

Campaign Action Toolkit

Your guide to
using information
and content for
Personalised Medicine
Awareness Month,
November 2021



European Cancer
Patient Coalition



**CRACKING THE
CANCER CODE**

PERSONALISED MEDICINE
AWARENESS MONTH 2021

CRACKING THE CANCER CODE

2021

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INTRODUCTION TO PERSONALISED MEDICINE AWARENESS MONTH 2021

What is Personalised Medicine Awareness Month?

Too many people diagnosed with cancer do not have access to the personalised treatment they need and deserve. This can be due to a lack of awareness and education amongst patients and healthcare professionals, or a variety of access challenges such as pricing, reimbursement or limited availability. Molecular testing is the key to unlocking these treatments and now is the time for change.

In November 2021, the European Cancer Patient Coalition will promote the importance of access to cancer molecular testing during a month-long advocacy campaign, “Cracking the Cancer Code”

The European Cancer Patient Coalition and our member organisations believe that people living with cancer should be informed about all available treatment options and be empowered to make the best decisions for their health, together with their healthcare team. That’s why we are working towards ensuring all Europeans with cancer and at risk of getting cancer have appropriate access to cancer molecular testing. This will help to promote better diagnosis, more targeted follow up and a truly personalised treatment.

What is Personalised Medicine?

Traditionally, cancer treatment has focused on the location of the cancer in the body. Depending on the type

of cancer, patients receive specific treatments such as chemotherapy, surgery, radiotherapy or immunotherapy. Unfortunately, not every patient with cancer responds to these treatments in the same way: What works for one person may not work for another, and some may suffer serious side effects from treatment that is also ineffective. This can lead to emotional and financial distress, placing a serious burden on people with cancer, as well as on their families, carers and health systems.

Now, thanks to breakthrough technological advances, it is becoming possible to treat people with cancer based on ‘who’ they are, not ‘where’ their cancer is located. Improved treatment and quality of care means fewer side-effects and distress, as well as faster access for people with cancer to new and more effective treatment options – all of which improve the quality of life for people with cancer.

Molecular testing is a way to do this, and it is already available for many types of cancer. However, its use in Europe varies by country, because in many countries diagnostic tests are not used regularly in clinical practice and are therefore not reimbursed or available to all people with cancer.

Why does Personalised Medicine Awareness Month matter?

Each year, over 3 million people are diagnosed with cancer in Europe. We need governments to ensure the means to identify people who may benefit from more effective targeted cancer treatment, and avoid treatment-related toxicity where possible, all whilst helping to ensure the sustainability of our healthcare systems.

One such way to address this is with cancer molecular testing and personalised medicine, a targeted approach to the prevention, diagnosis and treatment of cancer. For instance, cancer biomarkers are molecules that are usually produced by cancer cells, which can then be detected in bodily tissues or fluids. They can be patient-specific, rather than tumour-specific, which means they can help identify people who have cancer or who are at risk of developing cancer, and help to select or predict those people who are likely to derive therapeutic benefit from specific treatments.

Awareness about cancer molecular testing remains low – only 23% of European doctors feel that their patients are always fully informed about molecular or biomarker testing. The use of cancer molecular testing in Europe also varies by country, because in many countries diagnostic tests are not integrated into clinical practice and are not reimbursed or available to all people with cancer. This needs to change.

Who is behind Personalised Medicine Awareness Month?

Personalised Medicine Awareness Month is an initiative of the European Cancer Patient Coalition (ECPC) – the largest European cancer patients’ umbrella organisation. ECPC is the voice of cancer patients in Europe. With over 450 members, covering all 27 EU member states and many other European and non-European countries, ECPC represents patients affected by all types of cancers, from the most common to the rarest.

The European Cancer Patient Coalition, together with its members will continue this month-long campaign throughout the month of November.

In 2021, the European Cancer Patient Coalition gratefully acknowledges the support of Roche, BMS, Daichi Sankyo, Astellas, Sanofi and Eli Lilly.

Who is this toolkit for?

The European Cancer Patient Coalition has developed this guide to help our member patient organisations to participate in Personalised Medicine Awareness Month campaign, and make the most of the tools and materials, which were developed together with experts. It contains things like key messages, patient case studies, social media materials – to help patient organisations to promote the campaign at national level in their country. As part of the toolkit, you will find templates for Press Releases, outreach letter to policymakers, pledge and call for action – to help raise awareness and gather commitment.

Many of the materials in this toolkit are also available in several European languages, including: Czech, Dutch, Finnish, French, German, Greek, Italian, Lithuanian, Polish, Romanian, and Spanish. To find these, go to the ECPC website.

I’m a patient, what can I do?

Molecular testing can be used to help you and your healthcare team make informed decisions about your treatment and follow-up. The European Cancer Patient Coalition provides resources on its website to help you learn more about Personalised Medicine.

Stay informed, share information, and be sure to start conversations with your doctor to find out about molecular testing, its availability and reimbursement in your country.

Add your voice to the growing movement to campaign for access to molecular testing and personalised treatment. Sign our pledge, share it with your networks online and offline and be sure to contact your local patient organisation for more information.

I’m a patient, how can I get involved?

1. Contact your health professional, local patient association or support group to find information on molecular testing and personalised medicine.
2. Stay up-to-date with information shared by ECPC on Twitter @cancereu or Facebook @ECPCfb
3. Share the Personalised Medicine Awareness Month charter to make sure that everyone, from family and friends to elected decision makers in your area, knows about molecular testing and personalised medicine and why improved access is vital for people with cancer.

For more information about the campaign

Share your questions with Twitter @cancereu or Facebook @ECPCfb or get in touch via email at:
• Aina Errando, ainalaura.errando@ecpc.org
• Adela Maghear, adela.maghear@ecpc.org

Check out
#CrackingTheCancerCode
#PMAM21

INFOGRAPHIC USING PATIENT LANGUAGE



In the context of cancer, **personalised medicine is a treatment approach tailored specifically to certain biological features of your tumour.** As this therapy has been designed to target your particular tumour subtype, its chances of success are potentially higher than a more traditional non-targeted approach (i.e., chemotherapy is at present the most used non-targeted treatment approach for cancer).



Personalised medicine aims to deliver to you **“the right treatment, at the right dose, at the right time,”** thus maximizing the chances for this personalised treatment to work for you, controlling your disease and preserving your quality of life.



Cancer biomarkers or companion diagnostics are diagnostic tests that can detect specific feature(s) within your sample that characterize your individual tumour. Liquid biopsies, where characteristics of the tumour are picked up within the patient’s blood without the need for a tissue sample, are also being used.



It is best delivered in recognised cancer centres where a multidisciplinary team (MDT) of specialized staff will take into discussion and agree upon your particular diagnostic work-up and treatment considering your opinions and preferences. **The MDT brings together all relevant expertise required to manage your specific cancer** and will include oncologists, radiotherapists, oncology surgeons, cancer nurses, pathologists, molecular biologists, geneticists, technologists and other relevant specialists, depending on your specific disease.



Once the cancer biomarker has indicated which treatment option is the best for you, your multidisciplinary team will deliver your specific treatment. Depending on the results of your biomarker test, there may be more than one option for treatment, so you will have the chance to discuss your options with your multidisciplinary team. The treatment may involve targeting of a gene or protein that is characteristic of your particular tumour, or of a biological pathway that is in some way altered in your cancer.



Is personalised cancer medicine for all? Well, stimulating your immune system to fight your cancer (the promising treatment avenue of immunotherapy) offers potential for certain tumour types, so you may be tested to see for example if your PDL-1 gene is active. PDL-1 is one of a number of cancer biomarkers that can determine if an immunotherapeutic intervention is suitable for you. However, while immunotherapy approaches have shown promise, much research still needs to be done before it becomes a standard-of-care.



The key feature of personalised medicine is the specificity of the treatment approach, such that tumour cells are targeted for elimination while normal cells and tissues in your body are spared from any potential treatment side effects. The clinical team aim is both to treat your tumour successfully, but also as far as possible to preserve your quality of life.



While you might respond to the initial treatment, your tumour may become resistant to that treatment over time, leading to the reemergence of your cancer. The development of 2nd and 3rd generation personalised medicines for particular tumour subtypes has enhanced our ability to combat treatment resistance and these newer drugs may be employed in your current or future treatment.

CONTACTS AND DISCLAIMER

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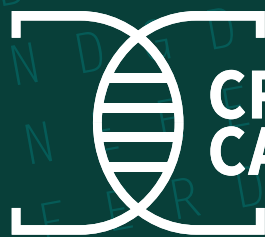
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AN INITIATIVE OF THE EUROPEAN CANCER PATIENT COALITION

ecpc.org/get-involved/personalised-medicine-awareness-month



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