Big data in health
IMI’s HARMONY Project
How to improve healthcare services through big data and research

19th June, European Parliament, Brussels
The volume of health-care data is constantly growing.

Health care generates a vast amount of clinical data, which is collected and stored electronically. The average person is likely to generate more than one million gigabytes of health-related data in their lifetime, 30% of which at the genetic level.

Currently, medical data doubles every year. By 2020, it is expected to double every 73 days.

Source: University of Iowa, Carver College of Medicine, 2014.
We need to share and re-use data, always for the benefit of patients

While improving clinical practice, we build up a more digital and sustainable health-care system.
Our health-care systems generate billions of data that can be used to help patients.

- Improved outcomes
- Reduced variation
- Increased efficiency

Data re-use

- Transparent outcomes data (big and deep data sources)
- Identify current best practices
- Feedback and learning
- Optimize treatment and change behaviour

Sustainable health care

Funded by
Harmonization of outcome measures and endpoint definitions for HMs at European level

Increase the application of omics data in clinical practice

Speed up drug development, access pathways and bench-to-bedside process

Building a high-quality Big Data platform on haematological malignancies

HARMONY is the biggest BD4BO Project within IMI

Big Data to meet the biggest needs in Hematologic Malignancies

Funded by IMI and EFPIA
53 organisations from 11 countries, working across 7 hematological malignancies
HARMONY Bench-to-Bedside Projects: working on specific questions by disease

AML
- Identification of gene-gene interactions and impact on disease outcome
- 5+ groups
- 4500+ patients

CLL
- Large-scale mutation analysis - Novel prognostic/predictive scheme for improved risk stratification aimed at personalized medicine
- ERIC: 24+ groups
- 5000+ patients

MM
- Revised International Staging System for MM in the European clinical trial population and evaluation of the efficacy of different novel agents and treatment approaches

APL
- Open issues in the management of acute promyelocytic leukemia

Pediatrics / ALL
- Definition of a common data set in childhood malignancies for cross entity analysis comparison of pediatric and adult data

Funded by IMI, Innovative Medicines Initiative, EFPIA, and others.
 Hosting with ISO 27001 + 27002

Roles segregation

ISO

Firewall with two levels

Audit access to platform: who, when, where, what, and how

Virtual Private Network

Nobody has access to the data

Named access

Risk analysis

De-facto anonymisation

“Technical and organisational measures to protect data”

- Technical anonymisation
  - Supression
  - Generalisation
  - Perturbation
- Organizational security
  - Policies
  - Processes
  - Contracts
- Data Access Restrictions

Our HARMONY Platform is completely safe and compliant with GDPR

Funded by
New technologies can be safely incorporated into healthcare

Digitalisation leads to a sustainable health-care system

Development of tools that improve clinical practice

Benefiting patients while protecting our health-care systems

Preserving patients’ privacy while promoting research

There are initiatives and solutions that can benefit both patients and health care systems
Promoting and investing in Big Data will prove to be beneficial for the whole society
Thank you!
Any questions?
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