

INTERREGIONAL COORDINATION FOR A FAST AND DEEP UPTAKE OF PERSONALISED HEALTH





STAATSMINISTERIUM FÜR WISSENSCHAFT KULTUR UND TOURISMUS











GIANNI D'ERRICO – Toscana Life Sciences



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THE BACKGROUND OF REGIONS4PERMED

Local and regional communities and governments have a key role in delivering the benefits of the digital transformation to the public.

- 1. They are responsible for 50% of public investment in the EU,
- 2. receive 25% of tax revenues and
- 3. are a major public employer.

IN EU THERE ARE 74 REGIONAL LEGISLATIVE ASSEMBLIES, AROUND 280 REGIONS, AND 80 000 LOCAL AUTHORITIES IN EUROPE





THE EUROPEAN PATHWAY ON PERSONALISED MEDICINE



THE IC-PERMED FAMILY ON PERSONALISED MEDICINE







AT EU LEVEL (S3-wise)

Mapping regional Health R&I priorities Region's P&I Smart Specialisation Strategies (PIS3)

Region's R&I Smart Specialisation Strategies (RIS3)

134 RIS3 out of the 145 analysed **include Health R&I** as one of their priorities





No Health R&I priority in the RIS3

Health R&I priority in the RIS3



BACKGROUND INFORMATION - AT EU LEVEL (S3-wise)

Personalised Medicine in the RIS3 priorities

51 RIS3 out of the 145 analysed, **explicitly prioritise Personalised Medicine (35%)**



No Personalised Medicine priority in the RIS3



Personalised/stratified/precision Medicine priority in the RIS3





REGIONS4PERMED – PROJECT OBJECTIVES

Overarching Goals

- 1. Coordinate European regional policies and innovation programmes in Personalised Medicine in order to accelerate the employment of PM for citizens and patients
- 2. Strengthen Industrial Specialisation areas in Europe and allow Personalised Medicine to flourish as an Emerging Industry
- Enable interregional joint investment on Personalised Medicine and Health and Provide guidance to the European Commission for the next Multiannual Financial Framework 2021-2027 and Horizon Europe
- 4. Provide guidance to EC, Member States and regional authorities on the next ESIF Operational Programme



REGIONS4PERMED – SPECIFIC OBJECTIVES

- 1. Organise the technical dialogue among regions around five Key Strategic Areas
- 2. Provide a final Action Plan of strategic areas of investments
- 3. Establish a HUB of European initiatives and partnerships on Personalised Medicine (PerMed HUB)
- 4. Release guidelines to regional authorities on how PM can boost local economies and keep the EU competitive and how to tackle Personalised Medicine within the Smart Specialisation Strategies



REGIONS4PERMED – MAIN PILLARS





REGIONS4PERMED – WORK METHODOLOGY





REGIONS4PERMED – THE POLICY DIALOGUE

CONFERENCE

Technical event with high level experts, aimed at acquiring technical knowledge on the Thematic Area

In SITU VISITS

Visit to some high level organization which is carrying out innovative programs/or activities



WORKSHOP

Event aimed at sharing the technical knowledge with other regions and regional representatives, national and international stakeholders on PM, create synergies and develop joint initiatives

CAPACITY BUILDING & CO-CREATION MEETING

Consortium meetings aimed at brainstorm and plan the TA activities. Experts can be invited .



REGIONS4PERMED – THE KICK-OFF CONFERENCE

Regions4PerMed

Kick-off Conference Milan 28.11.2018





BIG DATA eHR and HEALTH GOVERNANCE



CONFERENCE

BIG DATA, ELECTRONIC HEALTH RECORDS AND HEALTH GOVERNANCE MAY 9TH, 2019

Regions4PerMed is an H2020 project whose focus is the coordination of regional policies and innovation programmes in Personalised Health and Medicines to accelerate its deployment for citizens and patients. The project has the overarching goal to align strategies and financial instruments, identify key investment areas and release a strategic European agenda in order to reinforce the cooperation between H2020 and ESIF on Personalised health and Medicines aspects...

More info



WORKSHOP

BIG DATA, ELECTRONIC HEALTH RECORDS AND HEALTH GOVERNANCE SEPTEMBER 23RD, 2019

After the successful conference held in May, we are glad to invite you to the workshop titled "Big Data, electronic health records and health governance". The aim of the Workshop is to explore one of the key thematic areas of the Regions4Permed project, which is understanding how big data and digitalisation can support measures to promote health, as well as to reform health systems, easing the transition to new patient-centred care models, and to new integrated care structures. We will be..

More info

+ 150 participants 30+ Regions



Report released in April 2020

https://www.regions4permed.eu/big-data/



INTERNTATIONAL CONFERENCE







Regualatory aspects Approach

Working group on digital health	set up to support our work in this area and provide expertise – February 2018	
EHDEN	Project making federated data network of allowing access to the data of 100 million EU citizens standardised to a common data model	
Digital Health Europe	Project implementing the Commission's Communication on the transformation of digital health	Digital Health Europe
Data Saves Lives	Project looking at providing lay-language information on the re-use of patient data	
EMA/HMA Big Data Report	Contribution and feedback to this report on behalf of EPF (by working group)	
Commission Recommendation on EHR	Position on the Commission's work and follow-up on involving patients in this work	
Contribution to many initiatives	Commission's eHealth Stakeholder group and new upcoming structures; i~HD Task Force on the GDPR implementation; BBMRI-ERIC Stakeholder Forum	



National Approach







Regional Approach



1,74

"Implementation of the use of information derived from Whole Genome Sequencing as a clinical tool for personalised medicine in Navarre Public Health Service (SNS)"

- Translational research, innovation & genomics industry development



Sequencing 1,000 whole genomes from SNS patients with rare diseases (>200 RD catalogue).



NAVARRABIOMED



Nafarroako 😿 Gobierno Gobernua 🕨 de Navarra





NAVARRA REGION



INTERREGIONAL CONFERENCE

POLICY AREA 1 Data integration and interoperability

• Topics discussed:

a) Infrastructural (technology enabling) interventions;

b) Data organisation (eHR and biobanks) and healthcare systems interoperability;

c) Ethical issues related to usability;

d) Privacy and legal interventions to ensure data security and general public acceptance of health data utilization.

POLICY AREA 2 Investments on big data infrastructures

• Topics discussed:

a) Public investments at regional level;

b) Structural funds, S3 Platforms and interregional investments;

c) Private investments to support multiregional investment pipelines;

d) Public-private-partnerships

POLICY AREA 3 Healthcare organisations in a changing environment

•Topics discussed:

a) New models for earlier "taking care approach" (enabling prevention and prediction

b) approaches)

c) Continuity of care and management of chronicity

d) Healthcare budgeting, reimbursement models;

e) Healthcare staff, challenges of data integration in hospitals and general medical care

Topics discussed: YAREA 4 Promoting access to data

a) Access to data for researchers to advance clinical research;

•b) Access to data for innovators for new and improved solutions;

•c) Access to data for citizens to improve self-management, as a new form of patients engagement



Outcomes | Data integratration and interoperability

- Regions can and should play an important role, but they should work in a synergic way, or they can also be as obstacle to the interoperability at the national level
- Semantic, standardization and ICT are priorities for data integration and interoperability
- Importance of culture for stakeholders at each level: patients, care-givers, governments



Outcomes | Data Infrastructures

Investments in big data infrastructure

Examples given:

- IMI Harmony: harmonised data storage; specific to haematology; 51 partners
- IMI EHDEN: federated network with common data model; 22 partners (to be launched in Nov 2019)
- Codex4SMEs: providing SMEs access to biobank services; 10 partners, including 2 biobanks
- Associazone Big Data (ABD) / Bologna Tecnopolo / Bologna computing & big data hub

1. Responsibilities of different stakeholders, going beyond their original remit

- Governments: making data from health system accessible
- Biobanks: making working with companies/SMEs a priority (LU/AT/ET)
- Industry: co-investing in infrastructure and public-private partnerships; creating value for patients
- Hospitals: using data not only for research but also outcomes analyses
- All: share data!



Outcomes | Data Infrastructures - 2

- 2. Bringing stakeholders together & overcoming collaboration challenges
- Establishing trust among stakeholders
- Creating a common understanding
- Ensure incentives for collaboration & data-sharing (research interest, financial compensation, increased efficiency, etc)
- Join European projects: IMI / Interreg / EOSC / EuroHPC JU / BBMRI etc.
- SME policies / SME-friendly data-sharing conditions
- Important role for regional governments

Involve regional governments in consortia!

3. Strategic vision for life science

- Bringing together health and innovation policy
- Covering primary care, secondary care, SME networks, etc.



Outcomes | Healthcare Organisations in a changing environment

Middle of a perfect storm with chronicity, ageing society polypharmacy climate change combined with digital tools, connectivity, patient expectations changing

Need to move from a reactive to a proactive system

- 1) Understand the tech
- 2) Understand the processes
- 3) Prepare the workforce

Underestimate the need to support organisational change

Different perspectives - all demonstrate provider organisations can be developed to problem solve and use digital to address needs.



- 1. Generation and access to data are strictly connected.
- 2. To make good use of them, data need to be of high quality. Hence, increasing the amount of quality data available is a priority, although how to organise them and how to make them accessible is a multilevel decision.
- 3. Patients are the owners and the generators of data. Although most of them are aware of what data are, not everyone knows their value and what benefits they can bring. More patients' expertise is needed.
- 4. The administrators, especially the regional policy makers who have a deeper understanding of the need of the territory, shall have a say on the structure of the databases, who can access them and to what level

REGIONS4PERMED – THE INTERREGIONAL COMMITTEE



Regional Authorities

Agreed – Waiting for Lol

Regional technological stakeholders

Joining through a Framework agreement with the Ministry of Health



PUBLICATIONS

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¹ Fondazione Toscana Life Sciences, Siena, Italy

³ Lower Silesian Voivodeship Marshall Office,

² International Scientific Projects Section,

Wroclaw Medical University, Poland

⁴ Division of Medical Social, Sciences,

³ Family Medicine Department,

Wroclaw Medical University, Poland

Wroclaw Medical University, Poland

Wroclaw, Poland

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OPINION

Towards a European health rese innovation cloud (HRIC)

F. M. Aarestrup¹, A. Albevatti^{2,3}, W. J. Armitage⁴, C. Auffrav^{5*}, L. Augello⁶ J. G. Bjaalie¹⁰, M. Black¹¹, N. Blomberg^{12*}, P. Bogaert¹³, M. Bubak¹⁴, B. Clae G. D'Errico¹⁷, A. Di Meglio¹⁸, N. Forgo¹⁹, C. Gans-Combe²⁰, A. E. Gray²¹, I. (G. Hemmrich-Stanisak²⁴, L. Hjorth²⁵, Y. Ioannidis²⁶, S. Jarmalaite²⁷, A. Kel²⁸ GIANNI D'ERICO^{1 E-G} M. Laszlo³², A. Maas³³, L. Magalhaes³⁴, I. Manneh-Vangramberen³⁵, E. Mor P. Oksvold³⁹, N. P. Oxtoby⁴⁰, I. Perseil⁴¹, V. Pezoulas⁴², O. Riess⁴³, H. Riper⁴, ORCID: 0000-0003-1715-8958</sup> F. Sanz⁴⁷, M. Tayeb^{2,3}, G. Thomassen⁴⁸, J. Van Bussel⁴⁹, M. Van den Bulcke ANTONI ZWIEFKA^{3 E-G}

Abstract

The European Union (EU) initiative on the Digital Transformation of Health ar conditions necessary for building a secure, flexible, and decentralized digital Health Research and Innovation Cloud (HRIC) within this environment should health research across the EU, in compliance with data protection legislation participants. Such a HRIC should learn from and build on existing data infrast focus on the concrete needs of the community in terms of technologies, go ethics requirements. Here, we describe the vision and expected benefits of d activities and present a roadmap that fosters the opportunities while answer HRIC. For this, we put forward five specific recommendations and action poil built on established standards and guidelines, providing cloud technologies infrastructure; ii) is developed and certified to the highest standards of interc trusted by all stakeholders; iii) is supported by a robust ethical and legal fram General Data Protection Regulation (GDPR); iv) establishes a proper environm data and medical scientists; and v) stimulates research and innovation in tran and private initiatives and partnerships funded by the EU through Horizon 2

HEALTH TECHNOLOGIES AND SMART

& INTEGRATED CARE - KEY ACTION 2 STAGE OF THE REGIONS4PERMED (H2020) PROJECT

Reviews

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ORCID: 0000-0002-1300-9229 Dominik Krzyżanowski^{3,4 e-g}

· ORCID: 0000-0003-0255-7163 DONATA KURPAS^{5 E-G} · ORCID: 0000-0002-6996-8920

A-study design, B-data collection, C-statistical analysis, D-interpretation of data, E-manuscript preparation, F-literature review, G-sourcing of

ABSTRACT

Consumer and system-wide gains remain limited by an outmoded policy regime. With scientific innova running far ahead of public policy, physicians, researchers and patients are not receiving full advantage of latest developments. European health systems require a seamless and rapid flow of digital information, inc ing genomic, clinical outcome, and claims data. Research derived from clinical care must feed back into ass ment, in order to advance care quality for consumers. National health systems are heterogeneous; the solut and required fundamental approaches differ between the European member states and are not entirely po ble and scalable. To date, this applies not only to general systemic aspects but particularly to cross-border re bursement issues and the exchange of treatment and patient data.

To answer those needs, an international consortium was established to implement the project "Interregi coordination for a fast and deep uptake of personalised health": Regions4PerMed. A cycle of international even such as conferences, in situ visits and workshops, has been planned. Interdisciplinary groups of experts exchange thoughts and experiences to design solutions that could be implemented in the various healthcare tems. Regions4PerMed aims to coordinate regional policies and innovation programmes in personalised r icine and personalised health to accelerate the deployment of personalised health for patients. Key Action dedicated to health technologies and smart and integrated care.

KEYWORDS: health technology, e-health, m-health, integrated healthcare, personalised medicine, personalised medici ized health

INTERREGIONAL COORDINATION FOR A FAST AND DEEP UPTAKE OF PERSONALISED HEALTH (REGIONS4PERMED) - MULTIDISCIPLINARY CONSORTIUM UNDER THE H2020 PROJECT

Reviews

GIANNI D'ERRICO¹ PAOLA GIULIA CORMIO¹ PAOLA BELLO² MARTA DUDA-SIKUŁA³ · ORCID: 0000-0003-1715-895

ANTONI ZWIEFKA⁴ • ORCID: 0000-0002-1300-9229 DOMINIK KRZYŻANOWSKI^{4,5}

EVA-MARIA STEGEMANN⁶

BEATRIZ ALLEGUE REQUEIJO⁷ JOSÉ MARÍA ROMERO FIDALGO⁷ DONATA KURPAS⁸ + ORCID: 0000-0002-6996-8920

¹ Fondazione Toscana Life Sciences, Siena, Italy

- ² Fondazione Regionale per la Ricerca Biomedica, Milano, Italy
- ³ International Scientific Projects Section. Wroclaw Medical University, Poland
- ⁴ Lower Silesian Voivodeship Marshall Office, Wroclaw, Poland
- ^a Division of Medical Social Sciences, Wroclaw Medical University, Poland
- ⁴ Saxon State Ministry for Higher Education, Research and the Arts, Dresden, Germany
- ⁷ Galician Health Knowledge Agency ACIS,
- Santiago de Compostela, Spain
- * Family Medicine Department, Wroclaw Medical University, Poland

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ABSTRACT

Personalised medicine (PM) represents a paradigm shift away from the 'one size fits all' approach to the treatment and care of patients with a particular condition, to one which uses emergent technologies such as diagnostic tests, functional genomic technologies, and molecular pathway profiling to better manage patients' health and employ target therapies. The current challenge for national and regional authorities is to facilitate the shift from a reactive healthcare system based on episodic and acute care models to a personalized health (PH) system that uses preventive and predictive measures, where at-risk individuals are stratified to intervene before the onset of symptoms or risk is predicted using cutting-edge technologies before symptoms appear. While PH is paving the way toward better and more efficient patient care, it still lacks the cooperation and coordination needed to organise the fragmented field, which is a severe drawback to its development and to the placement of effective financial investments. For this reason, it is crucial to direct major efforts towards coordinating and aligning relevant stakeholders across Europe and beyond, creating a participatory approach, building trust, enabling a multi-stakeholder process, and channeling investments towards PH. Thus, Regions4PerMed aims to coordinate regional policies and innovation programmes in PM and PH to accelerate the deployment of PH for patients.





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OUR TEAM & OUR CONTACTS







in Regions4PerMed

info@regions4permed.eu