Big Data for
Better Outcomes

IMI2 Big Data for Better Outcomes

Supporting the evolution towards outcomes-focused sustainable healthcare systems in Europe

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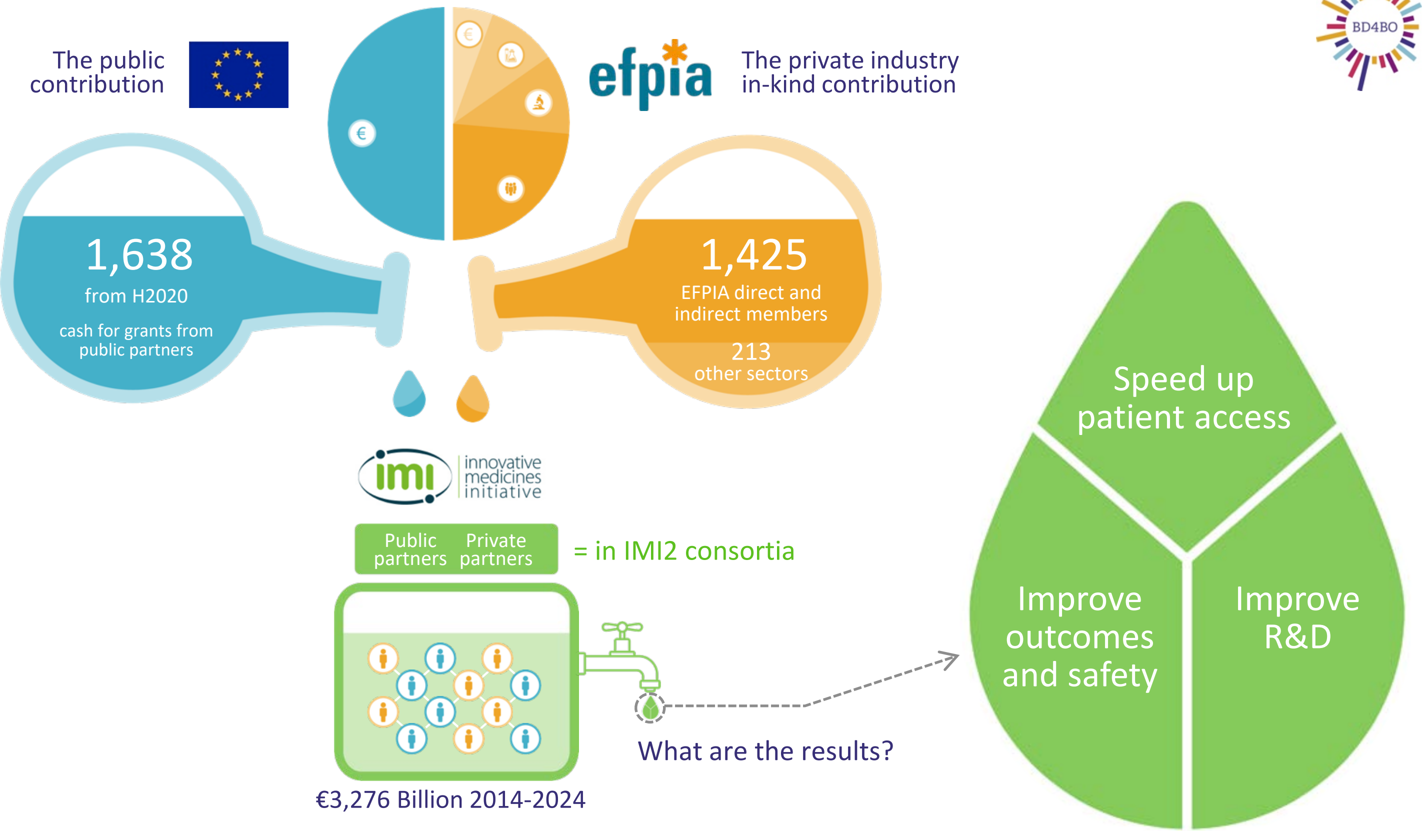
7th EMWA Symposium

Real-World Evidence: A Central Role for Medical Communicators

9 May 2019

World’s largest life sciences PPP



The public contribution

The private industry in-kind contribution

1,638
from H2020
cash for grants from public partners

1,425
EFPIA direct and indirect members
213
other sectors

Public partners | Private partners = in IMI2 consortia

€3,276 Billion 2014-2024

What are the results?

Speed up patient access

Improve outcomes and safety

Improve R&D

- € Cash
- Consumables
- Laboratories
- People

Evolution of Big Data in IMI

2016-2024 Big Data for Better Outcomes

2013-2018 European Medical Informatics Framework

2013-2016 GetReal

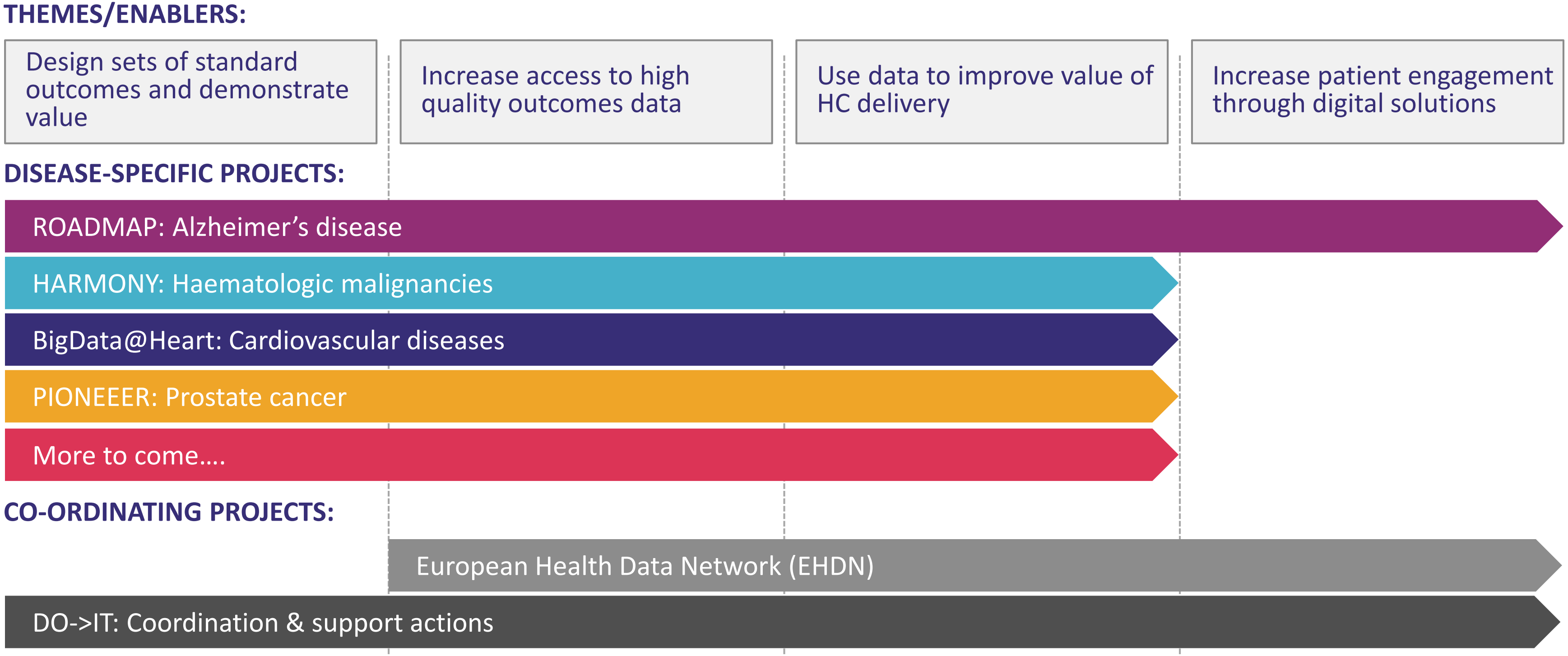
2011-2016 Electronic Health Records for Clinical Research

IMI

Improve health outcomes and healthcare systems in Europe by maximising the potential of Big Data

BD4BO Mission

Mission: Improve health outcomes and healthcare systems in Europe by maximising the potential of Big Data



THEMES/ENABLERS:

- Design sets of standard outcomes and demonstrate value
- Increase access to high quality outcomes data
- Use data to improve value of HC delivery
- Increase patient engagement through digital solutions

DISEASE-SPECIFIC PROJECTS:

- ROADMAP: Alzheimer’s disease
- HARMONY: Haematologic malignancies
- BigData@Heart: Cardiovascular diseases
- PIONEEER: Prostate cancer
- More to come….

CO-ORDINATING PROJECTS:

- European Health Data Network (EHDN)
- DO->IT: Coordination & support actions

BD4BO Overview

ROADMAP
Real world Outcomes across the AD spectrum for better care

BD4BO

Objective	Expected outputs	Timeline
Provide the foundation for a Europe-wide, integrated data environment and framework for RWE across the spectrum of Alzheimer’s disease	• Minimum set of measurable real-world patient outcomes • Identification of data sources and outline a data integration strategy for RWE outcomes • Development of new methods for collecting RWE data to improve health care value for Alzheimer’s Disease • Recommendations for disease progression and health economic modelling • Guiding principles and recommendations from regulators, HTA bodies and payers for the development and incorporation of RWE	2016 - 2018

Objective	Expected outputs	Timeline
Improve the outcomes of patients with haematological malignancies through the use of Big Data sharing among all relevant stakeholders.	• A clinical data-sharing platform including Big Data series from patients with hematological malignancies • A community of European hematological malignancies stakeholders • Meaningful and harmonised clinical endpoints and outcome measures in hematological malignancies • Tools for analysing complex data sets including genomic data • Biomarkers that will contribute to timely patient access to more effective and better tolerated innovative therapies • A framework for legal, ethical and governance issues	2017 - 2021

Haematogical malignancies

BigData@Heart

BD4BO

Objective	Expected outputs	Timeline
Deliver clinically-relevant disease phenotypes, scalable insights from RWE and insights driving drug development and personalised medicine through advanced analytics	• Definitions of diseases and outcomes that are universal, computable and relevant for patients, clinicians, industry and regulators • Informatics platforms that link, visualise and harmonise data sources of varying types, completeness and structure • Data science techniques to identify new phenotypes and construct personalised predictive models • Guidelines that allow for cross-border usage of Big Data sources acknowledging ethical and legal constraints as well as data security	2017 – 2022

Cardiovascular diseases

www.bigdata-heart.eu

PIONEER

Objective	Expected outputs	Timeline
• To improve stratification of patients throughout the course of the disease **• To improve individualisation of treatments for patients to achieve better disease outcomes** **• To improve harmonisation of care across EU member states reducing inequality** **• To improve real world evidence-based shared decision making**	• Definitions of diseases, outcomes and DPFs for different stages of PCa that are universal, computable and relevant for patients, clinicians, industry and regulators • Data access agreements • Informatics platforms that link, visualise and harmonise data sources of varying types, completeness and structure • Data science techniques to identify new phenotypes and construct personalised predictive models and nomograms • Research results and policy papers	2018 – 2023

European Health Data and Evidence Network (EHDEN)

A federated network of relevant and high quality data sources

Objective	Expected outputs	Timeline
As an enabling component of the BD4BO programme – to deliver the vision of large-scale medical outcomes research that develops a data network to enable other researchers to ‘find’ and safely ‘reuse’ data.	• An open, transparent call process for third party data providers, with financial support for mapping to OMOP common data model • Delivery of an operational, federated network equivalent to a representative 20% of the EU population, or approximately 100 million people (~200 data sets) • Data quality management framework, supportive of both validation and benchmarking • Certification of SMEs across the RWE technical continuum with relevant experience in innovative services for data providers and/or consumers • Evolution of health outcomes research and incorporation of novel data sources	2018 – 2023

DO-IT

DO→IT

The overarching coordination structure for all BD4BO projects

BD4BO

Objective	Expected outputs	Timeline
Serve as the pivotal point of programme coordination providing expertise for communication, collaboration, dissemination and stakeholder engagement for some areas common for all BD4BO projects	• Develop and coordinate the BD4BO programme strategy • Identify best practice for data management & collection • Build an online repository to share knowledge and learning • Lead and coordinate communication activities of the BD4BO programme and related projects • Facilitate stakeholder engagement with key healthcare system stakeholders to foster discussion and build consensus • Develop minimum data privacy standards, explanatory information and training material for Informed Consent Forms	2017 – 2019

Ethicists

Healthcare Professionals

Pharmaceutical Industry

Economists

Policy Makers

Regulators

Bioinformaticians,
Data Scientists & ICT

HTA bodies

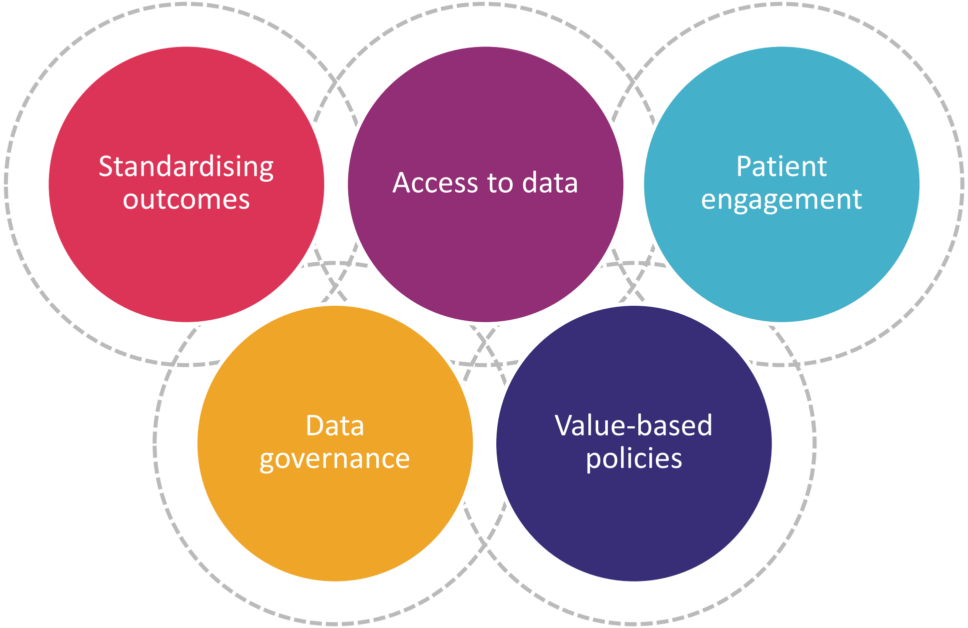
Stakeholder Engagement

Benefits for Society

System-level | **Patient-level** | **Disease-level** | **Trial/product-level**

BD4BO Expected Impact

Improve health outcomes and healthcare systems in Europe by maximising the potential of Big Data



- Standardising outcomes
- Access to data
- Patient engagement
- Data governance
- Value-based policies

DO->IT Partners

Coordinating Partner: London School of Economics and Political Science

Industry Lead: Novartis

PUBLIC PARTNERS

National Institute for Health and Care Excellence
Dental and Pharmaceutical Benefits Agency
European Cancer Patient Coalition
European Multiple Sclerosis Platform
Semmelweis University
Imperial College London
Swedish Institute for Health Economics
Centre for Research in Healthcare Management – Università Bocconi
Norwegian Institute of Public Health
University of Liverpool
Norwegian Medicines Agency
Technology, Methods and Infrastructure for Networked Medical Research
Inserm Toulouse

PRIVATE PARTNERS

The Association of the British Pharmaceutical Industry
Amgen
Bayer
Boehringer Ingelheim
Celgene
European Federation of Pharmaceutical Industries and Associations
Farmaindustria
GlaxoSmithKline
Health iQ
Intersystems
Janssen Pharmaceutica NV
Eli Lilly and Company
Merck
MSD
Novo Nordisk
Pfizer
Roche
Sanofi
Servier
UCB
Association of Research-Based Pharmaceutical Companies

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Thank you!

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