



EUROPEAN
CANCER
PATIENT
COALITION

Personalised Medicine – The future of Drug Development

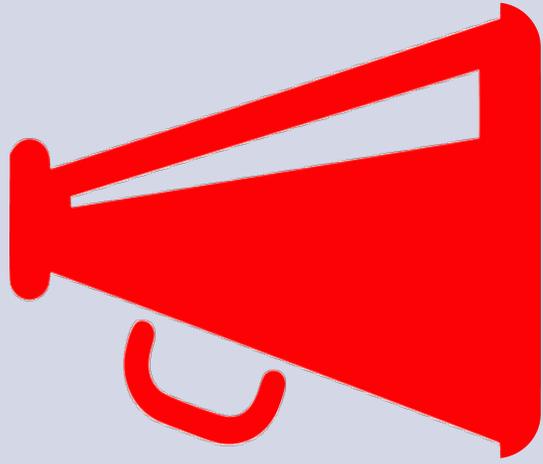
Patient Advocate's Perspective – September 24, 2018

Prof. Francesco de Lorenzo, ECPC President

Who are we?

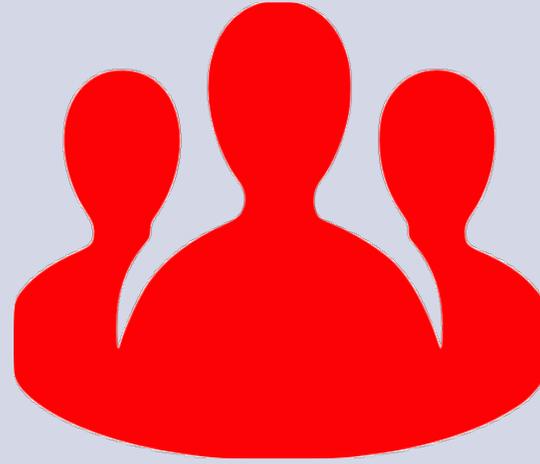
- **ECPC is the largest European cancer patients' umbrella organisation.**
- Representing more than 400 organisations in 46 EU and non-EU countries.
- **Our Vision**

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.



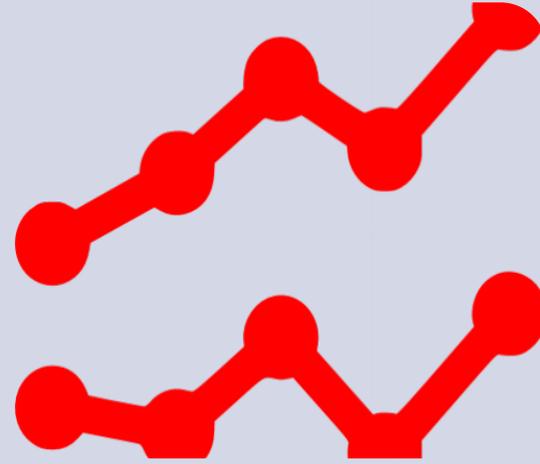
Advocacy

Position papers
Policy
Awareness



Capacity-Building

Working groups
Education
Annual Congress



Research

IMI PREFER
FP7 eSMART



Partnerships

iPAAC
EMA
ESMO

Genomics in Cancer

The debate is no longer if personalised medicine will impact cancer care, but rather whether Europe is capable of delivering the complex infrastructure needed for universal coverage and equitable access to health care.

Testing is as important as the treatment

- Biomarker testing, molecular testing, and whole genomic sequencing represent a largely overlooked aspect of personalised medicine, despite personalised medicine being entirely reliant on them.
 - We need to help politicians recognise that testing is as important as the treatment. If these issues are not resolved they will cause enormous suffering to patients who will be exposed to the unnecessary toxicity of drugs to which they've no chance of responding.
 - In the long term, lack of testing will result in unsustainable health care systems.
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Biomarker testing challenges in Europe

Biomarkers are essential part of a targeted approach to the prevention, diagnosis and treatment of cancer, based on an individuals specific profile.

- **Accessibility** of biomarker testing varies from country to country, but also within cities and regions. Biomarker diagnostics are often performed at larger hospitals only, access to which may add additional barriers to timely diagnosis.
 - **Administrative barriers** lead to delays and higher waiting periods for biomarker test results which vary from a few days to an entire month in some countries. There is no established organization between hospitals to perform test and share the results of these tests effectively.
 - **Reimbursement** of biomarker testing also varies by country. For example, the RAS Biomarker Testing is reimbursed at varying rates in 21 of the 28 EU Member States.
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Two orders of solutions: EU-level & national level

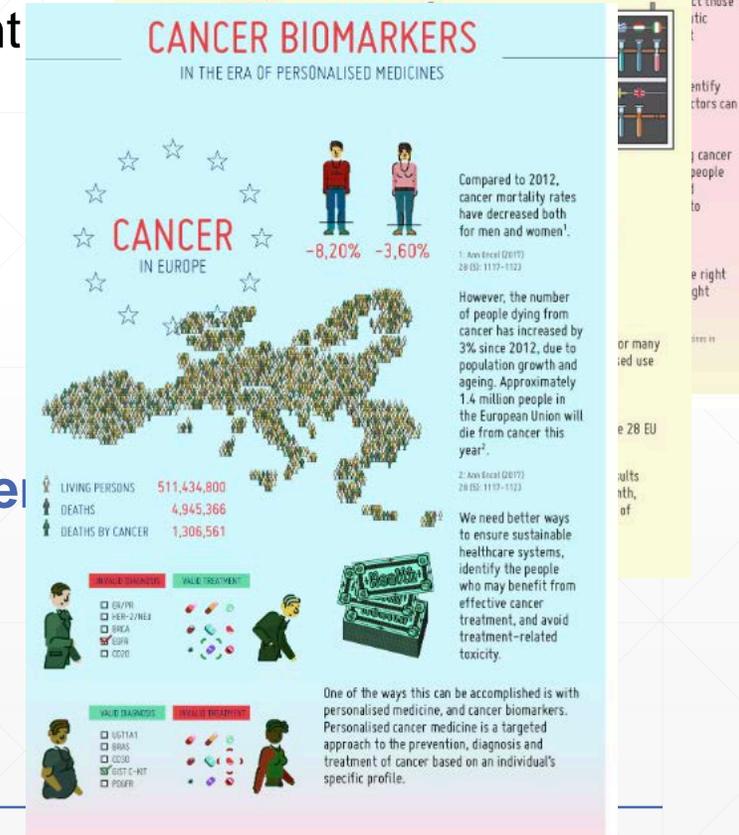
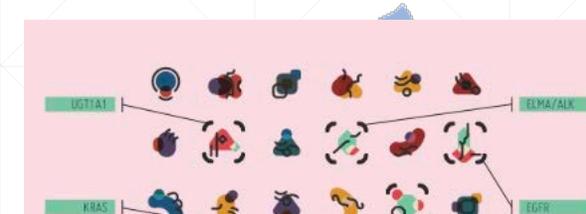
- **EU-level:**
 - Promote research and development in biomarkers
 - Adapt regulatory frameworks to the specificities of new health technologies
 - Harmonise Health Technology Assessment at EU level
- **National level:**
 - Healthcare expenditures in cancer must match burden of disease
 - Need to train patient advocates and HCPs on the importance of biomarker testing
 - Adapt reimbursement frameworks to the specificities of new health technologies

Suggestions to improve training on innovative cancer medicines

- ❑ **More education for patients and healthcare professionals**
- ❑ As personalized medicine depends on the disease, **personalized medicine should be considered generally in the guidelines of** the respective disease, including possibilities and limitations of diagnostic procedures
- ❑ The medical trainee should be exposed **both to diagnostic technology and clinical management** of the patient - this should refer equally to the training of **laboratory specialists** and to **trainees in clinical disciplines, all health care professionals**

Working together

- ECPC and CDDF have an **ongoing collaboration** on biomarkers and personalised medicine
- CDDF has already been great source of updated and relevant info on cancer immunotherapies
- **Patient education:**
 - Based on the successes of the ECPC Immuno-Oncology Platform
 - Produce together more accurate **information on biomarkers**
- Final objective: **raise awareness and educate** patients/policymakers



ECPC Personalised Medicine Awareness Month

- In November, ECPC will launch **the first Awareness Month on Personalised Medicine** focusing on molecular and biomarker testing
- Developed in close **cooperation with CDDF** and European Alliance for Personalised Medicine
- **Awareness, Education and Advocacy** aimed at patients and patient organisations, healthcare professionals and policymakers.



The European Cancer Patient Coalition is calling for:

- Increased access to biomarker testing
- Increased awareness of biomarkers
- A harmonization framework for biomarker testing across Europe



Increased Access

- **Increase Biomarker Literacy:** Health authorities, physicians and patient groups need to improve awareness regarding genetic testing.

Communication focused upon access to testing and how it can aid in patient care provides an important opportunity to engage patients in managing their health as active partners and inform them about break-through developments in medical technologies.



Increased Awareness

- **Improve access:** The development of biomarker-based diagnostics can facilitate faster diagnosis, a targeted personalised treatment plan, and help avoid waste of resources on ineffective treatments. Diagnostics tests need to be integrated in the clinical setting and be affordable and available to all patients.



Harmonised framework

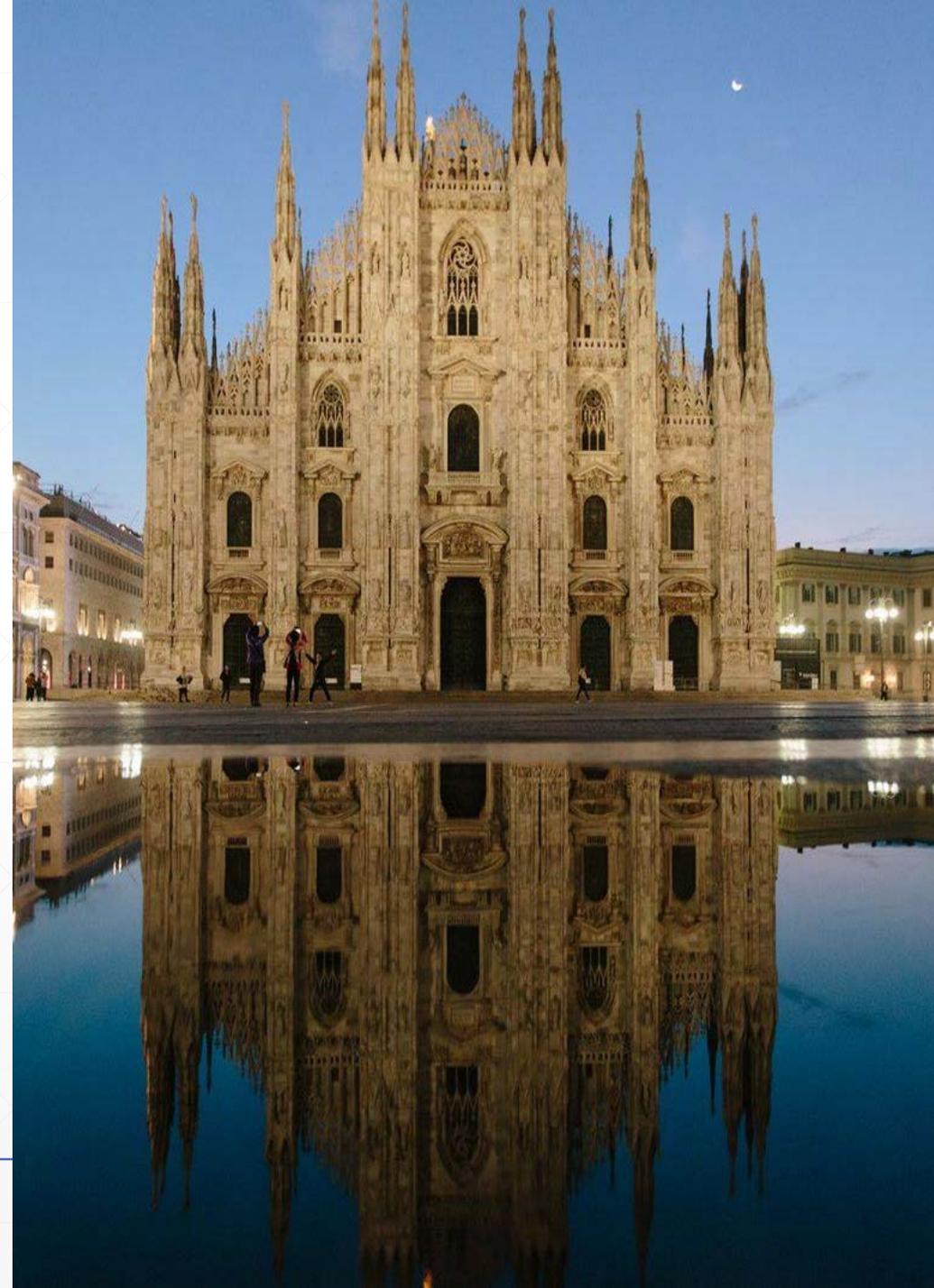
- **The regulatory and reimbursement processes must be adapted to the specificities of new technologies.** Hospitals and other clinical settings have to adapt to respond to some of its challenges such as quality and assurance of the diagnosis or data privacy. A better integration of diagnostic regulations into therapeutic regulatory frameworks could improve the reimbursement and access of biomarker tests.



Conclusion

Concluding event on
28 November in **Milan**

as part of the Patient Track at
the European Alliance for
Personalised Medicine
congress.

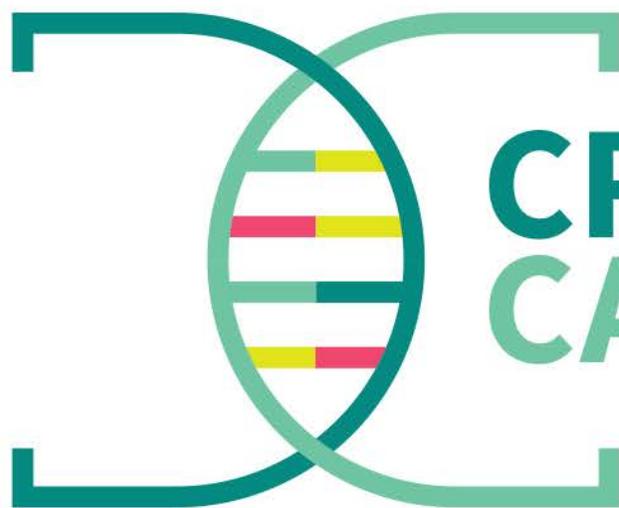


Thank you

www.ecpc.org/edu/personalisedmedicine



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CRACKING THE CANCER CODE

PERSONALISED MEDICINE
AWARENESS MONTH 2018

AN INITIATIVE OF THE EUROPEAN CANCER PATIENT COALITION