Value of diagnostic information

*Patient Advocate’s Perspective*

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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.
Testing is as important as the treatment

- Diagnostic testing represents 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 diagnostic information in unsustainable health care systems.
Diagnostic testing challenges in Europe

Diagnostic information is an essential part of a targeted approach to the prevention, diagnosis and treatment of cancer, based on an individual's specific profile.

- **Accessibility** of diagnostic information varies from country to country, but also within cities and regions. 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 diagnostic information 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 diagnostic testing also varies by country. For example, the RAS Biomarker Testing is reimbursed at varying rates in 21 of the 28 EU Member States.
Results from diagnostic tests can take from 7 to 30 days, depending on the country.
Only 23% of doctors felt that their patients were always fully informed about diagnostic tests.

http://doi.org/10.1634/theoncologist.2015-0279
The European Cancer Patient Coalition is calling for:

▪ Increased access to diagnostic testing
▪ Increased awareness of diagnostic information
▪ A harmonization framework for diagnostic testing across Europe

ECPC Personalised Medicine Awareness Month

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

www.ecpc.org/personalisedmedicine2018
Personalised Medicine Month digital toolkit
Social media calendar for Twitter and Facebook

www.ecpc.org/personalisedmedicine2018

Thank you

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CRACKING THE CANCER CODE
PERSONALISED MEDICINE AWARENESS MONTH 2018

AN INITIATIVE OF THE EUROPEAN CANCER PATIENT COALITION