ICPerMed
INTERNATIONAL CONSORTIUM

State of the Art Report 2023

Imprint

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Authors
The ICPerMed Secretariat, represented by The French National Research Agency (ANR), Dr Michael Joulie, Dr Mathias Vetillard and Dr Monika Frenzel, on behalf of the International Consortium for Personalised Medicine, ICPerMed, with valuable contribution of the ICPerMed Executive Committee.

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Contact
The French National Research Agency (ANR)
Dr Monika Frenzel
E-mail: ICPerMed@agencerecherche.fr

ICPerMed Secretariat
E-mail: ICPerMed@dlr.de
ICPerMed webpage: http://www.icpermed.eu

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Executive Summary

The International Consortium for Personalised Medicine publishes a state-of-the-art report on an annual basis and seeks to facilitate the follow-up of the development of personalised medicine research and its implementation throughout Europe and beyond.

The ICPerMed consortium is continuously growing, attracts and welcomes more and more international partners. The advantages to become an ICPerMed member and steps to be taken for membership are outlined.

ICPerMed is continuously mapping activities in the field of personalised medicine to promote achievements and successes in research and implementation as well as to honour activities of ICPerMed member organisations. A set of initiatives and activities supporting personalised medicine development and implementation are presented in this 2023 report.

Furthermore, ICPerMed outlines shortly its activities of the past year until February 2024, like workshops, ICPerMed Family events, education and training activities, collection and presentation of Best Practices. New ICPerMed videos and publications are also available on the ICPerMed YouTube Channel.

This 2023 report, is also outlining the contribution of the consortium in the preparation of the European Partnership for Personalised Medicine (EP PerMed) proposal and the Strategic Research and Innovation Agenda for Personalised Medicine (SRIA for PM, 2023). The EP PerMed that started on November 1st is shortly presented.

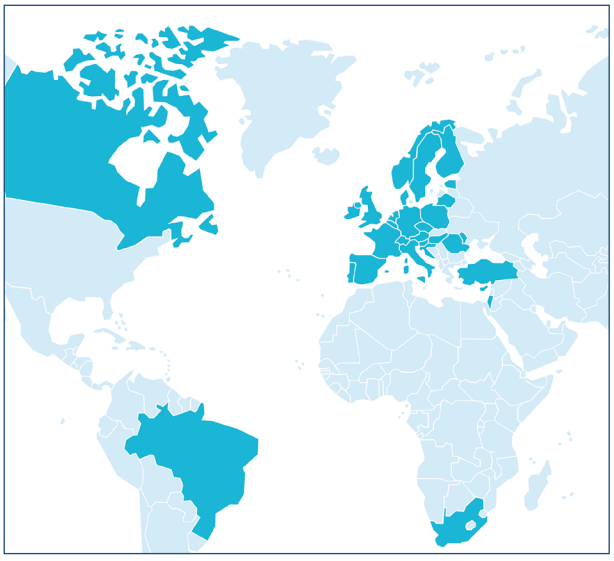
State of the Art Report 2023

1. International Consortium for Personalised Medicine

The International Consortium for Personalised Medicine (ICPerMed) serves since 2016 as a strategic platform, bringing together high-level policy makers such as research and innovation ministries, health ministries, and regional authorities as well as European regional and national funding organisations, to foster a common understanding of personalised medicine and the defragmentation of the personalised medicine environment by aligning strategies in research funding and at the policy level. ICPerMed initiates and drives strategic reflections and the development of strategic documents, i.e. the ICPerMed Action Plan in 2017 and the Vision Paper in 2019, as well as the Strategic Research and Innovation agenda for Personalised Medicine (SRIA for PM, 2023) as support for the European Partnership for Personalised Medicine (EP PerMed).

ICPerMed is open for new members worldwide:

The membership does not require any monetary commitment. Participation is in-kind for all members (i.e. travel to meetings of the ICPerMed consortium and personnel efforts are not reimbursed). A membership seeking and eligible organisation needs to fill in and sign the "letter-of-intent" and "contact form" as well as to prepare a "letter of motivation" stating the reasons for desiring to join ICPerMed[1].



The Executive Committee of ICPerMed, i.e. all members, meets twice a year. The meetings are held in different formats (physical meetings, online meetings and hybrid meetings) to allow every member to join independent on the location the meeting. ICPerMed members are asked to report regularly on (research or other) activities related to personalised medicine/health in their country.

Some advantaged to be an ICPerMed member are:

- Access to first-hand information concerning developments in the field of personalised medicine, research and technology developments, implementation models but also funding and collaboration opportunities.
- Sharing and promoting activities, organisations and teams from the own country, e.g. promoting the research community or important stakeholders leads to a better connection of the local research and innovation community with other communities/stakeholders worldwide.
- Common development and alignment of strategies in the field of personalised medicine. The development of common strategies can support the development of national strategies, hence national allocation of resources, but also leverage external funding as well as initiate co-funding activities (combination and optimal use of funding and resources). Each member can bring forward the needs and interests of the own country but also find strategic alignment that enable cross-border collaboration on different levels.

The ICPerMed consortium warmly welcomes as new members recently joining in July 2033 the Academy of Scientific Research and Technology (ASRT)[2]. ASRT is a national coordinating body and funding organisation for research and

1 For more information regarding the ICPerMed membership, please consult the ICPerMed website: https://www.icpermed.eu/en/icpermed-members.php

2 http://www.asrt.sci.eg/

innovation in Egypt. It serves as Egypt's national house of expertise, and national think tank in the field of Science, Technology and Innovation. ASRT is the first organisation from Egypt to join ICPerMed. This is a big step towards ICPerMed's internationalisation, which is an important aim of ICPerMed in order to align research and funding activities on an international level.

Therewith, ICPerMed currently brings together 50 public and private 'not-for-profit' health research funding and policy organisations from 31 countries, seven European regions and four continents. The European Commission (EC) participates in ICPerMed as observer.

ICPerMed Working Groups push reflections in four topics:

The ICPerMed Executive Committee was supported over the last three (3) years by four (4) Working Groups, consisting of ICPerMed members and external experts, that will end in 2024. ICPerMed will continue its joint reflections in the next years with the focus on "International collaboration" and "Policy Aspects" in the field of or supporting the personalised medicine environment.

The Working Groups (WG) "Clinical Studies in Personalised Medicine", "Personalised Medicine in Healthcare", "Education, Empowerment and Engagement in Personalised Medicine" and "Health Economic Value of Personalised Medicine" contributed to the organisation of events (i.e. the workshop 2022, the two ICPerMed Family events), training activities (see StoA2022) and the development of strategic documents:

- The WG "Clinical Studies in Personalised Medicine" developed in collaboration with the ICPerMed Family CSA project PERMIT the document "Optimizing Clinical Research for Personalised Medicine: Recommendations for Funders, Regulators and Policy Makers"[3].

- The WG "Personalised Medicine in Healthcare" developed the document "Challenges, Opportunities and Facilitators in Implementing Personalised Medicine" accompanied by a methodology document and a Policy Brief[4].

- The WG "Health Economic Value of Personalised Medicine" is finalising a reflection paper that will soon being available via the ICPerMed website.

ICPerMed thanks all four Working Groups for their contribution to the success of ICPerMed.

ICPerMed provides a platform to initiate and support communication and exchange on personalised medicine research, funding and implementation:

Since January 2024, ICPerMed counts more than 1000 followers on LinkedIn. In a new video[5], ICPerMed, together with renown experts in the field, underlines the need for collaboration to enable personalised medicine to form together the future of medicine.

3 https://www.icpermed.eu/media/content/ICPerMed_Clinical Studies.pdf
4 https://www.icpermed.eu/en/1184.php
5 https://www.youtube.com/watch?v=0NwRFnHRmj8

To actively foster exchanges on personalised medicine research, funding and implementation, the following internal meetings, public events and activities took place between November 2022 and February 2024:

- **ICPerMed Executive Committee meetings:** The ICPerMed members and observers met on October 07, 2022 (in Paris, hybrid meeting), on May 09-10, 2023 (online meeting), on November 16, 2023 (Siena, hybrid meeting) and on February 01, 2024 (online meeting) to discuss and plan strategy and future activities.

- **The 2nd ICPerMed Family meeting:** The "ICPerMed Family Meeting – Staying connected to shape the future of Personalised Medicine" took place as online event on October 19, 2023. The aim of the meeting was to discuss the outcomes of the ICPerMed Working Groups and the ending ERA Net ERA PerMed[6] as well as internationalisation of ICPerMed and aspects of prevention in personalised medicine. It also included an outlook about the new European Partnership for Personalised Medicine (EP PerMed). The importance of the sustainability of ICPerMed achievements was emphasised. The meeting report is available on the ICPerMed website[7].

- Biannual ICPerMed events:
  - ICPerMed Workshop "Preparing the Future for Personalised Medicine: EP PerMed", on invitation only (hybrid event), in Pamplona on January 17-18, 2023. Panellists and international and national experts in the field of personalised medicine discussed three main areas needed to achieve the full potential a personalised medicine approaches: research, innovation and implementation, which successfully contributed to redefine the SRIA for PM (2023) and the development of EP PerMed proposal. The active and fruitful participation of panellists and experts, both on-site and virtually, allowed to collect and consider more, new and crucial insights into the challenges around the implementation of personalised medicine approaches. The agenda and the presentations of the different sessions can be downloaded on the ICPerMed website[8]. A workshop report, summarising the discussions is also available[9].
  - ICPerMed Workshop "Advancing Personalised Medicine through Technology Development", on invitation only (hybrid event), in Siena on November 14-15, 2023. This pivotal workshop took an in-depth look at the technological innovations shaping personalised medicine today. Speakers and workshop participants discussed how these can be used in personalised medicine approaches. The workshop facilitated the discussion and the exchange of experiences, ideas, perspectives between international and regional high-level experts in the field. The agenda, the presentations of the different sessions, video statements of speakers, a workshop video as well as the workshop agenda and a document presenting the speakers are available on the ICPerMed website[10]. A workshop report, summarising the discussions is also available.

- **Extended General Assembly (ExtGeA):** On January 24, 2024, all partners of ICPerMed and the EP PerMed met for the first time in Brussels (hybrid meeting) in the so called Extended General Assembly. Both initiatives will come together regularly as ExtGeA to discussed synergies in order to promote the translation of personalised medicine into practice.

ICPerMed representatives also participated in numerous external meetings to present the work and activities of ICPerMed, the so called "ICPerMed Family", but also the preparations regarding the upcoming EP PerMed proposal and the SRIA for PM (2023).

6 https://erapermed.isciii.es/

7 https://www.icpermed.eu/media/content/ICPerMed_Family%20Meeting_10_2023.pdf

8 https://www.icpermed.eu/en/ICPerMed-Workshop-2023-1048.php

9 https://www.icpermed.eu/media/content/ICPerMed_Workshop%20January_2023_REPORT.pdf

10 https://www.icpermed.eu/en/icpermed-workshop-11-2023-siena-1107.php

Training course fostering exchanges with and the active involvement of the personalised medicine community:

- 3rd ICPerMed Training Event "Research Infrastructures in Personalised Medicine: use, advantages and challenges" took place on September 22, 2023 (online event)

The aim of this training was the promotion of the use of European Research Infrastructures in the biomedical field to better inform researchers on the potential use of Biological and Medical Research Infrastructures and the benefits arising from their use, to accelerate excellence, innovation and translation, but also make them aware of the barriers to be overcome.

Examples of best practices[11] in personalised medicine are presented and promoted on the ICPerMed website and through the **ICPerMed Recognition**[12]**:**

- New Best Practice example:
  - *"Mosaic Initiative: a Launchpad for Personalised Medicine"* – Mosaic, Psifas in Hebrew, is Israel's National Genomic Medicine Initiative. It is developing a unique infrastructure for facilitating large scale prospective studies based on advanced integration of community and hospitals longitudinal retrospective clinical data, fully sequenced genomes and a platform for patient recall and follow up studies.
- ICPerMed Recognition 2022 "Data Sharing in Personalised Medicine Clinical Research" winners – congratulations![13]
  - *"Databases and registers toward Barcoding Multiple Sclerosis"*, Mario.A. Battaglia, Italy
  - *"The first international federated clinical registry on rare head and neck cancers"*, Annalisa Trama, Italy
  - *"Data sharing and re-use in the framework of the ArtiPro ERA PerMed project"*, Julia Stingl, Germany
- ICPerMed Recognition 2023 "Fostering Personalised Medicine Implementation Through Research" winners – congratulations![14]
  - *"Deep Mutagenesis to Understand, predict and prevent Amyloid Aggregation in Alzheimer's Disease"*, Mireia Seuma, Spain
  - *"Predicting Outcomes for Crohn's disease using a molecular biomarker"*, Nurulamin Noor, United Kingdom
  - *"Centre for Research of Genodermatosis and Epidermolysis Bullosa, finding answers to rare skin diseases"*, Laura Valinotto, Argentina

Furthermore, ICPerMed, supported by the ICPerMed Secretariat, published:

- the ICPerMed flyer **"Open Access in Personalised Medicine"**[15] that compiles guidelines for research projects working in the field of personalised medicine concerning Open Science and Open Access that are key aspects of Responsible Research and Innovation (RRI).

- the document **"Overcome Barriers in Personalised Medicine Research"**[16]. One aim of ICPerMed is to accelerate the translation and implementation of results of personalised medicine research projects. In order to understand the barriers and gaps currently encountered by researchers, the ICPerMed Secretariat conducted and analysed a survey with researchers from personalised medicine projects. The results of the analysis, including potential strategies to overcome the barriers, are now available.

11 https://www.icpermed.eu/en/best_practice_examples.php
12 https://www.icpermed.eu/en/icpermed-academy.php
13 https://www.icpermed.eu/en/933.php
14 https://www.icpermed.eu/en/icpermed-recognition-2023-1077.php
15 https://www.icpermed.eu/en/1090.php
16 https://www.icpermed.eu/en/overcome-barriers-in-personalised-medicine-research-1109.php

2. European Partnership for Personalised Medicine – EP PerMed

The European Partnership for Personalised Medicine (EP PerMed)[17] has started officially on November 1st, 2023. It aims to improve future healthcare for all citizens through personalised therapy, diagnosis and prevention. With a total budget of around 375 million euros, provided by the European Union (EU) and more than 50 partners, EP PerMed will not only significantly support the transnational development of PM approaches over the next ten years, but also their successful translation into clinical practice.

Background- Within EP PerMed, several earlier European initiatives are joined under one roof. EP PerMed will leverage their achievements and knowledge but also continue their activities. The **CSA PerMed** (Coordination and Support Action, 2013-2015) developed and published the first personalised medicine Strategic Research and Innovation Agenda (SRIA) and therewith initiated the coordination efforts of European stakeholders, to allow synergies and a more efficient use of resources by avoiding duplication, working in parallel or in silos, and to provide recommendations to foster personalised medicine in transnational research and individual health systems. Thereafter, several personalised medicine dedicated or related initiatives were started. To mention a few examples: **ICPerMed** and related CSAs funded by the EU, together building the so called **"ICPerMed Family"**, the ERA-NET Cofund on personalised medicine, **ERA PerMed (2017-2023, final brochure published[18])**, but also other initiatives supporting a personalised medicine endorsing environment as the **1+ Million Genomes Initiative** (1+MG) connected to the Beyond 1 Million Genomes (B1MG) project and several **ESFRI** (European Strategy Forum on Research Infrastructures) projects, especially in the areas of biomedical research and data collection and analysis.

The common vision of the European Partnership for Personalised Medicine and the Strategic Research and Innovation Agenda for Personalised Medicine is to improve health outcomes within sustainable healthcare systems through research, development, innovation and implementation of personalised medicine approaches for the benefit of patients, citizens, and society.

Synergies- The Partnership will create synergies with other EU and initiatives under the Horizon Europe framework programme, including funding activities of the **Cluster Health**, the **Marie Skłodowska-Curie** Actions (programme for doctoral education and postdoctoral training), other European Partnerships in health (e.g. ERA4Health, THCS – Transforming Health and Care Systems and new ones expected to start in near future) and the **Cancer Mission**. The Partnership will also engage and collaborate with key European research and innovations infrastructures. By building respective synergies, EP PerMed will be able to define complementary actions preventing duplication of efforts (either human, financial or other) to achieve more ambitious and wider objectives. A continuous exchange of information will be maintained and joint activities and cooperation between EP PerMed and other initiatives will be supported to optimise the tasks and impact of the EP PerMed activities. These joint activities will include:

- Co-create and implement, advertise and disseminate training programmes on key aspects related to personalised medicine research and innovation.
- Organise networking activities, e.g. joint sessions within organised events and meetings.
- Jointly develop strategic and policy documents.
- Collaborate in communication, dissemination activities, and direct exchange of knowledge.

Long term vision- EP PerMed's vision is developed in the Strategic Research and Innovation Agenda (SRIA) for Personalised Medicine (SRIA for PM, 2023) published on 28 April, 2023[19]. The SRIA was developed by the joined forces of

17 https://www.eppermed.eu/

18 https://www.icpermed.eu/en/era-permed-final-brochure-published-1163.php

19 https://www.icpermed.eu/en/strategic-research-and-innovation-agenda-for-personalised-medicine-1100.php

the European Commission and the Member States, including several regions. These activities were strongly supported by ICPerMed and related EU-funded coordination and support actions as well as the ERA PerMed and national initiatives.

EP PerMed, the Partnership for developing a Personalised Medicine Value Continuum and System of Health- The personalised medicine "value continuum" or "system of health", as outlined in the SRIA for PM (2023), integrates research, innovation and implementation aspects. Thereby, results from one sector should feed into the next step, but also give feedback to previous steps in the **value chain**, forming a **cycle of knowledge** and insights that flows in both directions. EP PerMed's activities aim to support all aspects, key players and elements in this circle.

Structuration- The Partnership has a duration of 10 years. EP PerMed brings into action the theory outlined in the SRIA for PM (2023) by connecting in one single unique platform the personalised medicine "value continuum": Work Package (WP)2 **Research Funding**, WP3 **Innovation**, WP4 **Implementation**, WP5 **Synergies and Overarching Cooperation**, together with a centralising WP1 **Coordination** (including strategy supporting and communication activities). The circle representing the Personalised Medicine "System of Health" is also reflected in the logo of the EP PerMed.

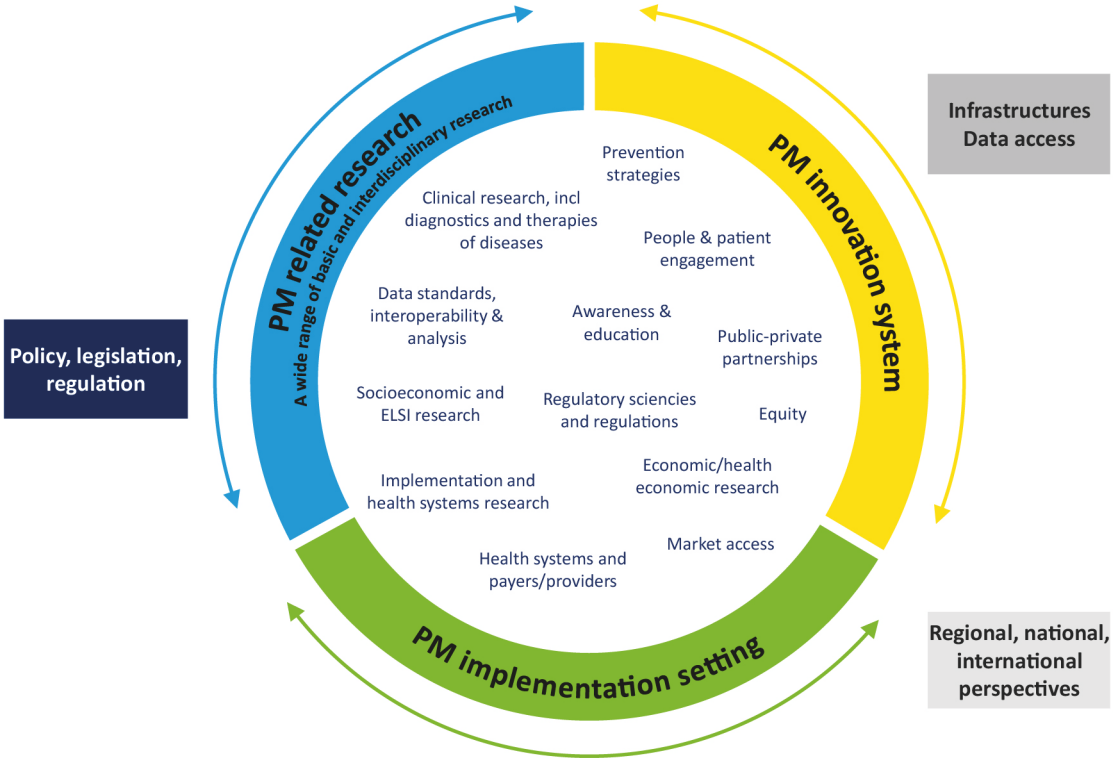
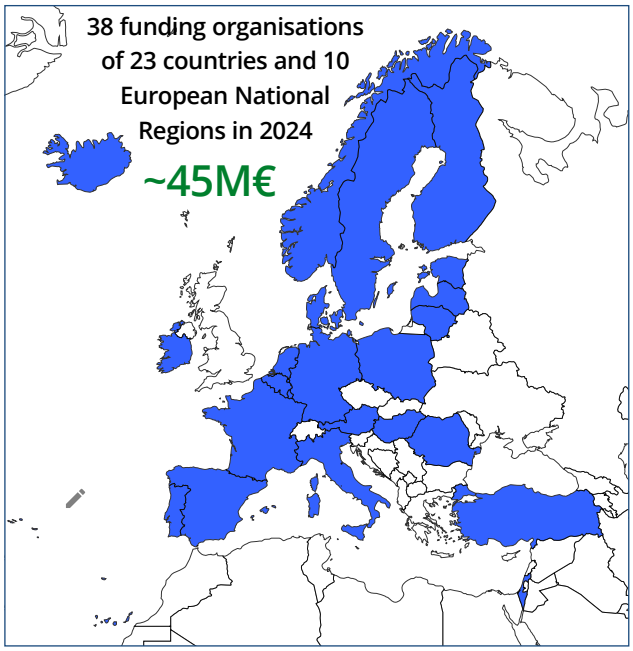


Figure 1: The Personalised Medicine "System of Health" (The EP PerMed: 'The Strategic Research & Innovation Agenda (SRIA) for Personalised Medicine' (2023))

EP PerMeds first Joint Transnational Call (JTC) "PM Targets, JTC2024"- The JTC2024 was launched on January 2nd, 2024 and aims to fund research that fosters the identification or validation of targets for personalised medicine approaches. Applicants submitting a proposal to this call must combine the research on new and advanced targets with companion biomarker research. Consortia are required to be transnational, interdisciplinary and trans-sectoral as well as to clearly outline the personalised medicine perspective in the research proposed. The funding organisations participating in this call particularly wish to promote innovative, interdisciplinary collaboration and to encourage translational research proposals in human health.



3. Snapshot: Initiatives and activities supporting personalised medicine

ICPerMed is continuously mapping activities and advancements in the field of personalised medicine in order to promote achievements and successes in the field as well as to honour activities of ICPerMed member organisations or countries. A set of significant personalised medicine related or supporting initiatives is presented in this section:

- Integrating CARE Principles in Indigenous Data Governance
- Canada's New Guidelines for Human Genomics Research Consent
- Paving the Way for France's Digital Health Revolution
- Key Outcomes from the IPPOSI Citizen's Jury on Genomics in Ireland
- Ireland's National Strategy for Advancing Genetics and Genomics
- HEAL ITALIA: Pioneering Precision Medicine in Italy
- Norway Advances Healthcare with Personalised Medicine Strategy
- Romania Pioneers in Personalised Medicine with Landmark Legislation

Integrating CARE Principles in Indigenous Data Governance

To address the challenges Indigenous communities face in data management, the International Indigenous Data Sovereignty Interest Group under the Research Data Alliance introduced the CARE Principles for Indigenous Data Governance. These principles aim to balance Indigenous rights and interests with the demands of open data and big data initiatives.

CARE - Collective Benefit, Authority to Control, Responsibility, Ethics - focuses on people and purpose, emphasising data's role in Indigenous innovation and self-determination. Developed in collaboration with Indigenous peoples, scholars, non-profits, and governments, these principles offer a human-centric approach to data governance. While the FAIR Principles (Findable, Accessible, Interoperable, Reusable) address technical data management aspects, CARE introduces a necessary human perspective. This integration encourages a comprehensive "Be FAIR and CARE" approach in data stewardship.

Current open data trends often neglect Indigenous rights and interests, focusing more on data sharing than on power dynamics and historical contexts. CARE Principles advocate for Indigenous control over data usage, aligning with Indigenous worldviews and ensuring collective benefits. The CARE Principles represent a significant step in making data governance inclusive and respectful of Indigenous rights, encouraging a balanced approach in global data sharing and innovation practices. For more information:
https://www.gida-global.org/care

Canada's New Guidelines for Human Genomics Research Consent

Canada is introducing a policy to standardise consent documents for human genomics research, coinciding with the 2023 launch of the Canadian Human Genome Library (CHGL). This initiative aims to streamline ethics approval processes and enhance data sharing across the country, facilitating advanced machine learning applications to better understand genetic factors in health and disease.

The integration of human genomics into clinical care necessitates a collective approach to data analysis, significantly impacting health and disease predisposition research. The CHGL will serve as a central hub for genomic data, adhering to FAIR data principles, and fostering international research collaborations.

A standardised set of tools and procedures, including a core set of consent elements, will be implemented. This will not only reduce bureaucratic burdens but also support educational and training material development. These measures

are critical for maximising CHGL's utility and enabling effective genomic data sharing in Canada, including future data types like epigenetic profiles.

This policy represents a significant advancement in ethical and consistent approaches to human genomics research in Canada, setting a precedent for global health research collaborations. For more information:
https://www.cmaj.ca/content/194/44/E1500

Paving the Way for France's Digital Health Revolution

The Priority Research Programme and Equipment (PEPR) for Digital Health led by INSERM (French National Institute of Health and Medical Research) and INRIA (National Institute for Research in Digital Science and Technology), announced in 2021 as a key component of France's 2030 digital health strategy, was officially launched in 2023 with a budget of 60 million euros.

PEPR Digital Health aims to achieve scientific breakthroughs and develop disruptive digital health technologies within a decade. It focuses on improving diagnostics, refining patient care, and accurately predicting health status changes. Central to its mission is the development of systems and algorithms for managing and exploiting burgeoning health data volumes.

The programme's dual focus includes:

1. Acquiring comprehensive biological and medical data for each patient, spanning a wide spectrum from DNA to environmental interactions.

2. Developing a digital twin for personalised and evolving patient care.

This initiative brings together over 150 laboratories, numerous universities, “grandes écoles” (French institutions of higher education), and hospital establishments, fostering a collaborative environment that spans the academic, clinical, and private sectors.

PEPR Digital Health's research concentrates on four key areas:

1. Innovative methods for analysing multi-scale health data.

2. Technical and sociodemographic solutions for personalised health data utilisation.

3. Advanced applications in cardiovascular and

4. neuroscience fields.

This collaborative effort aims to integrate diverse competencies across public research, education, healthcare, and healthtech companies, thereby enhancing the French ecosystem in health and digital technology.

As a part of the broader France 2030 initiative, PEPR Digital Health exemplifies a strategic investment in research and technology to strengthen French ecosystem in digital health. It underscores a national commitment to harnessing digital technologies and data for the transformative development of 21st-century healthcare solutions, benefiting patients, citizens, and healthcare professionals.

Key Outcomes from the IPPOSI Citizen’s Jury on Genomics in Ireland

The Irish Platform for Patient Organisations, Science and Industry (IPPOSI), in partnership with the RCSI University's Public Patient Involvement (PPI) Office, facilitated a crucial Citizens’ Jury event to discuss the future of genomics in Ireland. This event led to the publication of 22 recommendations, emphasising the importance of genomics in healthcare and research.

Summary of Recommendations:

1. Targeted Use of Genomics: The jury advocates for the application of genomics in healthcare solely for disease diagnosis and treatment, explicitly excluding aesthetic purposes. Individual choice and a clear consent process should govern the sharing of genomic data for research.

2. National Genomics Programme: A recommendation was made to establish a national genomics programme in Ireland, foster-

ing trusted public-private partnerships. The proposal includes the creation of a new state agency to oversee this programme.

3. Data Security and Management: The jury suggests setting up a national genomics database for secure data storage and management. They recommend serious consequences for data breaches or misuse and suggest appointing a mediator to handle related complaints.

4. Consent and Personal Management of Data: Individuals should have the ability to access and manage their genomic data, with an 'opt-in' choice for data sharing. The consent process should be informative, allowing time for individuals to make informed decisions.

5. Public Engagement and Education: Emphasising the need for sustained public debate and literacy in genomics, the jury calls for inclusive public engagement strategies and educational efforts to inform and involve the public in decisions about genomic healthcare.

The IPPOSI Citizens' Jury's recommendations present a comprehensive framework for the advancement of genomics in Ireland. These guidelines stress the need for ethical use, secure data handling, informed consent, and robust public engagement, aiming to shape national-level planning and action in genomics for the foreseeable future.
For more information: https://ipposi.ie/2022-citizens-jury-on-genomics/

Ireland's National Strategy for Advancing Genetics and Genomics

The Strategic Programmes Office of the Irish Healthcare system (HSE) led the development of Ireland's National Strategy for Genetics and Genomics. This pioneering strategy provides a detailed roadmap for the integration of genetics and genomics within the Irish healthcare framework. The strategy aims to improve health outcomes, reduce healthcare costs, and stimulate scientific innovation.

Key Strategic Areas:

1. National Coordination: A national office will oversee genetic and genomic clinical services and research, address policy gaps, and implement the strategy.

2. Patient and Public Involvement (PPI) and Partnerships: Aligned with the Sláintecare vision, the strategy promotes an equitable, patient-centered genetics service supported by robust governance, skilled workforce, and strong partnerships.

3. Workforce Development: Plans for recruiting, retaining, and training specialised staff, including genetic counsellors and clinical scientists, are integral for developing expertise in genetics and genomics.

4. Enhancing Clinical Services: Transitioning genetics and genomics into routine healthcare and supporting evidence-based testing will create integrated, multidisciplinary care pathways.

5. Infrastructure Strengthening: Investment in infrastructure for sample collection, testing, storage, and analysis is crucial for both patient care and research. The strategy includes reviewing and enhancing data capacity and capability.

Ireland's National Strategy for Genetics and Genomics represents a significant step towards modernising healthcare and research through the integration of advanced genetic and genomic practices. This strategic framework sets the stage for improved healthcare outcomes and positions Ireland at the forefront of genetic and genomic medicine. For more information: https://www.hse.ie/eng/about/who/strategic-programmes-office-overview/national-strategy-for-accelerating-genetic-and-genomic-medicine-in-ireland/

HEAL ITALIA: Pioneering Precision Medicine in Italy

HEAL ITALIA marks a significant milestone as Italy's first Foundation coordinating a multidisciplinary network to modernise its National Health System. This initiative brings together universities, the IRCCSs (Scientific Institute for

Research, Hospitalization and Healthcare), companies, scientists, and researchers, focusing on translational research for advanced diagnostics and therapies in cancer, cardiovascular, metabolic, and rare diseases. With a budget of 118.76 million euros, largely subsidised by the Italian Ministry of Research (MUR), the project aims to revolutionise precision medicine in Italy. It represents a paradigm shift in healthcare, adopting personalised strategies for disease prevention, diagnosis, and treatment based on individual characteristics, thereby placing patients at the healthcare system's core.

The project adopts a holistic approach, integrating fundamental and translational research with technology transfer. This synergy involves academic, clinical, and private sectors, with the project's activities conducted across eight "spokes" coordinated by a central hub responsible for overall management and coordination.

HEAL ITALIA's primary goal is to establish research chains where public and private sectors work together to advance personalised medicine processes and products. It seeks to develop new, cost-effective, and evidence-based diagnostic pathways for early and precise detection and monitoring of various diseases. Furthermore, the project aims to bridge regional disparities in healthcare across Italy, promoting interregional collaboration to implement effective, standardised clinical practices.

HEAL ITALIA embodies a significant leap towards advanced healthcare in Italy, striving to bring precision medicine to the forefront. Through its collaborative, interdisciplinary framework, the project promises to deliver groundbreaking advancements in disease prediction, detection, and treatment, ultimately reshaping the landscape of Italian healthcare and research. For more information: https://www.healitalia.eu/en/

Norway Advances Healthcare with Personalised Medicine Strategy

The Norwegian Ministry of Health and Care Services has launched the Norwegian Strategy for Personalised Medicine (2023-2030), marking a pivotal shift in the nation's healthcare approach. This innovative strategy aims to integrate personalised medicine into the fabric of Norway's healthcare system, prioritising tailored treatments and modern medical technologies.

The strategy, building on the 2017 initiative, is supported by a 36 million euros investment, focusing on genomics, precision diagnostics, and a groundbreaking oncology clinical trial. This step signifies Norway's commitment to leading healthcare advancements through personalised approaches.

A key aspect of the strategy is transitioning from a hospital-centric model to patient pathways. Incorporating multi-omics and artificial intelligence (AI) in data analysis, the strategy adopts a diagnosis-neutral approach, showcasing Norway's move towards more advanced, patient-focused healthcare solutions.

The strategy revolves around three main pillars:

1. Access and Integration: Guaranteeing equitable access to personalised medicine and its seamless integration into patient care and research.
2. Competence Development: Enhancing the knowledge and skills within healthcare services to effectively implement personalised medicine.
3. Data Management: Focusing on the secure and efficient handling of health data, with an emphasis on privacy and data integrity.

A cornerstone of the strategy is establishing the National Genome Centre, a comprehensive platform for genomic data management, including sequencing and pathology integration. Additionally, the strategy involves a collaborative effort across health agencies, focusing on guideline monitoring, service development, and the advancement of personalised medicine in healthcare.

For more information: https://www.regjeringen.no/no/dokumenter/strategi-for-persontilpasset-medisin/id2959463/

Romania Pioneers in Personalised Medicine with Landmark Legislation

Romania has established itself as a global leader in healthcare innovation by passing the world's first law granting

patients and citizens the right to personalised medicine. This historic legislation marks a significant milestone in the country's healthcare journey.

The law, evolving from Romania's first Personalised Medicine Conference in 2016, signifies a commitment to integrating science, policy, and real-life implementation in healthcare. It enhances the existing patient rights laws by incorporating a definition of personalised medicine, affirming the right to such medicine based on medical recommendations, and enforcing mandatory informed consent. Key to this legislation is the emphasis on thorough patient information, including risk-benefit analysis, and compliance with the General Data Protection Regulation (GDPR) for data handling.

The impact of this legislation is far-reaching, acting on various areas of healthcare including collaboration, infrastructure development, education, training, regulation, and ethics. This law not only strengthens the healthcare system within Romania but also sets a precedent for other countries in the adoption of personalised medicine.

In a recent move, the Romanian Government has further solidified its position in advancing personalised medicine by joining the 1+ Million Genomes initiative[20]. This action underscores Romania's role in the global healthcare landscape, promoting a future where medicine is more tailored to individual patient needs.

20 https://digital-strategy.ec.europa.eu/fr/news/1million-genomes-initiative-new-roadmap-adopted-scale-and-sustainability-phase

Outlook

The CSA ICPerMed Secretariat[21], funded by the European Union, provided over two editions since 2016 logistical and financial support to the ICPerMed. The CSA is now coming to an end in February 2024. ICPerMed thanks the teams of the DLR Project Management Agency (Germany), the French National Funding Agency (ANR, France), the Italian Ministry of Health (IT-MoH, Italy) and the Carlos III Health Institute (ISCIII, Spain) for the collaboration and the support over the last years.

ICPerMed will continue its efforts starting from March 2024 in close collaboration with the EP PerMed, and with a special focus on "International collaboration" and "Policy Aspects" around personalised medicine. New ICPerMed events are planned in 2025 and we are looking forward to meeting and further exchanging with the personalised medicine community.

Stay tuned for ICPerMed's activities via our newsletter[22], the ICPerMed website and through the ICPerMed YouTube channel, X (former Twitter) and via LinkedIn.

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21 https://www.icpermed.eu/en/icpermed-secretariat.php
22 https://www.icpermed.eu/en/services-newsletter.php