EUROPEAN
CANCER
PATIENT
COALITION

Patients as partners in 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.

Advocacy

Position papers
Policy
Awareness

Capacity-Building

Working groups
Education
Annual Congress

Research

IMI PREFER
IMI DO-IT
IMI PIONEER

Partnerships

iPAAC
EMA
EAU

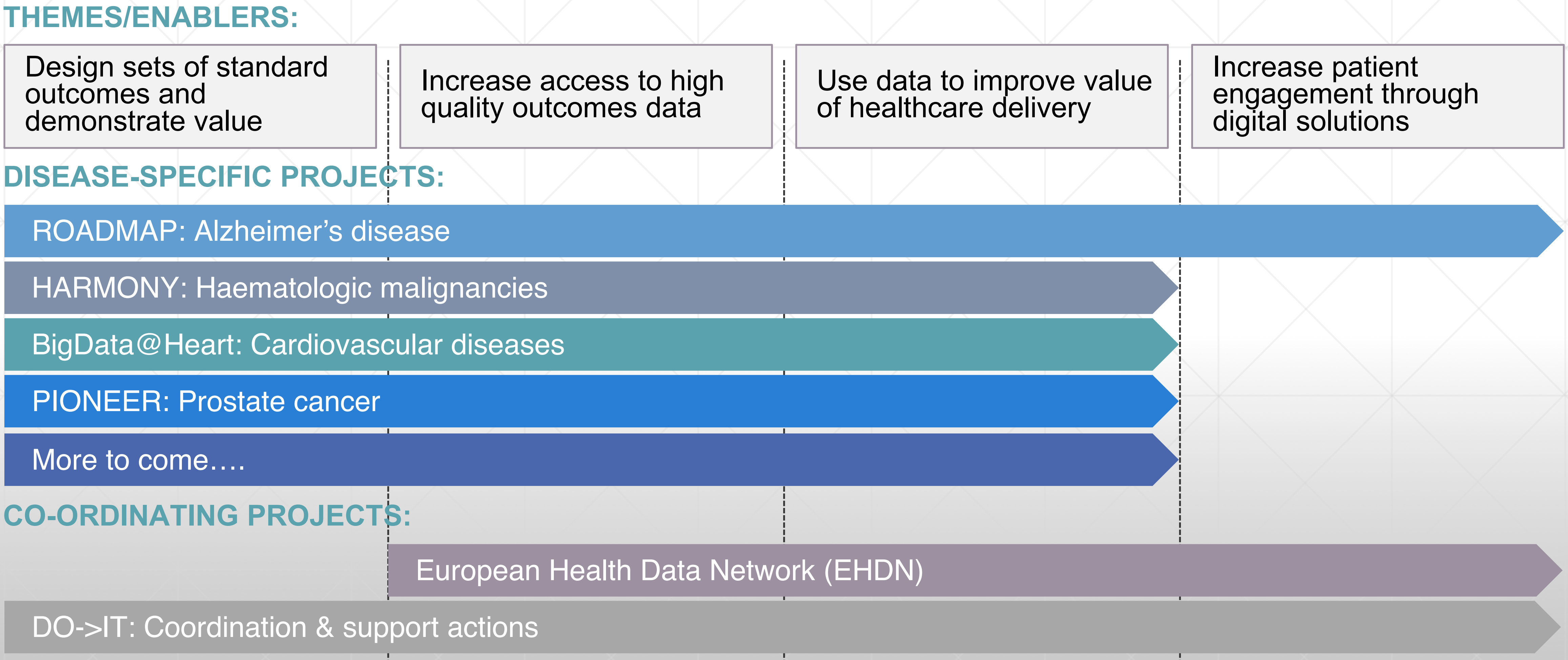
Patient-centred research, policy, and care

- 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

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.

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 healthcare delivery
- Increase patient engagement through digital solutions

DISEASE-SPECIFIC PROJECTS:

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

CO-ORDINATING PROJECTS:

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

Big Data 4 Better Outcomes Overview

Big Data for Better Outcomes

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

Introducing PIONEER

Who we are

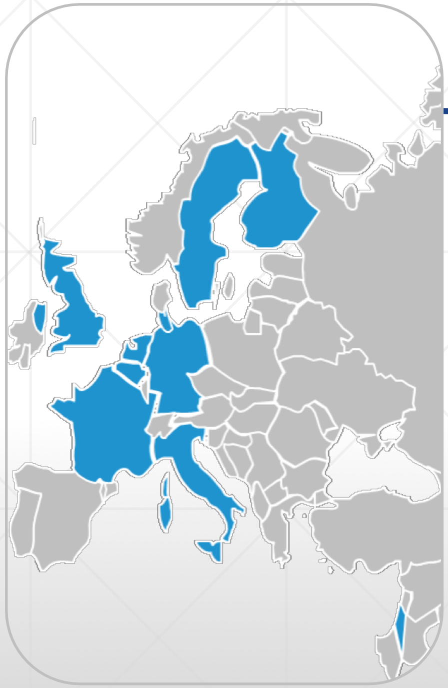
- Launched in May 2018, PIONEER brings together all relevant stakeholders in the field of prostate cancer research as well as clinical and social care.
- Five year (2018-2023) 12 M€ program.

Our goal

To ensure the optimal care for all European men diagnosed with prostate cancer by unlocking the potential of big data and big data analytics.

PIONEER Consortium

32 stakeholders from across 9 countries



UNIVERSITÀ VITA-SALUTE SAN RAFFAELE
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GÖTEBORGS UNIVERSITET
Imperial College London
Radboudumc university medical center
KING'S College LONDON
Erasmus MC Universitair Medisch Centrum Rotterdam
UNIVERSITY OF TAMPERE
UNIVERSITY OF ABERDEEN
Universitätsklinikum Hamburg-Eppendorf

BAYER
SANOFI
astellas
janssen Pharmaceutical companies of Johnson&Johnson
VARIAN medical systems
ORION
COVANCE SOLUTIONS MADE REAL
sas

EUROPEAN CANCER PATIENT COALITION
ecancer
European Alliance for Personalised Medicine

eisbm European Institute for Systems Biology & Medicine
IHE The Swedish Institute for Health Economics Institutet för Hälso- och Sjukvårdsekonomi
מכון ויצמן למדע WEIZMANN INSTITUTE OF SCIENCE
ICHOM
EORTC European Organisation for Research and Treatment of Cancer
Fraunhofer IZI

Pinsent Masons
ttopstart Science and business consultants
thehyve
eau European Association of Urology

PIONEER Deliverables

- A single innovative data platform in which existing ‘big data’ from prostate cancer patients across different stages of the disease has been standardised and integrated.
- A community of all European prostate cancer stakeholders including urologists, oncologists, HTAs, policy makers, industry, patients, data scientists, regulators, and economists.
- Meaningful and standardised clinical endpoints and outcome measures for localised, locally advanced, and advanced metastatic prostate cancer.
- Tools for analysing complex data sets including genomic data.
- A framework for legal, ethical and governance issues which will allow for cross-boarder usage of big data sources whilst acknowledging data security constraints.

Thank you

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European Cancer Patient Coalition

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