Horizon 2020

SC1-HCO-01-2018-2019-2020: Actions in support of the International Consortium for personalised Medicine

SAPHIRe Work package 5

Deliverable 5.3

Plan for the sustainable engagement with stakeholders

Date delivered:

November 2021 (M35)

Author:

Sorcha Finnegan

Deliverable Lead Beneficiary (2)

REGIONAL AGENCY FOR PUBLIC HEALTH AND SOCIAL WELL-BEING (PHA)

D5.3

PROJECT	
Project Title	Securing Adoption of Personalised Health in Regions
Project Acronym	SAPHIRe
Grant agreement no.	825046
Project start date	1 December 2018
DOCUMENT	
Title	Plan for the sustainable engagement with stakeholders
Deliverable number	5.3
Report Authors	Sorcha Finnegan
Contributing partners	
Start date	1 December 2018
Delivery date	25 November 2021
Actual delivery date	05 November 2021
Dissemination level	PU
Status	Complete

Change history		
Version	Remark	Date
001		26.11.2021
002		

Project coordinator	Operations coordinator
Kathleen D'Hondt	Okker Van Batenburg

Contents

1. Executive Summary

The aim of the Plan for the sustainable engagement with stakeholders (herein referred to as the stakeholder engagement strategy) for the SAPHIRe project is to prepare a workable strategy to involve stakeholders in SAPHIRe's activities, both during the project and ensuring project legacy.

The SAPHIRe project aims to structure the application of personalised medicine (PM) at regional level, and in this way contribute to the implementation and reach of the International Consortium for Personalised Medicine (ICPerMed) and the roll-out of PM in Europe. To facilitate this, stakeholders from a local to a European level will be consulted. These stakeholders will include a mix of policy and decision makers, representatives from healthcare, academia, research funders, industry and cluster organisations. Stakeholders will actively be involved throughout the entire project; they will support SAPHIRe by providing feedback, directly providing their expertise by participating in activities such as workshops, round tables and conferences.

This document outlines the plans to include these stakeholders in SAPHIRe activities through a process of communication, consultation and collaboration.

2 Project Objectives

The overall objective of the action is to structure the application of personalised medicine (PM) at regional level, and in this way contribute to the implementation and reach of the International Consortium for Personalised Medicine (ICPerMed) and the roll-out of PM in Europe. The action should establish and support networking between regions and interregional cooperation, in particular linking remote or sparsely populated regions with regions harbouring critical mass of medical and PM expertise, while taking into account broader socio-economic and cultural aspects.

The specific objectives are:

- Getting insight and obtaining overview of the level of adoption of PM in European regions (identifying and mapping, including finding complementarities);
- Classifying regions on a scale from well advanced to less developed and modest in the area of PM, with special emphasis on remote or sparsely populated regions and EU-13 regions;
- Establishing contacts with selected and interested regions through regional authorities and representatives from cluster organisations, public research entities, leading hospitals and other stakeholders. Create inclusiveness (new value chains) and collaboration within selected regions and develop mechanisms for interregional collaboration in such a way that remote or sparsely populated regions and regions in EU-13 countries can benefit from

regions that are considered leaders in implementation of PM for better health and well-being;

- Establish interregional collaborations and, if appropriate, develop linkages to existing INTERREG projects or interregional partnerships of Thematic Smart Specialisation Platforms;

- Identify and address the specific needs for regional-national dialogue: regional authorities have different levels of independency among the different EU Member States and

- Align, where relevant, research funding with ongoing or foreseen investments from Structural Funds - in particular, the European Regional Development Fund (ERDF) - and other funding sources.

3 Detailed report on deliverable

3.1 Understanding Stakeholder Engagement

A stakeholder can be defined as a key individual or group of people that are impacted by the project or are critical to the success of the project. They are "groups without whose support the organization would cease to exist" (Freeman et al., 1983). For this report, a stakeholder is any individual, group of people, or institution/organisation that has an interest in SAPHIRe and its activities. This includes those who will be affected by the project and those who will influence the projects' activities and outcomes.

Stakeholder engagement can be described as a continuous, inclusive process between a company or organisation and those potentially impacted that encompasses a range of activities and approaches, and spans the entire life of a project (International Finance Corporation, 2007).

The community of stakeholders will be SAPHIRe's greatest asset, it is therefore essential that SAPHIRe engages with its stakeholders throughout the lifetime of the project in order to:

- Maximise the chances of project success

- Gain/maintain support from stakeholders

- Encourage wider cooperation with the project

- Anticipate stakeholder needs/wants and incorporate into the plan to foster support

- Help improve quality of project deliverables

For the SAPHIRe project two groups of stakeholders have been considered:

1. **External stakeholders**: These are individuals or organisations who are not initially involved with the project but who may become involved, and who may influence the projects' outputs and may be influenced by the project. These include: policy and decision makers,

representatives from government, healthcare, academia, research funders, industry and cluster organisations.

2. **Internal stakeholders**: These are the SAPHIRe Consortium partners:

- Flanders Government, Department of Economy, Science and Innovation (Vlaams Gewest - VLO EWI, BE)

- The Public Health Agency, Northern Ireland (PHA, NI, UK)

- EIT Health InnoStars (HU)

- EuroBioForum (NL)

3.2 Identifying SAPHIRe External Stakeholders

At the beginning of the project a stakeholder database was compiled. This was done, at first, using personal contacts. The list has evolved following responses from newsletters, follow-up from surveys/workshops/webinars and as a result of social media. This list has grown over the course of the project and has continually been added to.

SAPHIRe has created a stakeholder's platform. This brings regions together from different innovation levels and different levels of adoption of PM. This Stakeholders' Platform consists of a number of different communities:

- The major community includes regional authorities and major regional actors using or interested in PM approaches. The target group in this community consists of ministries, funding institutions, politicians and government representatives, and experts and opinion leaders on international, EU, national, regional and local level.

- A second community is addressing cluster organisations and major industry partners, including SMEs addressing PM.

- Another community is providing a forum to scientists, healthcare professionals, patient organisations and broader public to generate awareness on progress and opportunities, but also on the needs for this field to advance, such as standardised procedures and access to databases and other infrastructure, and needs for coordinated approaches.

- Finally, a major community consists of representatives from other relevant initiatives in the field of PM.

Building upon Task 2.1 (inventory intelligence), Task 2.2 (Stakeholder position and demand articulation in regions) aimed to reach out to regional stakeholders to verify the state of affairs regarding PM and to establish their wants/needs in the (future) adoption of PM in the region. This was done using already established contacts in regions, and through follow-up activities after surveys/workshops/webinars, conferences, round tables. These contacts then formed the basis for
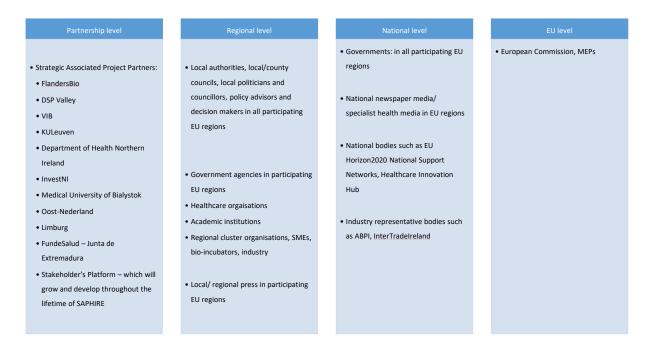
the SAPHIRe Stakeholders platform. The Stakeholders Platform grew organically throughout the lifetime of the project, ultimately it will be the views and opinions from the stakeholders platform that will advise on the actions to be undertaken to follow up on the implementation of the ICPerMed roadmap and Action Plan to implement PM, as well as on the socio-economic implications of the outcome of the SAPHIRe project.

3.2.1 SAPHIRe stakeholder groups

External SAPHIRe stakeholders can be described on four levels:

1. Partnership level
2. National level
3. Regional level
4. European level

Below is a summary of the individuals/organisations that comprise these different levels. This summary is not exhaustive and has evolved during the lifetime of the project.

Partnership level	Regional level	National level	EU level
• Strategic Associated Project Partners: • FlandersBio • DSP Valley • VIB • KULeuven • Department of Health Northern Ireland • InvestNI • Medical University of Bialystok • Oost-Nederland • Limburg • FundeSalud – Junta de Extremadura • Stakeholder's Platform – which will grow and develop throughout the lifetime of SAPHIRE	• Local authorities, local/county councils, local politicians and councillors, policy advisors and decision makers in all participating EU regions • Government agencies in participating EU regions • Healthcare orgaisations • Academic institutions • Regional cluster organisations, SMEs, bio-incubators, industry • Local/ regional press in participating EU regions	• Governments: in all participating EU regions • National newspaper media/ specialist health media in EU regions • National bodies such as EU Horizon2020 National Support Networks, Healthcare Innovation Hub • Industry representative bodies such as ABPI, InterTradeIreland	• European Commission, MEPs

3.3 Stakeholder engagement in SAPHIRe

3.3.1 Our aim for SAPHIRe

The aim of the SAPHIRe stakeholder engagement strategy is to continually improve the way we engage with our stakeholders through the project's various channels. We have done this throughout the project, by keeping our stakeholders informed and involved in our activities. The engagement strategy was/is also a vital opportunity to identify issues and opportunities, and receive feedback.

Throughout the project we have communicated and collaborated with our stakeholders, it was important therefore that our communications were carefully targeted and we had the correct messaging. This helped ensure that attendance at SAPHIRe events was maximised and that we received quality contributions via our surveys and feedback. This in turn helped with stakeholder mapping and production of the SAPHIRe Roadmap as well as other project deliverables, as we were able to identify stakeholder wants/needs opportunities/challenges and future plans (e.g. RIS3).

3.3.2 What is a stakeholder engagement strategy?

A stakeholder engagement strategy identifies the needs of key groups and the Sponsor plays a vital role in ensuring those business needs are met (Murray-Webster, 2019). SAPHIRe's stakeholder engagement strategy will be used along with the SAPHIRe communication and dissemination plan (deliverable 5.1) to communicate with project stakeholders to achieve their input and support for the project.

3.3.3 Principles of stakeholder engagement

It should be noted that the engagement principles outlined in this strategy are nonexclusive and the level of engagement with stakeholders varied throughout the project. Stakeholder engagement evolved as the project continued.

The Association for Project Management have identified ten key principles of stakeholder engagement, these are summarised as follows:

1. **Communication**: Before aiming to engage and influence stakeholders, it is crucial to first understand the people you will be working with. Gathering information about stakeholders is an important first step.
2. **Consultation**: Regular consultation is essential to ensure the project is meeting the needs of the stakeholders, particularly in the early stages.
3. **Understand stakeholder behaviour**: Stakeholders will not always behave in a predictable, consistent or reliable manner. Understanding this can ensure productive relationships are maintained.
4. **Plan**: Careful planning before engaging with stakeholders is important.
5. **Focus on relationships**: Investing effort in identifying and building stakeholder relationships can increase confidence across the project environment, minimise uncertainty, and speed problem solving and decision-making.
6. **Forward plan**: Try to anticipate risks; taking simple and timely actions with stakeholders can significantly improve project delivery.
7. **Manage risk**: Stakeholders are important resources and should be treated as potential sources of risk and opportunity.

8. **Compromise**: Stakeholders will have different priorities/expectations, establish the most acceptable baseline across stakeholders. Assess the relative importance of all stakeholders to establish a weighted hierarchy against the project requirements and agreed by the project co-ordinator.

9. **Understand success**: Project success means different things to different people and it is important to understand what your stakeholder community perceives success to be for them.

10. **Take responsibility**: Stakeholder engagement is the responsibility of the entire project team. The entire project team has a role to play.

3.4 Approach to engagement

There are different ways to approach engagement, each method is valid, with different methods suited to different types of stakeholder.

The engagement approaches are outlined below (Stakeholdermap.com, 2010). SAPHIRe has used a variety of these approaches depending on the activity and the stakeholder group involved.

Engagement approach	Description
Partnership	Shared accountability and responsibility. Two-way engagement joint learning, decision making and actions
Participation	Part of the team, engaged in delivering tasks or with responsibility for a particular area/activity. Two-way engagement within limits of responsibility.
Consultation	Involved, but not responsible and not necessarily having influence outside of consultation boundaries. Limited two-way engagement: organisation asks questions, stakeholders answer.
Push communications	One-way engagement. Organisation may broadcast information to all stakeholders or target particular stakeholder groups using various channels, e.g. emails, letters, videos, social media, leaflets.
Pull communications	One-way engagement. Information is made available, and stakeholders choose whether to engage with it, e.g. web-pages

3.4.1 Engagement activities

SAPHIRe engaged its stakeholders through communication, collaboration and consultation; this process was vital for the successful implementation of the project, its objectives and deliverables.

- **Communication** was always a two-way process. We presented key information to our stakeholders, whilst encouraging feedback. We communicated as set out in the communication and dissemination plan (Deliverable 5.1).
- **Collaboration** through bilateral meetings with our stakeholders allowed us to create solutions that work for them. We did this through round-table discussions, workshops and conferences where we could discuss regional needs and priorities.
- **Consultation** gave stakeholders the opportunity to provide input, feedback and opinions. This input informed the direction of the project and helped plan future goals. We did this through a variety of methods including workshops, round tables and surveys.

3.4.2 Communication

According to Horizon2020: the beneficiaries must promote the action and its results, by providing targeted information to multiple audiences (including the media and the public), in a strategic and effective manner and possibly engaging in a two-way exchange.

SAPHIRe has produced a detailed communication and dissemination plan (Deliverable 5.1). Communication activities with stakeholder have been outlined in the communication plan. For the purpose of this stakeholder engagement strategy, a summary will be provided.

SAPHIRe communicated with its stakeholders throughout the entirety of the project. Through WP5 we engaged with the SAPHIRe community and promoted the actions of SAPHIRe. We communicated our plans, requests and outputs to local, regional and European stakeholders.

For the success of SAPHIRe, we rely on input from our stakeholders to drive the project forward, communication was therefore always a two-way process. We communicated through the various channels outlined in our communication plan.

We used the following channels/tools for communication:

- Workshops, webinars and conferences
- Round tables and bilateral meetings
- Surveys
- Social media – Twitter, LinkedIn, Facebook
- SAPHIRe website
- Newsletters

- Press releases
- Factsheets
- Emails
- Personal contacts

3.4.3 Collaboration and Consultation

Collaboration is the process of two or more people, entities or organizations working together to complete a task or achieve a goal (Marinez-Moyano, 2006); Consultation is defined as the act of exchanging information and opinions about something in order to reach a better understanding of it or to make a decision, or a meeting for this purpose (Consultation, 2021).

SAPHIRe worked with its stakeholders to understand what their needs and priorities were, in order to develop plans and solutions that would bring mutual benefit. SAPHIRe are creating a Roadmap for regional implementation of PM. To create this roadmap we have consulted and collaborated with regional policy makers, decision makers, health authorities, academic institutions, cluster organisations and industry representatives to understand specific regional needs. The inventory generated in WP2 formed the basis for the roadmap, crucially though - active workshop participation, and, round table talks provided a forum for regional representatives to provide information.

3.4.4 Solution In One Day (SIOD©) Workshop

As well as workshops, conferences and surveys SAPHIRe developed the Solution In One Day (SIOD©) workshop. The SIOD workshop:

- Gathered stakeholders from region(s) with an interest in promoting PM research, innovation and implementation.
- Shared insights from regional initiatives and best practices in PM with other regions/experts.
- Discussed the most urgent drivers and barriers to promote, develop and deploy a PM strategy for region(s).
- Identified potential areas for joint investment agendas and cross-project collaboration with other regions.

3.4.5 Workshops, webinars and conferences

Over the lifetime of the project, the SAPHIRe Consortium have organised a variety of workshops, webinars and conferences focused on personalised health. These events have attracted a wide range

of stakeholders from across Europe and have included speakers and audience members from academia, healthcare, government, cluster organisations, industry etc. These events have provided a platform for open discussion and sharing of ideas and best practice. This has allowed SAPHIRe to interact with stakeholders and understand their opinions and requirements. Information from these events has been used to help draft the SAPHIRe Roadmap (D3.6) and Deliverable 5.5: Recommendations on the implementation of PM in regions.

3.4.6 Surveys

SAPHIRe has developed and distributed two surveys to stakeholders. The first survey: survey on Organisation of Personalised Health related Competences in EU Countries & Regions, was to try to create a comprehensive overview of the organisation of competences related to personalised medicine at the different regional levels across Europe. The responses from our stakeholders have fed into the SAPHIRe Observatory.

The second survey: to have a clear view on PM policies in regions in Europe was to try to understand existing policies, funding instruments, implementation and performance of personalised medicine in the European regions (see Deliverables 2.1-2.4). Responses from our stakeholders can be found here.

3.4.7   Summary of engagement activities

Below is a summary of how SAPHIRe engaged with each stakeholder group through various activities and events.

Stakeholder organisation, group, individual	Potential role in the activity	Engagement strategy - How will we engage them?	Follow-up strategy – Plans for feedback, continued engagement
Partnership level	Engagement in: webinars, active brokerage, interviews, future projects, promotion, awareness	Invitation to events, issue of press releases, connect through social media, newsletters, personal contacts and dialogue at events, surveys	Follow-up emails after events
Regional level	Engagement in: webinars, workshops, round tables,	Invitation to events, issue of press releases, connect through social	Continued engagement through WP4 events – workshops and round

	active brokerage, interviews, future projects promotion, awareness	media, newsletters, emails to key personnel, active brokerage and dialogue at events, surveys	tables. Follow-up communications after each workshop/meeting with action plan "to-do" list.
National level	Engagement in: future projects, EU funding Awareness: present results, promotion, knowledge exchange	Emails to key personnel, issue of press releases, connect through social media, newsletters, reports	Follow-up emails when relevant,
EU level	Promotion, inform about project results	Report with supporting letter, end of project report, updates on EU Participant Portal	Feedback through EU portal via project officer

4 SAPHIRe project legacy

Ensuring legacy beyond the lifetime of the SAPHIRe project is vital. In order to achieve this, it is crucial to ensure communication and dissemination of SAPHIRe-related activities and results to all stakeholders. Several outputs from the project will contribute to the legacy. All deliverables from the SAPHIRe project are/will be available on the SAPHIRe website, these can be accessed and downloaded and used by our stakeholders. Workshops that were recorded are all available on the SAPHIRe website and YouTube channel, as is the preventive medicine interview series.

The SAPHIRe Roadmap will be a crucial document contributing to legacy of the project. It is the intention that the Roadmap will be disseminated and utilised by stakeholders, long after the project ends. The roadmap will be a reference/guidance document and will offer advice and inspiration for European regions and regional representatives to increase the implementation of personalised medicine in their region.

5 Conclusion

This document outlines how sustainable engagement with stakeholders was achieved for the SAPHIRe project. Engaging stakeholders early on in the project and maintaining those key relationships is important when building trust and integrity. It is vital to try to establish long-lasting relationships with stakeholders in order to ensure project success.

The methods of stakeholder engagement and the reason for engagement are also critical in the process. SAPHIRe used a variety of approaches to stakeholder engagement comprising methods such as face-to-face meetings, round tables, surveys, conferences etc. The intent behind engagement is to understand regional stakeholder wants/needs and their views in relation to personalised health-related issues.

We tried to ensure, as much as possible, that our stakeholders represented a wide variety of our target audience.

It is anticipated that this document will provide a useful reference for stakeholder engagement activity for the SAPHIRe project.

6 References

1. Apm Body Of Knowledge 7Th Edition And Evolving Project Leadership Pack. (2021). S.L.: Association For Project M

2. Freeman, R.E. and Reed, D.L. (1983). Stockholders and Stakeholders: A New Perspective on Corporate Governance. *California Management Review*, 25(3), pp.88–106.

3. Dictionary.cambridge.org. 2021. *Consultation*. [online] Available at: <https://dictionary.cambridge.org/dictionary/english/consultation> [Accessed 29 October 2021].

4. Marinez-Moyano, I. J. *Exploring the Dynamics of Collaboration in Interorganizational Settings*, Ch. 4, p. 83, in Schuman (Editor). Creating a Culture of Collaboration. Jossey-bass, 2006.

5. Sequeira, D. and Warner, M. (2007). *Stakeholder engagement: a good practice handbook for companies doing business in emerging markets*. Washington, D.C., U.S.A.: International Finance Corporation.

6. Stakeholdermap.com. (2010). *Engaging Stakeholders - A strategy for Stakeholder Engagement*. [online] Available at: https://www.stakeholdermap.com/stakeholder-engagement.html [Accessed 20 October 2021].