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Report on personalised medicine Round Table events showcasing regional best practices Date delivered: 14 April 2022

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## Background

SAPHIRe is a coordination action which has as overarching longterm goal to structure the application of personalised health (PH) at regional level. Regions have an important role to play as they may often be considered as powerhouses for innovation. The adoption of personalised health will drive the transition towards sustainable healthcare and personalised health and will further boost innovation. Three large pillars of activities were organised by SAPHIRe to develop the work throughout the project: **Observe, Network** and **Support**.

In this context a series of roundtables have been organised to reach out to regions that are less advanced in the development of personalised medicine and health. The roundtables were organised and executed by EIT Health InnoStars, one of the partners in the SAPHIRe project. InnoStars acts as an EIT Health CLC (Co-Location Center), providing coverage of healthcare innovation activities across the so-called RIS (Regional Innovation Scheme) countries. The EIT Regional Innovation Scheme (EIT RIS) was introduced in 2014 to advance the innovation performance of more countries and their regions across Europe, especially countries with moderate or modest innovation scores as defined by the European Innovation Scoreboard. Since its establishment, the EIT RIS, which is steered by the EIT and implemented by its Knowledge and Innovation Communities (KICs), has successfully led to a significant expansion of EIT Community activities to more countries and regions across Europe, contributing to a pan-European spread of EIT Community engagement opportunities and networks. At present, the EIT RIS consists of 17 European countries, including Bulgaria, Croatia, Cyprus, Czech Republic, Estonia, Greece, Hungary, Italy, Latvia, Lithuania, Malta, Poland, Portugal, Romania, Slovakia, Slovenia, Spain.

The SAPHIRe Personalised Health Roundtables have been conducted to meet one of the SAPHIRe project aims – to **Observe**. A mapping exercise, additional to that represented in SAPHIRe's Observatory will address specific needs of regions in RIS countries, while taking the different levels of personalised health maturity into account.

SAPHIRe in the first-place addresses regional personalised medicine (PM) policies, starting from the idea that regions are ideal drivers for innovation.

The specific objective of the roundtables was to reach out to sparsely populated regions, remote regions, and/or modest/moderate regions in terms of research, innovation, and implementation of personalised medicine and health. RIS regions were contacted and involved in an attempt to create an interface between regions with different personalised medicine-Readiness-Levels in order to learn, share and collaborate.

In an extensive effort to contact relevant regional representatives from the RIS countries, it turned out to be particularly difficult to identify and interact with regional policymakers. On the other hand, representatives of academia were much more receptive to the invitations to take part in the roundtables. A total of 6 roundtables took place, covering 20 NUTS2 regions from the following countries: Lithuania, Romania, Greece, Poland, Portugal, Hungary, Bulgaria and Italy. In total, about 26 regional experts confirmed participation in the roundtable meetings, including one from Croatia, Serbia and Slovakia. However, a total of 6 regional experts had to cancel last minute due to health reasons, or simply did not show up. Only the Polish region Wielkopolska was represented by an official of the regional authority. Other participants were in the majority academics from universities or research centres. Five participants represented respectively a patient organisation, an entrepreneurial development institute, a personalised medicine association, a regional development agency and a cluster organisation. See Annex 1 for more details.

The roundtables took place in February 2022. The detailed findings from each Roundtable meeting have been detailed in the appropriate sections describing each meeting (see Annex 2).

## Summary of the roundtable discussions – Personalised medicine in RIS regions

## 1. Focus of the roundtables

The dialogue in each roundtable was organised around the same four main themes, with specific questions:

- 1. **Policies and Strategies** what kind of public policy exists in the region for supporting personalised medicine, and personalised health?
- 2. **State of Affairs** how widespread is personalised medicine in the respective region? In what sort of disciplines is it employed, and how often? What sort of barriers stand in the way of it's more widespread use or acceptance in the population?
- 3. **Current projects** In what sort of projects are the local institutions involved? , With what kind of goals and what sort of funding?
- 4. **Future Projects** what sort of plans do local institutions have for future projects? What kind of needs do they have to be able to implement them?

## 2. Policy Feedback

While reaching out to regional institutions in the RIS countries, we encountered difficulties in identifying the right contacts within regional governments and establishing a working relation with them. There is an apparent lack of contact between the scientific community (predominantly EIT Health InnoStars/RIS contacts) and the regional governments. There is also a lack of insight in portfolios and pipelines in the regions and

thus an incomplete picture of regional capacities & capabilities, which may be leading to wrong conclusions; as a result, it is still difficult to assess the personalised medicine-Readiness-Level in these regions.

There is significant variability in policy support for personalised health from region to region. In some regions support is at least partially established, and governments at regional and national levels have strategies to support certain better developed niches linked to personalised health. According to the interviews that we conducted, the subfields of medicine that receive widest financial support both in terms of research development and for initiatives to develop personalised medicine, are especially oncology and haematology.

In other regions policy support to develop personalised health is still emergent; from our data we could conclude that in these regions there are almost no strategies at national or regional level to finance, support and encourage the development of personalised medicine, while the academics present in the roundtables vocalised a clear commitment and interest to further develop and implement personalised medicine in their regions. In some cases, representatives of regional institutions noted that they often lack the relevant equipment to conduct the necessary research projects. It was noted that public-private partnerships may be supportive in giving access to and taking advantage of regional resources and expertise, and in connecting to private often more national or global resources. Academic institutions have an interest in the development of personalised medicine and networks that sustain innovation and intervention in the foreseeable future, but have limited insights and influence on regional policy.

In Portugal, Poland, Greece and Romania, where participating regions made references to regional as well as national strategies related to personalised medicine, participating experts manifested confusion on conflicting approaches and priorities. For example, in the RIS3 plans of Romania NW personalised medicine was a priority until 2020, as well as in the 2018-2022 National R&D strategy, recommending the mobilisation of regional funds for research projects. However, starting 2021, personalised medicine has been removed from the Romanian NW RIS3, with the result that regional funding for research projects is no longer available. Similar occurrences have also been mentioned by Greek and Portuguese participants, but in fewer details.

## 3. Research and Innovation Feedback

Where personalised medicine was mentioned in regional policies, the resource allocation varied from region to region. Apart from some participant regions from Poland, Portugal and Lithuania, with emerging initiatives towards adoption, most participants displayed policy support, where existent, towards research and development. Also, very few support and funding is currently allocated towards patient's education in order to further aid their empowerment in the participant regions. Whether representatives of regional

institutions do or do not mention personalised medicine as a priority, there is a general lack of interregional or international collaborative efforts felt among the participants, as all RIS3 priorities from participant regions are focused on the regional geographical limits, with little emphasis on interregional or international collaboration. In our target group, existing personalised medicine priorities in RIS3s are focusing on genetic and genomic data, as well as biomarkers, but have little coverage of the epigenetical aspects of precision medicine. The only mentioning of environmental and behavioural factors as part of personalised medicine was in Romania's Bucuresti-Ilfov Region, referring to a national strategy still to be voted on. This is an issue to be addressed in the development of future personalised medicine policies, both regionally and at broader levels.

The identified research projects from the interviewed regions have a strong focus on biomarkers and genomic data, as a means to facilitate precision treatment in the future. There was, however, one project involving three participating regions in the roundtables, one from Romania, one from Greece and one from Bulgaria, focusing on awareness raising and improving trust in personalised medicine. This project had limited focus on precision vaccines, but it was one of the very few projects actively involving the patients. Furthermore, it is a good example of a research project reuniting three poor or moderate innovator regions under the Twinning funding call.

Participants involved in the roundtables also displayed limited understanding of personalised medicine practices and of personalised medicine medium-long term impacts on healthcare systems, as well as limited insight in regional/national personalised medicine policies. One of the most important aspects that should be improved are communication and information flow. Only to some degree regional personalised medicine policies were found in Portugal and Lithuania. However, there is little emphasis on concrete steps towards large-scale adoption of personalised medicine - patients and patient organisations are insufficiently involved and there is little synergy with the state budget for the actual practice of personalised medicine.

#### Recommendations

Given the aforementioned hurdles in reaching out to regional policymakers/authorities and inquiring about the personalised medicine-Readiness levels in the involved regions, policy recommendations are limited to the findings resulting from the Roundtables process.

1. Develop a better understanding of personalised medicine impact on regional healthcare ecosystems

This item is generally recognised by regional policymakers in the regions taking part in the roundtables. The development of policy revolving around personalised medicine has limited medium and long-term strategic vision on healthcare system impacts. It is becoming clear that personalised medicine can help reduce the burden and load on Healthcare professionals. Demonstrators and pilot projects may be more convincing to encourage implementation. Prevention, a pillar of personalised medicine, is proven to reduce overall expenditure.

A better understanding can be acquired through a thorough consultation and awareness creation among with regional experts such as healthcare professionals, researchers, industrialists and, ultimately, patients / patient organisations.

#### 2. Thorough HTA frameworks and methodologies

To increase and advance adoption of personalised medicine at regional levels, public authorities, policymakers, and Healthcare professionals require a better understanding of the medium- and long-term impact of personalised medicine. There is a need for thorough Health Technology Assessment (HTA to demonstrate the added value of personalised medicine. Furthermore, appropriate assessment supports authorities in developing adequate reimbursement models and procurement frameworks, adapted to regional needs.

#### 3. Mobilize funds towards personalised medicine development and adoption

As mentioned by all roundtable participants, insufficient resources are the main barrier to accelerated and large-scale development and adoption of personalised medicine. The financial needs span from acquisition of appropriate equipment to reimbursement of services by state and/or private stakeholders. Increasing expenditure in personalised medicine in four main directions - R&D, infrastructure, capacity building, and awareness-raising - will result in regional healthcare ecosystems demonstrating a general decrease in disease burden and an increase in healthy life years at the regional level.

## 4. Identify and capitalize on systemic synergies

Another common finding is that Healthcare professionals and researchers are not synchronized in delivering diagnostics or care. More often than not, personalised medicine in the interviewed regions is an on-demand, costly service not affordable to the general population. The research and development efforts are somewhat divergent from those of practitioners.

This gap can be bridged through policy encouraging and funding demand-driven projects that solve specific and real regional needs. Furthermore, synergies have

been observed between national personalised medicine policy and regional initiatives. However, to avoid waste of resources and gain a multiplier effect on personalised medicine advancements, thorough knowledge of available policies that have regional impact is needed. Furthermore, in the development of policy, it is essential to conduct consultation with all possible sources of health services reimbursement, varying from national insurance mechanisms to national programmes for specific diseases and leading up to private insurance companies.

#### 5. Interregional dimension

We consider it essential to reinforce, by means of regional policy, the need to cooperate with other regions, in this case, more advanced regions in terms of personalised medicine readiness levels. Transfer of best practices, methodologies, frameworks and even specific approaches on identified problems represents a valid means to avoid unnecessary expenditure and leads to accelerated adoption of personalised medicine. Mechanisms should be developed that support problem identification, organisation, formulation of joint-projects, acquire/re-allocation of financial means and monitoring of progress.

#### 6. Regard personalised medicine in its entirety

Findings from the roundtables showed that most personalised medicine efforts are concentrated around different types of cancer and genetic and biomarker testing (but our findings might be biased given our pool of participants). While it is obvious that cancer and rare diseases are a substantial part of personalised medicine application domains, the application fields of personalised medicine are considerably broader. It is therefore recommended that future policy regarding personalised medicine adopt a broader vision on the matter, including areas of intervention and domains of application beyond those commonly mentioned.

#### 7. Look beyond programming periods

By definition, RIS3 strategies coincide with the European Multiannual Financial Framework (MFF). This means that policies and strategies define goals and performance indicators currently for the 2021-2027 period. However, for personalised medicine to manifest an advancement in public health, it requires time, awareness raising and impact assessment. It is therefore important to develop policies that go beyond the programming periods, and take into account the effects of personalised medicine implementation, adoption, as well as R&D over the course of a longer period of time.

ANNEX 1 List of pa	articipants in round	table discussions
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Country	Region	Name	Organisation	Field of Activity
Bulgaria	BG34 Southeast Region	Prof. Emil Slavov Slavov	Trakia University, Department of Molecular Biology, Immunology and Medical Genetics	Professor, researcher, local policymaker
Greece	EL30 Attica	Piyi Papadaki	Fleming Research Centre	Infrastructure manager / innovation consultant - pMedGR National Research Infrastructure
Greece	EL61 Thessaly	Maria Pournari	iED (Institute of Entrepeneurship Developmlent)	Proposals & networking manager of iED
Greece	EL62 Ionian Islands	Dr. Themistoklis Exarchos	Ionian University, department of informatics	Assistant Professor, worked on Interreg Ilonet, topics: machine learning, data mining
Greece	EL63 West Greece	Diana Portan	University of Patras, Greece & Advanced centre of medical and pharmaceutical research of Targu Mures, Romania	Dr. of Bioengineering, researcher
Hungary	HU11 Budapest	Balázs Nagy	Hungarian Association for Personalised Medicine (Centre for health technology assessment)	Associate professor at Semmelweis University, Health Economics, Health technology assessment, health insurance, health policy, healthcare financing
Hungary	HU23 Pécs	Noémi Liber	University of Pécs, Institute for Transdisciplinary Studies	Deputy director and innovation expert

Italy	ITF3 Campania	Prof. Daniela Terracciano	Federico II University of Naples	Associate professor of clinical pathology
Lithuania	LT	Lolita Sileikiene	Lithuanian University of Health Sciences, Department of Preventive Medicine	Lecturer at Lithuanian University of Health Sciences
Lithuania	LT	Laurynas Jarukas	Lithuanian University of Health Sciences, Department of Preventive Medicine	Head of Development Department at Lithuanian University of Health Sciences
Lithuania	LT	Auksė Domeikienė	Lithuanian University of Health Sciences (LSMU), Department of Family Medicine, Faculty of Medicine	President of the Lithuanian Obesity Association, Associate professor of Lithuanian University of Health Sciences (LUHS), Head of the department of preventive medicine (LUHS)
Poland	PL41 Wielkopolska	Jaroslaw Cieszkiewicz	Regional Government, Public Health Department	Head of the Public Health and Addiction Prevention Department, Wielkopolskie province
Poland	PL71 Lodzkie	Professor Ewa Balcerczak	Medical University of Lodz	Head of the chair of laboratory and molecular diagnostic, rector's proxy for postgraduate education
Portugal	PT16 Central	Manuel Santos	University of Aveiro	Director of Health Sciences at the university of Aveiro, director of iBiMed, creator of Aveiro RNA biology laboratory and the national facility for DNA micro-arrays, coordinator of the GenomePT consortium
Portugal	PT17 Lisboa	Tamara Hussong Milagre	European Patient Advocacy Group, European Reference Network (ERN) for patients with genetic tumour risk syndromes (GENTURIS)	President of EVITA and ePAG Representative at European Reference Network GENTURIS

Portugal	PT18 Alentejo	Hernâni Zão Oliveira	University of Evora	Professor, founder of BRIGHT, beyond research and information graphics for health and technology
Romania	R011 NW Region	Prof. Ioana Berindan- Neagoe	UMF Cluj	director research centre for functional genomics, biomedicine and translational medicine
Romania	R012 Centru Region	Prof. Claudia Bănescu	UMFST Targu Mures, Medical University	Head of genetics, morphological sciences, Medicine
Romania	RO21 NE Region	Lidia Tereza Betoaea	NE RDA (North-East Regional Development Agency)	program manager @Rubik Hub, expert smart specialisation strategy
Romania	RO21 NE Region	Carmen Mihai	Cluster Imago MOL	Cluster manager at Cluster IMAGO-MOL
Romania	RO22 SE Region	Dr. Alina Martinescu	University Ovidius Constanta, Medical Genetics, Faculty of Medicine	lecturer and researcher
Romania	RO32 Bucharest- Ilfov	Marius Geanta	President Centre for Innovation in Medicine	Co-founder of the Centre for innovation in Medicine and national task force manager for Romania of Public Health Genomics Network, expert on the European personalised medicine development platform, member of the European Alliance of personalised medicine

## ANNEX2 - Structure of roundtables

The roundtable participants were contacted via e-mail, starting from an existing EIT Health InnoStars database of contacts with expertise and interest in personalised medicine and health, explaining the aims of the SAPHIRe project, as well as the reason for conducting the meetings. In total, about 60 potential participants were contacted. The following Agenda was proposed and sent together with the invitation:

#### Introduction - 10 min

- Introduction from the moderator (quick summary of SAPHIRe project, purpose of roundtable)
- Introduction of participants

## Policies & strategies - 15-20 min

- PM/ PH related priorities in the RIS3 strategy for 2021-2027
- PM/ PH related priorities and funding opportunities in ERDF 2021-2027

## personalised medicine state of affairs - 15-20 min

- Implementation level of PM/ PH in the region, good practices, unmet needs
- Need for PM/ PH policy support and funding in the region

## Current interregional project/partnerships – 15-20 min

• Ongoing national and international projects and collaborations related to PM/ PH (examples)

## Future interregional project/partnerships – 15-20 min

• Intentions and plans to participate in national and international projects and collaborations related to PM/ PH

## Closing - 15 min

- Closing remarks and thoughts from participants
- Wrap up and next steps by the moderator

The roundtable meetings were allocated an average of 90 minutes. Most of them took between 80 and 90 minutes, with just one lasting 100 minutes. In general, the allocated time frame was sufficient to cover the aspects mentioned in the agenda. The introduction was done using a visual presentation with slides provided by the project team. The roundtable moderator was Dr. Zaki Milhem, an external EIT Health InnoStars Expert. All the meetings took place on **Microsoft Teams Platform**. During each meeting, the moderator asked participants permission to record the meetings, which was agreed upon by all the participants.

For a better understanding of the Regional personalised medicine landscape, a supplementary online software was used - **Miro** (<u>www.miro.com</u>). This tool allows for online collaborative activities and is accessible via a shareable link (also shared in the MS Teams chat section). The moderator created a Miro Canvas that was reflective of the roundtable agenda and allowed participants to fill in the information as replies to the questions raised. This approach increased engagement and generated a sense of interactivity and collaboration.

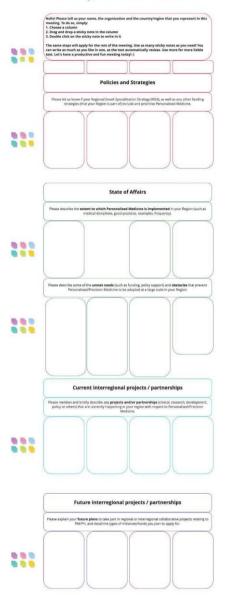
## The Miro Personalised Medicine Roundtable Canvas had the following structure:

The initial part contains instructions on how to use Miro. On the left side of each section, there are digital versions of sticky notes, which participants dragged and dropped in the respective boxes, in order to add their inputs on each question/section.

The dialogue was organised around four main themes, with specific questions for each of them, as follows:

- 1. **Policies and Strategies** what kind of public policy exists in the region for supporting personalised medicine, and personalised health?
- 2. **State of Affairs** how widespread is personalised medicine in the respective region? In what sort of disciplines is it employed, and how often? What sort of barriers stand in the way of its more widespread use or acceptance in the population?
- 3. **Current projects** In what sort of projects are the regional institutions involved? , With what kind of goals and what sort of funding?
- 4. **Future Projects** what sort of plans do regional institutions have for future projects? What kind of needs do they have to be able to implement them?

The filled-in Miro canvases covering the detailed findings for each meeting for each roundtable meeting are available in Annex 2. These canvases served as the main output of the roundtables and a building block for this report, containing a synthesis of findings on each raised aspect.



SAPHIRe Personalised Medicine Roundtable Monday, Feb 14th 2022, 15 CET

# ANNEX 3 - Detailed Findings from Roundtables

## Disclaimer:

The findings in the interviews represent the views of the participants themselves, not the official views of the organisations they represent or those of the regions involved.

## Roundtable 1 - February 14th 2022 - 15:00 CET

#### Links mentioned in chat:

https://news.ki.se/self-paced-online-course-through-stanford-university-partneringwith-the-public-and-patients-in

Participants:

Organisation	Field of Activity	Region	Country
University of Aveiro	Academia	PT16 Central	Portugal
iED (Institute of Entrepreneurship Development)	Project management and networking	EL61 Thessaly	Greece
Ionian University, department of informatics	Academia	EL62 Ionian Islands	Greece

1. Policies and Strategies.

First, we wanted to ascertain in which regions personalised medicine is a priority. We asked: "Please let us know if your Regional Smart Specialization Strategy (RIS3), as well as any other funding strategies (that your Region is part of) include and prioritise Personalised Medicine."

The level at which personalised medicine is prioritised in different regions varies greatly as it can be glanced from participants' responses.

- University of Aveiro; Centro region of Portugal: "Our region prioritised Personalised Medicine and has already funded a 1M€ project to prepare a medium/long term strategy. The 3 universities and all hospitals of the region are involved. The national government also nominated a work group to prepare a strategy for Genome Medicine for the country."
- IED, Thessaly, Greece: "Thessaly, my region, does not include nor prioritise Personalised Medicine. Almost 5.000.000€ were given to 4 PMUs for Oncology, by

Siemens and the Greek government; 2 PMU's in Athens, 1 in Thessaloniki and 1 in Crete."

- Ionian Islands: "There is no mention of PM in the Ionian Islands, but there are attempts at the National level. The initial focus is on oncology and CVD (cardiovascular disease) and neurodegenerative and rheumatoid diseases follow."
- 2. State of Affairs

We posed the following question to our participants: "Please describe the extent to which Personalised Medicine is implemented in your Region (such as medical disciplines, good practices, examples, frequency, etc.)."

There exist some attempts to implement personalised medicine regionally.

- Centro Region of Portugal: "We have pilot projects only driven by academic researchers, in oncology, diabetes and COPD.".
- Thessaly, Greece: "In Thessaly, none of the public nor private clinics work with Precision Medicine, which is one of the reasons we decided to develop a relevant EDIH here."
- Ionian Islands: "Oncology and CVD in Athens and Crete. ND diseases and other autoimmune diseases are pending regulatory approvals."

# A further point of interest we inquired upon was: "Please describe some of the unmet needs (such as funding, policy support) and obstacles that prevent Personalised/Precision Medicine to be adopted at a large scale in your Region."

Our interviewees noted several obstacles that are currently having a prohibitive effect on the development of personalised medicine.

- Centro Region of Portugal: "Obstacles: small number of clinical geneticists available, lack of funding and infrastructure to support personalised medicine, inadequate legislation and regulatory framework to introduce personalised medicine in routine clinical practice. Very heavy workload of clinicians. Few experts and multidisciplinary teams for integration of clinical data, biobanks, genomics data and reporting."
- Thessaly, Greece: "There is a lack of bridging the gap between research and the market / research and government administration."
- Ionian Islands: "Focus on diseases with a large genetic background. Identify the missing pieces from clinical trials to everyday clinical practice."

3. Current interregional projects / partnerships

We posed the following question to our participants: "Please mention and briefly describe any projects and/or partnerships (clinical, research, development, policy or others) that are currently happening in your region with respect to Personalised/Precision Medicine."

Unfortunately, there are really few projects currently unfolding:

- Centro Region of Portugal: "Genome Medicine project funded by the regional authority (CCDRC), involving academia and hospitals (mentioned above)."
- Ionian Islands: "Existing collaboration of Ionian University with Altoida A.G. for precision medicine methodologies for early detection of Alzheimer's disease, based mainly on digital biomarkers."
- 4. Future interregional projects / partnerships

To ascertain the level of regional interest for developments in personalised medicine we asked: "Please explain your future plans to take part in regional or interregional collaborative projects relating to PM/PH and detail the types of initiatives/funds you plan to apply for.

- Centro Region of Portugal: "The Portuguese genome, integrated in the European 1+MG and the European genome project. Funding is still unclear."
- Thessaly, Greece: "We could offer our ecosystem which consists of healthcare providers, Tech companies, Universities labs and departments etc. For sure open the discussion also to the public through patient's associations and active doctors in PM. We would need good practices to be brought here on a European level and then explore what we could do on a national level with the rest of the PM entities which already exist."
- Ionian Islands: "Personalised medicine calls of Horizon Europe."

## Roundtable 2 - February 15th 2022 - 15:00 CET

## Links mentioned in the chat:

https://www.saphire-eu.eu/saphirefinalevent https://nkfih.gov.hu/english/national-smart-specialisation-strategy/s3-strategy-2021-2027

## Participants:

Organisation	Field of Activity	Region	Country
Fleming Research Centre	Management	EL30 Attica	Greece
University of Patras, Greece & Advanced centre of medical and pharmaceutical research of Targu Mures, Romania	Academia	EL63 West Greece	Greece
University of Pécs, Institute for Transdisciplinary Studies	Management/ Academia	HU23 Pécs	Hungary
Regional Government, Public Health Department	Public policy	PL41 Wielkopolska	Poland

## 1. Policies and Strategies

First, we wanted to ascertain in which regions personalised medicine is a priority. We asked: "Please let us know if your Regional Smart Specialization Strategy (RIS3), as well as any other funding strategies (that your Region is part of) include and prioritise Personalised Medicine."

The level at which personalised medicine is prioritised in different regions varies greatly as it can be glanced from participants' responses.

- Attica: "PM is part of the RIS3 strategy both at the national level as well as the Regional (Attica) level."
- West Greece: "National and European proposals, applied mainly by State University as a main applicant in cooperation with companies. personalised medicine is usually assured by foreign partners within these projects."
- Pécs: "General expectation from gov/population to develop in PM"
- Wielkopolska:
  - a. Regional Innovation Strategy for Wielkopolska up to 2030

- b. The Wielkopolska Region Development Strategy up to 2030.
- c. Healthy future Strategic Frame for Health Care System for the period 2021
  2027 (national)"

## 2. State of Affairs

## We posed the following question to our participants: "Please describe the extent to which Personalised Medicine is implemented in your Region (such as medical disciplines, good practices, examples, frequency)."

There exist some attempts to implement personalised medicine regionally.

- Attica: "Partially implemented at the research level in several disciplines, especially through the use of high- end technological platforms."
- West Greece: "personalised medicine can go to any extent with the condition that it doesn't affect patients' integrity and there is NO CLONING INTENTION. There is a need to elaborate a new detailed protocol for each study. Huge paperwork!"
- Pécs: "Oncology is in private refinement, if it is approved by the regional oncoteam, public funding is possible."
- Wielkopolska: "There are attempts in oncology, geriatrics, biobanking, physiotherapy and genome sequencing."

# A further point of interest we inquired upon was : "Please describe some of the unmet needs (such as funding, policy support) and obstacles that prevent Personalised/Precision Medicine to be adopted at a large scale in your Region."

Our interviewees noted several obstacles that are currently having a prohibitive effect on the development of personalised medicine.

- Attica: "Necessity for continuous funding as well as alignment with EU policies, access to necessary technologies and tools, need for increased public awareness".
- West Attica: "There is a great need of a special unit with multidisciplinary background and a centralised platform which would enable a guided protocol and connect patients, physicians, researchers, stakeholders."
- Pécs: "Funding, high-tech infrastructure".
- Wielkopolska: "Funds, high- tech infrastructure, public fear of PM, weak coordination and cooperation between public and private sectors."

3. Current interregional projects / partnerships

We posed the following question to our participants: "Please mention and briefly describe any projects and/or partnerships (clinical, research, development, policy or others) that are currently happening in your region with respect to Personalised/Precision Medicine."

Unfortunately, there are insufficient projects currently unfolding:

- Attica: "Some projects implemented at the national level through NSRF 2014-2020, as well as EU ERA Permed etc. There is room for much more."
- West Attica: "Biomimetic nanocomposite 3D scaffolds for bone regeneration: Control of osteogenesis and angiogenesis through physicochemical stimuli (T2EDK-03681)."
- Wielkopolska: "Inpronko proton therapy in oncology Covid monitor."
- 4. Future interregional projects / partnerships

To ascertain the level of regional interest for developments in personalised medicine we asked: "Please explain your future plans to take part in regional or interregional collaborative projects relating to PM/PH and detail the types of initiatives/funds you plan to apply for."

- Attica: "We look forward to interactions with clinical/research/policy makers at the EU level to facilitate further implementation of PM in our region."
- West Attica: "Enabling patients' positive feedback to the European Healthcare system via volunteering and active involvement in medical research. The ideal way towards an innovative and personalised medicine strategy is under evaluation".
- Regional Government, Public Health Department: "EU policy on Cancer initiatives, ERRiN, fit for patient therapies, obesity treatment and prevention."

#### Roundtable 3 - February 16th 2022 - 15:00 CET

Participants:
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Organisation	Field of Activity	Region	Country
UMF Cluj	Academia/ Management	RO11 NW Region	Romania
Medical University of Lodz	Academia/ Management	PL71 Lodzkie	Poland
UMFST Targu Mures, Medical University	Academia/ Management	RO12 Centru Region	Romania

#### 1. Policies and Strategies

# We asked: "Please let us know if your Regional Smart Specialization Strategy (RIS3), as well as any other funding strategies (that your Region is part of) include and prioritise Personalised Medicine."

The level at which personalised medicine is prioritised in different regions varies greatly as it can be glanced from participants' responses.

- Romania NW: "At the national level the strategy includes personalised medicine especially for noncommunicable diseases: cancer, cardiovascular disease, diabetes, obesity at regional level some other areas in the country have included a strategy for personalised medicine. Being at national level all regions comply with the achievement of personalised medicine."
- Lodzkie: "In Poland: oncology (breast cancer, NSCLC, colorectal cancer, hepatocellular cancer) hemato oncology, neurology (sclerosis multiplex, spinal muscular atrophy)."
- Romania Centru: "National project acute myeloid leukaemia, there are some funds at national level for neurology and rare disease."
- 2. State of Affairs

# "Please describe the extent to which Personalised Medicine is implemented in your Region (such as medical disciplines, good practices, examples, frequency)."

There exist some attempts to implement personalised medicine regionally.

- Romania NW: "Especially hospitals that treat cancer, diabetes cardiovascular diseases in the region are using personalised medicine (here included clinical trials that are developed in the region) in the university curricula does not exist a personalised medicine discipline the personalised medicine in cancer intend to be more and more frequent not much done for prevention and genetic, genomic testing till now also for rare diseases financed by national programs."
- Lodzkie: "Oncology hospitals/centres (oncoLAB dedicated for children with hemato oncological disorders). Individual patients who pay for diagnostics."
- Romania Centru: "For treatment of rare disease and acute leukaemia (in hospitals)."

# A further point of interest we inquired upon was : "Please describe some of the unmet needs (such as funding, policy support) and obstacles that prevent Personalised/Precision Medicine to be adopted at a large scale in your Region."

Our interviewees noted several obstacles that are currently having a prohibitive effect on the development of personalised medicine.

- Romania NW: "Money, lack of collaboration with companies including private genomic centres that could offer testing at good prices. Personalised medicine is better for early stages but not for advanced stages in cancer; the majority of patients are coming into the clinic in stage III- IV metastatic diseases where personalised medicine is less efficient. There is a lack of prevention programs and EDUCATION. Many genetic laboratories in the clinics are not working, lack knowhow and support."
- Lodzkie: "Too low funds, poor access to medical data (medical data from patients are not collected, lack of national program), additional criteria for inclusion of patients to therapies."
- UMFST Targu Mures: "The funds are small and come gradually and it is difficult to purchase reagents in time, the law for acquisition make it difficult, we need some equipment, it is possible to test only the patients hospitalised in our Emergency County Hospital, due to some rules of local insurance department, lack of collaboration."
- 3. Current interregional projects / partnerships

"Please mention and briefly describe any projects and/or partnerships (clinical, research, development, policy or others) that are currently happening in your region with respect to personalised/Precision Medicine."

Unfortunately there are really few projects currently unfolding:

- Romania NW: "European projects: Danube project D-Care health support and education for older people including personalised medicine adapted to their needs. personalised medicine in CRC Marie Curie Projects Aptamers as carriers for cancer therapy National projects: breast, renal, prostate, CRC, lung cancers, using personalised medicine use of BCG vaccine for other diseases immuno oncology for lung cancer, AI project for CRC Digital pathology, lung cancer for PM CLoud POC project for big data storage and archive."
- Lodzkie: "Serum metabolome profiling in breast cancer risk assessment (SEMPRA project); cervical cancer; head and neck cancers; oncoLAB (childhood ALL in Poland); PersonALL."
- Romania Centru: "A polygenic prognostic score for AML, NGS for myeloproliferative disorders, (UEFISCDI projects)."
- 4. Future interregional projects / partnerships

"Please explain your future plans to take part in regional or interregional collaborative projects relating to PM/PH and detail the types of initiatives/funds you plan to apply for.

- Romania NW: "Development of collaboration public private sector, national and European calls, establishment of a consortium that can apply to multiple calls based on the expertise, access to federated genomic data, access to comprehensive cancer centres for Europeans, call partnerships between universities, hospitals, SMEs, (like people invited today)."
- Lodzkie: "access to molecular data (database) from other centres/other countries; participation in projects which include more patients and give them the possibility to refund cost of diagnostics."
- Romania Centru: "Implementation of new methods, instruction of people, increasing the tests in PM by increasing the number of collaboration and of projects."

#### Roundtable 4 - February 17th 2022 - 15:00 CET

Participants:

Organisation	Field of Activity	Region	Country
Hungarian Association for personalised Medicine (Centre for health technology assessment)	Academia / Management	HU11 Budapest	Hungary
University Ovidius Constanta, Medical Genetics, Faculty of Medicine	Academia	RO22 SE Region	Romania
University of Evora	Academia	PT18 Alentejo	Portugal
NE RDA (North-East Regional Development Agency)	Public policy	RO21 NE Region	Romania
Cluster Imago MOL	Management / Networking	RO21 NE Region	Romania

#### 1. Policies and Strategies

"Please let us know if your Regional Smart Specialization Strategy (RIS3), as well as any other funding strategies (that your Region is part of) include and prioritise personalised Medicine."

The level at which personalised medicine is prioritised in different regions varies greatly as it can be glanced from participants' responses.

- HU Budapest: "No, in Eastern Europe I do not know of any central funding initiatives. Although I am not the person who is looking for funding; I rather assist others to get funding with the means of HTA."
- SE Romania: "No, I do not know of any funding initiatives in my region."
- Alentejo Portugal: "Alentejo is one of the regions lined up with the National Strategy for personalised Medicine. However, the specific context of RIS3 in Alentejo is more focused on the development of new Health Institutions (New hospital and new Academic Center)."

- NE Romania: "Yes, it is a niche, so it is included in RIS3 funding."
- NE Romania: "Precision medicine is one of the niches of the priority sector -"health" in NE Romania RIS3, and probably under National 3."

## 2. State of Affairs

# "Please describe the extent to which Personalised Medicine is implemented in your Region (such as medical disciplines, good practices, examples, frequency)."

There exist some attempts to implement personalised medicine regionally.

- HU Budapest: "I do not see governmental funding behind, but... what I can see is that pharma companies explore and invest in PM, to better identify their target groups and get a larger market. This is not always a success story as the value of PM is difficult to explore (you need proper HTA analysis etc.). Private technology developers of course are looking for funding opportunities. national and EU."
- SE Romania: "We do not have governmental funding, only some pharmaceutical companies try to cover some genetic tests for PM."
- Alentejo Portugal: "As a region, Alentejo wants to have more activities in this domain (the University wants to incorporate the Medicine course). The LifeSpan chair is one example of activity that wants to use personalised Medicine in the area of Cardiology."
- NE Romania: "I don't know any good practices, only start-ups that test their products."
- NE Romania: "Regional Institute of Oncology is running screening programs for certain types of cancers. They have also TRANSCEND and they are looking forward to translating biomarkers in the clinical practice."

# A further point of interest we inquired upon was: "Please describe some of the unmet needs (such as funding, policy support) and obstacles that prevent Personalised/Precision Medicine to be adopted at a large scale in your Region."

Our interviewees noted several obstacles that are currently having a prohibitive effect on the development of personalised medicine.

• HU Budapest: "We have a Ministry of Innovation and Technology that could be the driving force here, but I do not know how active they are in the field of PM. I have not seen a lot from them. The national funding budget could have a fear of finding new patients that need to be financed as PM identifies them. This could be a strong obstacle in Hungary. What could move things forward is the growing private health insurance market/provider markets. that is trying to stratify patients and give them the best care."

- SE Romania: "I do not know how the national funding budget could finance PM in Romania."
- Alentejo Portugal: "Alentejo doesn't have a Medicine course in its region. We are connected with the course in Lisbon. Some infrastructure is being developed now, which means some activities can take some time to be implemented. Also, there is a lack of alignment of stakeholders, but there is space to increase the interaction between them."
- NE Romania: "Legislation. lack of know- how and lack of dedicated funding."
- NE Romania: "Funding support for educational programs, for supporting the technology transfer, to create digital health data spaces and legislation adoption."
- 3. Current interregional projects / partnerships

# "Please mention and briefly describe any projects and/or partnerships (clinical, research, development, policy or others) that are currently happening in your region with respect to Personalised/Precision Medicine."

Unfortunately, there are really few projects currently unfolding:

- HU Budapest: "HecoPerMed: <a href="https://hecopermed.eu/">https://hecopermed.eu/</a> health economics of personalised medicine. We are also involved in an ERAPerMEd project about multiple myeloma. We do the economic evaluation of the technology under development. We teach methods of early HTA of technologies for EITHealth (as associate partners)."
- SE Romania: "No current projects or partnerships."
- Alentejo Portugal: "There are some projects related to Health Innovation, but without having a focus on Personalised Medicine. An EIT Health project about Open Innovation University Hospitals are being developed. Also, the LifeSpan chair is being supported by Siemens Healthineers."
- NE Romania: "Not sure."
- NE Romania: "IRO -ESEI ERA CHAIR. MEDIC- NEST PROJECT IMAGO. REVERT PROJECT IMAGO"
- 4. Future interregional projects / partnerships

# "Please explain your future plans to take part in regional or interregional collaborative projects relating to PM/PH and detail the types of initiatives/funds you plan to apply for."

- HU Budapest: "We can bring in the valuation of innovative technology through the means of health technology assessment. What is the value of innovation? How can you measure it? What do you need to do to justify your value even at an early stage? It is a must for finding funding opportunities and to be able to sell the technology to investors, and also to get reimbursement. We do this and teach how to do this as well, in a number of EU funded projects within and outside of EIT Health."
- SE Romania: "I need some equipment for the molecular lab at the Faculty of Medicine to start a project."
- Alentejo Portugal: "The University of Évora is very pleased to join, and to collaborate in these areas: i. Personalised Medicine Literacy; ii. Collaborative Intelligence between stakeholders; iii. Increase the development of solutions through entrepreneurship and gamification; iv. To measure the efficacy of projects using our Living Lab."

## Roundtable 5 - February 18th 2022 - 15:00 CET

Links mentioned in the chat:

https://strata.gov.lt/en/component/content/article/26-smart-specialisation/63reports-and-analyses https://www.kaunoklinikos.lt/contacts/coordinating-center-for-rare-and-

undiagnosed-diseases-/

https://kaunoklinikos.lt/apie-mus/projektine-veikla/vykdomi-projektai.html

Participants:

Organisation	Occupation	Region	Country
Lithuanian University of Health Sciences, Department of Preventive Medicine	Academia / Research	LT	Lithuania
Lithuanian University of Health Sciences, Department of Preventive Medicine	Academia / Development & Public funding	LT	Lithuania
President Centre for Innovation in Medicine	Medical professional / Researcher	RO32 Bucharest-Ilfov	Romania
Lithuanian University of Health Sciences (LSMU), Department of Family Medicine, Faculty of Medicine	Medical professional / Academia	LT	Lithuania

## 1. Policies and Strategies

"Please let us know if your Regional Smart Specialization Strategy (RIS3), as well as any other funding strategies (that your Region is part of) include and prioritise Personalised Medicine."

The level at which personalised medicine is prioritised in different regions varies greatly as it can be glanced from participants' responses:

- Lithuania: "LT progress strategy for 2030."
- Lithuania: "RIS3 molecular technologies for medicine and biopharmaceuticals; advanced applied technologies for personal and public health; advanced medical

engineering for early diagnosis and treatment. LT life science industry guidelines. Lithuanian Health Strategy 2014–2025. 2021-2030 National Progress Plan."

- Romania Bucharest-Ilfov: "Smart specialisationStrategy (national and regional level) was rejected by EC. Health is part of this, but no data yet on PM. NCCP include PM (links with BECA and Cancer Mission) Health Operational Program 2021-2027 include PM PNRR could help, but no clear data yet."
- Lithuania: "Smart Specialization in Lithuania. The purpose of Smart Specialisation is to transform the Lithuanian economy and increase its competitiveness by concentrating resources on selected priorities1. Economic transformation is understood as structural change that leads to growth of economic activities characterised by high productivity, knowledge and human capital intensity. A priority is defined as development (or adaptation) and commercialisation of thematically- focused innovative technologies or processes that have high potential to transform Lithuanian economy, while concentrating available research, development and innovation (RDI) potential and responding to global trends and challenges. The proposed priorities fall within six RDI areas approved by Resolution of the Government of the Republic of Lithuania No 951 of 14 October 2013. The priorities have been proposed by the representatives of research, businesses, non- governmental sectors and the Government who worked in six expert teams. Three discussions concerning each priority area were held. The discussions were based on: proposals received during broad consultation with the research and business communities; results of the survey of research, development and innovation valleys; thematic reports on future challenges, trends and technologies (6 reports for each priority area) and analysis of existing RDI strengths (6 reports for each priority area. Health technologies and biotechnologies Molecular technologies for medicine and biopharmacy Intelligent applied technologies for personal and public health Advanced medical engineering for early diagnostics and treatment."
- 2. State of Affairs

# "Please describe the extent to which Personalised Medicine is implemented in your Region (such as medical disciplines, good practices, examples, frequency)."

There exist some attempts to implement personalised medicine regionally.

- Lithuania: "Hospital of LSMU Kauno klinikos has a Coordinating centre for rare and undiagnosed diseases. Multidisciplinary approach is implemented in 25 centres of rare diseases, 5 are true members, 9 affiliated members of European Reference Networks (ERNs)."
- Lithuania: "1. Rare diseases individual diagnostics based on networks and databases. Rare diseases treatments with personalised solutions and therapies. 2.

Oncology treatment with biologic therapy products for diagnostics and treatment. 3.Telemedicine in emergency medicine and emergency conditions (network with University hospitals and live consultations during procedures and surgeries. 4.Individualised rehabilitation programs and lifestyle medicine teams integrated in primary care."

- Romania Bucharest-Ilfov: "Biomarker testing in oncology (paid by industry delays in diagnosis). Not all patients benefit from ESMO guidelines recommendations in fact. Targeted therapies reimbursed (but not biomarkers). First CAR- T therapy reimbursed; no patients treated yet. No data from other therapeutic areas."
- Lithuania: "Innovative technologies for oncology diagnosis, treatment and research. Continuing care for patients with chronic diseases (TELELISPA). Provision of emergency telemedicine services in emergency departments. "Increasing the effectiveness of oncological screening programs in the regions of Central and Western Lithuania."

# A further point of interest we inquired upon was : "Please describe some of the unmet needs (such as funding, policy support) and obstacles that prevent Personalised/Precision Medicine to be adopted at a large scale in your Region."

Our interviewees noted several obstacles that are currently having a prohibitive effect on the development of personalised medicine.

- Lithuania: "1. Financing problems. 2. Sustainability and development issues due to the pandemic situation. 3. Lack of communications with partners due to data exchange barriers."
- Lithuania: "1. Limited national health insurance budget. 2. Long and difficult way to confirm PM technologies/therapies (accreditation to national health insurance). 3. Lack of skills and time to develop competencies from MD side (PM managers, strategic plans for hospitals or patients/conditions)."
- Romania Bucharest-Ilfov: "Perception about PM: something for the future, all about oncology, too expensive, low interest: academia, patients, industry, Healthcare professionals, all about biomarkers (excl. behaviour, digital etc). Unmet needs: education, collaboration, funding, policy framework."
- 3. Current interregional projects / partnerships

"Please mention and briefly describe any projects and/or partnerships (clinical, research, development, policy or others) that are currently happening in your region with respect to Personalised/Precision Medicine."

Unfortunately, there are really few projects currently unfolding:

- Lithuania: <u>https://kaunoklinikos.lt/apie-mus/projektine-veikla/vykdomi-projektai.html</u>
- Lithuania: <u>https://lsmuni.lt/lt/veikla/projektine-veikla/tarptautiniai-projektai</u>
- Romania Bucharest-Ilfov: "ITFoC, PECAN, CIVIS project, Cancer behaviour attitudes and perceptions of ongoing educational project on PM."
- 4. Future interregional projects / partnerships

Please explain your future plans to take part in regional or interregional collaborative projects relating to PM/PH and detail the types of initiatives/funds you plan to apply for.

- Lithuania: "1. personalised medicine in public health. 2. Developing database inclusion and evaluation."
- Lithuania: "Interregional: 1. Horizon Europe (Cancer, Behaviour medicine). Regional: 2. A mission- based science and innovation program. Interregional: 3. Sponsored research initiatives."
- Romania Bucharest-Ilfov: "behaviour studies, policy on PM, new models on education for PM (citizens, patients, Healthcare professionals, decision makers) building a PM hub in the region (twinning?) all the key players in the region together."
- Lithuania: "Personalised Medicine integration in Health and Public Care settings."

#### Roundtable 6 - February 24th 2022 - 15:00 CET

Participants:

Organisation	Occupation	Region	Country
Trakia University, Department of Molecular Biology, Immunology and Medical Genetics	Academia / Regional Policymaker	BG34 South East Region	Bulgaria
Federico II University of Naples	Academia	ITF3 Campania	Italy
European Patient Advocacy Group, European Reference Network (ERN) for patients with genetic tumour risk syndromes (GENTURIS)	Patient advocate	PT17 Lisboa	Portugal

## 1. Policies and Strategies

"Please let us know if your Regional Smart Specialization Strategy (RIS3), as well as any other funding strategies (that your Region is part of) include and prioritise Personalised Medicine."

The level at which personalised medicine is prioritised in different regions varies greatly as it can be glanced from participants' responses.

- Bulgaria SE: "Not enough"
- Italy Campania: "Not widely"
- Portugal Lisboa: "EVITA Platform for any citizen preoccupied with its cancer risk, any genetic mutation carrier and any cancer patient, mainly < 50 years of age or with a rare cancer. Until now, no public funding but a private consortium to guarantee self- sustainability."
- 2. State of Affairs

We posed the following question to our participants: "Please describe the extent to which Personalised Medicine is implemented in your Region (such as medical disciplines, good practices, examples, frequency)."

There exist some attempts to implement personalised medicine regionally.

- Bulgaria SE: "Immunogenetic and genetics of thrombosis. Education and training of the medical staff."
- Italy Campania: "Only pharmacogenomics for few cancers."
- Portugal Lisboa: "Education in personalised medicine for stakeholders. Standardised patient journeys required."

A further point of interest we inquired upon was: "Please describe some of the unmet needs (such as funding, policy support) and obstacles that prevent Personalised/Precision Medicine to be adopted at a large scale in your Region."

Our interviewees noted several obstacles that are currently having a prohibitive effect on the development of personalised medicine.

- Bulgaria SE: "Policy support, legislation, funding"
- Italy Campania: "Clinicians did not accept to change therapies"
- Portugal Lisboa: "Insufficient identification of genetic mutation carriers. Proof of value may change policy"
- 3. Current interregional projects / partnerships

We posed the following question to our participants: "Please mention and briefly describe any projects and/or partnerships (clinical, research, development, policy or others) that are currently happening in your region with respect to Personalised/Precision Medicine."

Unfortunately, there are really few projects currently unfolding:

- Bulgaria SE: "TWINNING on vaccination and trust in the medical system (with Greece and Romania)."
- Italy Campania: "Only the use of EGFR mutations in lung cancer."
- Portugal Lisboa: "new biomarker for ovarian cancer patients and sensitivity to treatments (responders), breast organoids to understand better when cancer starts, behaviour of breast cancer in BRCA2- P carriers."
- 4. Future interregional projects / partnerships

To ascertain the level of regional interest for developments in personalised medicine we asked: "Please explain your future plans to take part in regional or interregional collaborative projects relating to PM/PH and detail the types of initiatives/funds you plan to apply for."

- Italy Campania: "Biosensor for prostate cancer diagnosis"
- Portugal Lisboa: "biomarker for early detection of ovarian cancer. Regional and European public funding"