https://www.infarmed.pt/web/infarmed/infarmed/-/journal_content/56/15786/8844725
European Society for Medical Oncology (ESMO) Preceptorship on Hereditary Cancer Genetics 2023	29-30 September 2023 Paris, France	https://www.esmo.org/meeting-calendar/esmo-preceptorship-on-hereditary-cancer-genetics-2023-paris
MENA Organization for Rare Diseases Annual Meeting & Exhibition 2024	1-4 February 2024, Dubai, United Arab Emirates	https://menararediseases.com/
Association for Clinical Data Management 24	3-5 March 2024, Copenhagen, Denmark	https://acdmconference.org/
European Human Genetics Conference	10-13 June 2023, Glasgow, Scotland, UK	https://2023.eshg.org/
Porto Cancer Meeting	Date to be disclosed for 2024 Porto, Portugal	
Hereditary Diffuse Gastric Cancer and Hereditary Lobular Breast Cancer Consensus Clinical Guidelines Meeting – IGCLC 2024	13-15 June 2024 Porto, Portugal	



Chapter 3

**Updates to Exploitation Strategy
and Plan**



3. Updates to Exploitation Strategy and Plan

The initial exploitation strategy and plan for PREVENTABLE was developed under the scope of deliverable **D6.1** and will be detailed in deliverable **D6.5 – Sustainability and Exploitation Strategy 1** (M6, June 2023) and further updated in deliverable **D6.6 – Sustainability and Exploitation Strategy 2** (M30, June 2025). In this section, a general overview on the approach being developed for sustainability and exploitation is presented, considering the sensitive nature of the content included in D6.5.

Overall, the primary objective of the Sustainability and Exploitation strategy is to attain a specific set of goals and objectives that align with the main aim of PREVENTABLE. The approach used in this strategy (**Figure 9**) is to identify and outline the target audiences, anticipated impacts, and exploitable outcomes. To effectively accomplish the objectives laid out in this strategy, an action plan has been devised, encompassing short-term, mid-term, and long-term actions to maximize the impact and sustainability of the project beyond its lifetime. Each component of the Sustainability and Exploitation strategy and action plan are described in more detail in **D6.5** and is tightly intertwined with the communication and dissemination strategy and plan established on **D6.1** and **D6.2**, as it comprises a set of activities aiming to openly disclose project results for others to use and reaching out to relevant stakeholders.



Figure 9 Approach for PREVENTABLE Sustainability and Exploitation strategy and action plan.



Chapter 4

Final Remarks



4. Final Remarks

The **Deliverable 6.2** provides an update and upgrade on the previously developed deliverable **D6.1**. The strategy presented here will be continuously monitored over time, and any necessary updates to this plan will be implemented to ensure successful outreach while maintaining effectiveness. Any changes and updates will be included under the scope of deliverable **D6.3 “Dissemination & Exploitation Plan, including communication activities and RTRS-specific content 3”** (M12, December 2023). Additionally, the exploitation strategy will be further developed under **D6.5 “Sustainability and Exploitation Strategy 1”** (M6, June 2023) and **D6.6 “Sustainability and Exploitation Strategy 2”** (M30, June 2025).



Preventable

SUSTAINABLE CARE FOR RARE TUMOUR RISK SYNDROMES