Campaign Action Toolkit

Your guide to using information and content for Personalised Medicine Awareness Month, November 2018
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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. This needs to change. Molecular testing is the key to unlocking these treatments and now is the time for change. This is why ECPC is launching a pan-European Personalised Medicine Awareness Month to bring about new conversations on treatment options for European citizens.

In 2018, throughout the month of November, 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 ECPC is 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.

Click here to download this section as a separate document for ease of use.

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 420 members, covering all 28 EU member states and many other European and non-European countries, ECPC represents patients affected by all types of cancers, from the rarest to the most common.

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

The European Cancer Patient Coalition is working in collaboration with European Alliance for Personalised Medicine, Cancer Drug Development Forum and International Quality Network for Pathology.

The European Cancer Patient Coalition gratefully acknowledges the support of AbbVie, AstraZeneca, Bristol-Myers Squibb, Cancer Drug Development Forum, Genomic Health, Johnson & Johnson, Merck, MSD, Roche, Takeda.

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 campaigns, 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, Finnish, French, German, Greek, Italian, Lithuanian, Polish, Romanian, and Spanish. To find these, go to the ECPC website.

To download this toolkit please visit epcp.org/personalisedmedicine2018 or scan the QR code below.

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 @ECPCfr.
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 @ECPCfr or get in touch via email at:
- Alex Fili CVEs, alex.fili CVEs@ecpc.org
- Anna Rek, anna.rek@ecpc.org

Check out #CrackingTheCancerCode #PMAM18
MESSAGE GRID – PERSONALISED MEDICINE AWARENESS MONTH 2018

How to use the message grid

This message grid was developed with an overarching goal – to increase awareness within the patient community around molecular testing and the critical role it plays in cancer treatment and personalized medicine and raise a joint call for increased access to molecular testing.

The key messages form the basis of many of the campaign materials and communication tools and are slightly adjusted for each of the audiences: patients, healthcare professionals and policymakers. You can use the below messages to personalise your communication and advocacy campaigns at national level to better suit local needs of people with cancer, considering local sensitivities, political situation etc.

**HCPs should be supported with clear information and up-to-date training on molecular testing.**

Policymakers and governments, who wish to improve the lives of cancer patients, should endeavour to support better utilisation and access to molecular testing through appropriate funding and reimbursement mechanisms.

**Treat people with cancer based on who they are, not where their cancer is located.**

We need better ways to ensure sustainable healthcare systems, which will identify the people who may benefit from more effective cancer treatment and personalisation.

How to use the patient case studies

Patients themselves are the greatest advocates and present a real-life example of the benefits molecular testing and personalised medicine can bring. These case studies form part of Personalised Medicine Awareness Month campaign communication and can be used at national level to showcase real world examples from the lives of real people with cancer.

Although the cancer diagnosis was a life-changing moment for Renate, she does not let it rule her life: “I want to make the ‘here and now’ as positive as possible. For me this is easier without chemo. I’m still incredibly happy that I did not need chemotherapy. I’m a confident person and I am optimistic about the future.”

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- Policymakers and governments, who wish to improve the lives of cancer patients, should endeavour to support better utilisation and access to molecular testing through appropriate funding and reimbursement mechanisms.
- **Treat people with cancer based on who they are, not where their cancer is located.**
- We need better ways to ensure sustainable healthcare systems, which will identify the people who may benefit from more effective cancer treatment and personalisation.

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| Patients themselves are the greatest advocates and present a real-life example of the benefits molecular testing and personalised medicine can bring. These case studies form part of Personalised Medicine Awareness Month campaign communication and can be used at national level to showcase real world examples from the lives of real people with cancer. |
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**Personalized Medicine Awareness Month**

**Cracking the Cancer Code**

**Goal:**

In November 2018, ECPC will promote the importance of access to cancer molecular testing during a month-long advocacy campaign: “Cracking the Cancer Code”

Too many people with cancer are being denied access to the personalised treatment they deserve. Molecular testing is the key to unlocking these treatments and now is the time to change. This is why ECPC is launching a joint European Personalised Medicine Awareness Month to bring about new conversations on treatment options for European citizens.

**What evidence base was used to inform the message grid?**

- Increased access and decreased waiting times for high quality molecular testing to make personal healthcare more of a reality across Europe.
- More information and education for patients, professionals, and the public on the potential of molecular testing and its availability in Europe.
- Personalised and more efficient and equitable framework across Europe which could increase access to, and potentially validate clinical, molecular testing.

**What audience need to be reached about testing?**

- Patients
- HCPs
- Policymakers

**What evidence base was used to inform the message grid?**

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**PATIENT CASE STUDIES – PERSONAL STORIES**

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<th><strong>BARBARA</strong>, cancer survivor from France</th>
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<td>I was diagnosed with estrogen receptor positive and progesterone receptor negative stage 2b breast cancer in 1999. My treatment included both endocrine therapy and 6 cycles of docetaxel chemotherapy. Within 12 months of diagnosis, I learned about genetic testing for hereditary cancer risk. I was positive for the BRCA1 gene. This knowledge made a huge difference in my treatment plan. I met physicians who specialize in breast cancer genetics and received comprehensive support from the American Cancer Society. As a result, I underwent preventative mastectomy surgery and subsequent genetic testing on my daughter. My case study is a testament to the importance of molecular testing and personalized medicine.</td>
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<th><strong>CHRISTINE S.</strong>, living with breast cancer</th>
<th><strong>Value message</strong></th>
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<td>I was diagnosed with early-stage breast cancer, my gynaecologic oncologist told me about the test. I was diagnosed with an estrogen receptor positive breast cancer with triple negative characteristics. I underwent a mastectomy and chemotherapy. For several reasons, I followed the advice of my surgeon and chose to undergo surgery and take the test. The results arrived (about 10 days after sending the biopsy to California), it turned out that I could actually avoid chemotherapy if I wanted to. As I am a trained biologist, I was able to discuss my illness with my oncologist, who then discussed the results with me and my family. The advice I received was meaningful and helped me to understand the options available to me. It turned out that I had a genetic mutation and I could potentially use a targeted drug that was not available to other patients. My case study demonstrates the importance of personalized medicine and molecular testing.</td>
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Would you like to share your story to support and inspire others living with cancer?

Please get in touch via email or share your story on social media:

@cancereu

#CrackingTheCancerCode

#PMAM18
How to use the infographic and video animation

The European Cancer Patient Coalition has developed an educational video animation and infographic to raise awareness about cancer molecular testing and cancer biomarkers. You may use both materials to support your advocacy and education efforts with patients, healthcare professionals and policy-makers and to reinforce and visualise your messages.

PRESS RELEASE TEMPLATE

How to use the press release template

This template press release can be used at national level in your country, to showcase your support and involvement in Personalised Medicine Awareness Month. You can adjust this template according to your local needs and experiences, and it is also available in several languages.

NEWSLETTER TEMPLATE

How to use the newsletter template

You can use the newsletter article to help promote the Personalised Medicine Awareness Month ahead of November and also throughout the campaign. This template newsletter can be shared with your stakeholder network at national level in your country, to showcase your support and involvement in Personalised Medicine Awareness Month. You can adjust this template according to your local needs and experiences, and it is also available in several languages.
PATIENT CHARTER/CALL TO ACTION

How to use Patient Charter to Action

The ECPC Personalised Medicine Awareness Month presents an opportunity to meet with policymakers in your country to raise awareness and understanding of the importance of molecular testing and personalised medicine. This template can be used to contact policymakers and call for improved access to molecular testing.

How to use the Policymaker Outreach Letter

The ECPC Personalised Medicine Awareness Month presents an opportunity to meet with policymakers in your country to raise awareness and understanding of the importance of molecular testing and personalised medicine.

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POLICYMAKER PLEDGE TEMPLATE

How to use the Policymaker Pledge Template

The ECPC Personalised Medicine Awareness Month presents an opportunity to meet with policymakers in your country to raise awareness and understanding of the importance of molecular testing and personalised medicine.

The template pledge can be used to promote commitment from policymakers at all levels, and in light of European Elections 2019 – to garner commitment for European wide progress towards a harmonised and more efficient regulatory framework.

The good news is that many cancers can be effectively treated. As medical technologies continue to rapidly evolve we are better equipped than ever to deal with this ever-present threat. One of these ground-breaking innovations is molecular testing. It allows a doctor to personalise cancer care for people who have cancer or who are at risk of cancer and help to select or predict those patients who are likely to derive therapeutic benefit from specific treatments such as chemotherapy, surgery, radiotherapy or immunotherapy.

Molecular testing is the analysis of various cancer biomarkers. Cancer biomarkers are molecules that guide personalised treatment decisions. Unfortunately, the use of molecular testing in Europe varies by country. In some countries molecular testing is not reimbursed or available to all people with cancer. This needs to change.

The burden of cancer is growing across Europe. 3.7 million people are diagnosed with cancer each year. In 2019, the number of new cancer cases is estimated at 2.8 million. With time, the majority of cancers are incurable, so prevention and early detection are crucial. Non-invasive, simple, and cost-effective methods of early cancer detection and diagnosis are urgently needed. Molecular testing such as biomarker testing or genomic profiling helps to assess risk, supports early detection and personalised healthcare more of a reality across Europe; for high quality molecular testing to make access to, and potentially reduce the cost of, molecular testing.

The ECPC Personalised Medicine Awareness Month is an initiative of

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SOCIAL MEDIA MATERIALS

How to use social media content

Personalised Medicine Awareness Month social media materials are available for you to download and use. The content calendar contains information and posts for you to repurpose on social media platforms. Use this, along with branded images and case studies to promote awareness online. You can also add your own content to talk about what you or your organization is doing to raise awareness. We welcome new content!

Please remember to tag ECPC @cancereu and use relevant hashtags so we can track levels of conversation: #CrackingTheCancerCode and #PMAM18

CAMPAIGN LOGOS & DESIGN GUIDELINES

Please click to download

Click image to download

Click image to download

Click image to download

Click image to download

#CrackingTheCancerCode and #PMAM18

VISUAL GUIDELINES | 2018

Click images to download

"I recommend this test to all those who may be able to benefit from it!"

"I am alive against all odds. I was told I would die."

"Christine, living with breast cancer"

"Barbara, colorectal cancer survivor"

"We call for:"

- Improved access to innovative and personalized testing for high quality and efficient testing
- Integration of personal and healthcare more of a reality across Europe
- Better awareness of the importance of molecular testing and accessibility, which could reduce costs and potentially increase survival rates
CONTACTS AND DISCLAIMER

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The European Cancer Patient Coalition gratefully acknowledges the support of AbbVie, AstraZeneca, Bristol-Myers Squibb, Cancer Drug Development Forum, Genomic Health, Johnson & Johnson, Merck, MSD, Roche, Takeda.