



D1.3 Stakeholder Platform

G.A.C. Group



Co-Funded by the European Union



Project acronym	PROPHET
Project title	A Personalised Prevention roadmap for the future Healthcare
Thematic priority	HORIZON-HLTH-2021-STAYHLTH-01
Type of action	Coordination and Support Action (CSA)
Grant Agreement	101057721
Deliverable number and title	D1.3 Stakeholder Forum
Work package	WP1
Due date	28/02/2023
Submission date	28/02/2023
Start date of the project	01/09/2022
End date of the project	31/08/2026
Deliverable responsible partner	GAC
Version	1.0
Status	
Author(s) name(s)	Eva Fadil (GAC), Julie Saccomano (GAC), Mélanie Rochet (GAC), Sibylle Bui (GAC), Charlotte Alcouffe (GAC)
Contributing partners	Mario Masiello (UCSC), Roberta Pastorino (UCSC)
Reviewer(s)	Maaïke Droogers (EUPHA), Claire Brugerolles (EUPHA)
Document type	<input type="checkbox"/> R – Report <input checked="" type="checkbox"/> O – Other
Dissemination level	<input checked="" type="checkbox"/> PU – Public <input type="checkbox"/> SEN – Sensitive, limited under the conditions of the Grant Agreement



Disclaimer

Funded by the European Union. Views and opinions expressed are however those of the authors only and do not necessarily reflect those of the European Union. The European Union cannot be held responsible for them.

Versioning and contribution history

Version	Date	Modified by	Comments
0.1	01/09-15/12/2022	Mélanie Rochet (GAC)	Draft table of content & elements
0.1	01/09-7/11/2022	Julie Saccomano (GAC),	First draft version
0.2	23/01/2023	Sibylle Bui (GAC)	Addition of content in the first draft version
0.2	30/01/2023	Charlotte Alcouffe (GAC)	First draft version for review
0.3	31/01-8/02/2023	Eva Fadil (GAC)	Complete review and proofreading, final version for internal peer review
0.4	08/02-22/02/2023	Maaïke Droogers (EUPHA), Claire Brugerolles (EUPHA), Mario Masiello (UCSC) and Roberta Pastorino (UCSC)	Integration of partners' comments
1.0	27/02/2023	Charlotte Alcouffe (GAC) and Eva Fadil (GAC)	Final version

Deliverable abstract

The present document **D1.3 Stakeholder platform** is the third deliverable of Work Package 1 Development and Implementation of Strategic Research Agenda and Stakeholder engagement. This deliverable intends to present the framework of the platform developed by the PROPHET project that will serve for stakeholder consultation. It provides an overview of the Stakeholder Platform on what will be expected from it and the overall modus operandi of the Stakeholder Forum, i.e., the selection process of participating stakeholders, its management, the partners roles, and responsibilities, and how confidentiality issues will be dealt with. This stakeholder platform will be developed in line with the PROPHET D1.2 Stakeholder Engagement Strategy and will be the basis for information and knowledge sharing between the PROPHET team and the community of external experts.

Keywords

Stakeholder Platform, Stakeholder Forum, live platform, stakeholder engagement, community of experts



Table of content

Table of acronyms.....	5
Executive summary.....	6
1. Introduction	7
1.1. Context and background	7
2. What is the Stakeholder Forum?	8
2.1. Role and objectives of the Stakeholder Forum	8
Main objectives of the Stakeholder Forum.....	9
2.2. Composition of the Stakeholder Forum	10
2.3. Topics and timing for exchanges	11
3. Modus Operandi for interactions with and within the Stakeholder Forum	13
3.1. Selection and invitation process	13
3.2. PROPHET stakeholder engagement platform	15
3.3. Management of the Stakeholder Platform	15
3.4. Partners roles and responsibilities	16
3.5. Confidentiality issues	17
3.6. Resources	17
3.7. Timeline and duration	18
4. Conclusions	19
5. Annex – Terms of reference for the Stakeholder Forum	20



Table of acronyms

Acronym	Definition
C/D	Communication/Dissemination
CMP	Community Management Platform
DL	Deliverable Leader
EU	European Union
EUPHA	European Public Health Association (project partner)
GAC	G.A.C. Group (project partner)
PM	Personalised Medicine
PRECeDI	Personalised PREvention of Chronic Diseases
PROPHET	Personalised Prevention roadmap for the future hEalThcare
SP	Stakeholder Platform
SRIA	Strategic research and innovation agenda
UCSC	Università Cattolica del Sacro Cuore (project coordinator)
WP	Work Package
WPL	Work Package Leader



Executive summary

PROPHET aims at developing a European roadmap for the implementation of Personalized prevention approaches. It will be elaborated in close collaboration with experts from relevant stakeholder groups.

The PROPHET action is built around the main concept that, in order to define a roadmap for the adoption of Personalised Prevention approaches into the European health system that can ensure effectiveness, efficacy and equity in access, the design of a Strategic Research and Innovation Agenda (SRIA) for Personalised Prevention must be developed in co-creation with all the stakeholders relevant for Personalised Medicine (PM) approaches. Stakeholder engagement is a key driver in co-creation approaches, and as such it is a key principle of the PROPHET project. The overall action governance is based on the involvement of stakeholders that will be actively engaged in the PROPHET activities and in the definition of a SRIA on Personalised Prevention.

The PROPHET Platform, presented in this report, is a **stakeholder engagement tool** aimed at ensuring a co-creative approach throughout all the project activities. It will be used for the exchange with the PROPHET Forum, a group composed of external invited experts from relevant target groups.

This deliverable offers a detailed presentation of the Stakeholder Platform and Forum: in Chapter 2, its role and objectives, composition, and how it will be articulated with the various PROPHET activities; and in Chapter 3, its modus operandi, i.e., the selection process of participating stakeholders, its management, the partners roles and responsibilities, and how confidentiality issues will be dealt with. It includes in annex the Terms of Reference for the Stakeholders.

The purpose of this deliverable is to provide a reference document on the definition and presentation of the Platform that will be essential for the whole project.

1. Introduction

1.1. Context and background

EU Member States are facing growing pressures for ensuring effectiveness, efficiency, and quality of their health systems within the capacity of their public budgets. Population ageing, increasing prevalence of chronic conditions and short-term costs of new therapies led to substantial rise in health expenditures, putting sustainability of European health care systems at risk.

The challenges posed by the COVID-19 pandemic highlighted the urgent need of radically **transforming the health care systems to improve resilience and sustainability**. Furthermore, one third of the EU adult population is currently affected by at least one chronic disease. These conditions contribute to 75% of the overall mortality, and in the EU on average 18 years of the later stage of life are spent with at least one **chronic disease**. Given the potential **for effective preventive efforts** in postponing the onset of disease, improving quality of life and reducing healthcare costs, the “precision-revolution” needs to extend to **precision prevention** and take advantage of improvement in the understanding of individual biomarkers, behaviour and socio-economic risk profiles, and combine these with individual lifestyle and environmental level interventions to realize the prevention benefit in terms of both healthy life and cost savings.

In fact, **Personalised Medicine (PM)** approaches for prevention are still in a stage of infancy compared to those being implemented for disease diagnosis and treatment. The Personalised PREvention of Chronic Diseases (PRECeDI) consortium published in 2019 some recommendations for policymakers, scientists, and industries on how to integrate PM into chronic disease prevention. Since then, additional high-quality evidence-supported, preventive interventions for chronic diseases have been developed. However, such development needs to be accompanied by changes in healthcare systems: health services reorganisations, but also citizen engagement, health care professional’s education, and the broader social and legal aspects.

This is where the PROPHET Action (A PeRsOnalised Prevention roadmap for the future HEalThcare) will contribute. PROPHET vision endorses the ICPeRMed vision of "next generation" medicine in 2030 that is firmly centred on the individual’s personal characteristics and equitable access for all citizens to the best possible healthcare where Personalised Prevention is at the core.

PROPHET’s main expected outcome is the **design of a Strategic Research and Innovation Agenda for Personalised Prevention, developed in co-creation with all the stakeholders** involved in Personalised Medicine approaches.

The project also **strives to achieve 6 more specific outcomes** stemming from the topic description of the call, namely:



1. Fostering the collaboration among stakeholders in the field of Personalised Prevention towards the definition and implementation of a Strategic Research and Innovation Agenda on Personalised Prevention.
2. Developing a full understanding of the research advancements in Personalised Prevention.
3. Understanding the effectiveness, the clinical utility, key success factors and gaps of current personalised preventive approaches and their potential to be scaled up.
4. Supporting Public health authorities and strengthening their capacity to design, assess and implement personalised preventive approaches through the use of the PROPHET holistic framework.
5. Raising awareness among citizens including patients on the potential of Personalised Prevention to improve quality of life and health outcomes and engage them in defining personalised preventive services accepted and used by the public.
6. Raising awareness among Health Professionals, Life Sciences Companies, Insurers, Regulators and Policy Makers on the importance of creating collaborative relationships, also with the research community, for an effective and quick adoption of Personalised Prevention approaches.

This deliverable D1.3 “Stakeholder platform” follows the deliverable D1.1 “Stakeholder analysis”, that provides a mapping of the most important European players known and identified by the partners as relevant stakeholders to engage in PROPHET co-creation activities. It is elaborated jointly with deliverable D1.2 “Stakeholder engagement strategy”, that aims at developing a strategy to engage the various groups of relevant stakeholders in the project activities, their maximum level of engagement being characterised by them joining the PROPHET Stakeholder Forum that will be operating on the PROPHET Stakeholder Platform, both described hereafter.

2. What is the Stakeholder Forum?

2.1. Role and objectives of the Stakeholder Forum

The **PROPHET Stakeholder Forum is expected to become a long-lasting mechanism for European dialogue in Personalised Prevention.** During the project, the Stakeholder Forum will be a group of external participants engaged in the various project activities that partners can consult, when necessary, in addition to the existing Advisory Board.

It will therefore allow the participation of a large group of external stakeholders in the project to ensure that the views shared in the PROPHET documents and toolbox do not only represent the views of the project partners but are more broadly shared by all target groups. The



consultation and co-creation process adopted in the PROPHET project is expected to foster adherence and co-ownership of elaborated results.

Additionally, involving the Stakeholder Forum will allow to confront the views of the different target groups and choose for the more acceptable options. For example, several options or recommendations can be scientifically valid, but not necessarily accepted by the patients themselves, or not possible to implement for policy makers. The PROPHET stakeholder engagement through the Forum is thus based on a coordinated, harmonised and comprehensive research approach, i.e. a coordinated process that reviews stakeholders' needs and perspectives as well as strong evidences from research to reach a consensus on the topics and actions necessary to develop effective approaches in Personalised Prevention.

As previously mentioned, stakeholders will be engaged in assessment and SRIA building activities. The next subsections detail **how they will be involved and for what purpose**.

The Stakeholder Forum answers the need of project partners to involve a pool of experts in the project's activities. As different partners are in charge of engaging different groups of stakeholders, a tool was needed to allow all partners to know which stakeholders are actively engaged in the project, what their expertise is, how to contact them and make the best use of their engagement, and finally allow all actively engaged stakeholders to exchange with each other.

To that end, three levels of “stakeholder engagement” have been defined:

Engagement of TIER LEVEL 1: This tier includes stakeholders that will be directly engaged in the project through their review of documents, participation as speakers in events, sharing of knowledge and good practices, etc. These stakeholders will be part of the PROPHET Stakeholder Forum.

Collaboration with TIER LEVEL 2: This tier includes stakeholders with an interest in the project results. They will for example participate in events and may be willing to take a more active part in some specific activities without committing themselves to the project.

Dissemination of information to TIER LEVEL 3: This tier includes stakeholders with a potential general interest in the project. This is a wide group of stakeholders for the dissemination of outcomes, which the project partners won't necessarily have direct contact/exchanges with.

Stakeholders' engagement level 1 and 2 will be assessed during the initial contact established with them for the different project activities, by the concerned project partner.

Main objectives of the Stakeholder Forum

Through the experts involved in the Stakeholder Forum, **PROPHET partners will seek feedback and expertise for the following activities:**

- Participation in the survey and interviews foreseen in the mapping activity and development of the SRIA concept paper (a pool of representative stakeholders selected by UCSC will participate in the interviews, however, to be more



representative, the survey will need to address a larger number of participants. Ideally, the survey would be completed by around 100 stakeholders, representing the various PROPHET target groups.).

- Participation in a dedicated workshop on the Concept Paper.
- Participation in the Delphi survey after the workshop on the Concept Paper.
- Participation in the public consultation on the first SRIA version.
- Participation in the co-creation of action plans for the adoption of the framework in 3-4 countries.
- Support the project dissemination.
- Potentially be engaged as speakers in PROPHET events.
- Alignment and synergy with the International Consortium for Personalized Medicine (ICPerMed and CSA's family) and with the future European Partnership on Personalized Medicine.

2.2. Composition of the Stakeholder Forum

The project target groups have already been defined in the frame of the Stakeholder mapping (D1.1):

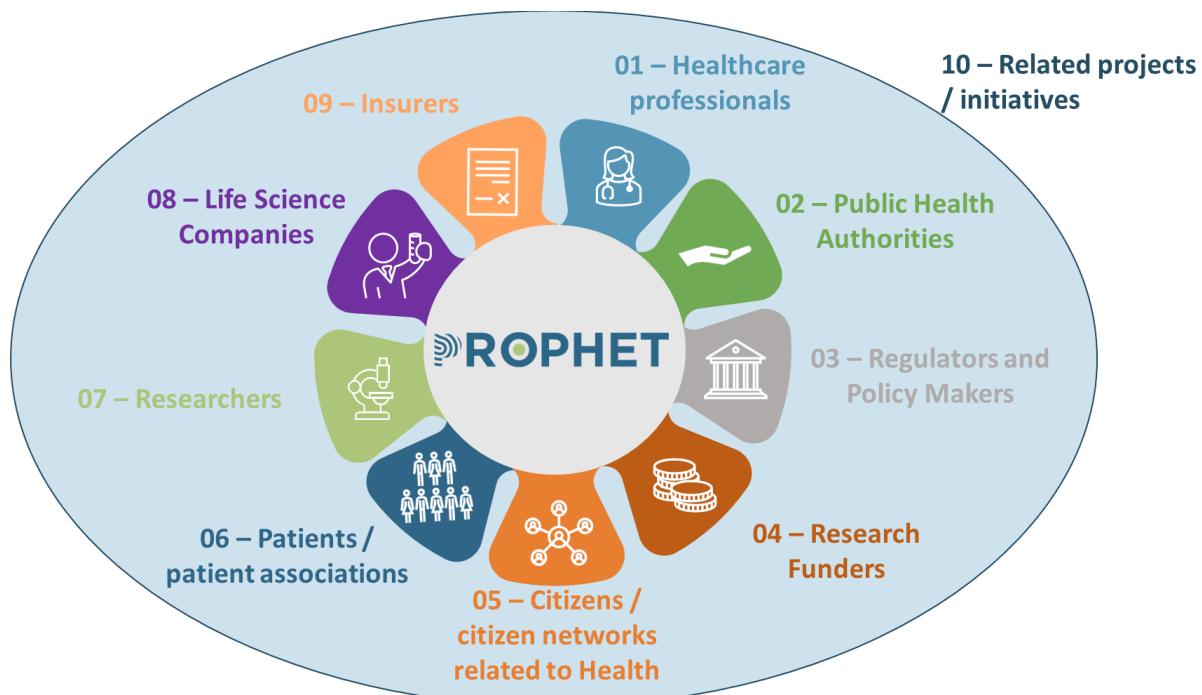


Figure 1. PROPHET target groups

These target groups are the basis for all stakeholders' involvement activities and for activities related to the communication and dissemination (C/D) of the project.



The Stakeholder Forum will be composed of stakeholders from each of the PROPHET target groups. These stakeholders will be selected thanks to a process developed in Section 3.1.

2.3. Topics and timing for exchanges

At this stage, PROPHET partners envisage to engage members of the Stakeholder Forum in the following activities:

Activity	Stakeholders to engage	What is expected from the Stakeholder Forum?	Timing
Alignment and synergy with the International Consortium for Personalized Medicine (ICPerMed and CSA's family) and with the future European Partnership on Personalized Medicine (EP PerMed) (activity leader: INSA, UCSC, ISCIII)	Researchers, healthcare professionals, Public Health Authorities and ICPerMed ambassadors	Contributions to the development of the vision and strategic development for the future of EP PerMed/ ICPerMed. Provide inputs on ICPerMed Family meetings and common activities, and consultations/discussions with ICPerMed thematic working groups. Participation in ICPerMed Family meetings and common activities, and consultations/discussions with ICPerMed thematic working groups.	M1-M48
Participation in the survey and interviews foreseen in the mapping activity and development of the SRIA concept paper (activity lead: KI, UCSC, INSA)	End users including health professionals, citizens and patients, regulators, insurers, policy makers, research and innovation organisations	Contributions and opinions on key issues (ELSI, infrastructure, technology, education, regulation, reimbursement policies, others) to understand critical factors that preclude the effective implementation of personalized prevention approaches at local/regional/national/global level	M1-M48
Participation in a dedicated workshop on the concept paper (activity lead: UCSC, KI)	Healthcare professionals, Public Health Authorities, Policy makers, research funders,	Feedback and inputs on the Concept Paper ("their voices")	M12 and M48



	citizens and patients' associations, researchers, life sciences companies		
Participation in the Delphi survey after the workshop on Concept Paper (activity lead: UCSC)	Experts (Researchers, healthcare professionals, Public Health Authorities)	Define key priorities and actions for a strategy on Personalised Prevention.	M13-M24 (End of year 2)
Participation in the public consultation on the first SRIA version (activity lead: UCSC)	Healthcare professionals, Public Health Authorities, Policy makers, research funders, citizens and patients' associations, researchers, life sciences companies	Feedbacks and inputs on the first version of SRIA	M25-M36
Participation in the co-creation of action plans for the adoption of the framework in 3-4 countries (activity lead: UTARTU)	Healthcare professionals, Public Health Authorities, Policy makers, research funders, citizens and patients' associations, researchers, life sciences companies	Feedback on the different healthcare systems in the 4 countries (government, private or mixed)	M37-M46
Support the project dissemination (activity lead: GAC)	All stakeholders	Share PROPHET related news/ material/ documentation among their networks. Provide support in disseminating project material and relevant information's. Raise awareness about the project in general and its results.	From M6 until M48
Potentially be engaged as speakers in PROPHET events (activity lead: UCSC)	All stakeholders	Raise awareness about the project results.	M4-M48



3. Modus Operandi for interactions with and within the Stakeholder Forum

The following guidelines have been developed to ensure the repartition of roles and activities for the set-up of the Stakeholder Forum, its management during its lifetime and at the end of the project. These guidelines may be updated by the project partners to ensure the smoothest process possible and avoid losing interested stakeholders.

3.1. Selection and invitation process

All partners will be in charge of identifying relevant stakeholders to participate in the Stakeholder Forum. This identification is done through D1.1 Stakeholder Analysis (Lead: GAC). The strategy to engage stakeholders (D1.2) is led by EUPHA.

A list of stakeholders per target group, relevant for the SRIA development, will be identified by the coordinator and the partners involved in activities of scientific Work Packages (WP1-WP5). The final decision of who to invite to the Forum will be made by the project coordinator UCSC.

Once the first stakeholders to be invited to the PROPHET Forum have been identified, an invitation email will be sent to them. The invitation will be as simple as possible, to avoid a too technocratic approach and drafted by UCSC. Attached to this invitation will be the terms of reference for the PROPHET Stakeholder Forum (see Annex)

More members can be added to the Forum over time when deemed relevant. All PROPHET partners will be free to suggest additional experts. The suggestions are reviewed by the project coordinator (UCSC), who makes the final decision on who is invited to be part of the Forum.

For the first contact, the invitation will be sent to the stakeholders selected by EUPHA, as the partner in charge of the stakeholder engagement process, in a personal email. This will allow other partners to reach them independently for activities within the project (e.g. interviews). If consortium partners are already in touch with some targeted stakeholders, they will be copied to the invitation to support it.

An example of invitation can be found below:



Dear Stakeholder,

The European Public Health Association (EUPHA) is pleased to invite you to contribute to **“The Personalised Prevention Roadmap for the future healthcare in Europe” (PROPHET)** project. PROPHET is a Coordination and Support Action funded by the European Union’s Horizon Europe programme ‘Staying healthy in a rapidly changing society’ and is aligned with the International Consortium for Personalized Medicine (ICPerMed).

EUPHA is leader of the tasks related to stakeholder engagement and it would be a great pleasure for us to involve you in some of the scientific activities that will take place throughout the next years.

The Consortium consists of 18 partners across 12 countries working on the different dimensions of Personalised Prevention. The overall objective of PROPHET is to co-create with stakeholders a Personalised Prevention Roadmap for the future healthcare, in order to support the definition and implementation of innovative, sustainable and high-quality personalised strategies that are effective in preventing chronic diseases.

To reach its objectives, PROPHET will engage with organisations and individuals to contribute to the construction of a Strategic Research and Innovation Agenda (SRIA) to adopt Personalised Prevention approaches into EU health systems that will be co-created together with a large panel of stakeholders gathered in the PROPHET Stakeholder Forum. Personalised prevention strategies are in fact only possible if citizens, health professionals and policy makers are all aware of their potential and have the knowledge and resources to design and implement them.

More information about PROPHET is available in the press release of the project kick-off, available [here](#)¹.

We hope that this project is of your interest and that you will participate in our activities, for which you will be contacted in the short term by colleagues within the consortium. In case you have suggestions with regards to people that could contribute to PROPHET, we would be glad to welcome your suggestions. Attached to this invitation are the terms of reference for the PROPHET Stakeholder Forum.

We are looking forward working together on this initiative.

On behalf of the PROPHET consortium



3.2. PROPHET stakeholder engagement platform

For the exchange with and consultation of the Stakeholder Forum members, the PROPHET team has decided to use a platform tool which is easy to access and to use. For this matter, it has been agreed to make use of an existing technology for the Platform rather than creating a new one.

Indeed, the sharing of information with and among the community will be organised through a Google Docs virtual platform. It allows the upload of relevant documents and co-development of them on the platform.

In addition, Zoom will be used for the consultation of Stakeholder Forum members in videoconferences. Experience of the project partners has shown that Zoom is likely to be the videoconference tool mostly accepted by the relevant target group representatives.

Making use of these two existing well know platform solutions will ensure that no technical aspects could hinder the stakeholder consultation and engagement process.

Access to both platforms will only be granted to invited members of the Stakeholder Forum and project partners in order to ensure secure use of them.

The platform will be used only for the specific needs of the project. The next section will provide details on how the platform will be managed.

3.3. Management of the Stakeholder Platform

The Stakeholder Forum will be managed by project partner EUPHA who is in charge of the stakeholder engagement process. The Stakeholder Engagement Strategy will define in more details how the engagement into various project activities will be handled in operational terms.

The Stakeholder platform will be managed by EUPHA as well and will work as consultation and engagement tool with the community of experts where invited stakeholders will be able to exchange and start the co-creative process for the SRIA.

Only stakeholders that have received the invitation and accept it will have access to the group's discussions and documentation shared (future events, project results, etc.). Each member will have the possibility to communicate and discuss with the other members.



In addition, members of the Forum will have the possibility to have access to the mailing list of experts and contact each other independently. Consent for this information and contact sharing will be gathered from each Forum member. This will aim at fostering collaboration between stakeholders and partners in the development and implementation of the SRIA and other project activities.

From that point of view, the Forum will not require a day-to-day management from a technical perspective. However, partners will be able to seek specific Forum members' inputs on a given topic (see table with the activity overview in chapter 2.3) as well as setting deadlines and reminders.

3.4. Partners roles and responsibilities

To ensure stakeholders involvement and to take advantage of the Platform it is necessary to give an overview of the partners roles and responsibilities in the process, e.g., who is in charge of setting up the platform and the ones in charge of the activities and stakeholders contributions.

The roles and responsibilities of partners are described as follows:

UCSC (Work Package 1 leader)

- Coordination of the selection process of the Stakeholder Forum members and follow up of activities .
- Sharing of relevant information on PROPHET with the community of experts.
- Interaction and exchanges with the stakeholders.

EUPHA (task leader of T1.2)

- Stakeholder Engagement leader: in charge of the Stakeholder Engagement Strategy development and its implementation (with the support of partners).
- Responsible for the setting up and updating of the Stakeholder Platform serving the stakeholder engagement activities.
- Responsible for sending out invitations to the Forum to new stakeholders as requested by partners throughout the project.

G.A.C. (leader of D1.3)

- Deliverable D1.3 leader
- Support to EUPHA on the Platform set-up and its implementation.
- Sharing of PROPHET related news, material and other relevant information with the Stakeholders (through partners engaging directly with them).



Other project partners

All partners in charge of activities which require information sharing with and consultation of Stakeholder Forum members will pro-actively develop relevant information items and manage the consultation process for their activity autonomously, in line with the overall stakeholder engagement strategy. The partners have the possibility to exchange with the community of experts and share relevant information on PROPHET whenever necessary and relevant.

3.5. Confidentiality issues

Part of the materials developed with the Stakeholder Forum members will be made public, after their validation. Those documents will be circulated to the Forum Members, asking for comments and remarks where applicable until a certain deadline. If no feedback is provided until this deadline, the consortium will consider this to be an approval.

Forum members will be asked to give their consent that the data is shared within the consortium, in accordance with GDPR regulations. Forum members will, with the submission of their application, also agree to the process foreseen, i.e. in particular with regards to the group meetings and sharing of contact information. All partners and members of the Stakeholder Forum will have access to the list of other experts present in the Stakeholder Forum: their consent will be asked before sharing their names, email addresses and affiliation.

The Forum members' contributions will support the finalisation of project documentation. However, the members of the Stakeholder Forum will be asked, for each document they participate in, if they agree to appear publicly as contributors or not. Their exact contribution and comments done during a review of a document will not be made public.

When participating in an event as speaker, the Forum members will be asked specifically if they agree to be recorded and if they agree on the diffusion of the event on social medias such as Youtube.

All exchanges with the Stakeholder Forum members will be GDPR compliant.

3.6. Resources

Forum members' work will be completed on a voluntary basis: No travel costs are foreseen for the members of the Stakeholder Forum, as all contributions will be asked online. PROPHET can also not assume any financial compensation for the contributions provided.

On the contrary, no obligations are set to the involvement in the Forum, even though the PROPHET team will expect Forum members to contribute to the co-development work according to their expertise and target group they represent.



3.7. Timeline and duration

The Stakeholder Forum is established for the duration of the project and its sustainability will be explored in the deliverable D6.2 “Dissemination and exploitation strategy”. The same applies for the Stakeholder Platform information sharing and consultation tools.

However, experts are free to opt-out of the Stakeholder Forum whenever they want to. In that case, the project partners will try and replace him/her with another expert from the same target group, in order to bring a similar expertise to the project.



4. Conclusions

The stakeholder forum will be invited in M6 of the project (February 2023) onwards, based on the information from deliverable D1.1 Stakeholder analysis and D1.2 Stakeholder engagement strategy. This forum will allow stakeholders to contribute to the PROPHET project activities, including the co-creation of the Strategic Research and Innovation Agenda. At the same time the platform will allow for videoconference exchanges whenever considered relevant.

In addition, the PROPHET Platform and forum is complementary to the transversal work of “impact maximisation”, which includes both communication and dissemination activities (and beyond) and aims at leveraging results and bring them to an upper level, reaching the widest possible audience of relevant stakeholders and engaging them into the project activities and the exploitation of results.



5. Annex – Terms of reference for the Stakeholder Forum

The following chapters have been prepared to be sent out together with an invitation to join the Stakeholder Forum. It will be put on the PROPHET project template which includes the EU funding disclaimer and transformed into a pdf attachment.

Additional elements can be added prior to the sending as deemed relevant for the stakeholder engagement process.

Introduction

The PROPHET Stakeholder Forum is the structure through which PROPHET (see Box 1) engages with external stakeholders and collects their input on the project outcomes, most notably the Strategic Research and Innovation Agenda (SRIA) on personalised prevention.

The Forum members will be consulted for various engagement activities that are conducted within the scope of the PROPHET project including interviews, surveys, workshops and more.

Box 1. About the PROPHET project

The PerRsOnalized Prevention roadmap for the future hEalthcare (PROPHET) project is an initiative **funded by the European Union** to create and provide a **personalised prevention roadmap for future healthcare in Europe**.

Prevention is a high priority at the European level: **with 900,000 people in the EU dying prematurely every year** due to risk factors that can largely be prevented through a **shift from the treatment of established diseases to a “person-centered” disease prevention** and early diagnosis, where citizens and patients are equals and active partners in their care pathway.

The Personalised Prevention Roadmap for the future healthcare, that will be **co-created together with a large panel of stakeholders** gathered in the **PROPHET Stakeholder Forum**, aims at supporting the definition and implementation of innovative, sustainable and high-quality personalised strategies that are effective in preventing chronic diseases.

PROPHET expected outcomes:

- **Raise awareness among citizens/patients** about the potential of personalised prevention to improve their quality of life and **among Health professionals and policy makers**.
- **Strengthen personalised prevention collaboration among stakeholders** towards the definition and implementation of a **Strategic Research and Innovation Agenda (SRIA) on Personalised Prevention**.
- Knowledge exchange and clear understanding of research advancements in personalised prevention and **acknowledge their potential, including effectiveness and gaps, to be scaled up**.

PROPHET Consortium



The PROPHET Consortium consists of 28 partners and is composed of a multidisciplinary group of organisations across 12 countries working on the different dimensions of personalised prevention.

What is expected from PROPHET Stakeholder Forum members?

Have you received an invitation to give your input or take part in a PROPHET activity? First of all, **thank you** for considering the invitation. Your input is important to us and essential to co-create the personalised prevention roadmap for the future healthcare.

PROPHET proposes to benefit from stakeholders' expertise, using the Forum as the discussion platform to share and exchange ideas but also to engage all concerned stakeholders in one or more of the following activities:

- Participation in interviews foreseen in the mapping activity and development of the SRIA concept paper.
- Participation in the survey foreseen in the mapping activity and development of the SRIA concept paper.
- Participation in a dedicated workshop on the concept paper.
- Participation in the Delphi survey after the workshop on the concept paper.
- Participation in the public consultation on the first SRIA version.
- Participation in the co-creation of action plans for the adoption of the framework in 3-4 countries.
- Support the project dissemination.
- Potentially be engaged as speaker in PROPHET events.
- Alignment and synergy with the International Consortium for Personalized Medicine (ICPerMed) and with the future European Partnership on Personalized Medicine.

Stakeholders' role in the Forum

Furthermore, about your participation in the PROPHET Stakeholder Forum. It is:

- 1. On a voluntary basis** – no remuneration can be provided to the FORUM members. There is the possibility to step out of the FORUM at any time without giving reason, though of course we hope you stay with us to contribute to the SRIA development.
- 2. By invitation-only** – final decision on invitations is made by the PROPHET coordinator, UCSC. The stakeholder analysis (D1.1) forms the basis from which members for the Forum are selected.
- 3. As representative** – you are asked to participate in the Forum in your professional capacity, representing your organisation/company/institution (not in your individual capacity).



Data processing

For each Forum member, and with their consent, we will collect their names, email address and affiliation. This information will be shared with all PROPHET project partners, as well as the PROPHET Stakeholder Forum members. This will contribute to the aim of having a long-lasting, beyond the project's lifetime, pool of experts for having a European dialogue in personalised prevention.

Forum members will be asked to give their consent that the data is shared within the consortium, in accordance with GDPR regulations and will also agree to the process foreseen, i.e. in particular with regards to the group meetings and sharing of contact information.

Part of the materials developed with the Stakeholder Forum members will be made public, after their validation. The members of the Stakeholder Forum will be asked, for each document they participate in, if they agree to appear publicly as contributors or not. Their exact contribution and comments done during a review of a document will not be made public. In addition, when they will participate in an event as a speaker, Forum members will be asked specifically if they agree to be recorded and if they agree on the diffusion of the event on social medias such as YouTube.

For more information

Project Coordinator:

Stefania Boccia

Director, Section of Hygiene, University Department of Health Sciences and Public Health, Faculty of Medicine, Università Cattolica del Sacro Cuore, Fondazione Policlinico 'Agostino Gemelli' IRCCS

Project Manager:

Mario Masiello

Section of Hygiene, University Department of Health Sciences and Public Health, Università Cattolica del Sacro Cuore

mario.masiello@unicatt.it.

<https://www.prophetproject.eu/>