EUROPEAN
CANCER
PATIENT
COALITION

Empowering patients as data owners and partners for research and innovation

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Who are we?

- **ECPC is the largest European cancer patients' umbrella organisation.**
- Representing more than 400 organisations in 46 EU and non-EU countries.
- **Our Vision**

ECPC works for a **Europe of equality**, where all European cancer patients have **timely** and **affordable access** to the **best treatment and care available**, throughout their life. ECPC believes that **cancer patients are the most important partners** in the fight against cancer and against all the cancer-related issues affecting our society. Policy makers, researchers, doctors and industry should recognise cancer patients as **co-creators** of their own health.

Position papers
Policy
Awareness

Working groups
Education
Annual Meeting

PREFER
IMI-DO-IT
FP7 eSMART

CanCon
EMA
ESMO

Patient-centred research, policy, and care

- Patients have unique knowledge, perspectives and experiences
  - Enhance health services and strengthen the link between research and practice
- Understanding the diverse needs and preferences of patients
  - Optimal research, policy, and care
- ECPC advocates for patients to be acknowledged as equal partners
  - Working alongside researchers, policy-makers, and health professionals

Policy

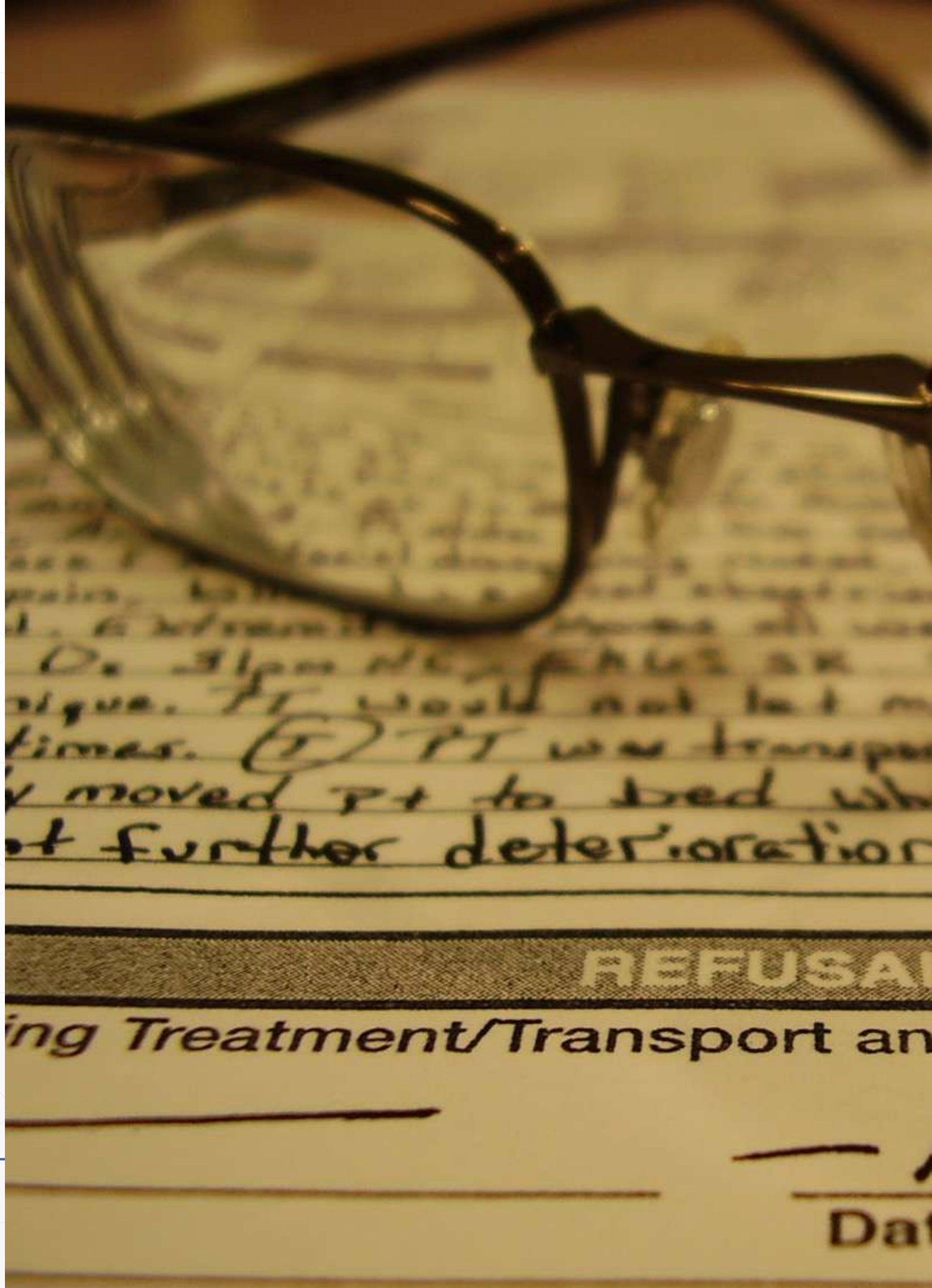
Patients and patient organisations must be involved in developing policies that result in improved survival and quality of life for people with cancer

Real world data

- Research and public health policies will increasingly be based on real world data.
- Patients are being recognised the owners of their own data, and as active partners in research.
- It is vital to design informed consent and data sharing procedures that strike a balance between encouraging research and ensuring patient privacy.

Patients as data owners

- The European Cancer Patient Coalition advocates for truly informed consent.
- Patients should have the right to access their own data, and to share with third parties.
- Patients should be informed about the scientific discoveries that emerge from studies conducted with their data.



Patients as research partners

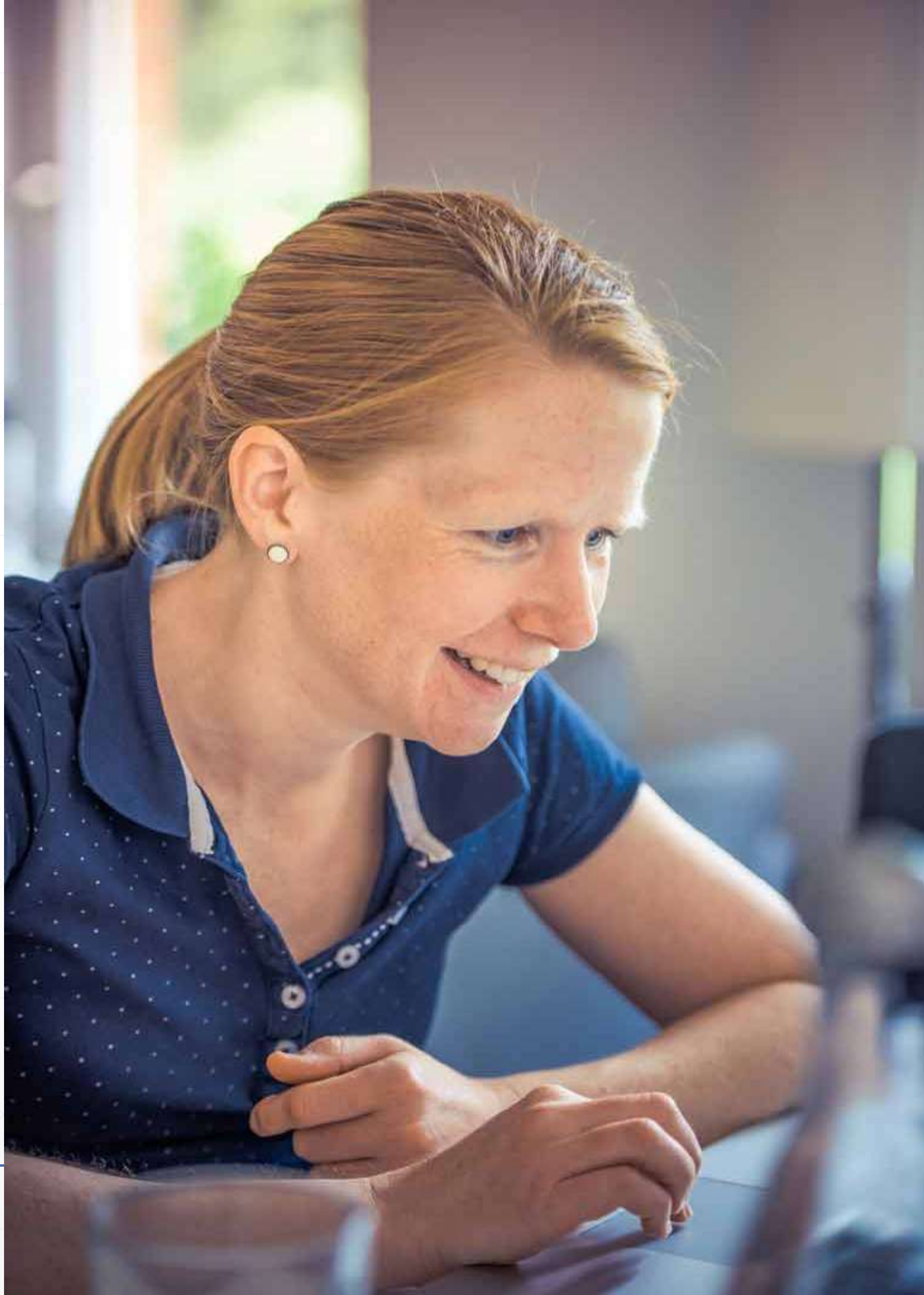
- Patient organisations should be involved in the drafting of informed consent forms
- Linking health data sources and using them in an appropriate way may improve health outcomes for patients.
- It may help to improve the development of medicines and techniques to treat patients in a more personalised manner.

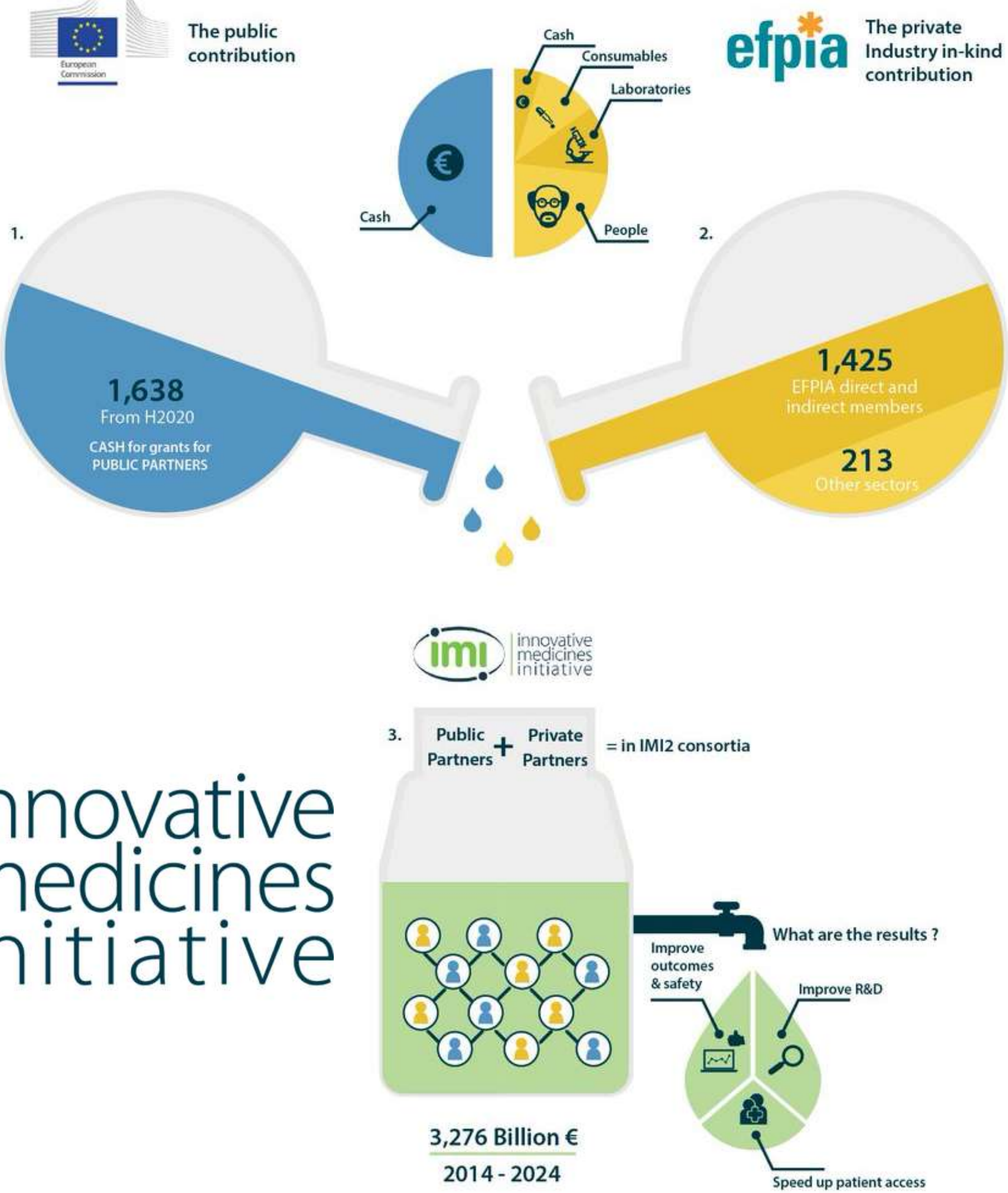
Biobanks

- Biobanks are a type of biorepository that stores human fluid and tissue samples for use in research
- Biobanks will become increasingly important
- The scientific community has to establish a dialogue to inform and empower people with cancer on the advantages related to the donation

Clinical trials

- People with cancer must have access to clinical trials that may be beneficial
- The European Cancer Patient Coalition has worked with Lilly to produce the innovative Clinical Trials Search Engine
- User friendly interface to search ClinicalTrials.gov for nearby relevant clinical trials that are recruiting patients





The public contribution

The private Industry in-kind contribution

Cash

Cash

Consumables

Laboratories

People

1\.

1,638
From H2020
CASH for grants for PUBLIC PARTNERS

2\.

1,425
EFPIA direct and indirect members

213
Other sectors

innovative medicines initiative

3\. Public Partners + Private Partners = in IMI2 consortia

What are the results ?

Improve outcomes & safety

Improve R&D

Speed up patient access

3,276 Billion €

2014 - 2024

imi innovative medicines initiative

Big Data for Better Outcomes

- Supports the evolution towards outcomes-focused and sustainable healthcare systems, maximising the opportunities offered by big and deep data sources
- Ambitious Big Data initiative focused on finding ways to leverage the Big Data for healthcare systems, including improved access, analysis and harmonisation

Big Data for Better Outcomes

efpia

imi

Patients as key

- Patients play a key role as consortium members and contributors, and are the ultimate beneficiaries of improved outcomes delivered by BD4BO.
- Patient organisations and other stakeholders will generate an iterative, consultative process to develop successive versions of minimum data privacy standards and structure.

European Cancer Patients

- The European Cancer Patient Coalition will collaborate with expert patient groups in order to develop the Informed Consent Forms and their supporting materials.
- The European Cancer Patient Coalition will participate in compiling concise and comprehensive documents which will provide patients with the basic knowledge to understand the importance and power of clinical trials, biobanking, and exploratory research such as biomarkers.

Big Data for Better Outcomes

efpia imi

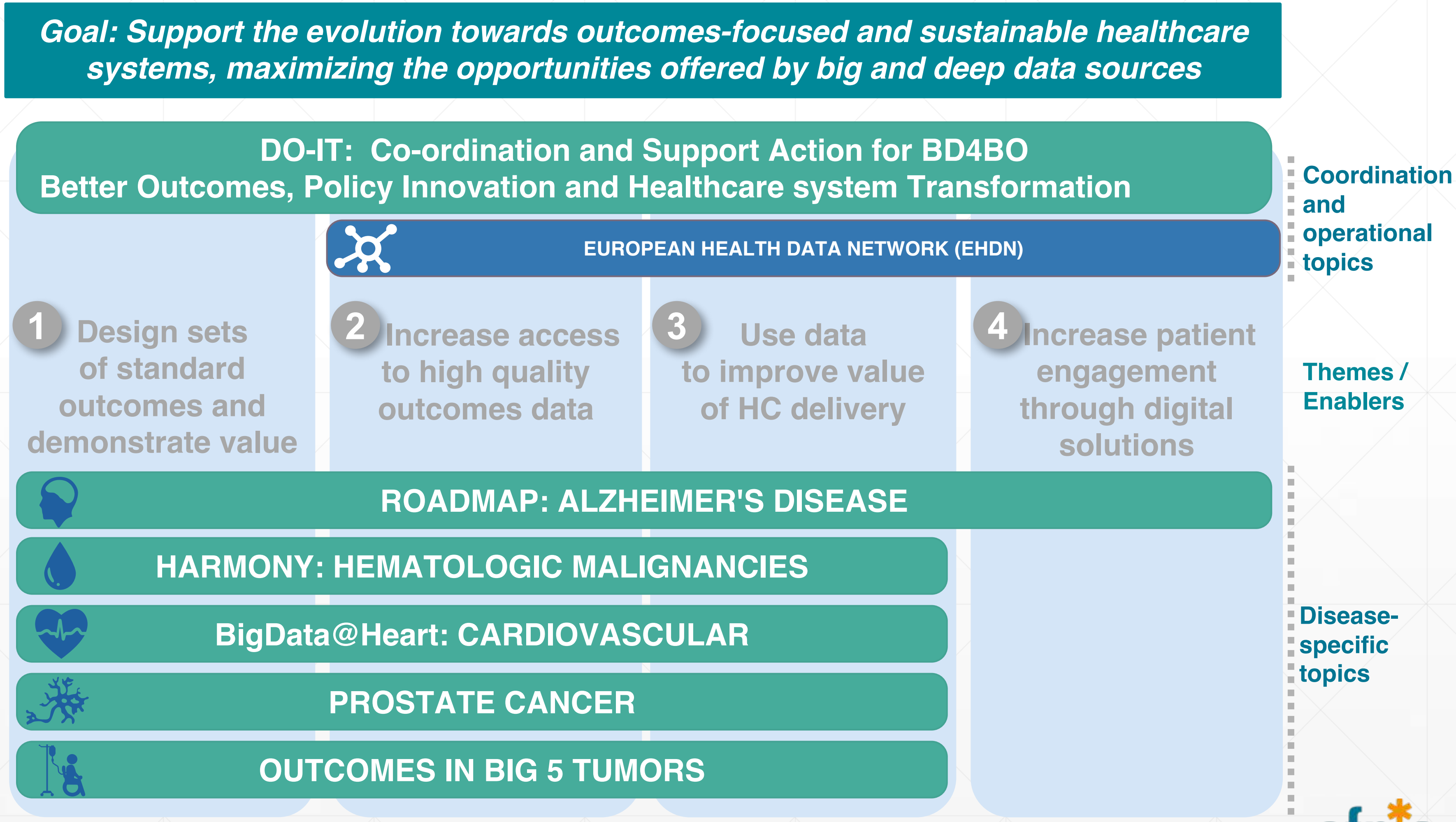
Expected real world impact

- Identifying, standardising and validating outcomes
- Making data accessible to all stakeholders in the research and innovation cycle
- Empowering and engaging people living with serious diseases
- Translating outcomes into actionable policy levers to promote value-based and outcomes-focused healthcare systems

Big Data for Better Outcomes

efpia imi

Big Data for Better Outcomes



Goal: Support the evolution towards outcomes-focused and sustainable healthcare systems, maximizing the opportunities offered by big and deep data sources

DO-IT: Co-ordination and Support Action for BD4BO
Better Outcomes, Policy Innovation and Healthcare system Transformation

EUROPEAN HEALTH DATA NETWORK (EHDN)

Coordination and operational topics

1 Design sets of standard outcomes and demonstrate value

2 Increase access to high quality outcomes data

3 Use data to improve value of HC delivery

4 Increase patient engagement through digital solutions

Themes / Enablers

ROADMAP: ALZHEIMER'S DISEASE

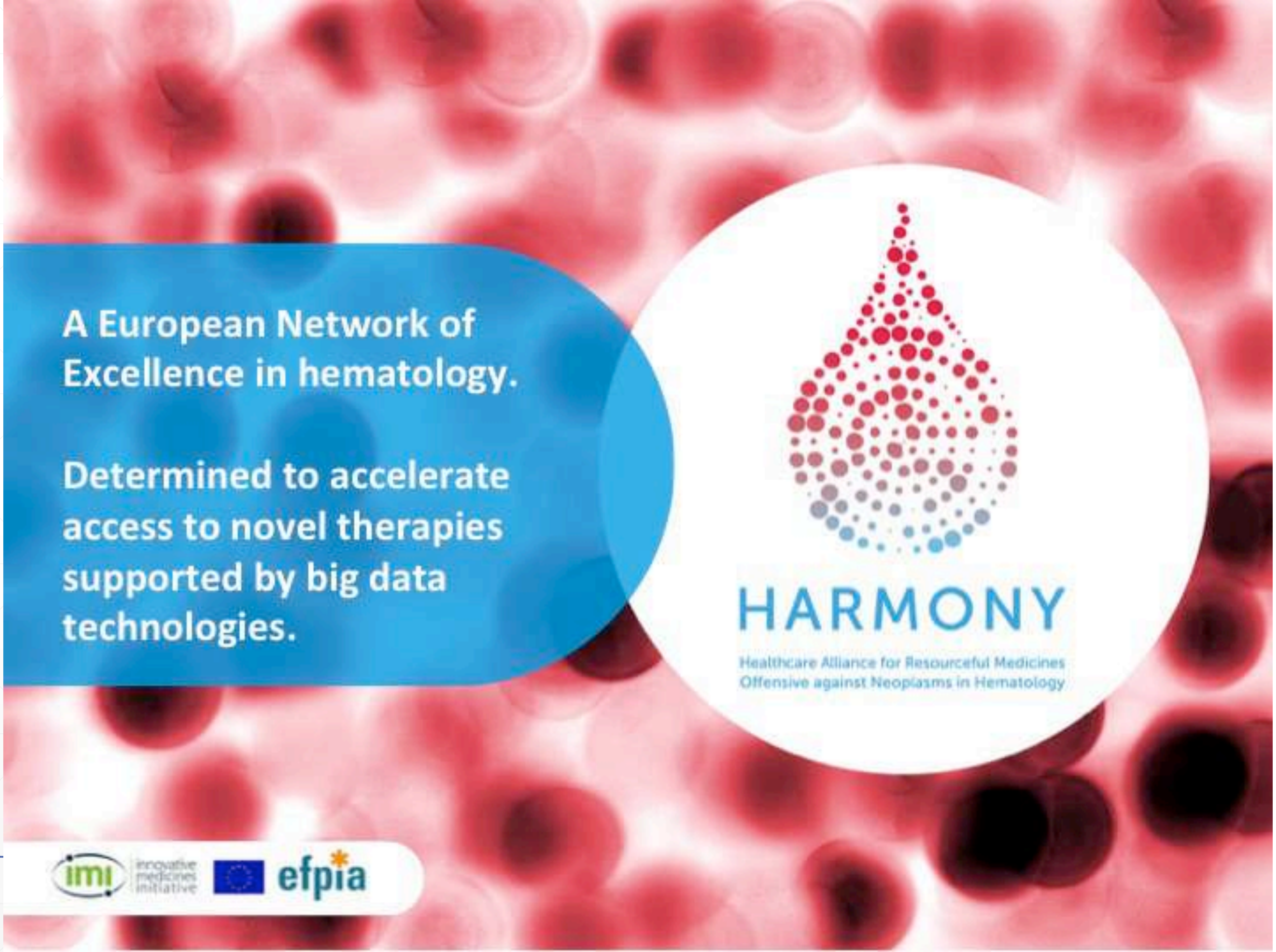
HARMONY: HEMATOLOGIC MALIGNANCIES

BigData@Heart: CARDIOVASCULAR

PROSTATE CANCER

OUTCOMES IN BIG 5 TUMORS

Disease-specific topics



A European Network of Excellence in hematology.

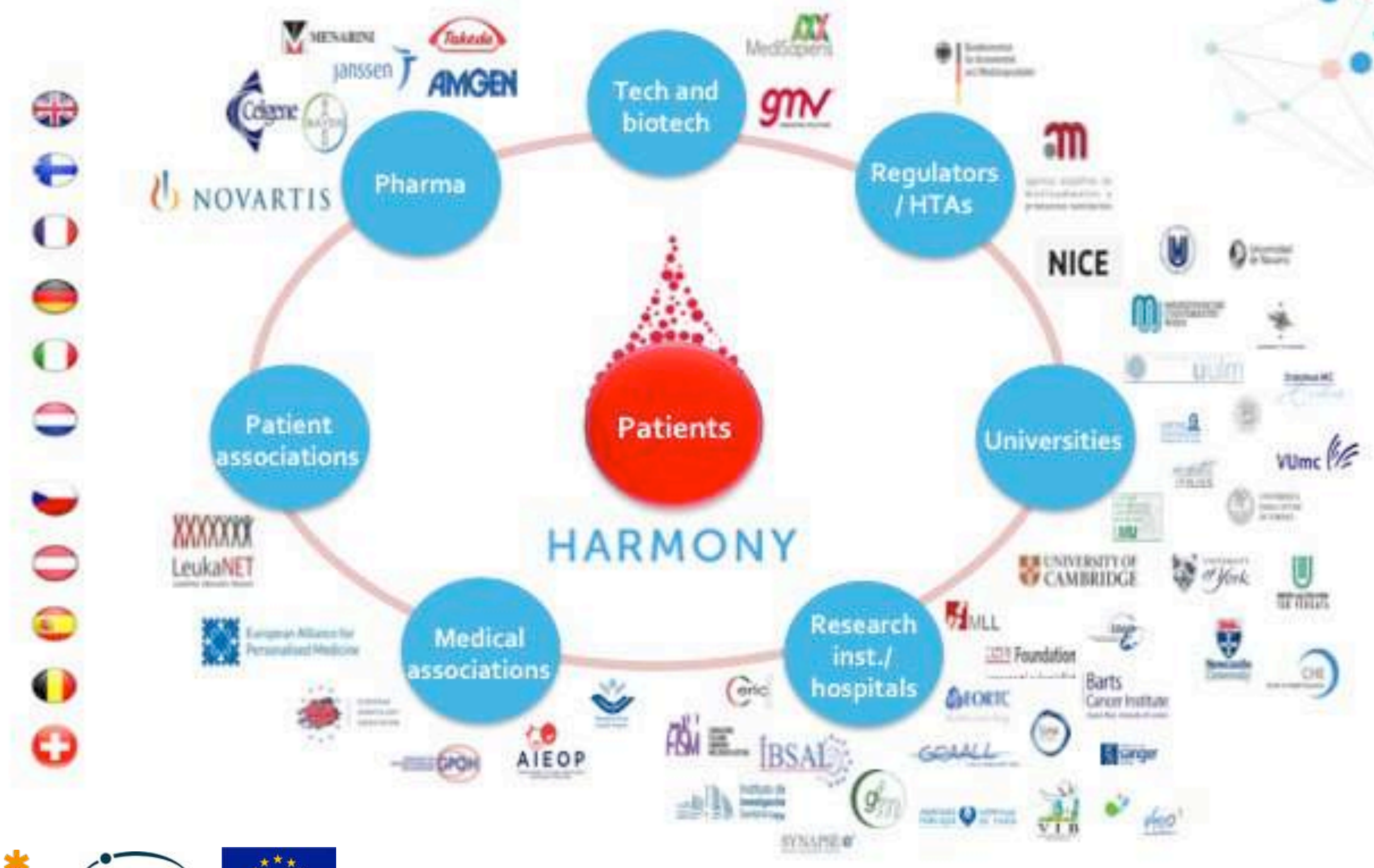
Determined to accelerate access to novel therapies supported by big data technologies.

HARMONY

Healthcare Alliance for Resourceful Medicines Offensive against Neoplasms in Hematology

A Public Private Partnership with Patient at the center

51 Partners: 44 organizations from 11 European Countries and 7 pharmaceutical companies.



Patients

Pharma

Tech and biotech

Regulators / HTAs

Universities

Research inst./ hospitals

Medical associations

Patient associations

HARMONY

efpia imi

HARMONY

- Will capture, integrate, analyze and harmonize anonymous patient data from high-quality multidisciplinary sources to unlock valuable knowledge on hematologic malignancies
- The final deliverable is a big data platform which integrates outcome measures and endpoint definitions for hematologic malignancies

The HARMONY and DO->IT projects have received funding from the Innovative Medicines Initiative 2 Joint Undertaking (IMI2) under grant agreement No. 116020 (“ROADMAP”) and No. 116055 (“DO->IT”). These Joint Undertakings receives support from the European Horizon 2020 research and innovation programme and European Federation of Pharmaceutical Industries and Associations (EFPIA).

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Thank you

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