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SAPHIRe Workpackage 2
Deliverable D2.4

Online database giving information on Personalised Medicine implementation in EU regions

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002		

Project coordinator	Operations coordinator
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1 Introduction

The SAPHIRe consortium supports regions in Europe - including remote, sparsely populated and regions with less strong innovating capacities - to structure the implementation and adoption of personalised medicine and personalised health (PM/PH) 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) interregional collaboration projects. Recommendations will be provided on funding and investments through the relevant financial instruments available.

2 SAPHIRe's Observatory

- A dynamic online tool for regional policymakers, funders and performers to share relevant information on their policies, instruments and innovation activities supporting PM/PH in European regions.
- An instrument for change and kick-start for networking and partnerships.

The SAPHIRe Observatory is the result of the activities as described in deliverables D.2.1 (Information Gathering Methodology), D.2.2 (Regional PM Profiles) and D.2.3 (Regional Complementarities to implement PM/PH). The Observatory is meant as a living document and starts as a pilot with ten regions that completed the survey as described in D.2.2. Regularly, new regions will be added and information updated during the lifetime of the SAPHIRe project.

3 Description and Methodology

The SAPHIRe Observatory presents information per region on the state of affairs in PM/PH developments and implementation. It should be noted that the level of detail differs per region, which however, does not affect the potential of the observatory. It is not intended to be complete, but rather to give an indication of the state of play. After all, not every region has the same level of maturity in the domain of PM/PH.

Creating this online observatory is a demanding process, due to extensive research. The steps of the selection procedure are the following:

1. Detailed information about each region's initiatives is collected and scanned;
2. The collected data is filtered by the SAPHIRe Observatory administrator;
3. The final collection is further examined by our team that judges whether the initiatives can be uploaded in the observatory.

Because all information gathered is valuable, we keep records of all initiatives found, even though they might not get through the selection process of the observatory.

Each region is screened for certain types of available information. This may differ per region. In general, the following minimum set of information needs to be identified:

- Region (incl. NUTS code)
- Main PM/PH domain (Policy or Innovation or Implementation)
- Supporting docs: Annual workplans, multi-annual plans, white papers, policy briefs, funding instruments, bio-clusters, etc.
- Website link(s)
- Main Regional Public-Private Partnerships (PPPs) (portfolio)
- Key words (optional)

4 Rationale

The reasons for launching the SAPHIRe Observatory can be summarised as follows:

- Information on PM/PH in Europe and its regions is very fragmentated;
- The topic of PM/PH is very diverse, and the stages of development with respect to research, innovation and implementation differ strongly from region to region;
- There is a need to identify which regions are doing what and why: key initiatives, key actors, etc.;
- There is a need for making information available for sharing between stakeholders in regions and other interested parties;
- The observatory offers a tool for analysing information, creating synergies and identifying leads for interregional co-operation and alliances throughout Europe.

REGIONS	SAPHIRe
• Awareness on the current situation in Europe • Detailed and up-to-date information about other countries and regions • Central point for new initiatives • Profiling/PR	• Awareness of the need for synergy • Profiling/PR • Prospective workshop attendants. • Website visitors • More data for the Observatory • Larger network
IC-PERMED	**EC**
• Linkage to regions: regional innovation strategies • ..	• Insight on capabilities & capacities in regions •

5 Press Release

The launch of the SAPHIRe Observatory will be announced by means of the following press release:
"**SAPHIRe has launched its Observatory**, an online database that allows the public to search for a

region in Europe and which will provide an overview of regional activities in personalised medicine,

as well as links to policy documents and major initiatives. Having all this information collated and

available in one place, the Observatory will be extremely useful for regional policymakers, funders and other key stakeholders to share relevant information on their policies, projects and innovation activities related to personalised medicine.

In July SAPHIRe launched a [survey](#) to gain insight into the current status of personalised medicine-related policies and activities across European regions. The information collected in the survey was used to develop the Observatory. As the Observatory is meant to be a living document and continued information gathering is crucial, the survey can still be accessed and regular updates of the Observatory are planned.

At present, the personalised medicine landscape in Europe is fragmented, and, it is not clear what policies and strategies exist. It is also unclear what personalised medicine-related activities and initiatives European regions are involved in.

SAPHIRe's aim is to help structure the adoption and implementation of personalised medicine at regional level by creating favourable ecosystems. This however, is a particularly challenging task; regions have many different developmental needs, and readiness levels are complicated by many factors, including the fact that policies emanate from many levels including EU, national and regional level, on a multitude of topics such as research, innovation, healthcare, data protection and socio-economic issues.

The information collected in the survey will also form part of SAPHIRe's mapping exercise, which will provide SAPHIRe with an insight into specific regional needs and requirements. This will provide SAPHIRe with information about regions' current personalised medicine-related activity, and, will feed into development of the SAPHIRe Stakeholder Platform. Ultimately this Platform will be a forum for joint regional collaboration, design, partnering, and identification of opportunities for joint actions between regions.
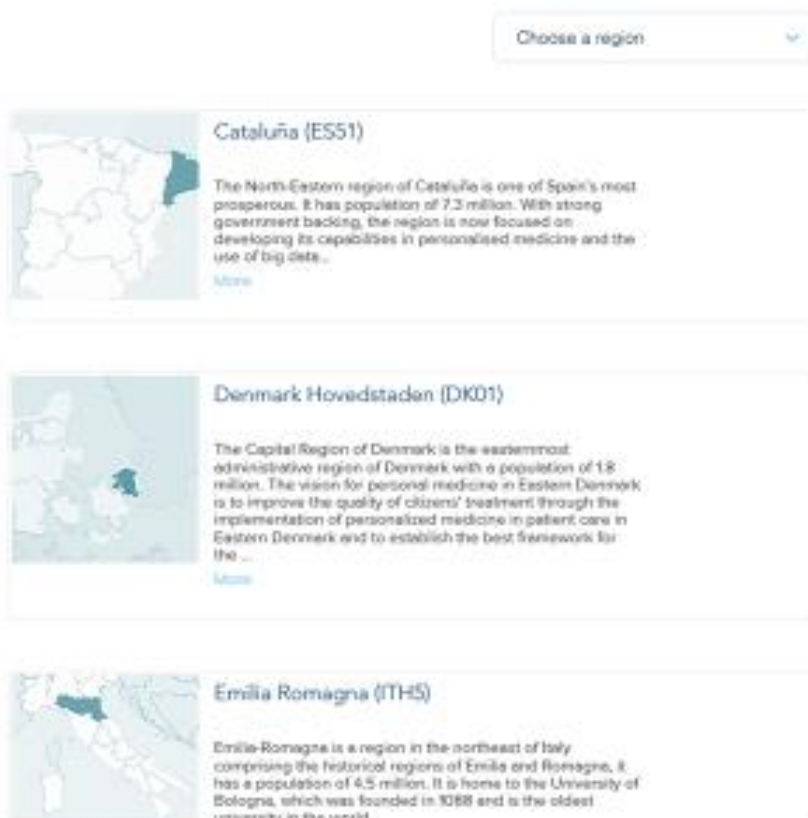
The Observatory has been launched as a pilot phase with ten regions currently in the database. The second phase of regions will be added in early 2020. The database will serve as a dynamic tool and we encourage regional stakeholders to contact us with updates."

6 Screen prints

The Observatory is accessible via SAPHIRe's website www.saphire-eu.eu. Below some screen prints of the observatory are shown:

This observatory has been created as a dynamic online tool for regional policymakers, funders and other key stakeholders to share relevant information on their policies, projects and

The database allows users to search for a region and will provide an overview of regional activities in precision medicine. If your region is not featured in the database and you would like it to be please contact us.

Choose a region

Cataluña (ES51)

The North-Eastern region of Cataluña is one of Spain's most prosperous. It has population of 7.3 million. With strong government backing, the region is now focused on developing its capabilities in personalised medicine and the use of big data...

More

Denmark Hovedstaden (DK01)

The Capital Region of Denmark is the easternmost administrative region of Denmark with a population of 1.8 million. The vision for personal medicine in Eastern Denmark is to improve the quality of citizens' treatment through the implementation of personalized medicine in patient care in Eastern Denmark and to establish the best framework for the ...

More

Emilia Romagna (ITH5)

Emilia-Romagna is a region in the northeast of Italy comprising the historical regions of Emilia and Romagna. It has a population of 4.5 million. It is home to the University of Bologna, which was founded in 1088 and is the oldest university in the world...

Cataluña (ES51)

The North-Eastern region of Cataluña is one of Spain's most prosperous. It has population of 7.3 million. With strong government backing, the region is now focused on developing its capabilities in personalised medicine and the use of big data.

The Catalan government's Research and Innovation in Health Directorate have stated that personalised medicine is a key priority for the region. The science and infrastructure are already available, the goal is to move to make personalised healthcare an area of interest and build on the available assets that exist within the region.

Regional website
https://icsalutsocial.cat/en/

Policy document (RIS3): Yes
Policy document PM(RIS3): Yes

Policy documents

1. National level: Recommendations proposal for a state strategy http://www.aegh.org/wp-content/uploads/2017/04/Propuesta-de-Recomendaciones-MPP-_-Def.pdf
2. National level: A status report about personalized medicine in Spain
   https://www.institutoroche.es/static/pdfs/MPP_EN_ESPANA_MAPA_DE_CCAA.pdf

Major initiatives

1. GCAT- Genomics for lyfe http://www.gcatbiobank.org/qui-som/en_index/Barcelona
2. Supercomputing Centre - Marenostrum Super computer, Genomics, molecular modeling, https://www.bsc.es/research-and-development/research-development
3. CRG- Centre for genomic regulation international biomedical research institute, genomics, bioinformatics, proteomics, tissue engineering https://www.crg.eu/en/content/about-us/general-information

Is the region represented in: Horizon2020; Regional Smart Specialisation Strategy Platforms/Partnerships (RIS3); EIT Health/InnoStars/Regional Innovation Scheme (RIS), other?

1. CeLac and European consortium for a personalized medicine approach to Gastric Cancer
2. IndividualizedPaediatricCure: Cloud-based virtual-patient models for precision paediatric oncology
3. EUCANCan: a federated network of aligned and interoperable infrastructures for the homogeneous analysis, management and sharing of genomic oncology data for Personalized Medicine

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Denmark Hovedstaden (DK01)

The Capital Region of Denmark is the easternmost administrative region of Denmark with a population of 1.8 million. The vision for personalized medicine in Eastern Denmark is to improve the quality of citizens' treatment through the implementation of personalized medicine in patient care in Eastern Denmark and to establish the best framework for the further research and development of personalized medicine.

With this in mind the Capital Region, the Zealand Region, the University of Copenhagen SUND and the Technical University of Denmark have joined forces to establish an infrastructure consisting of three common centres: Data Center East, Biobank Center East and Genome Center East.

Regional website
http://www.regionh.dk

Policy document (RIS3): Yes
Policy document PM(RIS3): Yes

Policy documents

1. Regional (national) level: Personalized Medicine in Eastern Denmark
   https://www.regionh.dk/personligmedicinoest/Sider/forside.aspx
2. National level: Danish National Genome Center https://eng.ngc.dk/

Major initiatives

1. iPSYCH https://ipsych.au.dk/about-ipsych/
2. PERSIMUNE http://www.persimune.dk/
3. Personalized Medicine in Eastern Denmark Genome, data and biobank https://www.regionh.dk/personligmedicinoest/Sider/forside.aspx