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Deliverable D2.1

Report summarising the information gathering from desk research:  
Regional ecosystems and frameworks for personalised medicine (PM)

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Annex: on-line survey questionnaire

## 1 Introduction

This report summarizes the way information is gathered from European regions - including sparsely populated and remote regions - on personalised medicine and its development and implementation. The methodology described in this deliverable is the starting point for building networks between regions and will finally lead to an observatory of regions, one way or the other active in the area of personalised medicine and health.

Next deliverables of this workpackage (WP2) are a report on regional PM profiles (D.2.2), a report on regional complementarities to implement PM (D.2.3) and finally an online database on PM implementation in European regions (D.2.4). It should be noted that the activities in workpackage 2 are not a once-only exercise, but will continue during the lifetime of the project.

## 2 Project Objectives

The SAPHIRE consortium supports regions in Europe to structure the implementation and adoption of personalised medicine in regional healthcare systems, involving all stakeholders across the entire value chain. SAPHIRE will initiate a platform by creating a network of regions and their ecosystems. Furthermore, SAPHIRE will stimulate the development and deployment of cross-border and/or interregional collaboration projects. Recommendations will be provided on funding and investments through the relevant financial instruments available.

Nowadays one can observe disruption in healthcare systems worldwide. These are caused by various factors: key enabling technologies (KETs) like genomics, the need for a transition from cure & care towards prediction & prevention, the full utilization of big data, the impact of lifestyle and self-management on individual health and wellbeing, the changing interaction between citizens/patients and healthcare professionals, the need to shift to value based healthcare, and the transformation towards a health approach rather than a disease approach.

The project activities include three elements:

- A thorough mapping exercise to address specific regional needs, while taken the different levels of PM adoption into account. Special attention will be given to link remote and sparsely populated regions and less strong innovating regions to regions that are more advanced in personalised medicine. A modular regional roadmap for personalised medicine implementation will be developed.
- The SAPHIRE network will include regional policy and decision makers, opinion leaders, regulatory agencies, regional development agencies, cluster organisations, healthcare actors, patient organisations and regional knowledge institutions, and will bring regional strengths, needs and barriers to the attention of national and European level.

- Instruments to support interregional collaborations and opportunities for funding or investment by the framework programme, the structural funds or the EIB will be identified. Alignment will also be made to regional smart specialisation initiatives focussing on personalised medicine.

### **3 Activities Workpackage 2**

As a basis for the SAPHIRE project it is necessary to get a good overview of the research, innovation and healthcare ecosystems related to PM in European regions. The project started with inventorying the current state of play of PM in regions across Europe. This entails the gathering and processing of relevant information concerning PM in regions: policies, research infrastructure, funding instruments, best practices of adoption, healthcare system, intra- and interregional collaborations, etc. Secondly, this WP will particularly focus on joint SWOT-analyses with regions to establish their current position as well as a forward look per region to implement PM. One of the centre-pieces of the SAPHIRE project is building of a Stakeholders' Platform including different communities active to implement PM in collaborative efforts (interregional, cross-border) and at different policy and authority levels (regional, national). WP2 will lay the basis of the Stakeholders' Platform building which will be expanded by WP4 (Activation and Acceleration) and WP5 (Dissemination and Exploitation) activities. The inventorying activities are not restricted to one year, but will be continued for reasons of updating and community building. All relevant information on PM in regions will be accessible through an online database.

### **4 Methodology**

There is currently no single-entry point for information on personalised medicine in regions. Most information is scattered in databases designed for specific purposes. Only for cluster organisations, the website of the European Cluster Collaboration Platform (ECCP) provides a toolkit for networking, collaboration and access to relevant information.

To gather information and to identify regional ecosystems and frameworks for research, innovation and adoption of PM the following tools are used:

1. Desk research
2. Interviews, meetings and site visits
3. Workshops
4. Survey

#### *4.1 Desk research (websites, documents and databases)*

To collect information on personalised medicine and health in regions the following databases are used:

- eye@RIS (RIS3 platform)
- European and Regional Innovation Scoreboards

- EUROSTAT
- European Cluster Collaboration Platform (ECCP)
- European Observatory for clusters and industrial change
- EU project database of Interreg (Keep)
- CORDIS

In addition, the websites and member lists of some European organisations provide useful information on regions, such as:

- Assembly of European Regions: AER e-he@lth network
- Committee of the Regions: CoR Interregional Group on Health & Wellbeing
- European Regional and Local Health Authorities (EUREGHA)
- European Regions Research and Innovation Network (ERRIN)
- Council of European Bioregions (CEBR)
- WHO Regions for Health Network (RHN).

Also Wikipedia is a useful information source.

#### 4.2 Interviews, meetings and site visits

The best way to get the most recent and up-to-date information is by speaking eye-to-eye with the people who are closely involved in the development and implementation of personalised medicine in the respective regions. Second best are meetings with regional representatives in Brussels: regional (and local) authorities are represented in more than 200 offices. Furthermore, interviews and meetings are organised with existing associations/networks of regions, ICPeMed members, running collaborative projects and partnerships, and relevant stakeholders' groupings.

Year-to-date, meetings/visits have been organised with the following regions:

Country	Region	Organisation
Austria	Lower Austria	Ecoplus, Niederösterreichs Wirtschaftsagentur
	Salzburgerland	Technologietransfer Salzburg ITG)
Denmark	Capital Region of DK	Centre for Regional Development
	South Denmark	EU Office Brussels
	5 DK regions	Danske Regioner
Finland	East & North Finland	EU Office Brussels
	Oulu Region	Council of the Oulu Region
France	Région Sud PACA	Regional Government
Italy	Emilia-Romagna	Innov. & Technology Transfer Regional Gov.
	Friuli-Venezia Giulia	Brussels Liaison Office
		Smart Health Cluster FVG
Netherlands	East Netherlands	Oost NL
Portugal	country-wide	National Parliament, Health Commission
Slovenia	country-wide	Slovenian Innovation Hub

Switzerland	country-wide	SwissCore, EU Office Brussels
	country-wide	Swiss Personalized Health Network SPHN
	Basel-Stadt	BaselArea.Swiss (DayOne)
UK	Scotland	Scotland Europe, EU Office Brussels

In addition, introductory talks have taken place with the following PM-related networks and initiatives:

- International Consortium for Personalised Medicine (ICPerMed)
- European Alliance for Personalised Medicine (EAPM)
- Network for European Regional and Local Health Authorities (EUREGHA)
- S3 Partnership for Personalised Medicine (under S3 Industrial Modernisation Platform)
- EIT Health InnoStars/RIS regions (Czech Republic, Slovenia, Sicilia)
- EIT Food4Health (1<sup>st</sup> European Roundtable for Prevention in Health)
- ScanBalt BioRegion
- BioPeople Cluster Denmark
- CSA Regions4PerMed
- European Hospital and Healthcare Federation (HOPE)
- Big Data Value Association (BVDA)

#### 4.3 Workshops

The first workshop “Needs & Barriers” (on invitation only) took place on 12-13 March 2019 in Brussels. Selection of participants was based on information gathering beforehand, taking into account a balanced geographical spread as well as a balanced mixture of PM advanced and less advanced regions. The workshop was attended by 19 regions from 15 countries. See table below:

Country	Region	Organisation
Belgium	Flanders	Flemish Government
		DSP Valley & flanders.health
		Centre for Human Genetics, KU Leuven
		flanders.bio
Denmark	Capital Region	Centre for Regional Development
	Zealand	Regional Government
Finland	Oulu Region	Council of Oulu Region
France	Région Sud PACA	Regional Government
Greece	Attica/Athens	Fleming Biomedical Sciences Research Center
Hungary	Central Hungary	National Health Insurance Fund, Budapest
Italy	Campania	University of Naples Federico II
		KronosDNA
	Lombardy	Synlab Italy srl

	Piedmont	Bioindustry Park Silvano Fumero
		EU Office Brussels
Netherlands	East Netherlands	Oost NL
Poland	Podlaskie	Medical University of Bialystok
Portugal	Lisbon	University of Lisbon, Faculty of Medicine
Romania	Neamt County	Regional Developm. Agency, North-East Rom.
Slovenia	country-wide	Slovenian Innovation Hub
		University Medical Center Ljubljana
Spain	Extremadura	MEDEA PM implementation programme
		FundeSalud, Regional Government
Sweden	Västra Götaland	Genomics Medicine Sweden
UK	Northern Ireland	Public Health Agency
	Scotland	Scotland Europe, EU Office Brussels

A next workshop will be held in October 2019 in Belfast on “Best Practices in PM”.

#### 4.4 Survey

In July 2019 a survey was launched to have a clear view on the existing and future policies, funding instruments, implementation and performance of personalised medicine in the European regions. To start with, the on-line questionnaire was sent out to about 150 regions, most of them having identified personalised medicine/health as a priority in their smart specialisation strategy (S3). The questionnaire is annexed to this report and can be found on the SAPHIRE website [www.saphire-eu.eu](http://www.saphire-eu.eu). First results are expected in October this year.



# Overview methodology

