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Report
1st Sino-EU-PerMed S&T Workshop

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Summary:

This is the first report on in total 3 planned S&T Workshops. The 1st Sino-EU - PerMed S&T Workshop was held as an online webinar and focused, among other selected topics on Perspectives in Personalised Medicine: genomics, rare diseases, devices

The Sino-EU-PerMed Project

Personalised Medicine (PerMed) approaches bring along immense potentials to improve diagnosis and treatment of diseases and to development of prevention strategies by considering individuals' geno- and phenotypes, biomedical data, and lifestyle or environmental data.

“Widening Sino-EU policy and research cooperation in Personalised Medicine” (Sino-EU-PerMed) aims at connecting ICPerMed strategies and activities with relevant Chinese stakeholders. As part of the project an inventory mapping and analysis of the PerMed landscape in China has been performed and published. In addition, the Sino-EU-PerMed consortium will exchange expertise and experts via virtual workshops. Delegation trips in China and Europe is also planned if the Covid-19 pandemic allows. Thereby we will gain a better EU-Sino mutual understanding of PerMed activities and related cultural aspects. By running a series of targeted workshops Sino-EU-PerMed will promote international standards and pave the way for future communication, collaboration, and undertakings.

Our consortium aims at promoting the unique and long-term impact of personalised medicine approaches on society in cooperation and in alignment with ICPerMed. The cooperation with China will strengthen the international aspects and the planned activities in Sino-EU-PerMed will allow ICPerMed to further strengthen Europe's leading role in this area and contribute to a successful implementation of PerMed in the global context and foster joint PerMed projects between Europe and China.

SINO-EU PerMed

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List of Abbreviations

Abbreviation	Explanation
1+MG,	1 Million Genomes Initiativ
b1+MG	Beyond 1 Million Genomes CSA
ELSA	Ethical, Legal and Social Aspects
EU	Europe
MDR	EU regulations for medical devices
PM	Personalised Medicine
R&I	Research and Innovation
WES	Whole Exon Sequencing
WGS	Whole Genome Sequencing

Report on 1st Sino-EU Permed Science & Technology Webinar:

Perspectives in Personalised Medicine: genomics, rare diseases, devices

13th September 2022, 8:00 – 13:00 CEST, 14:00 – 19:00 CST

A key part of the overall activities of the International Consortium of Personalised Medicine to align efforts in all areas of personalised medicine (PM), is to foster international coordination of research and innovation funding and policies.

To support these activities Sino-EU PerMed project, funded by the European Commission, undertakes several activities to promote interactions between China and EU within the area of personalised medicine. A key part of the project is to exchange expertise and PM knowledge via science and technology webinars, thereby promoting cooperation and networking activities.

This was the first of three planned science & technology webinars. The second one is planned to run later this year and the final webinar will be run in Q2 2023.

Due to the Covid pandemic, travel between China and EU is not possible. The event was therefore held as a webinar. A total of 81 participants had registered their participation. The webinar was attended by ca 40 participants. Due to the high fluctuation during the different sessions a total amount of no shows is difficult to estimate.

Examples from three areas of key importance for personalised medicine was presented at the webinar: genomics, rare disease, and devices. Within each area presentations from China and EU were given. In total 4 European and 4 Chinese scientists presented their work.

The official welcome was done by Research and Innovation Counselor Fuxiang He from the Embassy of the People's Republic of China in Denmark and by Alexandru Costescu from R&I Health unit at the European Commission.
Fuxiang emphasized China's commitment to including personalised medicine as a key part of their health care. This includes significant funding for data and IT development. He also highlighted several science and technology collaborations between China and Europe.
Alexandru Costescu highlighted the continued commitment and support from the European Commission to the area of personalised medicine and mentioned the upcoming European Partnership for Personalised Medicine as a key driver for the field in the future.

<u>The key take-homes from the 8 presentations and the concluding discussion can be summarized as follows:</u>

By an example from the hemofilia area (which is a rare bleeding disorder) it was demonstrated how insights and developments based on genomic studies can be turned into life-changing conditions for the patients, going from less effective symptom treatment to treatment with curative perspectives.

In the longer term it is important to have a broader view of health care and not only a limited focus on personalised medicine. This includes not only development of therapies, but also how the general health

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state of the publication is followed. Learnings from the Covid crisis are important, e.g. how analyses of viral content in waste water can help focus the measures taken to fight the infection. Concepts like “Precision public health” and “One Health” have been described. Another key learning is that biomedical, health and lifestyle data in a very broad sense is needed, and that tools to handle these vast data amounts are very important.

Development of datasets and access policies to these are pre-requisites for the further development of both personalised medicine and health care overall. Data are needed both for research & Innovation as well as for optimal treatment of the individual patient. This includes genomic (WGS, WES,) data as well as health care data. Mainly due to ELSA related issues, access to data in Europe, at regional, national level and cross-border has been difficult. Initiatives such as 1+MG, b1+MG and the upcoming European Health Data Space will hopefully help solve these problems. In China a lot of effort and resources has been put into the health data field, but similar access problems as in Europe are seen here. In addition, the recent Chinese data laws have made it very difficult to run co-projects including health data between China and EU.

(See: b1+MG Maturity Model, https://b1mg-project.eu/resources/, and EU Study on new Genomic Techniques, https://food.ec.europa.eu/plants/genetically-modified-organisms/new-techniques-biotechnology/ec-study-new-genomic-techniques_en).

In China a whole range of institutions have been set up to generate and handle biomedical and health care data With a strong focus on genomic data, an extensive amount of data has been collected and is ongoing at a relentless pace. Most of these institutions have a national focus and cannot be accessed at international level. However, a pilot initiative is being implemented to link some of these data sources to the International Nucleotide Sequence Data Base Collection (INSDC, https://www.insdc.org/).

To achieve full implementation of personalised medicine in health care it is essential to generate genomic data on a much larger scale. This includes genomic data from many more subpopulations around the world. To use these massive amounts of data it necessary to develop more advanced artificial intelligence and machine learning tools. In addition, phenotyping and development of much more extensive health record databases are needed (see e.g.: Commentary by Francis S. Collins, https://www.cell.com/cell/fulltext/S0092-8674(21)00058-1).

Implementation of personalised medicine solutions in health care systems are facing several challenges and hurdles globally, nevertheless some regional initiatives are proposing successful approaches. The pharmaNAGEN project in the region of Navarra in Spain is one good example of how to deliver pharmacogenetic-based treatment to patients. The project has succeeded in developing new tools to enable clinical use of NGS-based pharmacogenetic data, thereby bringing personalised medicine into daily clinical practice. Some of the major challenges in the project were to solve the IT/ELSA based issues in

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relation to using the data and to teach and motivate the health care professionals to use the system (see: https://www.youtube.com/watch?v=c9xKFx7WLac).

The medical device area is of key importance to personalised medicine. This relates both to testing/diagnostic tools as well as e.g. to tissue generation/regeneration and to tissue replacements. The latter area has developed rapidly and is now using very advanced methods such as 3D-printing and nano-spun fibers. The new EU regulations for medical devices (MDR) have meant further challenges in the development of this area. In China there are strict medical device regulations as well.

In conclusion, the participants discussed the three most important challenges right now in the further development and implementation of personalised medicine and agreement on the following:

- Access to biomedical and health care data, both nationally and internationally
- To identify the right patient cohorts
- In-depth phenotyping of patient cohorts

It was also mentioned that in the future there would be highly increased focus on prevention/personalised prevention.

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SINO-EU PerMed
Cooperation between China and Europe in Personalised Medicine

Webinar Program

08:00 – 08:20 **Welcome & Introduction**

Ejner Moltzen (Innovation Fund Denmark, WG4 Lead)

Fuxiang He (Counselor, Embassy of the People's Republic of China in Denmark)

Alexandru Costescu (Policy Officer, Health Research, European Commission)

08:20 – 09:45 **Genetic data and biosamples for PM: Developments and uses**

In both China and EU there has for several years been high focus on collecting genetic data and related biosamples to promote a personalised approach to healthcare, both regarding diagnostics, biomarkers, and treatments. Recent strategies and examples of use of such information for PM-based approaches will be presented.

- **Flora Peyvandi** (Scientific Director, IRCCS Maggiore Hospital, Milan)**: From standard to novel gene therapy in bleeding disorders**
- **Jie Huang** (Associate Professor and Principal Investigator at the School of Public Health and Emergency Management, Southern University of Science and Technology, Shenzhen)**: From Precision Health to One Health: COVID-19 driven challenges and opportunities for genomic testing and research**
- **Ruben Kok** (Director, Dutch Techcentre for Life Sciences, Utrecht)**: The 1+ Million Genomes Initiative**

09:45 - 10:00 **Short Break**

10:00 - 11:15 **Genetic data and biosamples for PM: Developments and uses, continued**

- **Yiming Bao** (Director of National Genomics Data Center, Beijing Institute of Genomics (BIG), Chinese Academy of Sciences (CAS) and China National Center for Bioinformation, Beijing): **Genomics data resource in China**
- **Hua Chen** (Professor and Group Leader at the Beijing Institute of Genomics, Chinese Academy of Sciences (CAS) and China National Center for Bioinformation, Beijing): **Personalized Medicine and Big Data: Where Are We Now? And Where to Go?**
- **Juan José Beloqui Lizaso** (Head of Pharmacogenetics at the Genomic Medicine Unit at Navarrabiomed, Pamplona): **PHARMANAGEN: Integrating pharmacogenetic data from NGS into a Health Service**

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11:15 - 12:00 **Devices: PM-related approaches in tissue regeneration**

Medical devices are of key importance in many PM-based treatments. The field of regeneration and replacement of defected tissues is a key topic in many diseases.

- **Mike Barbeck** (Group leader in vivo biomaterial research, Clinic and Policlinic for Dermatology and Venereology, University Medical Center Rostock)**: Current possibilities for hard and soft tissue regeneration and requirements for the materials of the future**
- **Jiajia Xue** (Professor, College of Materials Science and Engineering at Beijing University of Chemical Technology)**: Electrospun fibers for bone tissue regeneration**

12:00 - 12:45 **Panel discussion**

Translation of biomedical information into PM-based treatments in China and EU: opportunities and barriers

12:45 - 13:00 Conclusions and closure of webinar

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