



D1.2

Map of major funding agencies and stakeholders in Europe and China



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Abstract

This document aims to extend the mapping of Personalised Medicine in Europe and China. It answers the key questions of “who” are the important stakeholders involved in policymaking and programme creation and “what” are the concrete funding schemes provided in both geographic areas to promote the development of Personalised Medicine and related topics. It lists major existing and emerging initiatives to show “how” Personalised Medicine is implemented in detail and addresses important research and innovation actors active in the field. The mapping has been conducted through extensive desk research, the consultation of national contact points in health as well as the contribution of experts within the IC2PerMed consortium.

Keywords

Personalised Medicine, Precision Medicine, PM, ICPerMed, EU, EU Member States, China, Policy, Stakeholder, Funding Schemes, Initiatives, Innovation Actors, Research, R&I



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Contents

Executive Summary	8
1 Introduction.....	9
2 Methodology	10
3 Policy agencies and stakeholders related to Personalised Medicine.....	12
3.1 Policy agencies related to Personalised Medicine	12
3.1.1 Policy agencies in Europe	12
3.1.2 Policy agencies in EU Member States	15
3.1.3 Policy agencies in China.....	19
3.2 Stakeholders related to Personalised Medicine.....	21
3.2.1 Stakeholders in Europe.....	22
3.2.2 Stakeholders in EU Member States.....	26
3.2.3 Stakeholders in China	37
4 PM-related Funding Schemes and Programmes.....	39
4.1 Funding schemes and programmes in Europe	39
4.1.1 ERA-NET Cofunds.....	40
4.1.2 Additional funding schemes and programmes	42
4.2 Funding sources in EU Member States.....	44
4.3 Funding sources and providers in China	53
5 Existing and emerging Initiatives.....	56
5.1 Initiatives in Europe.....	57
5.1.1 ICPeMed-related coordination and support actions	57
5.1.2 PM-related initiatives in Europe.....	59
5.2 Initiatives in EU Member States	63
5.3 Initiatives in China	69
6 Main research and innovation actors.....	71
6.1 PM research and innovation actors in EU Member States	71
6.2 PM research and innovation actors in China	81
7 Conclusions.....	84
Appendix 1.....	86



List of Figures

Figure 1 – Overview on the applied methodology in D1.2.....	11
Figure 2 – Pillars of European public-public partnerships.....	40

List of Tables

Table 1 – Policy agencies in Europe	13
Table 2 – Policy agencies in EU Member States.....	15
Table 3 – Policy agencies in China.....	19
Table 4 – Stakeholders in Europe.....	22
Table 5 – Stakeholders in EU Member States	26
Table 6 – Stakeholders in China	38
Table 7 – ERA-NET Cofunds related to PM.....	40
Table 8 – Funding schemes and programmes in Europe	43
Table 9 – Funding sources in EU Member States.....	44
Table 10 – Funding sources and providers in China.....	54
Table 11 – CSAs related to Personalised Medicine	57
Table 12 – Existing and emerging initiatives in Europe.....	59
Table 13 – Existing and emerging initiatives in EU Member States.....	63
Table 14 – Existing and emerging initiatives in China	69
Table 15 – Research and innovation actors in EU Member States	72
Table 16 – Research and innovation actors in China	81



Abbreviations and Acronyms

Abbreviation, Acronym	Description
CSA	Coordination and Support Action
Chafea	Consumers, Health, Agriculture and Food Executive Agency
EC	European Commission
EIC	European Innovation Council
EJP RD	European Joint Programme on Rare Diseases
EMA	European Medicines Agency (London)
ERA-NET	European Research Area Networks
EU	European Union
FP	Framework programme
GCP	Good Clinical Practice
GDPR	General Data Protection Regulation
GMS	Genomic Medicine Sweden
H2020	Horizon 2020, 8 th European framework programme
IC2PerMed	Integrating in the ICPeMed project
ICPeMed	The International Consortium for Personalised Medicine
ICT	Information and Communication Technology
IMI	Innovative Medicine Initiative
IRDiRC	International Rare Diseases Research Consortium
JPIs	Joint Programming Initiatives
LAC	Latin American and Caribbean
MS	Member States
NCP	National Contact Points
NSFC	National Natural Science Foundation of China
P2P	Public-public partnerships
PH	Personalised Health
PM	Personalised Medicine
PPP	Private-public partnerships
REA	Research Executive Agency (EC)
SRIA	Strategic Research and Innovation Agenda
WHO	World Health Organization
WP	Work Package



Executive Summary

This document has been developed under the IC2PerMed project, funded by the European Union's Horizon 2020 research and innovation programme under grant agreement No 874694. The project aims to provide key solutions for enabling the convergence under ICPerMed consortium of European and Chinese stakeholders towards a common approach of Personalized Medicine (PM) research, innovation, development and implementation. The document focuses on the mapping of four key areas of the Personalised Medicine ecosystem in both Europe and China:

- Policy agencies and stakeholders in PM,
- PM-related funding schemes and programmes,
- Existing and emerging initiatives, and
- Main research and innovation actors.

The IC2PerMed consortium addresses the fundamental question of:

- Who is involved in policymaking and programme creation?
- What are the funding instruments of PM and which institutions are providing them?
- How are advances in PM supported and promoted by national and international initiatives?
- Who are the key research and innovation actors behind the constant progress in the field and playing an important role in bringing technological advances to the market?

The advancements in PM require close collaborations and cooperation with agencies at EU level and at MS national level, in the PM dimensions such as data access and use, bio-banking standardization, next generation sequencing, screening, biomarkers, sharpening the impact of R&D and early diagnostics. These policies, considering the gaps, facilitators, and barriers to their implementation, aim at protecting and improving the health of all citizens. The policy agencies offer scientific and technical services, supporting decision-making on PM technologies and the modernization of EU's health systems. Alongside with the elaboration of education programmes, these agencies ensure the translation of the advancements of personalised healthcare into health practice.

A continuous support from multiple stakeholders is fundamental for considering the PM as one of the priorities in the governments' agendas. A close collaboration of different stakeholders, including academic research networks, societies, advocacy groups, patients' organisations, is a key element in building a pan-European network that accelerate the strategic cooperation in PM implementation.

The field of PM has been one of the main priorities for the EC, which has funded a large amount of PM related projects and initiatives, encompassing health promotion and disease prevention, diagnostics, biomarkers, large-scale data challenges, technology development, omics sciences, preclinical and clinical research. The policies in People's Republic of China, aiming to improve access to the health and healthcare system, are planned, designed, elaborated, and supervised by the Chinese governments' ministries. The importance of PM has been addressed in several strategies such as the 13th and the 14th Five-Years-Plans, in which they use the definition of Precision Medicine. The role of Precision Medicine in public health has been considered in the Healthy China 2030 plan. The Chinese government has a major interest in Big Data and ICT solutions in genomics and has funded several projects and initiatives. The development of PM has been considered necessary in achieving the long-term goal of the People's Republic of China that aim to lower the hurdles to access public health and to make healthcare universal. This detailed mapping forms initial support to enhance collaborations between the European Union and the People's Republic of China. It further provides the basis for future activities planned within the IC2PerMed work packages.



1 Introduction

This document acts as a follow-up of the “D1.1 Scoping Paper: Review on health research and innovation priorities in Europe and China”. It further extends the mapping of Personalised Medicine (PM) in China and Europe answering the questions of:

- “**Who**” are on one hand important **agencies** involved in **policymaking** and **programme creation** as well as on the other hand **important stakeholders** related to Personalised Medicine,
- “**What**” are the concrete **funding schemes** providing financial support to the realization of PM-related projects, and
- “**How**” is Personalised Medicine implemented in detail listing major **existing and emerging initiatives** as well as key **research** and **innovation actors** in the field.

The term “Personalised Medicine” acts as an umbrella term for a new vision in medicine and healthcare and has been defined by the Council of the European Union as follows¹:

“However, it is widely understood that Personalised Medicine refers to a medical model using characterisation of individuals’ phenotypes and genotypes (e.g., molecular profiling, medical imaging, lifestyle data) for tailoring the right therapeutic strategy for the right person at the right time, and/or to determine the predisposition to disease and/or to deliver timely and targeted prevention. Personalised medicine relates to the broader concept of patient-centred care, which takes into account that, in general, healthcare systems need to better respond to patient needs.”

Another term frequently in use in the same context in various countries and especially in the People’s Republic of China is “Precision Medicine” and has been defined by the Chinese Academy of Sciences (CAS)² as:

“Precision medicine is a medical model for high-efficiency, low-cost prevention and treatment of diseases tailored to individual patients based on their genetic content.”

Due to the overlap in their definitions and the shared principle they describe, both terms - Personalised Medicine as well as Precision Medicine - are interchangeable and abbreviated to PM in this document.

The information presented here aims to complete the full picture of Personalised Medicine from the European and Chinese perspective, providing an overview on the highly multidisciplinary field of PM. The focus lies on the mapping of the entire PM ecosystem involving key policy agencies and stakeholders, funding schemes and programmes, existing and emerging initiatives as well as an overview on the main research and innovation actors. The application of PM principles in medicine requires considerable investments and is only possible through sustainable and cooperative efforts of all involved stakeholders, institutions, and programmes.

¹ Council conclusions on personalised medicine for patients (2015/C 421/03)

² China kicks off Precision Medicine Research - Chinese Academy of Science

http://english.cas.cn/newsroom/archive/news_archive/nu2016/201601/t20160111_158607.shtml



The information shown in this deliverable shall help in forming the basis for further bilateral intensification of collaboration and cooperation in PM between the European Union and the People's Republic of China, one of the central goals of the IC2PerMed project of the International Consortium for Personalised Medicine (ICPerMed)³.

2 Methodology

To conduct the mapping exercise, a three-step methodological process (see Figure 1) has been applied:

Step 1: Desk research (April 2020 to January 2021)

Step 2: Consultation of Horizon 2020 National Contact Points

Step 3: IC2PerMed survey of experts in PM (February 2021)

The desk research aimed to retrieve public available information on policy agencies, stakeholders, initiatives, and innovation actors related to PM.

Desk research

The desk research included information collection from institutional online repositories such as:

- European level:
 - European Union, European Commission
- EU Member state level:
 - Health ministries
 - Additional institutions related to public health
- China:
 - Ministry of Science and Technology of the People's Republic of China (MOST) and additional and additional institutions related to public health
- ICPerMed webpage

as well as grey literature search using Google®, Google® Scholar and Microsoft® Academic search engines in combination with a broad set of search terms. The mapping was further extended identifying relevant publicly available documents at the European and EU Member State level including information on the People's Republic of China.

Consultation of Horizon 2020 National Contact Points regarding health

The Horizon 2020 National Contact Points of EU Member States were contacted and, based on their suggestions and feedback, the obtained data from the desk research were further completed.

IC2PerMed survey of experts in PM

A survey was elaborated within the IC2PerMed Consortium, aiming to explore the current landscape of implementation, priorities, and challenges of Personalised Medicine in China and Europe, with a focus on Sino-European collaboration in this field. The survey was made available, from January 29th until February 28th, 2021 on the IC2PerMed website:

<https://www.ic2permed.eu/ic2permed-survey-on-china-eu-cooperation-over-personalised-medicine-developments/>

³ <https://www.icpermed.eu/en/icpermed.php>



The survey (Appendix 1) aimed at validating the identified PM mapping results through desk research and NCP consultation as well as retrieving of additional information organised in distinct sections.

Section 2 of the survey comprised two questions addressing the scope of D.1.2 regarding:

- Policy agencies/institutions that monitor or are involved in overseeing implementation/fostering of PM in the country under investigation
- Funding sources in the field of PM in the country under investigation

The information retrieved from the combined methodology of mapping was reported in tables, standardized for both EU and China.

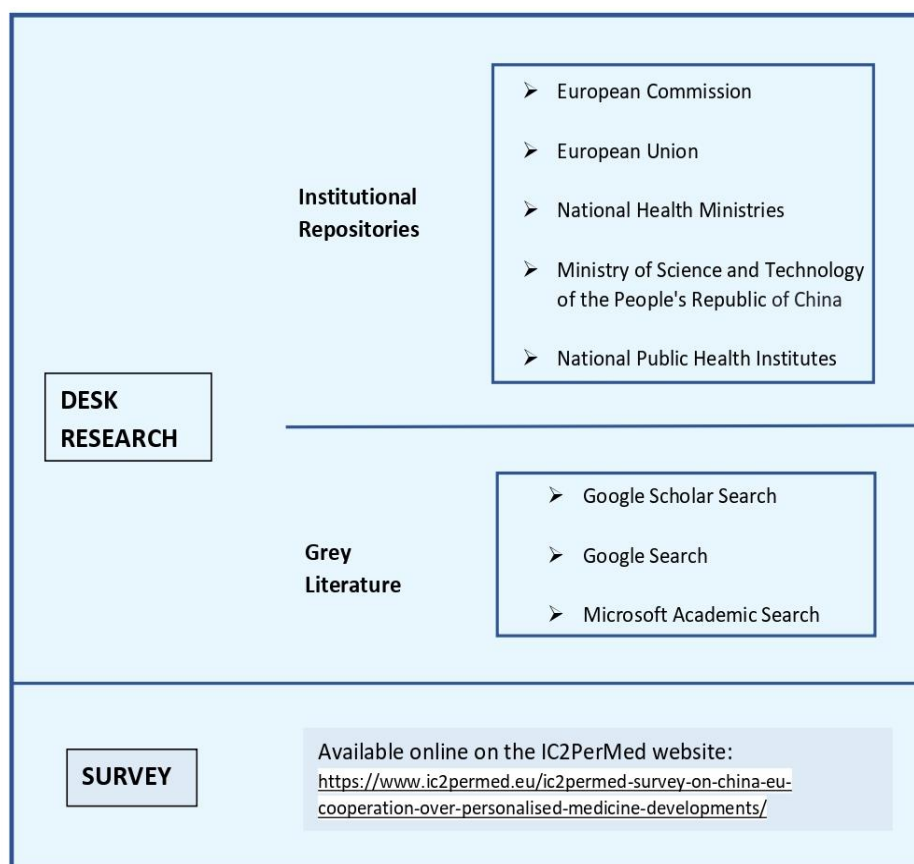


Figure 1 – Overview on the applied methodology in D1.2

3 Policy agencies and stakeholders related to Personalised Medicine

“D1.1 Scoping Paper: Review on health research and innovation priorities in Europe and China” listed policy measures, programmes and actions plans relevant for Personalised Medicine. This section summarizes main authors and initiators responsible for those measures and is structured in two subchapters focussing on:

1. Policy Agencies related to Personalised Medicine and
2. Stakeholders in Personalised Medicine

addressing the question of “what are the institutions and stakeholders behind policymaking and programme creation”.

3.1 Policy agencies related to Personalised Medicine

Policy agencies are responsible for the establishment, effective implementation, monitoring and enforcement of policies, also in health and health related fields.

A *policy cycle*⁴ is a complex series of decisions and includes the following stages:

- identification and definition of a problem,
- agenda-setting and advocacy,
- setting of goals and targets,
- formulation and selection of relevant options,
- policy implementation, evaluation, and feedback.

*An agency can be defined as a body that has its own legal personality and a certain degree of administrative and financial autonomy in carrying out its tasks as specified by the government.*⁵

3.1.1 Policy agencies in Europe

European agencies are considered as bodies aiming to establish and manage the cooperative relationships between the European Union and its Member States’ administrations. At the EU level, agencies have emerged as a strategic political compromise between the main institutional actors. As stated by the EC, it is expected that European agencies “will improve the way rules are applied and enforced across the Union.”

There are two main categories of agencies:

1. Community agencies⁶ (EC agencies) and
2. Council agencies⁷ (EU agencies).

Community agencies, due to their combination of effectiveness and technical expertise, have been considered as a mean to increase administrative capacity and to reduce the workload of the EC.

⁴ [https://www.oecd.org/officialdocuments/publicdisplaydocumentpdf/?cote=EDU/WKP\(2017\)11&docLanguage=En](https://www.oecd.org/officialdocuments/publicdisplaydocumentpdf/?cote=EDU/WKP(2017)11&docLanguage=En)

⁵ https://www.clingendael.org/sites/default/files/2018-12/PB_EU_Agencies_0.pdf

⁶ https://ec.europa.eu/info/departments_en

⁷ https://europa.eu/european-union/about-eu/agencies_en



Community agencies are part of the first EU pillar, the European Communities pillar, that covers economic, social and environmental policies.

Council agencies (EU Agencies) have been set up by the Council with a mandate for operation in the area of second and third pillar matters of the EU, the *Common Foreign and Security* pillar and *Police and Judicial Co-operation in Criminal Matter* pillar, respectively. The EC has the competencies to initiate policy and legislative proposals, ensuring that regional and local knowledge and conditions are considered when developing policy proposals.

An important feature of EU agencies is that they cooperate closely with national agencies. Policy agencies aim to conduct policies in terms of EU responsibilities and capacities. Agencies, at the EU or the national level, can contribute to fact-finding and supervision while the related networks that bind them together are required to ensure the emergence of epistemic communities with shared professional values.

In this chapter, we also include policy agencies that are not directly linked to the EU but play an important role in policy making at the European level, such as e.g. the WHO's European Observatory on Health Systems and Policies.

The major policy agencies at the EU level in the context of PM were identified, listed and described in Table 1.

Table 1 – Policy agencies in Europe

Name:	Consumers, Health, Agriculture and Food Executive Agency (CHAFAEA)
Source:	https://ec.europa.eu/chafea/about/mission_en.htm
Brief description: The Consumers, Health, Agriculture and Food Executive Agency (CHAFAEA) is an Executive Agency set up by the European Commission to manage four EU programmes on its behalf: Health Programme (DG SANTE); Consumer Programme; Better Training for Safer Food initiative - BTSF; Promotion of Agricultural Products Programme. CHAFAEA's mission is to provide high quality support to the beneficiaries and stakeholders, and to ensure that the actions funded by the four programmes deliver results and provide the Commission with valuable input for its policy tasks.	
Name:	Directorate-General for Health and Food Safety (SANTE)
Source:	https://knowledge4policy.ec.europa.eu/organisation/dg-sante-dg-health-food-safety_en
Brief description: The Directorate-General for Health and Food Safety (DG SANTE), until 2014 known as the Directorate-General for Health and Consumers (DG SANCO), is a Directorate-General of the European Commission. The DG is responsible for the implementation of European Union laws on the safety of food and other products, on consumers' rights and on the protection of people's health. In 2006, DG SANCO launched the public Health-EU portal to provide European citizens with easy access to comprehensive information on Public Health initiatives and programmes at EU level.	
Name:	European Data Protection Supervisor
Source:	https://edps.europa.eu/about-edps_en



Brief description: The European Data Protection Supervisor (EDPS) is the European Union's (EU) independent data protection authority. Its general mission includes: monitoring and ensuring the protection of personal data and privacy when EU institutions and bodies process individuals' personal information; advising EU institutions and bodies on all matters relating to personal data processing, on request or on by own initiative. In particular, EDPS is consulted by the European Commission on proposals for legislation, international agreements, as well as on implementing and delegating acts with impact on data protection and privacy; monitoring new technology that may affect the protection of personal information; intervene before the Court of Justice of the EU to provide expert advice on interpreting data protection law; cooperating with national supervisory authorities and other supervisory bodies to improve consistency in protecting personal information. The activities include: 1) developing and communicating an overall vision, thinking in global terms and proposing concrete recommendations and practical solutions; 2) providing policy guidance so as to meet new and unforeseen challenges in the area of data protection; 3) operating at the highest levels and developing and maintaining effective relationships with a diverse community of stakeholders in other EU institutions, Member States, non-EU countries and other national or international organisations.

Name:	European Medicines Agency (EMA)
Source:	https://www.ema.europa.eu/en

Brief description: The EMA is a decentralised agency of the European Union (EU). It began operating in 1995. The Agency is responsible for the scientific evaluation, supervision and safety monitoring of medicines in the EU. EMA protects public and animal health in EU Member States, as well as in the countries of the European Economic Area, by ensuring that all medicines available on the EU market are safe, effective and of high quality. EMA serves a market of over 500 million people living in the EU.

Name:	European Observatory on Health Systems and Policies
Source:	http://www.euro.who.int/en/about-us/partners/observatory

Brief description: The Observatory supports and promotes evidence-based health policymaking through comprehensive and rigorous analyses of the dynamics of health care systems in Europe. It engages directly with policymakers and experts, and works in partnership with research centres, governments, and international organizations to analyse health systems and policy trends. The Observatory is a partnership, hosted by WHO/Europe, which includes other international organizations (the European Commission, the World Bank); national and regional governments (Austria, Belgium, Finland, Ireland, Norway, Slovenia, Spain, Sweden, Switzerland, the United Kingdom and the Veneto Region of Italy); other health system organizations (the French National Union of Health Insurance Funds (UNCAM), the Health Foundation); and academia (the London School of Economics and Political Science (LSE) and the London School of Hygiene & Tropical Medicine (LSHTM)).

Name:	European Strategy Forum on Research Infrastructures activities (ESFRI)
Source:	https://www.esfri.eu



Brief description: The European Strategy Forum on Research Infrastructures was established in 2002, with a mandate from the EU Council to support a coherent and strategy-led approach to policymaking on research infrastructures in Europe, and facilitates multilateral initiatives leading to the better use and development of research infrastructures, at EU and international level. The forum typically meets four times a year and adheres to a set of procedural guidelines, reviewed every two years. In 2006, ESFRI published its first roadmap for the construction and development of the next generation of pan-European research infrastructures.

3.1.2 Policy agencies in EU Member States

At the national level of EU Member States, policies designed and enforced by governmental agencies, consist of a large part of rules and regulations. The process of policymaking in public administration is a cyclic process that includes five substantial stages⁸:

- 1) Initiation,
- 2) Preliminary drafting,
- 3) Public participation,
- 4) Final drafting, and
- 5) Reviewing.

The national ministries of the EU Member States (MS) play a significant role in determining the legislative and political agenda. Their policy plans should respond to the government's priorities, population's needs and be in accordance with international agreements and contracts. Ministries, aiming to implement policies more efficiently, also consider the issues arising from existing policies and potential implementation gaps. Within the policy system, the elaboration of policy proposals is one of the key roles attributed to ministries as only they have sufficiently detailed knowledge and practical experience on the issues and gaps that require policy response. Considering the primordial role of ministries in preparing and developing policies in each EU MS, they are therefore not listed in Table 2. For the EU Member States missing, no policy agencies with a direct relationship to Personalised Medicine has been identified and/or information is lacking.


Table 2 – Policy agencies in EU Member States

Country:	Austria 
Name:	AGES - Austrian Agency for Health and Food Safety Ltd.
Source:	https://www.ages.at/en/ages/basics
Brief description: The Austrian Agency for Health and Food Safety (AGES) is a company of the Republic of Austria, owned by the Austrian Federal Ministry of Labour, Social Affairs, Health and Consumer Protection and the Austrian Federal Ministry for Sustainability and Tourism. AGES supports the management of the federal ministries and the two federal agencies subordinated to it in questions relating to public health, animal health, food safety, medical and drug safety, food	

⁸ Boyer, William W. "Policy Making by Government Agencies." *Midwest Journal of Political Science*, vol. 4, no. 3, 1960, pp. 267–288. *JSTOR*, www.jstor.org/stable/2108978. Accessed 15 Mar. 2021




security and consumer protection along the food chain by providing professional and independent scientific expertise (as stated in Article 8 of the Austrian Health and Food Safety Act).

Country:	Belgium 
Name:	The Personalised Medicine Commission (ComPerMed)
Source:	https://www.compermed.be

Brief description: The Personalised Medicine Commission (ComPerMed) is a committee which brings together Belgian scientific expertise in this area. The objectives are to develop technical guidelines to permit quality assurance for the molecular tests, and specifically for the NGS tests, used in oncology and haemato-oncology; To define which molecular biomarkers (DNA) must, as a minimum, be analysed by NGS for each type of tumour (solid and haematological). The choice of these genes is based on the scientific evidence of its specific clinical use for that specific tumour type.

Country:	Estonia 
Name:	PRAXIS CENTER for Policy Studies
Source:	http://www.praxis.ee/



Brief description: PRAXIS Center for Policy Studies is an independent not-for-profit think tank based in Tallinn. Founded in 2000, the mission of PRAXIS is to improve and contribute to the policy-making process in Estonia by conducting independent research, providing strategic counsel to policy makers and fostering public debate. PRAXIS aims to develop this kind of practical knowledge as well as to offer its know-how and expertise to identify and tackle key problems in society and provide practical recommendations to policy makers.

Country:	Germany 
Name:	Federal Institute for Drugs and Medical Devices (BfArM)
Source:	https://www.bfarm.de/EN/Home/home_node.html

Brief description: The BfArM is an independent federal higher authority within the portfolio of the Federal Ministry of Health. At the BfArM, the most important aim is to increase the safety of medicinal products and thus that of the patients. Consequently, the BfArM makes a major contribution towards the prevention of risks to public health. The BfArM is a departmental research institute of the German Federal Government which conducts its own as well as independent research in order to fulfil its tasks pursuant to Section 4 sub-section 3 BfArM successor legislation. The BfArM's tasks serve both public health as well as the safety of medicinal products, narcotics and medical devices. As a federal institute, the BfArM fulfils sovereign tasks without economic purpose (i.e. without the intention of making a profit).

Name:	Federal Institute for Vaccines and Biomedicines (Paul-Ehrlich-Institut)
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Source:	https://www.pei.de/EN/institute/organisation/division-major-policy-issues-coordination/g-node.html	
<p>Brief description: The Paul-Ehrlich-Institut (PEI) is an Agency of the German Federal Ministry of Health. The Division for Major Policy Issues is involved from the coordination of internal processes at the Paul-Ehrlich-Institut to the implementation of international projects for the regulation of medicinal products – the division is active at the interfaces between many disciplines. The division's experts represent the PEI in relevant committees of the European Medicines Agency (EMA) and the Heads of Medicine Agencies (HMA). Furthermore, the division coordinates the PEI's cooperation with the World Health Organization (WHO), including the two WHO Collaborating Centres, and other international actors. A recent additional task is to position the PEI as a European reference laboratory (EU-RL) for in vitro diagnostic devices (IVDs) in accordance with the new European IVD Regulation and to foster the respective application of the PEI.</p>		
Country:	Spain	
Name:	Instituto de Salud Carlos III (ISCIII)	
Source:	https://eng.isciii.es/Paginas/Inicio.html	
<p>Brief description: The ISCIII contributes to improving the health of all citizens and to fight diseases through the promotion and funding of research and innovation in Health Sciences and Biomedicine and through the provision of ground-breaking scientific and technical services and educational programmes directed towards the National Health System. It is the main public funding organization of R&I in biomedicine in Spain. The ISCIII, in close coordination with other public authorities, represents Spain worldwide in the field of Public Health and Biomedical Research. It leads also the Spanish participation in different health international programs and consortiums (such as ICPeMed, ERA PerMed and other ERA-Nets, EJP RD, JPI AMR, JPND), as well as the Spanish membership in several European Biological and Medical Research Infrastructures (ESFRI).</p> <p>The objectives of the ISCIII are to 1) promote research aimed at protecting and improving health, financing highly-competitive and excellent research through the State's Health Research and Development Strategy and facilitating greater participation in international R+D+I programmes and projects; 2) conduct research within the National Health System (SNS) through its National Reference Centres, Research Institutes, Foundations, Networks, Consortia and Platforms for Scientific and Technical Services; 3) manage, develop and offer ground-breaking scientific and technical services throughout the country for the prevention and control of transmissible and non-transmissible diseases, environmental health, bio-products and others that may be harmful to public health; 4) Offer scientific and technical advisory services to support decision-making on healthcare technologies and services in the National Health System; and 5) develop educational programmes aimed at the entire National Health System and provide health information and scientific documentation services.</p>		
Country:	Sweden	
Name:	National Innovation Council	



Source:	https://www.government.se/government-policy/national-innovation-council
Brief description: The Swedish National Innovation Council (NIC) was created in February 2015. The existence of NIC has given innovation policy issues a much higher status and degree of importance both within the government itself and within government agencies, i.e. in the entire state apparatus. NIC is focused on innovation policy in a holistic way (and not on research policy – for which there is another council in Sweden). NIC has thereby become a major governance instrument to transform Swedish innovation policy from being partial and linear towards becoming holistic. The Council works to improve the Swedish innovation system and society's capacity to address innovation challenges.	
Country:	United Kingdom
Name:	Cancer Research UK
Source:	https://www.cancerresearchuk.org
Brief description: The Cancer Research UK carries out several activities. Their policy department develops evidence-based policy to inform Government decisions related to cancer and research and communicates our views to key decision makers.	
Name:	Health and Care Research Wales
Source:	https://healthandcareresearchwales.org/index.php/about
Brief description: Health and Care Research Wales is a national, multi-faceted, virtual organisation funded and overseen by the Welsh Government's Research and Development Division. It provides an infrastructure to support and increase capacity in research and development (R&D), runs a range of responsive funding schemes and manages the NHS R&D funding allocation.	
Name:	The Human Tissue Authority
Source:	https://www.hta.gov.uk
Brief description: The HTA is a regulator set up in 2005 following a series of events that, in the 1990s, revealed a hidden culture among hospitals of removing and retaining human organs and tissues without consent. The established legislation did not address this issue only, but also updated and brought together other laws related to human tissues and organs.	
Name:	National Health System (NHS)
Source:	https://www.england.nhs.uk
Brief description: The NHS comprises all publicly funded healthcare systems of the United Kingdom. It is there to improve citizens' health and wellbeing, supporting them to keep mentally and physically well, to get better when ill and, when full recovery is not possible, to stay as healthy as possible until	



the end of their lives. In addition, the NHS acts as an important policy maker in the UK in the area of health and healthcare.

Name:	Public Health England (PHE)
Source:	https://www.gov.uk/government/organisations/public-health-england

Brief description: Public Health England (PHE) is an executive agency of the Department of Health and Social Care in the United Kingdom. It exists to protect and improve the nation's health and wellbeing and reduce health inequalities.

3.1.3 Policy agencies in China

Since the beginning of China's economic reforms in the 1970's, the introduction of new health policies have profoundly changed the country's health system. The Chinese health system involves the complex interplay of a wide range of organisations⁹ where the central government acts as the main policy agent in charge of responding to major national challenges and the development of political strategies.

All Chinese health policy agencies therefore stand in close relationship with the executive branch, primarily through the central government and regional authorities. China's central government holds the final responsibility over national health legislations and policies. Table 3 below lists the main policy agencies related to the Chinese health system with special relevance to Personalised Medicine.

Table 3 – Policy agencies in China

Name:	The 14th Five-Year Plan for National Economic and Social Development of the People's Republic of China and the Outline of Vision Goals for 2035
Source:	http://www.gov.cn/xinwen/2021-03/13/content_5592681.htm
Brief description: The 14th Five-Year Plan states that, the health system has been improved: the average life expectancy has increased by 1 year and poverty has been eliminated. China wants to increase the financial investment in basic research, optimize the spending structure, implement tax incentives for companies to invest in basic research, encourage society to invest in multiple channels through donations and funding institutions, form a continuous and stable investment mechanism, and increase the proportion of basic research spending in R&I by more than 8%. China will strengthen the application of digital technology in response to public emergencies such as public health and improve data classification and hierarchical protection systems applicable to Big Data environments.	
Name:	Ministry of Science and Technology of the People's Republic of China (MOST)
Source:	http://en.most.gov.cn/eng/organization/mission/index.htm
Brief description: Department of Science and Technology for Social Development under MOST is responsible for the development of biotechnology with the Division of Biotechnology and Medicine.	

⁹ <https://www.commonwealthfund.org/international-health-policy-center/countries/china>



Name:	National Administration of Traditional Chinese Medicine
Source:	http://www.satcm.gov.cn/
Brief description: It sketches and implements related strategies, plans, policies, and standards for the development of Chinese medicine and ethnic medicine, it drafts relevant departmental laws, regulations and regulations, and participates in the planning and organization of major Chinese national medical projects. The Director of the Department of Medical Administration of the State Administration of Traditional Chinese Medicine pointed out that both Precision Medicine and Traditional Chinese Medicine are people-oriented explorations and research. Although the methods, theories and entry points are different, they can guide and learn from each other.	
Name:	National Development and Reform Commission
Source:	https://en.ndrc.gov.cn/
Brief description: NDRC is responsible for formulating strategies, plans and major policies for the development of high-tech industries and advance of industrial technologies.	
Name:	National Health Board
Source:	http://www.gov.cn/fuwu/bm/wsjkw/index.htm
Brief description: The main responsibilities of the National Health Board, also referred to as National Health and Wellness Commission, include the formulation of national health policies, drafting laws, regulations, policies and plans for the development of health and wellness undertakings as well as the formulation of departmental regulations and standards. It coordinates and promotes the deepening of the reform of the medical and health system and makes recommendations on major policies and policy measures. The National Health Board develops and organizes the implementation of disease prevention and control programmes, national immunization programmes and interventions on public health issues that seriously endanger people's health and develop catalogues of quarantine and surveillance of communicable diseases. An additional focus lies on the implementation of policies and measures to deal with the aging of the population, and to promote the construction of a health service system for the elderly and the integration of medical care.	
Name:	National Health Commission of the PRC
Source:	http://en.nhc.gov.cn/index.html
Brief description: The National Health Commission of China drafts laws and regulations for national health policies, but also policies, plans and measures to develop the public health services and to promote the equalization inclusiveness and convenience of basic public health services. It coordinates and plans the resource allocation of health services.	
Name:	National Medical Products Administration
Source:	http://english.nmpa.gov.cn/



Brief description: The NMPA is aimed at supervising the safety of drugs, medical devices and cosmetics; to regulate the registration of drugs, medical devices and cosmetics; to undertake standards management for drugs, medical devices and cosmetics, and so on.	
Name:	The National People's Congress
Source:	http://www.npc.gov.cn/englishnpc/
Brief description: It is responsible for health legislation, under the direct control of the State Council and the Central Committee of the Communist Party.	
Name:	National Health Board
Source:	http://www.gov.cn/fuwu/bm/wsjkw/index.htm
Brief description: The National Health and Wellness Commission organize the formulation of national health policies, draft of laws and regulations, policies and plans for the development of health and wellness. It coordinates and promote the deepening of the reform of the medical and health system and make recommendations on major policies and measures to deepen the reform of the medical and health system. It develops and organizes the implementation of disease prevention and control programmes, national immunization programmes and interventions on public health issues that seriously endanger people's health and develop catalogues of quarantine and surveillance of communicable diseases.	

3.2 Stakeholders related to Personalised Medicine

Personalised Medicine has the potential to transform healthcare. The process towards PM, that aims at better prediction, prevention and treatment of disease, is gaining pace all over Europe. Strong expectations are linked to the profound transformations of health and healthcare induced by the application of Personalised Medicine approaches such as the contribution of individual genomic differences, the importance of a patient's environment and lifestyle as well as the introduction of patient-tailored therapies. Healthcare systems that precisely target patients' needs eventually are thought to make better use of resources and generate population health benefits at lower costs¹⁰.

Currently however, a long-term structured approach to foster innovation in this area and to facilitate the rapid uptake of PM principles into clinical practice is still lacking. It therefore requires that stakeholders involved in all areas of Personalised Medicine face the key challenges and promote research, development, and implementation of PM.

According to Freeman¹¹, in a narrow sense, stakeholders are defined as all those identifiable groups or individuals on which an organisation depends for its survival and are sometimes referred to as primary stakeholders: stockholders, employees, customers, suppliers, and key government agencies. On a broader level, however, a stakeholder is any identifiable group or individual who can affect or is affected by organisation's performance in terms of production, policies, and work processes.

¹⁰ <https://cdn.sanity.io/files/0vv8moc6/ajmc/45aebaf56c76a5f1ff3ebdd34a6b6984790061b4.pdf>

¹¹ Freeman, R.E. (1984) Strategic Management: A Stakeholder Approach. Pitman, Boston



Here we define stakeholders as public interest groups, research institutions, government agencies, patient initiatives and industry organisations having a strong interest in PM. The integration of a diverse ecosystem of stakeholders is part of the complex challenge of the implementation of PM, alongside factors such as political commitment, joint production of data and standards by international consortia, and the standardization of clinical protocols.

3.2.1 Stakeholders in Europe

Table 4 below lists the stakeholders active in PM at the level of the European Union. They represent various bodies (e.g.: academic research networks, foundations, organisations, societies, etc.) often also extending beyond academic institutions and operating through policies and projects, which they often fund. Although the stakeholders have exponentially grown in numbers over the last years due to the rapid advancements in the field, at the EU level they are usually affiliated with academic institutions and rarely include for-profit companies.

The stakeholders' central aims are to further implement PM into clinical practice through the help from adjacent fields such as genomics, pharmacogenomics, and other omics sciences, and to create a supranational network fostering Personalised Medicine.

They have played a vital role in the rapid growth in the field of PM in areas such as:

- the implementation of databases pertaining genetic data,
- the promotion and development of research,
- the transfer and communication of knowledge from researchers and scientists in the wider scientific community,
- the exchange of knowledge and collaboration from public health experts, and
- the implementation of health improvement programmes.

Table 4 – Stakeholders in Europe

Name:	European Alliance for Personalised Medicine
Source:	https://www.euapm.eu
Brief description: The European Alliance for Personalised Medicine was launched in March 2012, with the aim of improving patient care by accelerating the development, delivery and uptake of personalised medicine and earlier diagnostics, through consensus. This alliance began its life as a response to the need for a wider understanding of priorities in personalised medicine and a more integrated approach among distinct lay and professional stakeholders.	
Name:	European Infrastructure for Translational Medicine (EATRIS)
Source:	https://eatris.eu/
Brief description: Translational research is a highly multi-disciplinary and complex undertaking. As a consequence, a major challenge in developing new innovations is understanding what steps need to be taken, and what expertise and technologies are suitable to perform these steps. Researchers in need of specialised support can approach EATRIS to seek guidance in the steps to be taken, by means of clinical, biological and technological expertise available within the infrastructure. Subsequently, EATRIS will match such needs with the competences within the infrastructure. In this	



way, EATRIS facilitates collaboration among academics, physicians, and developers. The Spanish National Health Institute Carlos III (ISCIII) is the funding agency in Spain supporting EATRIS.

Name:	The joint Personalised Medicine Working Group of the European Biopharmaceutical Enterprises (EBE) and the European Federation of Pharmaceutical Industries and Associations (EFPIA)
Source:	https://www.ebe-biopharma.eu/personalised-medicine/

Brief description: EBE is the European trade association that represents biopharmaceutical companies of all sizes operating in Europe. In 2010, EBE established a Working Group on Personalised Medicine, since mid-2015 it is a joint group with the European Federation of Pharmaceutical Industries and Associations (EFPIA). The activities of the Working Group include: 1) Regulatory inputs: The Personalised Medicine Working Group develops stakeholder input during the implementation of Regulation (EU) 2017/746 on in vitro diagnostic medical devices, adopted on 5th April 2017. This Regulation has significant impact on the field of personalised medicine through its provisions on companion diagnostics. 2) Benefit of personalised medicines to patients, society and healthcare systems: In 2017, EBE-EFPIA Personalised Medicine Working Group developed a Manifesto setting out policy elements considered essential to ensure that Personalised Medicine approaches and their paired diagnostic tests, also called companion diagnostics, successfully reach patients. 3) Registries and Biobanks: The Personalised Medicine Working Group ensures that the European Union is based on a landscape of standardized, well-coordinated and connected European registries and biobanks embracing genomics and clinical data with high quality e-health record systems.

Name:	European Science Foundation (ESF)
Source:	https://www.esf.org

Brief description: The European Science Foundation (ESF) is a non-governmental, internationally oriented, non-profit association established in France in 1974. ESF is committed to promoting the highest quality science in Europe to drive progress in research and innovation. They partner with diverse institutions by leading successful projects, facilitating informed decision-making through a broad range of science support partnerships: Research Project Grant Evaluation, the coordination of European projects, funding programmes and the administration of scientific platforms. Through its activities and instruments, ESF has made major contributions to science in a global context.

Name:	European Hospital and Healthcare Federation (HOPE)
Source:	http://www.hope.be

Brief description: HOPE, the European Hospital and Healthcare Federation, is a European non-profit organisation, created in 1966 representing national public and private hospital and healthcare associations and hospital, health, and social care services owners. With 37 organisations from the 28 Member States of the European Union, Switzerland and the Republic of Serbia, HOPE covers almost 80% of hospital care and is also active in the healthcare and social fields. HOPE's mission is to promote improvements in the health of citizens and a equally high standard of hospital care by the European Union, fostering efficiency, effectiveness and humanity in the organisation and



operations of hospital and health services. HOPE is representing its members in the European arena covering all policies with an impact on hospitals and health services. HOPE contributes to the legislative agenda but also to the non-legislative activities through participation in European projects and joint actions. Since its creation HOPE has produced comparative information on the ways healthcare systems are organised and financed. It includes a unique annual exchange programme as well for health professionals, together with study tours, workshops, and conferences.

Name:	European Public Health Association (EUPHA)
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Source:	https://eupha.org/index.php
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Brief description: EUPHA is an umbrella organisation for public health associations and institutes in Europe. EUPHA was founded in 1992 by 15 members (12 countries). EUPHA now has 86 members from 47 countries. EUPHA is an international, multidisciplinary, scientific organisation, bringing together around 19'000 public health experts for professional exchange and collaboration throughout Europe. EUPHA encourage a multidisciplinary approach to public health.

Name:	European Health Management Association (EHMA)
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Source:	https://ehma.org
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Brief description: EHMA is a non-profit membership organisation open to all those committed to improving health and healthcare. EHMA is principally focussed on the 'how' rather than the 'what' of healthcare. This focus on implementation has behind it the twin aims of improving the take up and successful implementation of health improvement programmes and spreading this learning back into the realms of health policy, education, and training.

Name:	The European Clinical Research Infrastructure Network (ECRIN)
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Source:	https://www.ecrin.org
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Brief description: A not-for-profit intergovernmental organisation that supports the conduct of multinational clinical trials in Europe.

Name:	European Cluster Collaboration Platform
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Source:	https://www.clustercollaboration.eu
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Brief description: The European Cluster Collaboration Platform is a service facility aiming to provide cluster organisations with modern tools. These tools allow to make efficient use of networking instruments (search/find potential partners and opportunities) and develop collaboration trans-nationally (within Europe) and internationally (beyond Europe). Also, they support the emergence of new value chains through cross-sectorial cooperation and access the latest quality information on cluster development. Finally, they improve their performance and increase their as well as their members' competitiveness.

Name:	European Society of Human Genetics
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Source:	https://www.eshg.org/index.php?id=home
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Brief description: The Society was founded in 1967. It is a recognised international non-for-profit organisation, with its own statutes. The ESHG is one of the founding members of the International Federation of Human Genetics Societies.	
Name:	Genomic Medicine Alliance
Source:	http://www.genomicmedicinealliance.org
Brief description: A global academic research network which aims to build and strengthen collaborative ties between academics, researchers, regulators, and members from the general public interested in genomic and personalized medicine. Since its establishment, the number of its members has expanded at a very rapid pace. Currently it consists of over 1.300 members (January 2018) from more than 70 countries worldwide. The Genomic Medicine Alliance members are coming from academia as well as from corporate and regulatory sectors, including developing countries and low-resources environments in the Middle East, Asia and Latin America. The primary goal of Genomic Medicine Alliance is the development of a network focusing on the translation of genomic knowledge into clinical practice. The key points that make Genomic Medicine Alliance different from existing consortia, research networks and initiatives in this field are: Membership is free of charge, flat governance structure, commitment to bring together genomics research institutions from developing countries with those from developed countries.	
Name:	The Golden Helix Foundation
Source:	http://www.goldenhelix.org
Brief description: The Golden Helix Foundation is an international non-profit research organization (registered London-based UK charity) aiming to advance research and education in the area of genome and personalized medicine. The Golden Helix Foundation aims to promote the development of research and the transfer and communication of knowledge from researchers and scientists in the wider scientific community through collaborative projects and conferences in the field of pharmacogenomics and personalized medicine.	
Name:	International Cancer Genome Consortium
Source:	https://icgc.org
Brief description: It was established to launch and coordinate a large number of research projects sharing a common goal of unravelling the genomic changes present in many forms of cancer that contribute to the burden of disease in people throughout the world.	
Name:	International Human Epigenome Consortium (IHEC) (*)
Source:	http://ihec-epigenomes.org
Brief description: IHEC is a global consortium with the primary goal of providing free access to high-resolution reference human epigenome maps for normal and disease cell types to the research community. IHEC will facilitate communication among the members and offer a forum for coordination, with the objective of avoiding redundant research efforts, implementing high data	





quality standards, and thus maximizing efficiency among the scientists working to understand, treat, and prevent diseases.	
Name:	Precision Medicine Forum
Source:	https://precisionmedicineforum.com
Brief description: The aim of the Precision Medicine Forum is to facilitate global collaboration in precision medicine what many see as the key to unlocking the promise of a personalised approach to healthcare.	

3.2.2 Stakeholders in EU Member States

Stakeholders active in Personalised Medicine in the EU Member States are summarized in


Table 5. Depending on the Member States they are based in, they often pursue a wide variety of diverse strategies. However, they all align in building a pan-European network to improve strategic collaboration and implementation of Personalised Medicine. Furthermore, they aim to promote innovation and quality in healthcare as well as to implement R&D programmes. Communication and dissemination of recent PM developments and achievements are often part of their core competences. To conclude, stakeholders are acts as key agents on the promotion of the population's wellbeing through Personalised Medicine approaches.

Table 5 – Stakeholders in EU Member States


Country:	Austria	
Name:	Austrian Platform for Personalized Medicine - ÖPPM	
Source:	www.personalized-medicine.at	
Brief description: The Austrian Platform for Personalized Medicine (ÖPPM) is targeting all interested individuals and stakeholders that are interested to contribute in research and implementation of personalized medicine in Austria. One of the platforms primary goals is to build a network of stakeholders that cover all different disciplines involved, to improve strategical collaboration and to deal even stronger with the field of personalized medicine in Austria, as well as in the European and international context. The ÖPPM has been founded at the end of 2017 and is funded by the Federal Ministry of Education, Science and Research (BMBWF).		
Country:	Croatia	
Name:	Croatian Academy of Sciences and Arts	
Source:	http://info.hazu.hr/hr	
Brief description: The Croatian Academy of Sciences and Arts promotes and organizes scientific research and encourages the application of its findings, develops artistic and cultural activities and is concerned with Croatian cultural heritage and its affirmation throughout the world. It publishes the results of scientific research and artistic creation, makes proposals and gives its opinion on the		




promotion of sciences and arts in the fields which are of special importance to the Republic of Croatia.

Country:	Cyprus 
Name:	The Cyprus Institute (Cyl)
Source:	https://www.cyi.ac.cy

Brief description: The Cyl has developed as an international science and technology organization, to strengthen the research community of Cyprus, help transform its economy to a knowledge-based one and to create a research hub for the Eastern Mediterranean region.

Country:	Czech Republic 
Name:	The Technology Centre of the Czech Academy of Sciences (TC CAS)
Source:	https://www.tc.cz/en

Brief description: TC CAS was established in 1994 as a non-profit association of legal entities. The TC is a key national institution providing services to the research and development organizations and innovative companies; it carries out oriented research in the area of science, technologies and innovations. The TC is a source of current information about European Framework programmes for research, development, and innovation.




Country:	Denmark 
Name:	Healthcare Denmark
Source:	https://www.healthcaredenmark.dk

Brief description: Healthcare Denmark is the international gateway to Danish healthcare and life science expertise and innovation. Healthcare Denmark is a public-private non-profit partnership.


Country:	Estonia 
Name:	Institute of Genomics (IG)
Source:	http://genomics.ut.ee/en

Brief description: The main aim of the Institute of Genomics (IG) is to promote the development of human genetic research, on one hand by providing a better understanding of the evolutionary history of human genome and its impact on disease development using population genetics tools to highlight how the present-day genetic diversity arose in humans. On the other hand, it collects information on health issues and genetics from the Estonian population and implements genomics data into medical practice acting as a developer of personalised medicine in Estonia, with the aim of improving population health. IG manages the Estonian Biobank, created for this purpose. It is a newly established institute at the University of Tartu combining two well-established research institutions: the Estonian Biocentre and the Estonian Genome Centre.



Name:	National Institute for Health Development	
Source:	https://www.regionaalhaigla.ee/en	
Brief description: The National Institute for Health Development is a government established research and development body collecting, connecting, and providing reliable national information from a multitude of sources, related to the health of the Estonian population		
Country:	Finland	
Name:	Finnish Institute for Health and Welfare (THL)	
Source:	https://thl.fi/en/web/thlfi-en	
Brief description: The Finnish Institute for Health and Welfare (THL) studies, monitors, and develops measures to promote the well-being and health of the population in Finland. They gather and produce information based on research and register data. They also provide expertise and solutions to support decision-making. They are an independent expert agency working under the Ministry of Social Affairs and Health.		
Country:	France	
Name:	French National Alliance for Life Sciences and Health (Aviesan)	
Source:	https://aviesan.fr/en	
Brief description: Aviesan has been set up in response to the commitment to further step up the French research performances by fostering its consistency, creativity and excellence. The purposes of Aviesan are to: coordinate the strategic analysis, scientific programming and operational implementation of life and health science research; give a fresh boost to translational research by speeding up the transfer of fundamental knowledge to clinical application; increase cross-disciplinarity by opening biology and medicine up to contributions from mathematics, physics, chemistry, information technology, engineering sciences, human and social sciences; ensure that projects are consistent in thematic and infrastructure terms; carry out clinical, economic and social promotion of knowledge, particularly by facilitating industrial partnerships; define shared standpoints in terms of European research and international cooperation; harmonize and cut down on red tape for laboratories so as to free up the creativity and excellence of teams.		
Name:	Inserm	
Source:	https://www.inserm.fr/en	
Brief description: It is a public research organization located in France and entirely dedicated to human health. Its objective is to promote the health of all by advancing knowledge about life and disease, treatment innovation and public health research.		
Country:	Germany	



Name:	Federal Centre for Health Education (BZgA)	
Source:	https://www.bzga.de/home/bzga	
Brief description: Health education is in the best interests of national health policy. Being an interdisciplinary and ongoing task, it is implemented by all levels of government in Germany, in a process involving the affected parties. Preventive healthcare and health preservation are the two top-priority goals of their work. Their measures and programmes contribute to reducing the incidence of new cases of disease in their key fields of education (primary prevention) and to improving the early detection of disease (secondary prevention), as well as to generally strengthening health-related potentials (health promotion). To this end, they strengthen people's knowledge, attitudes and abilities, enabling them to behave healthily, recognise and avoid risks, and thus assume responsibility for their own health and that of others.		
Name:	German Cancer Aid	
Source:	https://www.krebshilfe.de	
Brief description: Since 1974, the organization has been promoting projects to improve prevention, early detection, diagnostics, therapy, medical follow-up care, and psychosocial care. German Cancer Aid informs the public on matters regarding cancer, possible prevention methods and early detection. German Cancer Aid sees itself as an advocate for cancer patients and promotes the best possible care, in terms of medicine and public health policies, for all cancer patients in Germany. Together with its daughter organization, the Dr. Mildred Scheel Foundation for Cancer Research, it promotes various innovative research projects with the aim to develop new cancer therapies and diagnostic procedures. German Cancer Aid receives no public funds and finances their activities entirely from public voluntary donations.		
Name:	German Centre for Infection Research (DZIF)	
Source:	https://www.dzif.de/en/personalized-medicine	
Brief description: DZIF is involved in the development of new vaccines, diagnostics, and medicines all the way through preclinical and clinical trials, ideally with support from the industry even to market maturity. The goal of the German Centre for Infection Research is to accelerate the development of medical innovations. Its PM focus lies on the generation of individual specific treatment for patients with multidrug and extensively-drug resistant tuberculosis to increase the chances of recovery and cure. This involves using molecular resistance testing in order to specifically adapt to and optimise drug treatment for each individual patient.		
Country:	Greece	
Name:	Hellenic Network of Precision Medicine on Cancer	
Source:	https://oncopmnet.gr/?page_id=2921&lang=en#	
Brief description: The Hellenic Network of Precision Medicine on Cancer was founded on 17/05/2018 as an initiative of the Research and Innovation Department of the Ministry of Education,		




Research and Religion, in close collaboration with the Ministry of Health. The Network is funded by the Framework of the Hellenic Republic – Siemens Settlement Agreement. Its mission is to Connect the Network with the National Health System, to provide high-quality healthcare to Greek citizens, to enrich diagnosis knowledge and prediction outcome, to improve the targeted therapeutic treatment of cancer patients.

Country:	Hungary 
Name:	Eötvös Loránd Research Network (ELKH)
Source:	https://elkh.org/english/

Brief description: The Office is a national strategic and funding agency for scientific research, development and innovation. It is the primary source of advice on RDI policy for the Hungarian government, and the primary RDI funding agency. In addition, the mandate of the Office includes the preparation of the Hungarian RDI strategy and the representation of the Hungarian government and the Hungarian RDI community in international organizations. Operating as of January 2015, the Office's mission is to advance research development and innovation (RDI) policy in Hungary and ensure that the country increases competitiveness by adequately investing in RDI, funding excellent research and supporting innovation. The Office was created with the purpose to provide a stable institutional framework for the governmental coordination of the national research, development, and innovation ecosystem, provide predictable funding and implement an efficient and transparent use of available resources.

Country:	Ireland 
Name:	Systems Biology Ireland
Source:	http://www.ucd.ie/sbi

Brief description: Systems Biology Ireland investigates new therapeutic approaches to disease, with a focus on cancer at a systems level. They use a combination of traditional wet-lab and computational modelling approaches to understand cellular signalling networks.

Country:	Italy 
Name:	Agenzia Nazionale per i Servizi Sanitari Regionali (Agenas)
Source:	https://www.agenas.gov.it

Brief description: Agenas is a public agency established in 1993 as a technical-scientific body of the Ministry of Health. The main objectives of the Agency are to promote innovation and quality in healthcare, to perform comparative analysis of cost and effectiveness of services offered to the public and to provide technical support to the Ministry of Health and to the Regions.




Name:	Istituto Italiano di Tecnologia (IIT)
Source:	https://iit.it



Brief description: Istituto Italiano di Tecnologia (IIT) is a public research institute that adopts the organizational model of a private law firm. It was created with the objective of promoting Italy's technological development and higher education in science and technology IIT aims to promote excellence in basic and applied research and to promote the development of the national economy.	
Name:	Istituto Superiore di Sanità (ISS)
Source:	https://www.iss.it/en/home
Brief description: The ISS is the scientific advisory body of the National Health System in Italy, namely of the Ministry of Health, the Regions, and the Local Health Unit. The ISS undertakes research funding, management, and training functions in relation to public health in Italy.	
Country:	Latvia 
Name:	Latvian Biomedical Research and Study Centre (BMC)
Source:	http://www.biomed.lu.lv/en
Brief description: The BMC is a leading scientific institute in molecular biology and biomedicine. Perform basic and applied research in human genetics and disease mechanisms, cancer research, biotechnology and structural biology, molecular microbiology and virology, molecular pharmacology and drug targets.	
Country:	Lithuania 
Name:	Research Council of Lithuania
Source:	http://www.biomed.lu.lv/en
Brief description: The Research Council of Lithuania was founded in 1991 to fulfil the role of an expert institution tackling challenges of science development on a national level. The Council is a counsellor of the Lithuanian Parliament and the Government for matters concerning research and researchers' training. It also implements programme based competitive funding of research, administers most important Lithuanian science development programmes, evaluates research performance and represents Lithuanian science in various European institutions and other international organisations.	
Country:	Luxembourg 
Name:	Luxembourg Institute of Health (LIH)
Source:	https://www.lih.lu/page/aboutus
Brief description: The Luxembourg Institute of Health is a public research organisation at the forefront of biomedical sciences. With its strong expertise in population health, oncology, infection and immunity as well as storage and handling of biological samples, its research activities are dedicated to people's health. At the Luxembourg Institute of Health, more than 300 individuals are working together, aiming at investigating disease mechanisms and developing new diagnostics,	



innovative therapies and effective tools to implement personalised medicine. The institution is the first supplier of public health information in Luxembourg, a strong cooperation partner in local and international projects and an attractive training place for ambitious early-stage researchers.

Country:	The Netherlands	
Name:	National Institute for Public Health and the Environment	
Source:	https://www.rivm.nl/en/about-rivm	
Brief description: The National Institute for Public Health and the Environment has been promoting public health and safeguarding a healthy environment. It has a central role in infectious disease control and national prevention and population screening programmes. It conducts independent (scientific) research in the field of Public Health, Health Services, Environmental Safety and Security.		
Name:	Netherlands Institute for Health Services Research (NIVEL)	
Source:	https://www.nivel.nl/en	
Brief description: The Netherlands institute for Health Services Research is the national institute for health services research in the Netherlands. Health services research is the multidisciplinary field of scientific investigation that examines how social factors, financing systems, organisational structures and processes, health technologies and personal behaviours affect access to health care, its quality and costs and, ultimately, population health and well-being. Nivel is an independent organisation, which carries out high quality research with a demonstrable impact upon society.		
Country:	Poland	
Name:	Klaster Life Science Krakow	
Source:	https://lifescience.pl	
Brief description: Klaster Life Science Krakow was established in 2006 as a cooperation network of institutions and companies from the southern Poland macro-region that share this goals: creating a cooperation network in the area of Life Science, supporting entrepreneurship and innovation in the field of life science, combining and developing resources and competences in the field of life science.		
Country:	Portugal	
Name:	International Iberian Nanotechnology Laboratory (INL)	
Source:	https://inl.int	
Brief description: Located in Braga (North of Portugal), INL was founded by the governments of Portugal and Spain under an international legal framework to perform interdisciplinary research and to deploy and articulate nanotechnology for the benefit of society. INL aims to become the world-wide hub for nanotechnology addressing society's grand challenges. The INL research programme comprises four strategic fields of application of nanoscience and nanotechnology: Food and Environment monitoring, ICT, Renewable Energy and Health.		




Country:	Romania 
Name:	InoMed (Center for Innovation in Medicine)
Source:	https://ino-med.ro/index.html
<p>Brief description: InoMed is focused on the innovation in healthcare. Center for Innovation in Medicine is a non-governmental organisation which has the aim to shorten the time between the emergence of innovations in medical sector and their application for patients benefit in Romania and elsewhere. The Center for Innovation in Medicine serves as an independent platform for informed dialogue between all stakeholders in the field of omics medicine, personalised (precision) medicine, digital health, data oncology, immune-oncology, cancer research, biotechnology, systems biology and other hot scientific topics.</p>	
Country:	Slovenia 
Name:	National Institute of Public Health (NIJZ)
Source:	https://www.nijz.si
<p>Brief description: NIJZ is the central Slovenian institution for public health practice, research, and education. Its academic staff work on various tasks covering the areas of epidemiology of communicable and non-communicable diseases, health promotion, health protection, health system research and national coordination of preventive programmes in primary health care.</p>	
Country:	Spain 
Name:	Agencia Estatal de Investigación
Source:	https://www.ciencia.gob.es/portal/site/MICINN/aei
<p>Brief description: Instrument for public funding of R&D&I activities. Its purpose is to promote scientific and technical research in all areas of knowledge through the efficient allocation of public resources, to encourage collaboration between the agents in the R&D&I system and to support the generation of knowledge with a high scientific and technical, economic and social impact, including that oriented towards the challenges of society and the monitoring of funded activities.</p>	
Name:	Centro Nacional de Análisis Genético
Source:	https://www.cnag.crg.eu
<p>Brief description: The CNAG-CRG is a non-profit organization funded by the Spanish Ministry of Science and Innovation and the Catalan Government through the Economy and Knowledge Department and the Health Department. The mission of the Centro Nacional de Análisis Genético is to carry out projects in genome analysis that will lead to significant improvements in people's health and quality of life, in collaboration with the Catalan, Spanish, European and International research and clinical community.</p>	



Name:	Red de Investigación en Actividades Preventivas y Promoción de la Salud (rediAPP)
Source:	https://www.rediapp.org
Brief description: rediAPP is a research network that aims to generate knowledge that will benefit Primary Care, particularly concerning the efficacy, effectiveness and efficiency of new interventions in prevention and health promotion. rediAPP also aims to disseminate knowledge so that the public, the scientific community and the services' coordinators can integrate the prevention and apply the results to daily clinical practice and service management.	
Name:	Medical Technology Innovation Platform (ITEMAS)
Source:	https://www.itemas.org/en
Brief description: ITEMAS aims to promote innovation in medical technology as an essential tool in making the Spanish National Health System more sustainable. It also supports the development of the culture of innovation necessary to facilitate integration of all the relevant agents in the field of medical technology. The core of the ITEMAS comprises the innovation units of 29 large hospitals belonging to the Spanish National Health System, in addition to the Ministry of Health, Social Services and Equality and the National Center for Cardiovascular Research (CNIC).	
Name:	Spanish Association Against Cancer (AECC)
Source:	https://www.aecc.es/es
Brief description: The AECC aims to educate in health, support and accompany sick people and their families, and finance research projects that will allow a better diagnosis and treatment of cancer. They promote talent and provide stability to the professional career of researchers, encourage research in the clinical environment and facilitate the participation of Spanish researchers in international consortia. They also include a new line of grants aimed at promoting research into rare cancers. The AECC also participates in ERA PerMed calls as a funding organisation of personalised medicine research projects.	
Name:	Spanish Clinical Research Network (SCReN)
Source:	https://www.scren.es/en
Brief description: SCReN is a Platform that groups together 29 Clinical Research and Clinical Trial Units (UICECs) from 11 autonomous communities. It is a non-profit association. The objectives of its program are to achieve an advanced level of technical competence of the processes related to the development and management of clinical research, ensuring compliance with legal requirements and competence of the researchers involved in the platform's studies on methodological aspects and GCPs, etc.	
Name:	Spanish National Bioinformatics Institute (INB)
Source:	https://inb-elixir.es



Brief description: The INB serves in the coordination, integration and development of Spanish bioinformatics resources in projects in the areas of genomics, proteomics and translational medicine. It has contributed to the creation of a consistent computational infrastructure in the area of bioinformatics, participated in national and international genome projects, and trained bioinformatics users and developers.	
Name:	Spanish Network for Research in Infectious diseases (REIPI)
Source:	http://reipi.org
Brief description: REIPI is formed by 17 Spanish leading research groups in the field, and is funded by Ministerio de Ciencia, Innovación y Universidades, Instituto de Salud Carlos III, co-financed by European Development Regional Fund “A way to achieve Europe” ERDF. REIPI is a Research Network aimed at improving developing high quality basic, translational, and clinical research in the area of clinical microbiology and infectious diseases.	
Country:	Sweden 
Name:	Genomic Medicine Sweden (GMS)
Source:	https://genomicmedicine.se/en
Brief description: Genomic Medicine Sweden (GMS) was founded in 2018 with the aim of translating innovation in genomics into clinical practice and implementing a sustainable infrastructure for Precision Medicine in Sweden. GMS receives national funding from the Swedish Innovation Agency, Vinnova, as well as co-funding from the seven regions with university hospitals and the seven Swedish universities medical faculties. Its objectives are: 1) To enable the use of broad gene sequencing in healthcare for improved diagnostics and equal care for all patients 2) To establish a national genomics platform and knowledge database 3) To increase the use of genomics and health data for research, development and innovation 4) To increase participation in clinical trials 5) To identify prerequisites for primary prevention and early detection of complex diseases.	
Name:	National Genomics Infrastructure (NGI)
Source:	https://ngisweden.scilifelab.se
Brief description: The National Genomics Infrastructure (NGI) is hosted by Science for Life Laboratory (SciLifeLab), a Swedish national center for molecular biosciences with a focus on health and environmental research. NGI is one of the largest technical platforms both at SciLifeLab in terms of the number of projects and number of users. It provides access to technology for massively parallel sequencing and genotyping at all scales, and associated bioinformatics support to researchers based in Sweden.	
Name:	Nordforsk
Source:	https://www.nordforsk.org



Brief description: NordForsk is an organisation under the Nordic Council of Ministers that provides funding for and facilitates Nordic cooperation on research and research infrastructure. NordForsk, Innovation Fund Denmark, the Research Council of Norway, the Swedish Governmental Agency for Innovation Systems (Vinnova), the Icelandic Centre for Research (RANNÍS) and Innovaatorahoituskeskus Business Finland, are providing more than NOK 165 million in funding for seven Nordic projects that will target wider implementation of personalised medicine in the Nordic health care sector. The funded projects will enable Nordic players in personalised medicine to establish links across borders, thereby promoting personalised medicine and increasing Nordic visibility in the field. In addition, this large-scale Nordic initiative will further strengthen Nordic collaboration across institutions, hospitals, health organisations and companies.	
Name:	SwedenBIO
Source:	https://swedenbio.se
Brief description: SwedenBIO is the national non-profit association for the life science industry in Sweden, with more than 250 members. SwedenBIO's mission is to promote an environment bringing success and growth to the entire Swedish Life Science Industry.	
Name:	VINNOVA (*)
Source:	https://www.vinnova.se/en
Brief description: Vinnova is a government agency under the Ministry of Enterprise and Innovation, and the national contact authority for the EU framework programme for research and innovation. We're also the Swedish Government's expert authority in innovation policy It helps to build Sweden's innovation capacity, contributing to sustainable growth. Its vision is that Sweden is an innovative force in a sustainable world.	
Country:	United Kingdom 
Name:	Academy of Medical Sciences
Source:	https://acmedsci.ac.uk/policy/policy-projects/Stratified-medicine
Brief description: Academy of Medical Sciences is the independent body in the UK representing the diversity of medical science. Their mission is to advance biomedical and health research and its translation into benefits for society. The Academy of Medical Sciences has worked to outline the benefits of stratified approaches to medicine, and to address barriers to their widespread development and adoption.	
Name:	EPSRC Fast Assessment and Treatment in Healthcare (FAST Healthcare) NetworksPlus
Source:	http://www.fast-healthcare.org.uk
Brief description: FAST Healthcare is a response by the Engineering and Physical Sciences (EPS) community to this call. They are a network of academics with clinical, industrial and charity partners	



who are working to optimise treatment processes in public healthcare using an engineering methodology to develop practical solutions which can be realistically implemented.

Name:	Molecular Pathology Nodes (*)
Source:	https://mrc.ukri.org/research/initiatives/precision-medicine/molecular-pathology

Brief description: Molecular Pathology Nodes seeks to describe and understand the origins and mechanisms of disease at the level of macromolecules (for example DNA, RNA and protein) largely using patient samples. The MRC's mission is to encourage and support research to improve human health; to produce skilled researchers; to advance and disseminate knowledge and technology to improve the quality of life and economic competitiveness of the UK; to promote dialogue with the public about medical research.

Name:	National Institute for Biological Standards and Control (NIBSC)
Source:	https://www.nibsc.org/about_us.aspx

Brief description: NIBSC is a global leader in the characterisation, standardisation, and control of biological medicines. NIBSC plays a major national and international role in assuring the quality of biological medicines worldwide through the provision of biological reference materials, by testing products and carrying out applied research, through the development of standards and reference materials and through product control testing.

Name:	PHG Foundation
Source:	https://www.phgfoundation.org

Brief description: The PHG Foundation is a non-profit think tank with a special focus on how genomics and other emerging health technologies can provide more effective, personalised healthcare and deliver improvements in health for patients and citizens. In April 2018, became part of the University of Cambridge, as a linked exempt charity.

(*) means the information was obtained from ICPERMED platform.

3.2.3 Stakeholders in China

As for policy agencies, stakeholders in China are in close relationship with the central government and regional authorities. They must often also deal with local governmental bodies on the different administrative levels of the People's Republic of China¹² – mainly the provincial, prefecture and county level – which may have their own health commissions and bureaus of health.

Table 6 lists the main stakeholders in China related to Personalised Medicine. A clear separation from main research and innovation actors is often difficult due to the overlapping roles within the Chinese health system.

¹² https://www.fmprc.gov.cn/mfa_eng/ljzg_665465/zgjk_665467/3572_665469/t1140993.shtml



Table 6 – Stakeholders in China

Name:	Guangdong Provincial Institute of Precision Medical Application
Source:	https://bit.ly/3qZUQVp ¹³
Brief description: The institute wants to establish common communication and sharing platforms in various fields related to precision medicine, such as the institute of life science, biopharmaceuticals, big data, political research and financial investments, to gradually promote the implementation of projects and the development of precision medicine in China. In 2017 the Institute was officially recognized by the Provincial Department of Science and Technology (MOST).	
Name:	Institute of Lung Cancer of Guangdong Provincial People's Hospital
Source:	https://www.gdghospital.org.cn/office/IntroduceInfoID.aspx?bid=150
Brief description: It is a key medical specialty of Guangdong Province and a key discipline of Guangdong Provincial People's Hospital. It is also the first department in China with real significance to implement the comprehensive treatment of lung cancer with single disease and multiple disciplines.	
Name:	JF Healthcare
Source:	https://e.bjmu.edu.cn
Brief description: JF Healthcare supports primary care with advanced world-class AI, telemedicine and other technologies to enable accountable and affordable diagnostic services at primary care levels.	
Name:	Peking University Health Science Centre
Source:	https://e.bjmu.edu.cn
Brief description: PKUHSC is the first Medical Institution of Western medicine founded by Chinese Government, which is developing rapidly in the new era.	
Name:	Ruijin Hospital, Shanghai Jiao Tong University School of Medicine
Source:	https://www.shsmu.edu.cn/english/info/1030/1086.htm
Brief description: Renji Hospital, founded in 1844, is a municipal tertiary hospital affiliated to Shanghai Jiaotong University School of Medicine. The hospital has been engaged vigorously in international activities with foreign medical industries. In 2002, the hospital set up Quankang Medical Center to provide high quality service for foreigners.	
Name:	Shanghai Institute of Precision Medicine

¹³ <https://baike.baidu.com/item/%E5%B9%BF%E4%B8%9C%E7%9C%81%E7%B2%BE%E5%87%86%E5%8C%BB%E5%AD%A6%E5%BA%94%E7%94%A8%E5%AD%A6%E4%BC%9A/50572013>



Source:	http://www.shipm.cn/jyz_web/html/DefaultSite/jyz_xygk_xyjj/List/index.htm
Brief description: NDRC is responsible for formulating strategies, plans and major policies for the development of high-tech industries and advance of industrial technologies.	

4 PM-related Funding Schemes and Programmes

4.1 Funding schemes and programmes in Europe

The remarkable importance of the European research framework programmes for funding in Europe was already described in detail in *D1.1 – Programmes at EU level*. The major responsibility for the implementation of the research programmes and the management of EU research grants lies within the scope of the European Commission’s Research Executive Agency (REA)¹⁴.

Regarding European frontier research priorities, the European Union has created a dedicated public body for funding of scientific and technological research known as the European Research Council (ERC). It provides support to investigator-driven research excellency across all fields¹⁵ including PM-related basic research projects.

For the support of commercialization and financing of high-risk and high-impact technologies in the European Union, the EC has introduced the European Innovation Council¹⁶ (EIC) in a pilot phase under the H2020 framework programme. The EIC will be fully implemented from 2021 on under the new Horizon Europe framework programme and is dedicated to close-to-market applications focusing on top-class innovators, entrepreneurs, small companies and start-ups.

An additional instrument and source of funding for Personalised Medicine in Europe are the public-public partnerships (P2P) in EU Research under the Horizon 2020 Regulation¹⁷ - see Figure 2. P2P allow EU countries to draw up joint research programmes in which the EU may participate. The aim of public-public partnerships is to pool and coordinate national research efforts, to make better use of Europe's public research and development resources and to tackle common European challenges more effectively.

¹⁴ Research Executive Agency https://ec.europa.eu/info/departments/research-executive-agency_en

¹⁵ European Research Council <https://erc.europa.eu/>

¹⁶ European Innovation Council <https://ec.europa.eu/research/eic/index.cfm>

¹⁷ Article 26 - <https://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2013:347:0104:0173:EN:PDF>





Figure 2 – Pillars of European public-public partnerships

P2P are comprised of three pillars:

- ERA-NET Cofund¹⁸
- Joint-Programming Initiatives (JPIs)¹⁹
- Research initiatives based on Article 185²⁰ of the Treaty on the Functioning of the EU

4.1.1 ERA-NET Cofunds

European Research Area Networks (ERA-NETs) are funding schemes financed by the European Commission in various research fields. Their goal is to create a European Research Area (ERA) in which research is conducted and funded across countries, allowing research groups to jointly work on specific problems, exchange ideas, and benefit from cross border expertise. The ERA-NET Cofunds related to Personalised Medicine are listed in Table 7.

Of special importance is the ERA-NET Cofund “ERA PerMed” that is dedicated specifically to align national research strategies, promote excellence, reinforce the competitiveness of European players in PM.

Table 7 – ERA-NET Cofunds related to PM

Name:	ERACoSysMed
Source:	https://www.eracosysmed.eu
Brief description: The ERA-Net ERACoSysMed "Collaboration on systems medicine funding to promote the implementation of systems biology approaches in clinical research and medical practice" started in January 2015 as the first ERA-Net on Systems Medicine under the EU Framework Programme Horizon2020.	
Name:	ERA PerMed (*)

¹⁸ ERA-NET - <https://ec.europa.eu/programmes/horizon2020/en/h2020-section/era-net>

¹⁹ JPI - <https://ec.europa.eu/programmes/horizon2020/en/h2020-section/joint-programming-initiatives>

²⁰ Article 185 initiatives - <https://ec.europa.eu/programmes/horizon2020/en/h2020-section/article-185>



Source:	http://www.era-permed.eu
Brief description: ERA PerMed is a new ERA-Net Cofund, supported by 32 partners from 23 countries and cofunded by the European Commission. To align national research strategies, promote excellence, reinforce the competitiveness of European players in PM, and enhance the European collaboration with non-EU countries, national funding organisations have agreed to launch Joint Transnational Calls for collaborative innovative research projects in Personalised Medicine (PM).	
Name:	E-RARE
Source:	http://www.erare.eu
Brief description: The current E-Rare-3 project extended and strengthened the transnational cooperation on rare disease research by funding organizations in the 5-year period of 2015-2019, allowing to build on the experience and results of the previous ERA-Net programmes E-Rare-1 and E-Rare-2. It aims to provide an international model platform for implementing Joint Transnational Calls. The consortium comprises 25 institutions from 17 European countries. Its international dimension will be directly translated into close collaboration with IRDiRC and other relevant European and international initiatives.	
Name:	EuroNanoMed
Source:	https://euronanomed.net
Brief description: EuroNanoMed is a platform for funding agencies and ministries established in 2008. National and Regional research funding programmes join together with the goal of creating and funding collaborative research and innovation projects that can convert research in nanotechnology into practical gains in medicine. EuroNanoMed supports multidisciplinary and translational research and innovation projects that cover: Regenerative medicine, Diagnostics and Targeted delivery systems.	
Name	GENDER-NET Plus (*)
Source:	http://gender-net-plus.eu
Brief description: GENDER-NET Plus ERA-NET Cofund was launched September 15 th , 2017 and will run until 2022. The consortium of 16 committed organisations from 13 countries aims to strengthen transnational collaborations between research programme owners and managers, provide support to the promotion of gender equality through institutional change. Furthermore, the GENDER-NET Plus consortium aims to promote the integration of sex and gender analysis into research. This integration gives new knowledge and insights, which ultimately will benefit both women and men.	
Name	JPcofuND2
Source:	https://www.neurodegenerationresearch.eu/initiatives/jpco-fund-2/
Brief description: The initiative, lasting five years (2019-2024), has the aim to promote research aimed at deciphering the variability in the treatment of neurodegenerative diseases supported by	



highly personalised approaches for the greatest benefit of the patients. The Spanish National Health Institute Carlos III (ISCIII) acts as funding agency in this ERA-Net.

Name:	NEURON (*)
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Source:	https://www.neuron-eranet.eu
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Brief description: NEURON supports basic, clinical and translational research in the diverse fields of disease-related neuroscience. Ministries and funding organisations across Europe, Israel, Turkey and Canada have joined forces to conquer diseases of the brain and the nervous system. According to estimates by the World Health Organisation, more than one billion people suffer from them. Brain diseases are major causes for impaired quality of life. The ERA-NET NEURON aims to support research directed at a better understanding of brain diseases and their progression in order to pave the way for new or improved routes for diagnosis and therapy.

Name	TRANSCAN-2
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Source:	https://www.transcanfp7.eu/
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Brief description: The ERA-NET: Aligning national/regional translational cancer research programmes and activities - TRANSCAN-2 was a five-year project (2015-2019) funded by the European Commission under the EU framework programme Horizon2020. It is the continuation of the previous ERA-NET on translational cancer research TRANSCAN, funded under the FP7 from 2011 to 2014. TRANSCAN-2 is a collaborative network of ministries, funding agencies and research councils with programs in translational cancer research. The network is composed of 28 partners from 19 Countries. The project is coordinated by the Ministry of Health, Italy.

(*) means the information was obtained from IC2PERMED platform.

4.1.2 Additional funding schemes and programmes

European Joint Programming Initiatives²¹ (JPI) follow a structured and strategic process whereby EU Member States agree, on a voluntary basis and in a partnership approach, on common visions, the so-called Strategic Research and Innovation Agendas (SRIA), to address major societal challenges. They then develop and are implemented based on the common agenda specific Joint Programming Initiatives (JPI) including the launch of joint calls, fast track activities, knowledge hubs and task forces.

An additional mean allowing the EU to engage with Member States in jointly undertaken research programmes is Article 185 of the Treaty on the Functioning of the European Union (TFEU). Article 185's initiatives²² aim at addressing common challenges in specific research areas, by creating synergies between national and EU research programmes and investments, and aligning the often diverging and manifold national research efforts.

Public-private partnerships (PPP) bridge the EU's efforts in PM and bring in the expertise of the pharmaceutical industry. The most relevant in the field of PM is the Innovative Medicines Initiative

²¹ https://ec.europa.eu/info/research-and-innovation/research-area/agriculture-and-forestry/joint-programming-eu-countries_en

²² <https://www.era-learn.eu/partnerships-in-a-nutshell/type-of-networks/partnerships-under-horizon-2020/article-185-initiatives>



(IMI). Table 8 lists PM-related JPIs, the PM-related TFEU Article 185 initiative, Eurostars and the IMI as an example of a public-private partnership in PM. Nordforsk's NordicPermed funding scheme is also listed as an example of a European cooperation that is hosted outside of EU's research funding schemes and builds on the voluntary cooperation of in this case Nordic EU Member States.

Table 8 – Funding schemes and programmes in Europe

Name:	EU Joint Programme – Neurodegenerative Disease Research (JPND)
Source:	https://www.neurodegenerationresearch.eu
Brief description: The JPND is the largest global research initiative aimed at tackling the challenge of neurodegenerative diseases. JPND aims to increase coordinated investment between participating countries in research aimed at finding causes, developing cures, and identifying appropriate ways to care for those with neurodegenerative diseases.	
Name	European Joint Programme on Rare Diseases (EJP RD) (*)
Source:	https://www.ejprarediseases.org
Brief description: The European Joint Programme on Rare Diseases (EJP RD) brings together international institutions to create a comprehensive, sustainable ecosystem allowing a virtuous cycle between research, care and medical innovation. As recognized by the Council's Recommendation 2009/C 151/02, rare diseases (RD) are a prime example of a research area that can strongly profit from coordination on a European and international scale. RD research should be improved to overcome fragmentation, leading to efficacious use of data and resources, faster scientific progress and competitiveness, and most importantly to decrease unnecessary hardship and prolonged suffering of RD patients.	
Name	Eurostars
Source:	https://ec.europa.eu/programmes/horizon2020/en/h2020-section/eurostars-programme
Brief description: Eurostars is a joint programme between EUREKA and the European Commission. Eurostars supports the development of rapidly marketable innovative products, processes and services that help improve the daily lives of people around the world. Eurostars has been carefully developed to meet the specific needs of SMEs. It is an ideal first step in international cooperation, enabling small businesses to combine and share expertise and benefit from working beyond national borders.	
Name	Innovative Medicines Initiative (IMI)
Source:	https://www.imi.europa.eu/about-imi
Brief description: IMI is the world's biggest public-private partnership (PPP) in life sciences. It involves the European Union (represented by the European Commission) and the European pharmaceutical industry (represented by EFPIA, the European Federation of Pharmaceutical Industries and Associations).	



Name	JPIAMR
Source:	https://www.jpiamr.eu
Brief description: The Joint Programming Initiative on Antimicrobial Resistance (JPIAMR) ordinated national public investments and funds transnational research and activities within the six priority areas of the shared JPIAMR Strategic Research and Innovations Agenda (SRIA) – therapeutics, diagnostics, surveillance, transmission, environment and interventions. JPIAMR is seeking and supporting solutions to decrease transmissions of resistant bacteria, to lessen the burden of AMR on a global scale together with the 28 member countries.	
Name	Joint Programming Initiative ‘A Healthy Diet for a Healthy Life’ (JPI HDHL) (*)
Source:	https://www.healthydietforhealthylife.eu
Brief description: The Joint Programming Initiative a Healthy Diet for a Healthy Life (JPI HDHL) brings together 26 countries that align research programming and fund new research to prevent or minimise diet-related chronic diseases.	
Name:	Nordic Call on Personalised Medicine (NordicPermed) (*)
Source:	https://www.nordforsk.org
Brief description: NordicPermed facilitates and provides funding for Nordic research cooperation and research infrastructure. Funding is aimed specifically at institutions based in Denmark, Finland, Iceland, Norway, or Sweden.	

(*) means the information was obtained from ICPERMED platform.

4.2 Funding sources in EU Member States

Table 9 lists major PM-related funding schemes and programmes in the EU Member States.

Table 9 – Funding sources in EU Member States

Country:	Austria	
Name:	Austrian Science Fund (FWF) programmes	
Source:	https://www.fwf.ac.at/en/research-funding/fwf-programmes	
Brief description: The Austrian Science Fund (FWF) is Austria's central funding organization for basic research and open to all fields of science. The purpose of the FWF is to support the ongoing development of Austrian science and basic research at a high international level.		
Name:	Austrian Research Promotion Agency (FFG) programmes	
Source:	https://www.ffg.at/en/national-funding	



Brief description: The Austrian Research Promotion Agency (FFG) is the national funding agency for industrial research and development in Austria. The FFG also acts as the national contact point for the EU programme Horizon 2020 as well as other international programmes.	
Name:	Vienna Science and Technology Fund (WWTF)
Source:	https://www.wwtf.at/about/index.php?lang=EN
Brief description: The Vienna Science and Technology Fund (Wiener Wissenschafts-, Forschungs- und Technologiefonds) is a non-profit organisation established to promote science and research in Vienna. The Precision Medicine 2020 call invites researchers and clinical scientists at universities and non-university research institutions, who want to conduct a cutting-edge research project (2 to 4 years) with a major focus on precision medicine based on omics technologies and patient cohorts. Proposals should bring together scientists from different scientific disciplines such as biology, medicine and systems biology to foster interactive partnerships. Additional funding opportunities are available for collaborative projects between scientists in Vienna and Lower Austria.	
Country:	Denmark 
Name:	Grand Solutions
Source:	https://innovationsfonden.dk/en/programmes/grand-solutions
Brief description: Grand Solutions is aimed at collaborative projects based on excellent research focused on solutions of considerable societal value. Based on societal and business challenges, opportunities and innovation needs, Innovation Fund Denmark wants to enable cross-disciplinary investments in knowledge institutions and companies – private as well as public.	
Name:	Lundbeck Foundation
Source:	https://www.lundbeckfonden.com/en
Brief description: The Lundbeck Foundation is one of Denmark's largest commercial foundations, worth over DKK 60 billion, and awards research grants of around DKK 500 million each year to Danish-based, biomedical sciences research – primarily in the field of brain research. Projects may involve basic, clinical applied or epidemiological research – and should mainly focus on the brain.	
Country:	Estonia 
Name:	Estonian Research Council
Source:	https://www.etag.ee/en/
Brief description: The Estonian Research Council is a governmental foundation that was established to concentrate the funding of R&D and guarantee the better functioning of financing systems.	
Country:	Finland 
Name:	Personalised Health – From Genes to Society (pHealth) (*)



Source:	https://www.aka.fi/en/	
Brief description: The Academy Programme Personalised Health – From Genes to Society (pHealth) is centred on the concept of personalised medicine. The first and foremost theme of the programme is to produce data and tools to contribute to the understanding of individual characteristics at molecular level, and to using these data and tools for health promotion.		
Name:	Business Finland	
Source:	https://www.businessfinland.fi/en/for-finnish-customers/services/programs/personalized-health-finland	
Brief description: The personalized health program covers Finnish innovation and top-level research. It aims to create a new business around individualized healthcare platform.		
Country:	France	
Name:	French National Research Agency (ANR) (*)	
Source:	https://anr.fr/en	
Brief description: The French National Research Agency (ANR) is a public administrative institution under the authority of the French Ministry of Higher Education, Research, and Innovation. The agency funds project-based research carried out by public operators cooperating with each other or with private companies.		
Country:	Germany	
Name:	e:Med Systems Medicine (*)	
Source:	http://www.sys-med.de/en	
Brief description: e:Med has the objective of establishing systems medicine in Germany. e:Med promotes system-oriented research into diseases in order to facilitate improved prevention, more comprehensive diagnostics and individually adjusted therapy schemes in individualized medicine. The program brings together scientists with molecular-genetic, clinical, mathematical and information technology expertise, with the objective of ensuring that research results quickly benefit patients.		
Name:	Methods and tools for individualised medicine	
Source:	https://www.gesundheitsforschung-bmbf.de/de/methoden-werkzeuge-fuer-die-individualisierte-medizin.php	
Brief description: The funding method "Methods and tools for individualized medicine" supports individual and collaborative projects that develop new methods, tools and / or services in research and development for individualized medicine. The developed methods should be of primary		



importance and widely applicable and made freely accessible to users in research and development. This is intended to advance preclinical and clinical research on individualized medicine.

Name:	Individualized Medical Technology
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Source	https://www.bmbf.de/foerderungen/bekanntmachung-1286.html
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Brief description: The "Individualized Medical Technology" funding measure aims to support application and needs-oriented research and development on individualized forms of treatment. The funding is intended for industry-led, risky and precompetitive research and development collaborative projects where the development of new marketable medical technology solutions is required.

Name:	Innovations for Individualised Medicine
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Source:	https://www.gesundheitsforschung-bmbf.de/de/innovationen-fur-die-individualisierte-medizin.php
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Brief description: This measure supports research and development projects that aim to introduce new diagnostic and therapeutic methods and products in view of biomarker-based stratification and detection. The projects aim to exploit the influence of genes, proteins, and other molecules relevant to diseases and therapy for stratification and individualization.

Name:	Innovative Stem Cell Technologies for individualized Medicine
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Source:	https://www.bmbf.de/foerderungen/bekanntmachung-1070.html
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Brief description: The funding measure aims to promote preclinical research and development work that offer a significant contribution to unlocking the potential of new stem cell technologies for individualized medicine. This funding measure is part of the "Individualized Medicine: A New Path in Research and Healthcare" action plan of the Federal Government's Health Research Framework Program (https://www.bmbf.de/pub/Aktionsplan_Individualisiert_Medizin).

Country:	Hungary
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Name:	National Research, Development and Innovation Office (NRDI Office)
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Source:	https://nkfih.gov.hu/about-the-office
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Brief description: The Office is a national strategic and funding agency for scientific research, development, and innovation. It is the primary source of advice on RDI policy for the Hungarian government, and the primary RDI funding agency. In addition, the mandate of the Office includes the preparation of the Hungarian RDI strategy and the representation of the Hungarian government and the Hungarian RDI community in international organizations. Operating as of January 2015, the Office's mission is to advance research development and innovation (RDI) policy in Hungary and ensure that the country increases competitiveness by adequately investing in RDI, funding excellent research and supporting innovation. The Office was created with the purpose to provide a stable institutional framework for the governmental coordination of the national research, development



and innovation ecosystem, provide predictable funding and implement an efficient and transparent use of available resources.	
Country:	Ireland 
Name:	Health Research Board (HRB) (*)
Source:	https://www.hrb.ie
Brief description: The Health Research Board (HRB) is a state agency that supports research and provides evidence to prevent illness, improve health and transform patient care. The agency is funded mainly by the Department of Health, and Board members are appointed by the Minister for Health.	
Name:	Science Foundation Ireland (SFI)
Source:	https://www.sfi.ie
Brief description: SFI is the national foundation for investment in scientific and engineering research. Science Foundation Ireland funds research in the areas of science, technology, engineering, and mathematics (STEM) which promotes and assists the development and competitiveness of industry, enterprise and employment in Ireland. The Foundation also promotes and supports STEM education and engagement and creates awareness and understanding of the value of STEM to society and to the growth of the economy.	
Country:	Italy 
Name:	Deployment of Generic Cross Border eHealth Services in Italy (NCPeH) (*)
Source:	https://www.fascicolosanitario.gov.it/contesto-di-riferimento
Brief description: The National Contact Point for eHealth (NCPeH - National Contact Point for eHealth) is an infrastructure aimed at ensuring interoperability services for the cross-border exchange of health data and documents, for information relating to the Patient Summary and all 'ePrescription. In the context of European interoperability, it is the first tool to be promoted by the eHealth Network.	
Name:	Fondazione regionale per la ricerca biomedica (*)
Source:	http://www.frrb.it/en/home
Brief description: Fondazione regionale per la ricerca biomedica is a private law institution established by Lombardy Region in October 2011. Its aim is to promote and enhance scientific research in the field of Life Sciences, particularly in the biomedical field. FRRB represents one of the main strategic platforms for boosting progress, research, development and innovation in hospitals, universities and research centres focused on biomedical research and located in Lombardy Region.	



Name:	Centro nazionale per la prevenzione e il controllo delle malattie (CCM)
Source:	http://www.ccm-network.it/home.html
Brief description: The National Center for Disease Prevention and Control (CCM) is a coordinating body between the Ministry of Health and the Regions for surveillance, prevention and timely response to emergencies. Regarding personalized medicine, CCM through the funded projects aims to implement the 2010-2012 Italian National Prevention Plan and the 2017 Italian National Plan for Innovation of the Health System based on omics sciences.	
Country:	Latvia 
Name:	Latvian Council of Science
Source:	https://lzp.gov.lv/
Brief description: The Latvian Council of Science was established in 1991. In accordance with the Law on Scientific Activity, the Latvian Council of Science is a collegiate institution of the scientists under the supervision of the Ministry of Education and Science. The Council is a counsellor of the Latvian Government on matters concerning research and researchers' training. It advises on the formulation and implementation of science, higher education and R&D policy. The Council takes active part in project based competitive R&D funding, as well as promotes the development of Latvian researcher resources and fosters the international scientific cooperation.	
Country:	Lithuania 
Name:	Healthy ageing (*)
Source:	https://www.lmt.lt/en/research-commissioned-by-the-state/national-research-programmes/healthy-ageing/795
Brief description: The purpose of the programme "Healthy ageing" is to obtain new scientific knowledge required to extend the duration of life and guarantee at the same time good life quality. The programme seeks to comprehensively analyse and find solutions for issues regarding the healthy ageing through the development of science and technologies, promoting and funding fundamental and applied research.	
Country:	Luxembourg 
Name:	National Centre of Excellence (NCER) (*)
Source:	https://www.fnr.lu
Brief description: The NCER is the main funder of research activities in Luxembourg. It invests public funds and private donations into research projects in various branches of science and the humanities, with an emphasis on selected core strategic areas. It supports and coordinates activities	



to strengthen the link between science and society and to raise awareness for research. Also, it advises the Luxembourg government on research policy and strategy.

Name: CORE (*)

Source: <https://www.fnr.lu/funding-instruments/core>

Brief description: CORE is a multiannual thematic research programme to strengthen the scientific quality of Luxembourg's public research in the country's research priorities adopted by the Government on 20 December 2019.

Name: PRIDE (*)

Source: <https://www.fnr.lu/funding-instruments/pride>

Brief description: PRIDE is a programme for research intensive doctoral education. It aims to support the development of critical mass in key research areas, by attracting excellent PhD candidates to Luxembourg and offering them high quality research training. Under this programme, a block of PhD grants is awarded to a consortium of excellent researchers united around a coherent research and training programme. PRIDE is open to all domains of research and technological development.

Country: The Netherlands



Name: Dutch Research Council (NWO)

Source: <https://www.nwo.nl/en>

Brief description: NWO facilitates excellent, curiosity-driven disciplinary, interdisciplinary and multidisciplinary research. In this role, NWO focuses on all scientific disciplines and on the entire knowledge chain with an emphasis on fundamental research. NWO connects researchers from various disciplines and across the entire knowledge chain and brings researchers and societal partners together. NWO also funds human and physical resources' cost for scientific research and knowledge exchange and impacts activities of Dutch universities and public research institutes. NWO invites partners from the industry, the government and societal organisations to contribute with their own knowledge agendas and questions to the programming, realisation and co-funding of research.

Name: The Netherlands Organisation for Health Research and Development (ZonMw)

Source: <https://www.zonmw.nl/en>

Brief description: ZonMw's goal is to ensure that healthy people stay that way for as long as possible, that ill people recover as quickly and as much as possible and that people who require care and nursing receive the highest standard of services by focusing on prevention.



Country: Portugal



Name:	National open calls - Foundation for Science and Technology (*)	
Source:	https://www.fct.pt/index.phtml.en	
Brief description: The FCT is the Portuguese national funding agency for science, research and technology.		
Name:	2017 Call for SR&TD Project Grants (*)	
Source:	https://www.fct.pt/apoios/projectos/concursos/2017/index.phtml.en	
Brief description: 2017 Call for SR&TD Project Grants support innovative ideas that are relevant and make significant contributions to the advancement of scientific knowledge.		
Country:	Slovenia	
Name:	Slovenian Research Agency	
Source:	https://www.arrs.si/en/index.asp	
Brief description: The Agency aims to provide the scientific community with instruments enabling stable funding of scientific excellence. The continuing improvements of the instruments should enable fairer competition of scientists within all fields of science. Ambitious international presence of scientists should be reflected through thought leading publications, based on activities funded by the Agency and participation of researchers in eminent European and other international projects.		
Country:	Spain	
Name:	Accion Estrategica en Salud /Health research and Development strategy (*)	
Source:	https://www.isciii.es/QueHacemos/Financiacion/Paginas/Accion-Estrategica-en-Salud.aspx	
Brief description: The AES is an annual programmatic action launched by the National Health Institute Carlos III to provide funding to health research in Spain. It proposes a set of synergic and complementary instrumental actions that are framed in the State Subprograms for Training, Incorporation and Mobility, of the State Program for the Promotion of Talent and its Employability and in the Subprograms for Institutional Strengthening and Knowledge Generation of the State Program for Knowledge Generation and Strengthening of the Spanish R&D&I System.		
Name:	Centro para el Desarrollo Tecnológico Industrial (CDTI)	
Source:	http://www.cdti.es/	
Brief description: it consists of a Public Business Entity, under the Ministry of Science and Innovation, which promotes innovation and technological development of Spanish companies. It is the entity that channels request for aid and support for R&D&I projects from Spanish companies in the national and international spheres. The objective of the CDTI is to contribute to the		



improvement of the technological level of companies. CDTI is also one of the Spanish organizations managing Structural Funds for innovation activities.

Country:	Sweden 
Name:	Project Grants Medicine and Health, Clinical therapy (*)
Source:	https://www.vr.se/english.html
Brief description: The Swedish Research Council is Sweden's largest governmental research funding body and supports research of the highest quality within all scientific fields. Every year, it pays out almost 7 billion SEK to support Swedish research.	
Name:	Medtech4Health (*)
Source:	https://medtech4health.se
Brief description: Medtech4Health is a national Strategic Innovation Programme within medical technology. They work to implement more medical technological ideas and solutions in healthcare, and to create value for patients. To make this possible, they bring together stakeholders from healthcare, academia and business in regional nodes and in different types of projects. Through innovation, their aim is to streamline healthcare and strengthen the medical technology industry, nationally and internationally.	
Name:	SweLife (*)
Source	https://swelife.se/en
Brief description: SweLife supports collaboration within academia, industry and healthcare, with the goal to strengthen Life Science in Sweden and to improve public health. It is a strategic innovation programme, funded by the Swedish Government via the Swedish innovation agency, Vinnova, and by the programme's partners. Swelife is a facilitator.	
Country:	United Kingdom 
Name:	Stratified Medicine Initiative (*)
Source:	https://mrc.ukri.org/research/initiatives/precision-medicine/funding/
Brief description: The aims of the framework are to present a pathway for stratified medicine research that covers stratum discovery and verification, towards early clinical assessment; to identify critical questions when designing studies and draw attention to potential design pitfalls and sources of bias; to describe methodological approaches and resources to inform study design and analysis, drawing on appropriate guidance and case studies and to enable investigators working at different phases of the stratified medicine pipeline to integrate their work.	
Name:	Industrial Strategy Challenge Fund: for research and innovation



Source:	https://bit.ly/3tqDgeK ²³
Brief description: A fund to strengthen UK science and business innovation and take on the biggest challenges that society and industry face today.	

(*) means the information was obtained from ICPERMED platform.

4.3 Funding sources and providers in China

Since its creation in 1986, the National Natural Science Foundation of China has become one of the major funding providers and sponsors of basic research in the People’s Republic of China. It is directly linked to the Ministry of Science and Technology (MOST) as a vice-ministerial level statutory board. The NFSC operates several funding programmes that fall into two categories:

1. NSFC-designated research directions and priorities
2. Open programmes to support researcher-initiated research
 - Youth Science Fund
 - Open Application Fund

In 2018, China spent around the 6,6% of GDP on health care, which amounts to CNY 5,912 billion (USD 1,665 billion). 28% was financed by the central and local governments, 44% by publicly funded health insurance, private health insurance, or social health donations, and 28% was paid out-of-pocket.

The State Medical and Insurance Administration deals with the financing of its main public insurance schemes: Urban Employee Basic Medical Insurance (UEBMI), which is financed by employee and employer payroll taxes, with minimal government funding. Participation is mandatory for workers in urban areas, and Urban-Rural Resident Basic Medical Insurance (URBMI) covers rural residents, self-employed individuals, children, students, elderly adults, and others. The insurance is voluntary. Both of those are related to the hukou system.

An additional source of funding is the Strategic Research Programme of the Chinese Academy of Sciences (CAS). Related to Personalised Medicine, a new funding scheme has been introduced in October 2020 with the title “Precision Health Study of Chinese Population based on Multi-dimensional Big Data” Thanks to generous public funding, China has rapidly risen to a major player in basic scientific research over the last decade. The Chinese interest to invest in health is underlined also on the 14th Five-Years Plan: in Chapter 4, Section II called “Strengthen the originality of leading science and technology” in which is explained the propose to invest in scientific research. The “基因与生物技术 Genes and Biotechnology” program studies the application of genomic on elements as biology medicine, innovative vaccines, in vitro diagnostic and drugs. In Section VI “In-depth patriotic health campaign” is written that, China aims to promote a healthy, civil, and ecological lifestyle. To do this China wants to:

- Strengthen the construction of public health infrastructure

²³ <https://www.gov.uk/government/collections/industrial-strategy-challenge-fund-joint-research-and-innovation#from-data-to-early-diagnosis-and-precision-medicine>



- Promoting the improvement of sanitation
- Strengthen health education and the dissemination of health knowledge
- Spread the notions for a balanced diet, combat food waste and abuse of alcohol and tobacco.

In the following Table 10 is summarized the most important founding sources and providers in China related to Personalised Medicine.

Table 10 – Funding sources and providers in China

Name:	Ministry of Finance of the People’s Republic of China
Source:	http://en.most.gov.cn/eng/index.htm
Brief Description: It provides funding for government health subsidies, health insurance contributions and health system infrastructure. In 2020 it provided several funding to the Personalised Medicine programs in all of China (e.g. Mongolia, Shaanxi, Qingdao etc.).	
Name:	Ministry of Science and Technology of the People’s Republic of China (MOST)
Source:	http://www.mof.gov.cn/en/
Brief description: The Ministry of Science and Technology (MOST) is responsible for formulating national strategic guidelines for innovation-driven development as well as the creation of policies related to science, technology, and basic research. It plays a pivotal role in organizing the implementation, coordination, and promotion of the construction of a national innovation system. The ministry is preparing and supervising the implementation of major national science and technology projects, establishing a unified national science and technology management platform for the purpose of research project funding.	
Name:	National Development and Reform Commission
Source:	https://en.ndrc.gov.cn
Brief Description: It subsidizes health infrastructure plans and competition among health care providers.	
Name:	National Health Commission of the PRC
Source:	http://www.nhc.gov.cn
Brief description: The National Health Commission is the main national health agency in China. The commission formulates national health policies, coordinates and advances medical and health care reforms, supervises and administers public health, medical care, health emergency response, and family planning services. It is also affiliated with The State Administration of Traditional Chinese Medicine.	
Name:	National Natural Science Foundation of China
Source:	http://www.nsf.gov.cn/english/site_1/index.html



Brief description: Since its establishment, NSFC has comprehensively introduced and implemented a rigorous and objective merit-review system to fulfil its mission of supporting basic research, fostering talented researchers, developing international cooperation and promoting socioeconomic development. It is managed by the Ministry of Science and Technology but keeps its due independence in operation.	
Name:	National Science and Technology Major Project
Source:	http://www.nmp.gov.cn/
Brief description: The National Science and Technology Major Project supports breakthroughs in core technologies and resources integration in order to achieve key national goals.	
Name:	Beijing Medical and Health Foundation
Source:	http://www.ywjhh.org.cn/
Brief description: It was registered in Beijing Civil Affairs Bureau as a comprehensive charity foundation in public health field, which deals with capital raising and management in accordance with the law to fund scientific research, academic exchanges and other aspects of public welfare projects or activities.	
Name:	Chinese Academy of Sciences (CAS)
Source:	https://english.cas.cn/
Brief Description: The Chinese Academy of Sciences (CAS) is the national academy for natural sciences of the People's Republic of China. It was founded in November 1949 and has numerous institutes throughout the entire country. With around 48,500 researchers, it is also the largest research institution in the world.	
Name:	Chinese Academy of Medical Science (CAMS)
Source:	http://english.cams.cn/about.html
Brief Description: It works under the National Health Commission and is the national centre for health research. It is the only state academic centre for medical sciences in China and a multidisciplinary medical research institute. In addition, it collaborates with Peking Union Medical College (PUMC). The aim is to develop a world-class medical research and training, taking responsibility for advising the Chinese government on fundamental reforms of health care and medical education.	
Name:	Chinese Centre for Disease Control and Prevention
Source:	http://www.chinacdc.cn/en/



Brief Description: It is non-governmental agency that is administrated by the National Health Commission. The Chinese Centre for Disease Control and Prevention administers the distribution of funds for research into rare diseases, specific diseases and Personalised Medicine.	
Name:	Chinese Medicine Development Fund (Enterprise Support Programme)
Source:	https://www.cmdevfund.hk/main-en.php
Brief description: The main purpose of the Hong Kong Chinese Medicine Development Fund is to promote the development of the Chinese medicine and Chinese medicine drug sectors, enhance the overall standard of the industry, nurture talents for Chinese medicine, promote Chinese medicine-related research and enhance public knowledge and understanding of Chinese medicine. It offers matching funds to practitioners and institutions to facilitate the development of Chinese Medicine Industry in Hong Kong.	
Name:	EU-China Co-Funding Mechanism (CFM)
Source:	http://chinainnovationfunding.eu/eu-china-co-funding/
Brief Description: The EU-China Co-Funding Mechanism (CFM) is a joint initiative by the European Union and the Chinese Government to support joint research and innovation projects between European and Chinese research institutions and enterprises in strategic areas of common interest under the framework of Horizon 2020. Through the EU-China Co-Funding Mechanism, the Chinese Ministry of Science and Technology (MOST) will provide funding to China-based participants of H2020 research and innovation projects.	
Name:	Special Fund Project for the Development of Strategic Emerging Industries in Shenzhen
Source:	http://www.sz.gov.cn/cn/zjsz/fwts_1_3/tzfw/yhzc_1/content/post_1354424.html
Brief description: The Industry and Information Technology Bureau of Shenzhen Municipality launched the Special Fund Project for the Development of Strategic Emerging Industries in Shenzhen, supporting various areas including biomedicine.	

5 Existing and emerging Initiatives

There is no consensus usage over the term “initiative”. It is used broadly in the context of R&I, ranging from major missions such as the US Precision Medicine initiative announced in 2015²⁴ over more detailed actions and programmes to specific monothematic research projects. We therefore refer to the subchapters of this section to define the scope of the respective mapping exercises.

²⁴ Precision Medicine Initiative - <https://obamawhitehouse.archives.gov/precision-medicine>



5.1 Initiatives in Europe

Here we distinguish between the Horizon 2020 coordination and support actions (CSAs) in Personalised Medicine comprising international consortia funded by the European Commission (EC) on one hand, and high-ranking PM-related programmatic initiatives on the EU and EU Member State level on the other.

5.1.1 ICPeMed-related coordination and support actions

Coordination and support actions (CSA) of the Horizon 2020 framework programme consist of accompanying measures such as standardisation, dissemination, awareness-raising and communication, networking, coordination or support services, policy dialogues and mutual learning exercises and studies, including design studies for new infrastructure and may also include complementary activities of strategic planning, networking and coordination between programmes in different countries.

Starting in 2010, the European Commission organised a series of activities focusing on the role of 'omics'- related research in personalised medicine (e.g. genomics, proteomics, metabolomics, epigenomics, pharmacogenomics). This led to the establishment of the International Consortium for Personalised Medicine (ICPerMed) initiative by the joint action of EU Member States and other international partners.

Together ICPeMed member organisations²⁵ work to:

- Establish Europe as a global leader in personalised medicine research;
- Support the personalised medicine science base through a coordinated approach to research;
- Provide evidence to demonstrate the benefit of personalised medicine to citizens and healthcare systems; and
- Pave the way for personalised medicine approaches for citizens.

Table 11 comprises all current H2020 CSAs in the field of Personalised Medicine associated with the original initiative of ICPeMed.

Table 11 – CSAs related to Personalised Medicine

Name	ICPerMed Secretariat
Source:	https://www.icpermed.eu
<p>Brief description: The ICPeMed secretariat contributes to the success of ICPeMed by efficiently coordinating all consortium activities, by implementing an effective dissemination plan and by assisting in the development of a sustainability strategy. By monitoring ongoing research funding activities in Europe and beyond, the secretariat serves as the basis for evidence-informed allocation of research funding. ICPeMed secretariat provides professional support in organising ICPeMed events and the meetings of ICPeMed bodies. In addition, ICPeMed secretariat guides the dialogue with relevant stakeholders and initiatives. The organisational and logistical support of a secretariat maximises the unique and long-term impact of ICPeMed by strengthening Europe's leading role in the successful implementation of PM in the global context.</p>	

²⁵ https://ec.europa.eu/research/conferences/2016/permed2016/pdf/towards_ic_permed.pdf



Name	SAPHIRE
Source:	https://www.saphire-eu.eu
<p>Brief description: SAPHIRE stands for Securing Adoption of Personalised Health in Regions. The consortium’s focus lies on the implementation of PM across European regions. It tries to establish and support the networking between regions and interregional cooperation by linking remote or sparsely populated regions with regions harbouring critical mass of medical and PM expertise, while taking into account broader socio-economic and cultural aspects. Regions are considered as the new powerhouses for innovation and adoption of personalised health and will drive the transition towards sustainable healthcare and personalised health.</p>	
Name	Regions4PerMed
Source:	https://www.regions4permed.eu
<p>Brief description: Interregional coordination for a fast and deep uptake of personalised health, abbreviated to Regions4PerMed, is about the challenge for national and regional authorities to enable the shift from a “reactive” healthcare system (based on episodic and acute care model) to a “preventive” (stratifying at-risk individuals and ensure that preventive action is taken to intervene well before the onset of symptoms, let alone illness) and “predictive” (leverage and integrate cutting-edge technologies to not only stratify risk, but even predict risk and intervene even further upstream) system – the so called Personalised Health (PH). In the face of this potential huge leap forward, the fact that personalised health lacks the cooperation and coordination needed to organise the still very fragmented field is a severe drawback to its development and to the placement of investments in an effective manner. For this reason, it is crucial to direct major efforts towards coordinating and aligning relevant stakeholders in personalised health action across Europe and beyond; create a participatory approach; build trust; enable a multi-stakeholder process; channel investments towards PH.</p>	
Name	HEcoPerMed
Source:	https://hecopermed.eu
<p>Brief description: HEcoPerMed stands for “Healthcare- and pharma-economics in support of the International Consortium for Personalised Medicine”. The project responds to the demand for economic models that evaluate treatments made possible through innovations in Personalised Medicine. The CSA also seeks to identify funding and reimbursement mechanisms that provide financial incentives for the rapid development and uptake of such innovations. HEcoPerMed goes beyond current assessment and payment models in order to serve the need of PM for more comprehensive cost-effectiveness estimates – incorporating patient and societal perspectives – and for sustainable affordability of cutting-edge health innovations.</p>	
Name	PERMIT
Source:	https://permit-eu.org



Brief description: The aim of PERMIT, Personalised Medicine Trials, is to develop and disseminate recommendations on Personalised Medicine research methodology, aiming to ensure the scientific excellence, validity, robustness, reproducibility, and acceptability of results. The goal is to enhance PM research and optimised, innovative healthcare solutions.	
Name	EULAC PerMed
Source:	https://www.eulac-permed.eu
Brief description: EULAC PerMed project aims to integrate countries from the Latin American and Caribbean (LAC) region in the ICPerMed and the ERA-Net ERA PerMed, as a means to widen the international scope of PM R&I related policies, increasing and encouraging a worldwide implementation of PM approaches across the whole healthcare value chain. The project will also work towards facilitating the introduction of PM for the benefit of patients, citizens and society, with the ultimate goal of contributing to the UN Sustainable Development Goal No. 3 to “Ensure healthy lives and promote well-being for all at all ages”.	
Name	Sino-EU PerMed
Source:	https://www.sino-eu-permed.eu
Brief description: Sino-EU PerMed is IC2PerMed’s sister project. The personalised medicine approach to healthcare has been gaining ground in Europe and China. For that reason, the EU-funded SINO-EU-PerMed project will conduct a mapping of the PM landscape and stakeholders in China. It will also exchange expertise by organising study visits in China and the EU. Further on, technical task forces and a series of targeted workshops will be organised to promote communication and collaboration between experts in the field of personalised medicine in China and the EU. Sino-EU-PerMed aims at connecting International Consortium for Personalised Medicine (ICPerMed) strategies and activities with relevant Chinese stakeholders.	

5.1.2 PM-related initiatives in Europe

Table 12 summarizes independent pan-European initiatives in the context of Personalised Medicine.

Table 12 – Existing and emerging initiatives in Europe

Name	Big Data for Medical Analytics (BigMedilytics)
Source:	https://www.bigmedilytics.eu
Brief description: BigMedilytics has received funding from the EU’s Horizon 2020 program to pilot big data solutions to achieve better patient outcomes in healthcare at a lower cost. The three-year program is the largest EU-funded initiative to transform the region’s healthcare sector through the use of big data. It aims to improve patient outcomes and increase productivity in the health sector by applying Artificial Intelligence (AI) technologies to complex datasets across the data value chain. This includes data from patients, healthcare providers, health insurers and medical technology providers.	
Name:	Centre for Personalised Medicine



Source:	https://www.ulster.ac.uk/cpm
Brief description: The Centre for Personalised Medicine was established in April 2017 following an award of €8.6 million from the EU's INTERREG VA Programme and managed by the Special EU Programmes Body (www.SEUPB.eu). This cross-border collaborative project led by Stratified Medicine Ulster University includes 13 partner organisations. The five Research Clusters (RCs) will use the methods and technologies from personalised medicine and apply them to heart disease, emergency surgery, acute kidney injury, unscheduled care in diabetes and diagnostic accuracy in dementia. These are areas associated with significant clinical need and commercial potential and will benefit significantly from the interdisciplinary academic and commercial cross-border expertise and collaboration.	
Name:	ELIXIR
Source:	https://elixir-europe.org
Brief description: ELIXIR is an intergovernmental organisation that brings together life science resources from across Europe. These resources include databases, software tools, training materials, cloud storage and supercomputers. The goal of ELIXIR is to coordinate these resources so that they form a single infrastructure. This infrastructure makes it easier for scientists to find and share data, exchange expertise, and agree on best practices. Ultimately, it will help them gain new insights into how living organisms work.	
Name:	EU-PEARL
Source:	https://eu-pearl.eu
Brief description: EU-PEARL (acronym for EU patient-centric clinical trial platform) is a strategic partnership between the public and private sectors to shape the future of clinical trials. This innovative and challenging enterprise aims to create a tested and trusted framework for patient-centric integrated research platform (IRP) trials, through which novel techniques and treatments developed by multiple companies and organizations are tested in a platform trial. This project is funded by the Innovative Medicines Initiative (IMI), a large, far-reaching public-private partnership integrated by the European Union and the pharmaceutical industry to support research and innovation in life-science.	
Name:	European Association for Predictive, Preventive & Personalised Medicine (EPMA)
Source:	https://www.epmanet.eu
Brief description: The EPMA was founded in 2009 to cover deficits in medical sciences and healthcare. The main objective of the EPMA is to promote the paradigm change from delayed reactive medical services to evidence-based Predictive, Preventive & Personalised Medicine (PPPM) as an integrated science and healthcare practice.	
Name	European '1+ Million Genomes' Initiative



Source:	https://ec.europa.eu/digital-single-market/en/european-1-million-genomes-initiative
Brief description: This initiative is looking to achieve a cross-border access to genomic databases in Europe by 2022. In the declaration of cooperation “Towards access to at least 1 million sequenced genomes in the EU by 2022” the initiative defines a collaboration mechanism with the potential to improve disease prevention, allow for more personalised treatments and provide a sufficient scale for new clinically impactful research.	
Name:	HARMONY
Source:	https://www.harmony-alliance.eu
Brief description: The Healthcare Alliance for Resourceful Medicines Offensive against Neoplasms in Hematology (HARMONY) is about Big Data management techniques. Existing clinical and genomic data on patients with haematological malignancies across Europe are being pooled to create a quality database to enable more effective diagnosis and quicker prescription of more effective treatments. This project is funded by the Innovative Medicines Initiative IMI2.	
Name:	iASiS – Big Data for Precision Medicine
Source:	https://project-iasis.eu
Brief description: It seeks to integrate data from different sources, including genomics, electronic health records and bibliographic data to apply advanced analytical methods to discover useful patterns. Although information is readily available at this time, the bottleneck is the lack of infrastructure to collect, integrate and exploit health data to transform it into useful information for clinical decision-making. This project has received funding from the European Union's Horizon 2020 research and innovation programme.	
Name:	ICGC-Mining in the International Cancer Consortium ICGC (*)
Source:	https://icgc.org
Brief description: The ICGC was established to launch and coordinate many research projects sharing a common goal of unravelling the genomic changes present in many forms of cancer that contribute to the burden of disease in people throughout the world.	
Name	IMI 2 Joint Undertaking
Source	https://www.imi.europa.eu
Brief description: The Innovative Medicines Initiative Joint Undertaking (IMI 2 Joint Undertaking) supports collaborative research to improve the entire development process and make it more efficient, giving patients faster access to better and safer medicines. It improves and speeds up the development of medicines by supporting open collaboration on research to address shared challenges. It funds collaborative research projects that bring together all the parties involved in health research, including universities; the pharmaceutical and other industries; small and medium-	



sized businesses; patient organisations; medicine regulators. This approach brings results in areas of disease where safe, effective treatments are lacking (e.g. dementia) and/or where the impact on public health is greatest (e.g. diabetes, antimicrobial resistance). The Innovative Medicines Initiative Joint Undertaking also runs projects on cross-cutting issues such as medicine safety and big data. IMI 2 JU is a public-private partnership established as a 'joint undertaking' between the EU and the European Federation of Pharmaceutical Industries and Associations.

Name:	Nordic Alliance for Clinical Genomics (NACG)
Source:	https://nordicclinicalgenomics.org
Brief description: An independent, non-governmental, not-for-profit Nordic association. NACG aims to facilitate the responsible sharing of genomic data, bioinformatics tools, sequencing methods and best practices for interpretation of genomic data and to enhance quality of genomic data and processes and explore methodologies to provide assurance.	
Name:	Nordic Society of Human Genetics and Precision Medicine (NSHG-PM)
Source:	https://www.nshg-pm.org
Brief description: NSHG-PM was created in order to establish a Nordic framework for research into the genetics of human diseases, as well as into human evolution and population history. The society aims to accelerate discovery of disease susceptibility genes and genes' protection from diseases through integrated analyses, using multiple large-scale datasets and a range of experimental designs. The final aim is to translate these findings so that they can be used for precision medicine to improve public health and uphold and promote the highest legal, regulatory, social, and ethical standards.	
Name:	Orphanet
Source:	https://www.orpha.net/consor/cgi-bin/index.php?lng=EN
Brief description: Orphanet was established in 1997 at the advent of the internet in order to gather the scarce knowledge on rare diseases in an effort to improve diagnosis, care and treatment of patients with rare diseases. This initiative became a European endeavour from 2000, supported by grants from the European Commission: Orphanet has gradually grown to a network of 41 countries, within Europe and across the globe. Over the past 20 years, Orphanet has become the reference source of information on rare diseases. As such, Orphanet is committed to meeting new challenges arise from a rapidly evolving political, scientific, and informatics landscape. It is crucial to help all audiences access quality information amongst the plethora of information available online, to provide the means to identify rare disease patients and to contribute to generating knowledge by producing massive, computable, re-usable scientific data.	
Name:	Solving the unsolved Rare Diseases (Solve-RD)
Source:	http://solve-rd.eu





Brief description: It is a research project funded by the European Commission for five years (2018-2022). It echoes the ambitious goals set out by the International Rare Diseases Research Consortium (IRDiRC) to deliver diagnostic tests for rarest diseases by 2020. The current diagnostic and subsequent therapeutic management of rare diseases is still highly unsatisfactory for a large proportion of rare disease patients – the unsolved RD cases. For these unsolved rare diseases, we are unable to explain the aetiology responsible for the disease phenotype, predict the individual disease risk and/or rate of disease progression, and/or quantitate the risk of relatives to develop the same disorder. The Solve-RD project has received funding from the European Union’s Horizon 2020 research and innovation programme.	
Name:	SPIDIA for Personalised Medicine
Source:	https://www.spidia.eu
Brief description: Standardisation of generic Pre-analytical procedures for In-vitro DIAgnostics (SPIDIA) for Personalised Medicine aims to develop standardized protocols for the collection, preservation, storage, transport, and processing of samples used in tests associated with personalized medicine.	
Name:	Ubiquitous Pharmacogenomics (U-PGx)
Source:	http://upgx.eu
Brief description: The EU-funded project "Ubiquitous Pharmacogenomics" (U-PGx) is part of the Horizon 2020 program and aimed at driving the implementation of pharmacogenetics in diagnostic and clinical practice. A large panel of pharmacogenomic markers will be evaluated in terms of cost-effectiveness and patient outcomes in 7 European countries. The data will be incorporated in EHR.	



5.2 Initiatives in EU Member States

In Table 13 selected initiatives in Personalised Medicine of the EU Member States are listed and grouped by their countries.



Table 13 – Existing and emerging initiatives in EU Member States

Country:	Belgium	
Name:	Perso-Med	
Source:	http://www.perso-med.eu	
Brief description: Perso-Med was an Interreg IVA FWVL project, led by Eurasanté (France) and FlandersBio (Belgium). This project is an opportunity for companies from Nord-Pas de Calais and Flanders to enhance their competitiveness and innovative capacity on a common theme: the personalised medicine.		
Country:	Bulgaria	
Name:	Bulgarian Alliance for Precision and Personalized Medicine BAPPM	







Source:	http://bappm.bg/en/about-us	
<p>Brief description: The Bulgarian Alliance for Precision and Personalized Medicine BAPPM is a non-profit legal entity, which unites medical and other specialists with experience and professional interest in the field of molecular, genome, precision, and personalized medicine. BAPPM has created a structure, which unites expertise and efforts of highly qualified specialists with proven record in different medical fields and specializations. Given the multidisciplinary nature of personalized and precision, which crosses the lines of the current definitions for medical specializations and therapeutic areas, their further development and implementation require joined actions and specific steps by various medical specialists and areas in medicine, pharmacy, healthcare management and health policy.</p>		
Country:	Croatia	
Name:	Croatian Competitiveness Cluster for Personalized Medicine	
Source:	http://investcroatia.gov.hr/en/personalized-medicine	
<p>Brief description: The Croatian Competitiveness Cluster for Personalized Medicine aims at achieving interdisciplinary collaboration of scientists from all fields of biomedical science, enabling easier sharing, comparison and application of knowledge, data and samples, creating a unique “Personalized Ecosystem of Personalised Medicine”.</p>		
Country:	Czech Republic	
Name:	RES-Q	
Source:	https://www.qualityregistry.eu	
<p>Brief description: RES-Q is a Registry of Stroke Care Quality. Developed as an ESO East initiative, RES-Q was initially targeted primarily at Central and Eastern Europe. However, RES-Q is happy to welcome users from across the world. RES-Q is an initiative of the ESO East Project (European Stroke Organisation- Enhancing and Accelerating Stroke Treatment) to help registered sites and countries improve their stroke care system.</p>		
Country:	Denmark	
Name:	Biopeople	
Source:	https://biopeople.eu	
<p>Brief description: Biopeople is Denmark's Life Science Cluster hosted by the University of Copenhagen and with hubs at Aarhus University and Aalborg University Hospital. They are part of the Danish infrastructure for innovation as established by the Ministry of Higher Education and Science and are funded by public government grants and grants from EU, national and regional projects.</p>		
Name:	GenomeDenmark	



Source:	http://www.genomedenmark.dk/english	
Brief description: GenomeDenmark is a national platform for sequencing and bioinformatics, which includes universities, hospitals, and private firms. The platform is established through two large demonstration projects and investments in technological equipment.		
Country:	Estonia	
Name:	Clinical Leadership Projects in Personal Medicine in Precise Prevention of Breast Cancer and Cardiovascular Diseases (*)	
Source:	https://sisu.ut.ee/pmkliinilisedjuhtprojektid/avaleht	
Brief description: The main task of the pilot is to find methods that consent a safe access to genetic information from physicians, that enable physician's readiness for personalised medicine counselling and that allow patients to accurately receive information from their doctors. To study such an ample context, from laws and regulations to the physical infrastructure of healthcare facilities, which is also being mapped by clinical pilot projects, several preconditions are needed. At the end of the study, a model for the provision of personal medicine services is proposed in two studied areas, the implementation of which in everyday medicine requires policy decisions.		
Country:	Finland	
Name:	FinnGen	
Source:	https://biopeople.eu	
Brief description: FinnGen is one of the very first Personalised Medicine projects at this scale and the public-private collaborative nature of the project is exceptional compared to many ongoing studies. FinnGen brings together Finnish universities, hospitals and hospital districts, THL, Blood Service, biobanks and international pharmaceutical companies and hundreds of thousands of Finns. Because collaboration is the key to achieving breakthroughs in disease prevention, diagnosis, and treatment, collaboration is open to a broad range of stakeholders.		
Name:	Sequencing Initiative Suomi (SISu)	
Source:	http://www.sisuproject.fi	
Brief description: SISu offers a way to search for data on sequence variants in Finns. It provides valuable summary data for researchers and clinicians as well as other people having an interest in genetics in Finland. SISu allows to examine the attributes and appearance of different variants in Finnish cohorts and see their aggregate distribution in Finland visualized on a map. In the current version, users can search for summary data on single nucleotide variants and indels from exomes of over 10 000 individuals sequenced in disease-specific and population genetic studies. The SISu project is an international collaboration between multiple research groups aiming to build tools for genomic medicine. The first version of the SISu search engine was released in 2014. The project is coordinated in the Institute for Molecular Medicine Finland (FIMM) at the University of Helsinki.		



Country:	France 
Name:	The French Platform for Personalised Medicine (F2PMed)
Source:	http://precisionmedicine.tbiscientific.com
Brief description: Personalised medicine is an emerging medical model that promises to bring radical changes in healthcare. This platform has been launched to centralize all resources related to precision medicine and related technologies. Founded by Seraya Maouche, The French Platform for Personalised Medicine (F2PMed) is the first platform and mobile application for precision medicine in France.	
Country:	Germany 
Name:	Medical Informatics (*)
Source:	https://www.medizininformatik-initiative.de/en
Brief description: Medical informatics is strengthening research and advancing healthcare. The German Federal Ministry of Education and Research (BMBF) launched its medical informatics funding scheme to make data from healthcare and research more useful and meaningful. It provides around 160 million euros with the aim of strengthening medical research and improving patient care.	
Country:	Greece 
Name:	pMedGR
Source:	https://www.precisionmedicine.gr
Brief description: It aims to become a regional hub for the implementation, coordination and integration of personalized medicine approaches in South-East Europe, as part of a global network, offering centralized information on patient stratification, susceptibility factors and response to treatments for relevant regional populations. This hub will serve as a single-entry point for researchers and industry with an interest in targeting this area. Greece's strategic geopolitical position, which correlates with genetic characteristics that may be important to health and disease, render it ideal to serve as a paradigm for personalized approaches targeting an extended regional area, including south Italy, the Balkans, Turkey etc. Through pMedGR, Greece has the potential to become a South-East European Node for Personalized Medicine, linking Europe to emerging markets such as Asia, Africa and the Middle East.	
Country:	Luxembourg 
Name:	Personalised Medicine Consortium (PMC)
Source:	https://www.precisionmedicine.gr
Brief description: It is an initiative aiming to support research and make Luxembourg a leader in the adoption of personalised medicine into the national healthcare system. It brings together the	



Luxembourg Institute of Health (LIH), the LCSB (Luxembourg Centre for Systems Biomedicine), IBBL (Integrated BioBank of Luxembourg), the Laboratoire National de Santé (LNS) and the Life Sciences Research Unit (LSRU) of the University of Luxembourg (UNI).	
Country:	The Netherlands 
Name:	Health Valley Netherlands
Source:	https://www.healthvalley.nl/welcome-to-health-valley
Brief description: Health Valley Netherlands is the biggest Life Sciences & Health innovation network in the Netherlands. The network unites companies, care organisations, knowledge institutes and authorities, and enables them to grow stronger together.	
Name:	Sino-Dutch Centre for Preventive and Personalized Medicine (SD PPM)
Source:	http://metabolomicscentre.nl/sino-dutch-centre-preventive-and-personalized-medicine-sdppm
Brief description: It bridges the different philosophies underlying Western and Chinese medicine, based on scientific biochemical language following a Systems Biology approach.	
Country:	Poland 
Name:	Polish Coalition for Personalised Medicine
Source:	http://pkmp.org.pl
Brief description: The Polish Coalition for Personalised Medicine was established on 17th December 2015 in Warsaw. The aim of the initiative is to create conditions conducive to the development of personalised medicine in Poland by supporting the process of legislative changes and system in this area. The task of the Coalition will also be to support education in the field of personalised medicine solutions with a focus on all stakeholders in the system.	
Country:	Portugal 
Name:	Discoveries Centre
Source:	https://thediscoveriesctr.eu
Brief description: The Discoveries Centre will bring together the best research groups in Portugal in the regenerative and precision medicine fields. The complementary knowledge of these teams coupled with the high-level competences of UCL researchers, as well as the state-of-the-art equipment and unique infrastructure available at the Centre will allow the new institution to perform excellent research. It also will focus on multi-disciplinary research that can be translated into the development of innovative tools and applications for the prevention and treatment of a group of disorders, namely musculoskeletal, neurodegenerative and cardiovascular diseases.	



Country:	Spain	
Name:	Cell Therapy Network (TerCel)	
Source:	http://www.red-tercel.com/ing/index.asp	
<p>Brief description: The Cell Therapy Network (TerCel) is a collaborative project that began its activity under the first call RETICs of the Carlos III Health Institute in 2003 with the aim of promoting research in cell therapy and transfer scientific advances in this field to the patients of the National Health System. The TerCel Network is made up of 32 research groups from all over Spain that include more than 350 basic researchers, clinicians and medical professionals working together, under a multidisciplinary and cooperative approach, with the main objective of discovering and describing the mechanisms of beneficial actions of cell therapy in human diseases through the development of experimental approaches, including transplantation of autologous and heterologous cells from different cell populations (adult, embryonic or iPSC), to improve the health of patients.</p>		
Name:	Consortio Centro de Investigación Biomédica en Red, M.P, CIBER	
Source:	https://www.ciberisciii.es/en	
<p>Brief description: The aim of the Consorcio Centro de Investigación Biomédica en Red, M.P, CIBER, a public research consortium set up at the initiative of the Instituto de Salud Carlos III (ISCIII) is to further excellence research in Biomedicine and Health Sciences performed in the National Health System and in the Science and Technology System. To this end efforts and interdisciplinary and multi-institutional research are combined with a preferential dedication of financial resources around knowledge networks formed by centres and research groups reporting to different administrations and public and private institutions.</p>		
Name:	Maternal and child health and development research network	
Source:	http://www.redsamid.net/en	
<p>Brief description: SAMID Network comprises 13 research groups' which main objective is to promote translational research focused on pregnant women, newborns and infants until the end of adolescence, once full development has been reached. The main objective of the Maternal and child health and development research network is to study the different pathological processes, nutritional and environmental conditions of the perinatal and postnatal periods. It does this by addressing prematurity determinants, prevention and patient safety, environmental and pathogenetic factors, nutrition and child development as well as promoting research into new products and therapeutic procedures.</p>		
Country:	United Kingdom	
Name:	CSO programmes from NHS	
Source:	https://www.england.nhs.uk/healthcare-science/cso-programmes	



Brief description: The Chief Scientific Officer works with Genomics England, which was set up to deliver the 100,000 Genomes Project. With the consent of participants and the support of the public, it is creating a lasting legacy for patients, the NHS and the UK economy, through the sequencing of 100,000 genomes.

Name: Precision Medicine Scotland (PMS-IC)

Source: <https://www.precisionmedicinescotland.com>

Brief description: PMS-IC's focus is on linking Scotland's domain expertise, data assets and delivery capability to accelerate the adoption of Precision Medicine: new products and services for a global market.

5.3 Initiatives in China

Health initiatives are humanitarian initiatives that raise and disburse additional funds for disease. This section presents the health initiatives in China related to Personalised Medicine. China is investing in several initiatives related to it as it was presented in the last 14th Five -Years Plan. It wants, not only develop the research on Personalised Medicine, but at the same time, develop a communication strategy to communicate the importance and the value of Personalised Medicine and investing in international cooperation.

Table 14 lists important initiatives related to Personalised Medicine and health in China and complements the information provided by chapter *D1.1 – Programmes in China* that covers China's five-year development plans extensively. China's health initiatives not only aim at developing research on Personalised Medicine, but at the same time serve to build a communication strategy around the importance and the values of Personalised Medicine principles, leaning on investments and international cooperation.

Table 14 – Existing and emerging initiatives in China

Name:	China Environment and Health Initiative (CEHI)
Source:	https://www.ssrc.org/programs/view/china-environment-and-health/
Brief description: From 2006 to 2016 the China Environment and Health Initiative (CEHI) explored the threats to health arising from China's rapid industrialization and urbanization and the challenges they face for governance. The program took an interdisciplinary approach that fostered collaboration among researchers from the social, medical, and environmental sciences.	
Name:	Chinese Health Initiative (CHI)
Source:	https://www.smchealth.org/general-information/hua-ren-jian-kang-cu-jin-hui
Brief description: The initiative aims to support Chinese citizens living abroad in understanding the different health problems and services available in that country, so that they can make decisions that are beneficial to their health or to that of their loved ones. It supports public services with	



appropriate and correct language and cultural background to encourage more Chinese in the community to seek health and medical services and further achieve the effect of disease prevention. It works with all social classes in the community to expand the scope of reference services and services.

Name: Healthy China Action (2019-2023)

Source: <https://bit.ly/3bYLzbV26>

Brief description: The "Healthy China Action (2019-2030)" focuses on the two cornerstones of disease prevention and health promotion and proposes to carry out 15 important special actions to promote the transformation from the treatment of diseases to the centre of people's health and to prevent people from falling ill, decreasing the number of those getting sick. Special actions include dissemination of health knowledge, tobacco control, mental health promotion, prevention and treatment of cardiovascular and cerebrovascular diseases and cancer prevention and treatment.

Name: Healthy Silk Road/ Belt and Road

Source: <https://www.yidaiyilu.gov.cn/xwzx/gnxw/24012.htm>

Brief description: The current 5-year plan deviates from the previous 12 strategic plans, which focused on domestic economic growth. The proposed Belt and Road Initiative will provide a channel through which China will facilitate its global health strategy, especially in the global south, through commercial, cultural, and personnel exchanges that will improve bilateral and multilateral regional cooperation. The Belt and Road Initiative also provides a common platform to improve the capability of handling regional public health emergencies through epidemic information sharing, exchange of preventive and interventional methods, and training health professionals. The document underlines that the cooperation with the medical research institutes is encouraged. The Belt and Road hospital alliance is established, and joint and technical research is carried out in the fields of state-of-the-art medical technology, prevention of major diseases, vaccine research and development and clinical research. The creation of the Belt and Road Health Industry and The Alliance for Sustainable Development support the development of trade in health services, medical health tourism and health care and explores cooperation in the mutual recognition of standards of access to relevant medical equipment in belt and road countries.

Name: Strategic Plan for China-EU Cooperation

Source: <https://bit.ly/30V2LbP27>

Brief description: On 21st November 2013, Premier Li Keqiang of the Council of State co-chaired the 16th Meeting of China-EU Leaders with European Council President Van Rompuy and European Commission President Barroso in the Great Hall of the People. The two sides jointly formulated the 'Strategic Plan for China-EU Cooperation 2020'. This comprehensive strategic plan sets out the

²⁶ <https://baike.baidu.com/item/%E5%81%A5%E5%BA%B7%E4%B8%AD%E5%9B%BD%E8%A1%8C%E5%8A%A8%E5%BC%882019%E2%80%94%E5%B9%B4%E5%BC%89/23543779>

²⁷ <https://baike.baidu.com/item/%E4%B8%AD%E6%AC%A7%E5%90%88%E4%BD%9C2020%E6%88%98%E7%95%A5%E8%A7%84%E5%88%92/12573751?fr=aladdin>



common objective of strengthening China-EU cooperation in the areas of peace and security, prosperity, sustainable development and cultural and people-to-people exchanges. It will promote the China-EU comprehensive strategic partnership in future years of further development. Also, the Plan wants to expand dialogue and exchanges in the field of health, including cooperation with the World Health Organisation, in the areas of drug resistance, medical information and cancer prevention, and strengthen dialogue on drug supervision to protect the health and safety of citizens.

Name: Sustainable Development Plan of Shenzhen Municipality (2017-2030)

Source: http://www.gd.gov.cn/zwgk/wjk/zcfgk/content/post_2939398.html

Brief description: The plan emphasizes the importance of initiating Healthy Shenzhen Construction Project with precision medicine as a major point.

Name: The 13th Five-Year Plan for Hygiene and Health of Shenzhen

Source: <http://www.sz.gov.cn/szst2010/wgkzl/jcgk/jchgk/201612/P020161221591330095914.pdf>

Brief description: Precision medicine is highlighted in the plan to comprehensively improve the health level of citizens, establish a health service system with higher quality, build a healthier city and a medical and health highland.

6 Main research and innovation actors

Personalised Medicine promises to revolutionise healthcare, with its key goal of providing the right treatment to the right patient at the right time, and it thus has the potential of improving the quality of life of citizens and is helping to bring down healthcare costs. However, a major problem with the broader implementation of Personalised Medicine is patient access to new drugs, devices and treatments. The development of new medicines and the introduction of innovative products to the market can often be very cumbersome and, in some cases, it may require decades to get from bench to bedside. There are often difficulties surrounding development, continued investment, testing and approval to the market.

The generally slow and complex processes further undermine continued investments and contribute to a risk-averse environment in healthcare, which negatively impacts innovation. Therefore, the role of pioneer research and innovation actors in Personalised Medicine and public health is key to speed up the process of rapid translation of innovation in basic research into clinical practice. The following chapters map important research and innovation actors in Europe and China.

6.1 PM research and innovation actors in EU Member States

Technical limitations have hindered progress in the field of Personalised Medicine for many years. Thanks to recent innovations and technological progress in big data, artificial intelligence (AI), medical diagnostics, next-generation sequencing and data analysis, the field proceeds faster than ever before.

Companies play a pivotal role in the development and application of PM principles and act as important innovation actors. On one hand, there are data-driven medical research companies, particularly those



with prowess in AI and machine learning, that will lead the way in finding new precision medicines for patients. Just as financial firms can determine a consumer's credit score based on almost every aspect of a person's financial history, healthcare companies may soon be able to analyse a patient's entire medical history to determine which treatment could be best for that unique individual. These are the companies that will be able to take vast datasets and interpret them to determine which treatment options to explore and conduct further research on for any given patient. Large pharmaceutical companies that focus on cell therapy and/or immuno-oncology treatments could be key in this category.

On the other hand, medical diagnostics and analysis companies could lead the way toward the development and implementation of precision health. Medical testing and analytics companies that focus on gene sequencing, specialized medical screening through DNA analysis or molecular modification as therapies could all bring cutting-edge treatments to the healthcare industry. Companies in this category would not only need advanced medical technology, but also the capability of examining vast datasets of medical records and trials. The main PM research and innovation actors in Europe are represented by academic institutions, research centres, public and private scientific companies. In Europe, the ecosystem of innovation revolves around the integration of healthcare systems, regulatory bodies, CROs, IP offices, academia, start-ups and spinouts. Collaboration between different stakeholders, assisted by the need and the availability of enormous venture capitals, which are often a limiting factor, is fundamental. The major objectives of innovation actors are to change the thinking paradigm according to which the scientific society performs research, its outputs and its outcomes over a given time span, in order to define a new clinical practice, exploit the research translation and enable the medicine revolution. These processes are money consuming and they require new technologies.

The main PM research and innovation actors in Europe and its EU member states gather specialists' competences, technologies and resources aiming to set new standards of care, implement clinical practice and enable the use of big data. They work in strict and effective collaboration with different additional stakeholders, such as government agencies, hospitals, universities, and academic institutes. Innovation actors focus on both research and translation (or implementation), by identifying the specific needs and lead to possible practical solutions.

Table 15 lists key research and innovation actors with a strong focus on research centres.

Table 15 – Research and innovation actors in EU Member States

Country:	Austria 
Name:	AIT Austrian Institute of Technology
Source:	https://www.ait.ac.at/en/about-the-ait
Brief description: The AIT is Austria's largest research and technology organization. Among the European research institutes, AIT is a specialist in the key infrastructure issues of the future. As an Ingenious Partner to industry and public institutions, AIT is already researching and developing the technologies, methods, and tools of tomorrow - paving the way for the innovations of the day after tomorrow. The Republic of Austria (through the Federal Ministry for Climate Protection, Environment, Energy, Mobility, Innovation and Technology) has a share of 50.46%, while the Federation of Austrian Industries owns 49.54% of the AIT Austrian Institute of Technology.	



Name:	Centre for Precision Medicine
Source:	https://www.zpm.at/de
Brief description: The Medical University of Vienna is launching an extensive fund-raising campaign to raise awareness about precision medicine and to build a research centre. It is planned to complete the Centre for Precision Medicine on the MedUni General Hospital campus by 2022. It is intended to be one of the leading centres for research and development of treatments in this field and to play a major role in 21st-century medicine.	
Name:	Ludwig Boltzmann Institute Applied Diagnostics
Source:	https://www.applied-diagnostics.at
Brief description: It is a translational research institution with the aim of combining a team of transdisciplinary scientists, academic and industrial partners from several countries. It follows a new dual biomarker concept for tumour diagnosis. The focus of the institute lies on the development of non-invasive diagnostic methods linking molecular epigenetic and genetic signatures with molecular imaging biomarkers for PET and SPECT analysis. The combination of these two methods will allow for improved functional, spatial, and temporal assessment of tumour load and molecular tumour characterization.	
Country:	Belgium 
Name:	Innovative Medicines Initiative (IMI)
Source:	https://www.imi.europa.eu
Brief description: IMI is the world's biggest public-private partnership (PPP) in life sciences. It is a partnership between the European Union (represented by the European Commission) and the European pharmaceutical industry (represented by EFPIA, the European Federation of Pharmaceutical Industries and Associations).	
Name:	Sciensano
Source:	https://www.sciensano.be/en/about-sciensano
Brief description: Sciensano is a research institute and the national public health institute of Belgium. Its core business is scientific research in the fields of public health, animal health and food safety. Sciensano arose in 2018 from the merger of the former Veterinary and Agrochemical Research Centre and the former Scientific Institute of Public Health in order to be able to provide a comprehensive answer to the health challenges of the future, based on the One Health principle. Among health programmes, one is focussing on advanced molecular diagnostics in cancer aiming at improving diagnosis, prognosis and treatment require complex Next-Generation-Sequencing (NGS) analyses. To streamline the introduction of this new technology in the Healthcare system, Sciensano outlined a five-year program in the “Roadbook: Personalized medicine: the introduction of next-generation sequencing in routine diagnostics in oncology and hemato-oncology (2016-2020)”.	



Name:	The Personalised Medicine Commission (ComPerMed)	
Source:	https://www.compermed.be/en/	
Brief description: The aim of ComPerMed is to I) develop technical guidelines to permit quality assurance for the molecular tests, and specifically for the NGS tests, used in oncology and haemato-oncology; II) To define which molecular biomarkers (DNA) must, as a minimum, be analysed by NGS for each type of tumour (solid and haematological). The choice of these genes is based on the scientific evidence of its specific clinical use for that specific tumour type; and III) to work out, for each type of tumour, good clinical practices in the form of a workflow showing the various molecular tests to be carried out in routine clinical practice.		
Country:	Croatia	
Name:	Genos	
Source:	https://genos-glyco.com	
Brief description: Genos knowledge and expertise is available to any interested party in academia or industry through high-throughput glycan analysis and other commercial services that they offer, ranging from analytical chemistry to study design and statistical data analysis.		
Country:	Cyprus	
Name:	Computation-based Science and Technology Research Center (CaSToRC)	
Source:	https://castorc.cyi.ac.cy/about/castorc-overview	
Brief description: The Project pioneers the introduction, development and employment of intense computational methods and data to advance scientific and technological disciplines. Backed by Cyl's Tier-1 supercomputing facility, CaSToRC aspires to cultivate the use of High-Performance Computing (HPC) and Data Science in Cyprus and the Eastern Mediterranean and to serve the needs for computational and data intensive applications.		
Country:	Estonia	
Name:	The North Estonia Medical Centre	
Source:	https://tai.ee/en	
Brief description: As a regional hospital, it has the highest-level competence to provide specialised medical care. According to Medical Centre's statutes, their goal is to provide high-quality specialised medical care and ambulance services, to be the learning base of training that precedes and follows the acquiring of health care professionals' qualifications and does health care related study and research work.		
Country:	Finland	





Name:	Institute for Molecular Medicine Finland	
Source:	https://www.fimm.fi	
Brief description: FIMM is an independent translational research institute focusing on human genomics and precision medicine, under the umbrella of the Helsinki Institute of Life Science at the University of Helsinki. FIMM has a driving mission to perform innovative research on patients and populations targeted towards understanding drivers of health and disease. They aim to deliver improvements to the safety, efficacy, and efficiency of healthcare in Finland and beyond.		
Country:	France	
Name:	Genopole	
Source:	https://www.genopole.fr	
Brief description: Genopole is a French research centre in Évry-Courcouronnes focused on biotherapies, genetics, genomics, post-genomics, xenobiology and the development of biotechnology industries. It unites innovative high-tech life sciences companies, public and private research, and higher education facilities.		
Country:	Germany	
Name:	Heidelberg Centre for Personalized Oncology (DKFZ-HIPO)	
Source:	https://www.dkfz.de/en/hipo/	
Brief description: In 2011, the DKFZ has established the Heidelberg Center for Personalized Oncology (DKFZ-HIPO), which offers a program for personalised oncology with the aim to translate latest research and technologies from the “omics” fields (genomics, transcriptomics, etc.) and systems biology/medicine into clinical practice. The center integrates the following three areas of expertise: (1) Genome Analysis, (2) Computational Biology, and (3) Precision Oncology.		
Name:	Centre for Personalised Medicine (ZPM) in Tübingen	
Source:	https://uni-tuebingen.de/en/64728	
Brief description: The ZPM connects the diverse aspects of data production, data analysis, functional imaging, development of new therapies and their clinical trials to transfer the concept into clinical care. Together with the medical faculty, the University Hospital, and the University of Tübingen, the ZPM has launched different research projects, qualified to generate individual patient derived data, to integrate comprehensive data, and specially to analyse highly complex biological information. The overall goal of their efforts is the precise description of complex diseases in order to find new approaches for innovative therapies. The central questions of the Center for Personalised Medicine are geared to the well-established medical research areas of the University of Tübingen, namely oncology, immunology, cardiovascular diseases, neurobiology, and biology of infection.		
Name:	Berlin Institute of Health	



Source:	https://www.bihealth.org/en	
Brief description: The Berlin Institute of Health (BIH) is a biomedical research institution focusing on translational research and precision medicine. BIH is dedicated to improving the prediction in progressive diseases and developing advanced therapies for unmet medical needs in order to improve patients' health and quality of life.		
Country:	Greece	
Name:	Biomedical Research Foundation of the Academy of Athens (BRFAA)	
Source:	http://www.bioacademy.gr	
Brief description: The founding principle of BRFAA is to host both basic and clinical research, thus, providing an ideal setting for the emergence of translational activities (Medical Application). BRFAA is one of the few institutes with such character in Europe and is certainly unique for Greece. The main goal of BRFAA is to achieve excellence in the Biomedical Sciences by recruiting high quality investigators carrying out cutting-edge basic and translational research and by training young researchers in a state-of-the-art facility, which provide a particularly stimulating scientific environment and strong research infrastructures.		
Name:	Biomedical Sciences Research Centre "Alexander Fleming"	
Source:	https://www.fleming.gr	
Brief description: The scientists at BSRC "Alexander Fleming" perform cutting-edge research, aiming to understand molecular mechanisms of complex biological processes in health and disease. FLEMING is a non-profit organization operating under the auspices of the Greek General Secretariat for Research & Technology and is supported by the Greek government and by national, European, and international grants.		
Name:	Hellenic Pasteur Institute (HPI)	
Source:	https://www.pasteur.gr/en	
Brief description: Since its establishment in 1920, Hellenic Pasteur Institute (HPI) remains faithful to its mission, which is the prevention and treatment of Diseases through Basic Research, Education and Public Health Services. The traditional focus of the Institute has been on Infectious Diseases. Currently other diseases are also under study such as autoimmune, neurodegenerative, neuromuscular, neuroimmune and certain types of cancer. The Hellenic Pasteur Institute (HPI) is a Legal Entity of Public Law, non-profit organization supervised by the Ministry of Development and Investments and the Ministry of Health and is functioning under the Greek law concerning Research Centres and the Bilateral Agreement (4528/2018) between the Greek Government and the Pasteur Institute in Paris.		
Country:	Italy	
Name:	The National Research Council (CNR) (*)	



Source:	https://www.itb.cnr.it	
Brief description: It is the primary government agency with the task of fostering exceptional basic, biomedical and clinical research through intramural and extramural programs. Within the CNR, the National Institute of Biomedical Technologies (ITB) derives from the merge of different institutes and units of the CNR.		
Name:	TecnoMED Puglia	
Source:	https://www.tecnomedpuglia.it/en	
Brief description: The National Research Council-CNR and Regione Puglia have started the set-up of TecnoMED, a Technopole for precision medicine that will be in Lecce, at the Institute of Nanotechnology NANOTEC-CNR. TecnoMED will focus on translational medicine, a branch aimed at transferring medical-scientific knowledge to direct application on patients. The project has a budget of 30 million euro for four years, deriving from regional resources of the CNR and the Special Supplementary Fund for Research of the Ministry of Education, University and Research-MIUR. The project is the result of the synergy between NANOTEC-CNR, IRCCS Giovanni Paolo II Cancer Institute in Bari and University of Bari.		
Country:	Lithuania	
Name:	National Cancer Institute	
Source:	https://www.nvi.lt/en/	
Brief description: National Cancer Institute is the only specialised oncology institution in Lithuania. The Institute acts as the clinical cancer centre, certified and accredited by the Organisation of European Cancer Institutes.		
Country:	Luxembourg	
Name:	CLINNOVA	
Source:	https://digital-luxembourg.public.lu/news/clinnova-new-luxembourg-centre-excellence-digital-health-and-personalised-medicine	
Brief description: CLINNOVA's aim is to build a bridge between fundamental research and hospitals and ensure lab innovations reach clinical implementation and thereby benefit patients.		
Name:	Laboratoire National de Santé	
Source:	https://lns.lu/en	
Brief description: The Laboratoire National de Santé is a public institution operating under the supervision of the Ministry of Health in Luxembourg. Organized as a multidisciplinary institute, its four scientific departments and two diagnostic centres include services and units related to the fields		



of morphological and molecular pathology, genetics, medical biology, microbiology, forensic medicine and health protection.

Name: Luxembourg Centre for Systems Biomedicine (LCSB)

Source: <https://www.uni.lu/lcsb>

Brief description: The LCSB is accelerating biomedical research by closing the gap between systems biology and medical research. Collaboration between biologists, medical doctors, computer scientists, physicists, engineers and mathematicians offers new insights in complex systems like cells, organs, and organisms. The vision of the LCSB is to understand the mechanisms of complex biological systems and disease processes and to enable new ways to cure and prevent human diseases.

Name: Luxembourg HealthTech Cluster

Source: <https://www.luxinnovation.lu/cluster/luxembourg-healthtech-cluster>

Brief description: The Luxembourg HealthTech Cluster brings together national players involved in innovative health technologies. Its aim is to promote the development of new and existing companies through innovation, thereby contributing to economic growth and job creation. The cluster also strives to capitalise on the country's advanced digital expertise in order to stimulate the development and commercialisation of health technologies. It supports the development of sustainable and trusted services and products aimed for the European healthcare market in fields such as digital health, medical devices and software.

Country: Poland



Name: Warsaw Genomics

Source: <https://warsawgenomics.pl/en/#!>

Brief description: Warsaw Genomics consists of talented scientists whose primary mission is to study errors in the human genome for cancer, metabolic, and rare diseases using modern genetic analysis tools. Before the global outbreak of SARS-CoV-2 in 2020, Warsaw Genomics focused on their primary mission to study the genomic errors responsible for cancer, metabolic, and rare diseases in humans.

Country: Spain



Name: Centre for Genomic Regulation (CRG)

Source: <https://www.crg.eu/en>

Brief description: The Centre for Genomic Regulation (CRG) is an international biomedical research institute of excellence, created in July 2000. It is a non-profit foundation funded by the Catalan Government. The mission of the CRG is to discover and advance knowledge for the benefit of society, public health and economic prosperity. The CRG believes that the medicine of the future depends on the ground-breaking science of today. This requires an interdisciplinary scientific team focused



on understanding the complexity of life from the genome to the cell to a whole organism and its interaction with the environment, offering an integrated view of genetic diseases.	
Name:	Health Services Research on Chronic Patients Network (REDISSEC)
Source:	https://www.redissec.com/en
Brief description: REDISSEC is committed to developing excellence in the fields of research, development and innovation, in order to provide evidence on best practices and organizations, with the horizon of improvement in the results of the health care provided to chronic patients in Spain. REDISSEC is built on three main issues: the challenge of managing the phenomenon of chronicity, the need for more and better information and the obligation to increase research capacity in health policies and services in Spain.	
Name:	Roche Institute Foundation's
Source:	https://www.institutoroche.es/
Brief description: Its aim is to anticipate and transfer knowledge about Precision/Personalised Medicine, which means better management and better results for patients. They work to bring the Medicine of the Future to the present and thus contribute to Spain being at the forefront of innovation in health, for the benefit of society in general and of patients in particular.	
Name:	Spanish National Cancer Research Center (CNIO)
Source:	https://www.cnio.es/en
Brief description: CNIO is a Spanish centre specializing in cancer research. CNIO's goal is to develop new and more effective approaches to preventing, diagnosing and treating cancer. Apart from scientists widely regarded as among the world's best, CNIO is also positioned to take advantage of a pharmaceutical discovery program. At CNIO, our fundamental research is organized into different areas: basic research (Molecular Oncology, and Structural Biology); patient-oriented translational research (Human Cancer Genetics and Clinical Research); and innovation (Biotechnology and Experimental Therapeutics).	
Country:	Sweden 
Name:	Karolinska Institutet (KI)
Source:	https://ki.se/en
Brief description: KI is Sweden's single largest centre of medical academic research and offers the country's widest range of medical courses and programmes.	
Name:	Science for Life Laboratory (SciLifeLab)
Source:	https://www.scilifelab.se



Brief description: SciLifeLab is an institution for the advancement of molecular biosciences in Sweden. It started out in 2010 as a joint effort between four universities: Karolinska Institutet, KTH Royal Institute of Technology, Stockholm University and Uppsala University. Today, they support research activities in all major Swedish universities.	
Name:	Swedish Cancer Institute (SCI)
Source:	https://www.swedish.org/services/cancer-institute
Brief description: SCI is one of the Northwest's leading cancer treatment centres, they combine the newest, most advanced science with extraordinary medicine and patient-focused care in order to customize their treatment.	
Country:	United Kingdom 
Name:	Cell and Gene Catapult
Source:	https://ct.catapult.org.uk
Brief description: The Cell and Gene Therapy Catapult is a centre of excellence in innovation, with the core purpose of building a world-leading cell and gene therapy sector in the UK as a key part of a global industry. Supported by Innovate UK, their mission is to drive the growth of the industry by helping cell and gene therapy organisations across the world translate early-stage research into commercially viable and investable therapies.	
Name:	Wales Gene Park
Source:	http://www.walesgenepark.cardiff.ac.uk
Brief description: The Wales Gene Park aims to support the implementation of the Welsh Government's Genomics for Precision Medicine Strategy by promoting and facilitating high quality genetic and genomic health research in Wales. It does this by ensuring seamless translation of advances in genetics and genomics to improve NHS services and for commercialization, as well as guaranteeing the informed involvement of patients, public and professionals in the development of genomic medicine in Wales.	
Name:	Wellcome Sanger Institute
Source:	https://www.sanger.ac.uk
Brief description: The Wellcome Sanger Institute is one of the premier centres of genomic discovery and understanding in the world. It leads ambitious collaborations across the globe to provide the foundations for further research and transformative healthcare innovations. Its success is founded on the expertise and knowledge of its people and the Institute seeks to share its discoveries and techniques with the next generation of genomics scientists and researchers worldwide.	

(*) means the information was obtained from ICPERMED platform.



6.2 PM research and innovation actors in China

The People's Republic of China has identified research and innovation (R&I) as a key area to fuel its thriving economy and close the gap to Western countries. China is committed to an innovation driven development model that includes strong investments in the support and creation of globally recognized research and innovation actors. The Chinese government has therefore started to invest in 2016 over a time span of 15 years around 7.6 billion euro in the development of genetic technologies and their use in Precision Medicine. A special focus lies on whole genome sequencing, drug discovery, the creation of a high-performance computing clusters and the development of machine learning and artificial intelligence (AI) capabilities. Analysts have shown that, in terms of total R&I investments, China is currently the global leader in the field of Personalised Medicine.

Table 16 lists the main research and innovation actors in PM.

Table 16 – Research and innovation actors in China

Name:	Affiliated Tumour Hospital of Sun Yat-sen University
Source:	http://ps.sysucc.org.cn
Brief description: Cancer Prevention and Treatment Center of Sun Yat-sen University (Affiliated Cancer Hospital, Cancer Institute of Sun Yat-sen University) was established in March 1964, which is one of the first four cancer hospitals established in New China. The centre is one of the oncology bases with the largest scale and the strongest academic force in China, integrating medical treatment, teaching, scientific research and prevention. It undertakes the important task of national cancer prevention and control and plays a leading role in the cancer prevention and control work in the whole country, especially in south China, Hong Kong, Macao and Taiwan. Its discipline status and comprehensive strength rank in the national leading level.	
Name:	Beijing Institute of Genomics
Source:	http://english.big.cas.cn/
Brief description: The Chinese Academy of Sciences participated in the completion of the Human Genome Project and independently completed several important scientific projects such as the China Super Hybrid Rice Genome Project. With the rapid development of the science and bioinformatics genome, it was approved by the CAS in November 2006. The key genome science and information laboratory of the Chinese Academy of Sciences has been established. The laboratory has made several important discoveries in the human genome, biological big data, intergenerational inheritance and epigenome reprogramming and established the National Genome Science Data Center (NGDC) based on the laboratory, including the new coronavirus. A set of data resources Databases, including the 2019nCoV information database, provides important support for scientific research and epidemic prevention and control around the world.	
Name:	BGI
Source:	https://en.genomics.cn/en-about.html



Brief description: BGI is one of the world's leading life science and genomics organizations which provides equipment, technical support and solutions for the needs of national economies and people's livelihoods, such as precision medicine and precision health.	
Name:	Chinese Centre for Disease Control and Prevention
Source:	http://www.chinacdc.cn/en/
Brief description: The Chinese Centre for Disease Control and Prevention was established directly as an institution under the National Health Commission. It carries out disease prevention and control, organises the formulation of national public health technical programmes and guidelines, monitors diseases, participates in the preparedness and response to national public health emergencies, guides local governments in the implementation of national disease prevention and control plans and projects, and carries out global public health activities and international exchanges and cooperation in the field of public health, and performs relevant international assistance tasks.	
Name:	Chinese Society of Clinical Oncology (CSCO)
Source:	http://www.cSCO.org.cn/cn/ncontent.aspx?oid=8673
Brief description: The Chinese Society of Clinical Oncology (CSCO), founded in 1997, is a national, academic and non-profit professional group voluntarily formed by clinical oncology operators and related businesses and institutions. CSCO has long been engaged in continuous clinical oncology training and multicentre collaborative research, promoting the standardization of cancer diagnosis and treatment and improving the academic level of clinical oncology in China. It is also dedicated to research on Precision Medicine as evidenced by the creation and participation in the Oriental Oncology Precision Medicine Forum and Annual Meetings of Expert Committee on Anti-tumour Drug Safety Management.	
Name:	Genetron Health
Source:	https://www.genetronhealth.com
Brief description: Genetron Health is a leading and fast-growing precision oncology company in China that is committed to provide a one-stop, multi-scenario genomic profiling solutions in areas including early cancer screening, diagnosis and monitoring as well as biopharmaceutical services.	
Name:	Guangzhou Institute of Biomedicine and Health of the Chinese Academy of Science
Source:	http://english.gibh.cas.cn/aboutus/ourmission/
Brief Description: GIBH explores disease mechanism for disease control and prevention. It provides excellent R&D platform in biomedicine and functions as an incubator for bioengineering and pharmaceutical industries to support local economic development as well as national strategic science and technology programs.	



Name:	National Cancer Centre, Cancer Hospital of Chinese Academy of Medical Sciences (NCC)
Source:	http://www.cicams.ac.cn/Html/News/Main/249.html
Brief description: NCC is supported by the Cancer Hospital of Chinese Academy of Medical Sciences, a national research centre of cancer clinical medicine, which is a combination of hospital, education, research and prevention focusing on basic research and clinical treatment regarding cancer.	
Name:	National Administrative Centre for China's Agenda 21
Source:	http://www.acca21.org.cn/trs/000100020001/
Brief Description: The National Administrative Centre for China's Agenda 21 was established on March 25th, 1994 with the approval of the Office of the Central Organizing Committee and is a public assistance institution directly under the Ministry of Science and Technology. The centre has promoted the implementation of China's Agenda 21 and the country's sustainable development about medical science and technology, building on scientific and technological progress to promote sustainable development; develop a range of strategies and policies in the field of sustainable development.	
Name:	Institute of Precision Medicine and Health (IPMH)
Source:	https://en.ustb.edu.cn/research/research_institute/10471883.htm
Brief Description: The Precision Medicine and health research institute aims to carry out cutting-edge international research, form major original innovative achievements and transform them into applications, promote Beijing to become the national research centre of Precision Medicine and health management, and promote the development of Precision Medicine. With the help of Beijing's abundant hospital resources and social capital, the transformation and industrialization of scientific and technological achievements in the field of Precision Medicine will be accelerated to drive the development of relevant industries.	
Name:	Tsinghua University (THU)
Source:	https://www.tsinghua.edu.cn/en/
Brief description: Tsinghua University, one of China's most prestigious and influential universities, is dedicated to the well-being of Chinese society and to global development through the pursuit of education and research at the highest level of excellence.	



7 Conclusions

Personalised Medicine is a highly **interdisciplinary scientific** field of **continuous advances** and **technological innovations** that requires a strongly **supportive ecosystem**. In this document, we completed the mapping of *D1.1 Scoping Paper: Review on health research and innovation priorities in Europe and China* by addressing the various partners involved in the coordination of PM initiatives and the application of PM principles on various levels.

- **Chapter 3** provides an extensive overview on **Policy Agencies** and **Stakeholders related to PM** providing insight into which are the key institutions relevant for policymaking and programme creation in Europe and China, completing the mapping of Policy measures, Programmes and Action Plans of D1.1.
- **Chapter 4** focuses on how research actions and market innovations are financially supported through detailed **Funding Schemes and Programmes**, highlighting the pivotal role of key institutions and funding providers.
- **Chapter 5** is dedicated to a summary of important **Existing and Emerging Initiatives** related to PM concepts, key in the fast uptake of PM principles in public health and research.
- **Chapter 6** addresses those **Research and Innovation Actors** that perform basic research and bring innovation to the market.

With this map, the IC2PerMed consortium seeks to:

- identify the manifold PM actors in Europe and China,
- further complement the information map provided by the ICPeMed platform,
- map the current PM ecosystem, and
- provide input into a deepened Sino-European collaboration expanding the knowledge of both geographic areas that hopefully translates into a better understanding of one another.

At the EU level, policy agencies are responsible for the establishment, implementation, monitoring and enforcement of policies, which ensure the protection of people's health and their personal data and privacy across the Union. The advancements in PM require close collaborations and cooperation with national agencies of EU MS - notably in data access and use, bio-banking standardization, next generation sequencing, screening, biomarkers, sharpening the impact of R&D and early diagnostics. At the national level, the governmental ministries and/or national health institutes play a key role in determining the legislative and political agenda and implementing policies efficiently. Through targeted policies, the aim is to protect and improve the health of all citizens, to offer scientific and technical services, to support decision making on PM technologies and the modernization of EU's health systems, and to develop education programmes. Other policy agencies specialize in adapting and complementing existing policies, considering the gaps, facilitators, and barriers to their implementation, by accelerating the development of personalised healthcare and its translation into health practice.

In the process of policy planning in the EU, the involvement of various stakeholders - such as academic research networks, organisations or societies - has been crucial in building a pan-European network that is able to improve strategic collaboration in the implementation of PM approaches and facilitates informed decision-making. A continuous support from multiple stakeholders at the EU MS level is needed in order to help putting PM on the governments' agendas agenda and make it one of their top



priorities. PM is one of the main items under priority for the EC, and a large amount of PM related projects has been funded, addressing various aspects, such as disease prevention and health promotion, diagnostics, biomarkers, large-scale data gathering, technology development, omics sciences, clinical trial methodologies, preclinical and clinical research.

In China policies are controlled by the Chinese governments' ministries, which are designed to produce, release, and supervise policies to improve access to the health and healthcare system.

China has developed many initiatives and policies related the Five-Years-Plans, the 13th and the 14th in particular, in which the Chinese government has underlined the importance of Personalised Medicine, often preferentially named Precision Medicine in the People's Republic of China. It sees in Personalised Medicine an important step in the development of public health, for that it has evolved Personalised Medicine in the Healthy China 2030" plan. At the same time the Chinese government is interested in financing Big Data and genomics projects which are particularly relevant and developed in the country: the large Chinese population is suitable to collect and study Big Data, which are also important for genomics research. For that, Chinese government is working on laws which would discipline Big Data and protect the identity of its citizens.

The long-term goal of the People's Republic of China is to lower, as much as possible, the hurdles to access public health and to make healthcare truly universal. The strategy builds on expanding the national health insurance system to all citizens by covering all kinds of illnesses, the development of Personalised Medicine research is believed to be mandatory to reach this ambitious goal. To do this, China is strongly interested in improving relations with Europe to exchange ideas, opinions and experiences that are mutually beneficial, as it demonstrated by launching the Health Belt and Road initiative.

This mapping document acts as a dynamic living map to be further completed by IC2PerMed's ongoing and planned activities. It shows the extraordinary potential to expand cooperation between Europe and China generating synergies in the Personalised Medicine field.



Appendix 1

IC2PerMed survey on China-EU cooperation over Personalised Medicine developments

Description of the Project and aim of the Survey

Integrating China in the International Consortium for Personalised Medicine (IC2PerMed) project aims to support EU-China collaboration over the developments of Personalised Medicine research, innovations, and policies through the ICPerMed initiative, providing people with access to personalised, smart and inclusive healthcare solutions in the near future [Grant Agreement N. 874694] (<https://www.ic2permed.eu/>).

According to the Council of the European Union, Personalised Medicine is defined as a “medical model using characterisation of individuals’ phenotypes and genotypes (e.g. molecular profiling, medical imaging, lifestyle data) for tailoring the right therapeutic strategy for the right person at the right time, and/or to determine the predisposition to disease and/or to deliver timely and targeted prevention.”

You are invited to participate in a survey, elaborated within the IC2PerMed project, which aims to explore the current landscape of implementation, priorities, and challenges of Personalised Medicine in China and Europe, with a focus on Sino-European collaboration in this field.

The results of this survey will complement the ongoing mapping activities within IC2PerMed project, of which the preliminary findings can be consulted here²⁸. These results will be useful to have an overview of the past, current and future policy, research, and funding in Personalized Medicine in your country and will serve the basis for the Working Groups (WG) of the IC2PerMed project. The WGs’ activities will take advantage of the results of this survey, to support the project in developing recommendations for implementing the ICPerMed’s Action plan into China (<https://www.ic2permed.eu/working-groups/>).

The records from this questionnaire will be kept confidential and your data and responses will be anonymized and processed for the purpose of IC2PerMed project development only, in agreement with the project’s privacy policy (available at: <https://www.ic2permed.eu/gdpr>). Your data will be treated in accordance with GDPR regulation. If you wish to not disclose your personal data, you can fill in the questionnaire anonymously.

For any further information, please contact: IC2PerMed@unicatt.it.

Thank you very much for your participation

Walter Ricciardi, on behalf of IC2PerMed the consortium

If you agree to participate in this survey according to GDPR regulation, please click **Next**.

²⁸ <https://www.ic2permed.eu/publications-public-deliverables/>



SECTION 1: Personal details

(The questions with the symbol # are mandatory)

1. What is your nationality? (Open question) _____
2. Please indicate the country where you are currently working in # (Open question)
3. Please indicate your field(s) of expertise (Open question) _____
4. Which type of organisation or institution are you currently working for?
 - a. Government - Research & Innovation
 - b. Government - Health
 - c. Funding Agency
 - d. Innovation/Development Agency
 - e. Cluster organisation
 - f. Research institution
 - g. Hospital
 - h. Regulator
 - i. Patient organization
 - j. Private sector organization (e.g., biotechnology, information technology, pharma, health insurance company)
 - k. Other, please specify _____

SECTION 2: Policies and agencies in the country you are working in

In this section, you will be asked about your knowledge on policies (including policy measures, programmes, strategies, and action plans), agencies and funders in the field of Personalised Medicine in your respective country.

1. Are you aware of any **policies** focused on or related to Personalised Medicine in the country you are working in?
 - Yes*
 - No
 - I do not know

*If yes, please specify:

- Name(s)/title(s) _____
- Source or website, if available _____
- Any additional information you consider useful _____



*If yes, according to you, in which of the following fields so far have these policies had an impact on Personalised Medicine in the country you are working in (select up to three)?

- Citizens', patients' awareness and empowerment
- Health Professionals' education and curricula
- Practices and strategies for Personalised Medicine in sustainable health care
- Big data and ICT Solutions
- Bringing innovation to market
- Translating basic to clinical research and Beyond
- Research Funding
- Privacy/Ethical regulations
- Other (please specify) _____
- I do not know

2. What are the priority areas to be considered in policy planning in the field of Personalised Medicine in the country you are working in?

- Citizens' awareness and empowerment
- Health Professionals' education and curricula
- Practices and strategies for Personalised Medicine in sustainable health care
- Big data and ICT Solutions
- Bringing innovation to market
- Translating basic to clinical research and Beyond
- Research Funding
- Privacy/Ethical regulations
- Other (please specify) _____

3. According to your opinion, what are main obstacles to the planning, development, and implementation of policies in the field of Personalised Medicine, in the country you are working in?

_____ (Open question)

4. Please indicate the main policy agencies/institutions that monitor or are involved in overseeing implementation/fostering of Personalised Medicine in the country you are working in.

_____ (Open question)

5. To your knowledge, which are the **research priorities** in the field of Personalised Medicine in the country you are working in?

_____ (open question)

6. Please name important **funding sources** in the field of Personalised Medicine in the country you are working in.

_____ (open question)

7. Please name additional **relevant initiatives** (e.g., relevant national or international projects or consortia) related to Personalised Medicine in the country you are working in.

_____ (open question)



SECTION 3: Facilitators and barriers for collaborations between Europe and China in Personalised Medicine

1. Are you aware of any collaborations in the field of Personalised Medicine between Europe and China?
 - a. Yes*
 - b. No
 - c. I do not know

*If yes, please indicate:

Name of the project/collaboration _____

Source or website, if available _____

Any additional information you consider useful _____

2. In your view, which are the most relevant **facilitators or enabling factors** for EU-China collaborations in the field of Personalised Medicine?
_____ (open question)
3. In your view, which are the most relevant **barriers** for EU-China collaborations related to Personalised Medicine?
_____ (open question)
4. In your view, please indicate relevant **contextual aspects (social, cultural, economic, ethical, etc.)** to be taken into consideration in EU-China collaborations in the field of Personalised Medicine.
_____ (open question)
5. In your opinion, which actions should Chinese and European policy makers implement for intensifying EU-China collaboration in the field of Personalised Medicine?
_____ (open question))
6. In your opinion, which are the most important priorities and challenge areas towards EU-China collaborations in Personalised Medicine to be considered in the following areas?
(Please select up to three areas and specify the respective priorities)
 - a. Citizens', patients' awareness and empowerment
 - b. Health Professionals' education and curricula
 - c. Practices and strategies for Personalised Medicine in sustainable health care
 - d. Big data and ICT Solutions
 - e. Bringing innovation to market
 - f. Translating basic to clinical research and Beyond
 - g. Research Funding
 - h. Privacy/Ethical regulations



SECTION 4: WORKING GROUPS

In this section, you will be asked questions regarding the activities of the three Working Groups (WGs)²⁹. The WGs will focus on the following topics:

Working Group	Topics
WG1: “Shaping sustainable healthcare”	<ul style="list-style-type: none"> • Awareness and empowerment • Education and curricula • Personalised Medicine in sustainable healthcare
WG2: “Innovation & market”	<ul style="list-style-type: none"> • Big data and Information and Communication Technology (ICT) Solutions • Bringing innovation to market
WG3: “Research and clinical studies in Personalised Medicine”	<ul style="list-style-type: none"> • Translating basic to clinical research and Beyond • Research Funding

1. Are you already involved in the activities of any of the IC2PerMed Working Groups?
 - a. Yes*
 - b. No

2. a). If yes, in which Working Group are you or would you like to be involved?
 - a. Working Group 1: Shaping sustainable healthcare
 - b. Working Group 2: Innovation & market
 - c. Working Group 3: Research and clinical studies in Personalised Medicine

2. b) If no, would you like to be involved in Working Groups?
 - a. Yes, please specify
 - I. Working Group 1: Shaping sustainable healthcare
 - II. Working Group 2: Innovation & market
 - III. Working Group 3: Research and clinical studies in Personalised Medicine
 - b. No

Thank you very much for your participation! We would like to invite you to share the survey with your colleagues.

²⁹ <https://www.ic2permed.eu/working-groups/>

