

# **PROPHET Stakeholder Forum**

# **Terms of Reference**



## 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 cocreate 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
<a href="mario.masiello@unicatt.it">mario.masiello@unicatt.it</a>.

https://www.prophetproject.eu/





