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
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.

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PIONEER Consortium

32 stakeholders from across 9 countries
PIioneer 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.

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