ICPerMed statement concerning the Declaration towards access to 1 Million Genomes in the European Union by 2022

On 10 April 2018 13 Member States signed a declaration, initiated by the European Commission, to establish access to 1 Million Genomes in the EU by 2022. The International Consortium of Personalised Medicine (ICPerMed) has followed with interest the process of developing the declaration.

Recognising the great potential of personalised medicine to improve the prevention and diagnosis of disease and the treatment of patients, ICPerMed aims to coordinate and foster research to develop and evaluate personalised medicine approaches. But it is clear that further efforts are needed to overcome such challenges as:

− granting cross-border access to health related samples and data of European citizens in a secure, ethical and legally compliant way,
− developing common standards for data management and quality of data, and
− strengthening expertise in data analyses and interpretation.

These challenges are referenced in ICPerMed’s Action Plan which sets out clearly the research actions needed to advance the implementation of personalised medicine approaches in healthcare.

ICPerMed stresses the importance of collaboration and coordination in the field of personalised medicine. Therefore, to address the challenges, avoid fragmentation, and make personalised medicine a reality for citizens, ICPerMed strongly urges that coordination activities in health and personalised medicine build on established European initiatives and infrastructures in the field.

The International Consortium of Personalised Medicine (ICPerMed) brings together more than 30 authorities from EU member states and beyond. Members include Ministries of Research, Ministries of Health as well as public and private ‘not-for-profit’ health research funding and policy organisations. Currently the following countries are represented: Austria, Canada, the Republic of Croatia, Cyprus, Czech Republic, Denmark, Estonia, Finland, France, Germany, Hungary, Ireland, Israel, Italy, Lithuania, Luxembourg, Netherlands, Norway, Poland, Portugal, Republic of Moldova, Romania, Slovenia, Spain, Sweden, Switzerland and Turkey.

ICPerMed provides a platform to initiate and support cooperation in personalised medicine research, funding and implementation. The high level of participation enables ICPerMed to efficiently map the scientific and political landscape for personalised medicine, thus aligning research and funding activities at European and international level. Based on an extensive knowledge of activities in the field, ICPerMed members are developing and agreeing future research actions. In addition, ICPerMed aims to identify the requirements for a suitable framework to foster the development and implementation of personalised medicine in terms of infrastructures, resources and regulatory procedures.