



# EUROPEAN CANCER PATIENT COALITION

## Value of diagnostic information

*Patient Advocate's Perspective*

Ken Mastris, ECPC Board Member

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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.

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## Advocacy

Position papers  
Policy  
Awareness



## Capacity-Building

Working groups  
Education  
Annual Congress



## Research

IMI PREFER  
FP7 eSMART



## Partnerships

iPAAC  
EMA  
ESMO



## 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.

A joint initiative ECPC-EAPM



European Alliance for Personalised Medicine

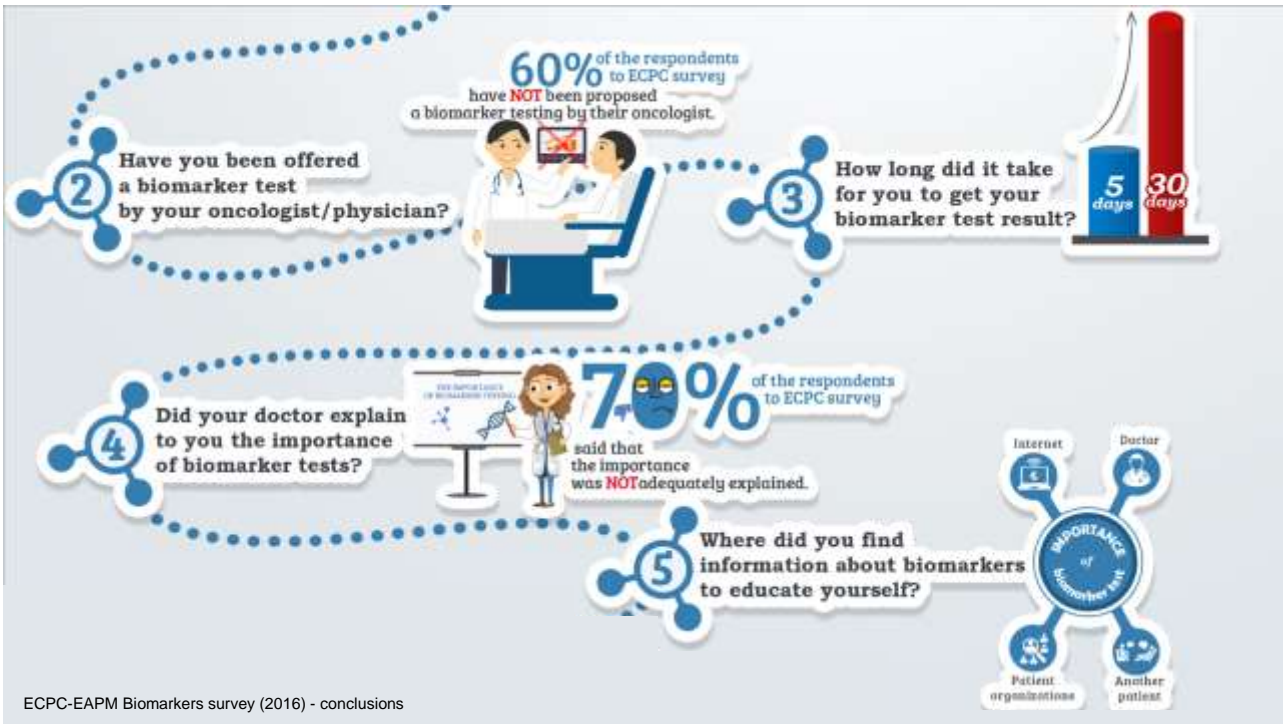
## PATIENT AWARENESS ON BIOMARKERS ACROSS EUROPE

1 Do you know that biomarkers can help doctors find the best treatment for you?

best score in the knowledge related to biomarkers  
aware of the concept but under a different name  
poor knowledge

70% of the respondents to ECPC survey are aware of the existence of biomarkers.

ECPC-EAPM Biomarkers survey (2016) - conclusions

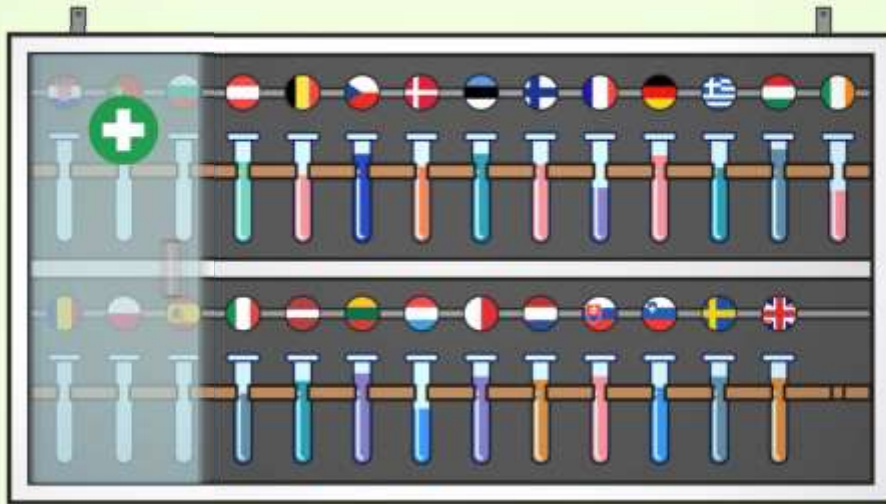


Results from diagnostic tests can take from 7 to 30 days, depending on the country



ECPC-EAPM Biomarkers survey (2016) - conclusions

## REIMBURSEMENT OF RAS BIOMARKER TESTING



ECPC-EAPM Biomarkers survey (2016) - conclusions



23%

Only 23% of doctors felt that their patients were always fully informed about diagnostic tests.

Ciardiello, F., Adams, R., Tabernero, J., Seufferlein, T., Taieb, J., Moiseyenko, V., ... Tejpar, S. (2016). Awareness, Understanding, and Adoption of Precision Medicine to Deliver Personalized Treatment for Patients With Cancer: A Multinational Survey Comparison of Physicians and Patients. *The Oncologist*, 21(3), 292–300. <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

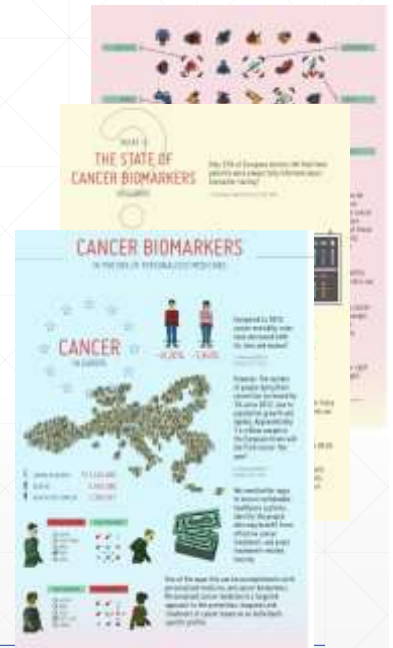


- In November, ECPC launched **the first Awareness Month on Personalised Medicine** focusing on molecular and biomarker testing
- Developed in close cooperation with European Alliance for Personalised Medicine
- **Awareness, Education and Advocacy** aimed at patients and patient organisations, healthcare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



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[www.ecpc.org/personalisedmedicine2018](http://www.ecpc.org/personalisedmedicine2018)



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## Personalised Medicine Month digital toolkit



[www.ecpc.org/personalisedmedicine2018](http://www.ecpc.org/personalisedmedicine2018)

## Social media calendar for Twitter and Facebook



[www.ecpc.org/personalisedmedicine2018](http://www.ecpc.org/personalisedmedicine2018)

# Thank you

[www.ecpc.org/personalisedmedicine2018](http://www.ecpc.org/personalisedmedicine2018)



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