



Campaign Action Toolkit

Your guide to
using information
and content for
Personalised Medicine
Awareness Month,
November 2018





CONTENTS

Introduction to Personalised Medicine Awareness Month 2018	4
Message Grid – Personalised Medicine Awareness Month 2018	6
Patient Case Studies – Personal stories	7
ECPC Infographic and Video Animation	8
Press Release Template	9
Newsletter template	9
Patient Charter/Call to Action	10
Policymaker Outreach Letter	10
Policymaker Pledge Template	11
Social Media Materials	12
Campaign Logos & Design Guidelines	13
Contacts and Disclaimer	14

INTRODUCTION TO PERSONALISED MEDICINE AWARENESS MONTH 2018

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

To download this toolkit please visit ecpc.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](https://twitter.com/cancereu) or Facebook [@ECPCfb](https://www.facebook.com/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](https://twitter.com/cancereu) or Facebook [@ECPCfb](https://www.facebook.com/ECPCfb) or get in touch via email at:

- Alex Filicevas, alex.filicevas@ecpc.org
- Anna Rek, anna.rek@ecpc.org

Check out

[#CrackingTheCancerCode](https://twitter.com/ECPCfb)
[#PMAM18](https://twitter.com/ECPCfb)

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 personalised 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.



Click image to download

**Personalised Medicine Awareness Month
Cracking the Cancer Code**

Goal: Increase awareness within the patient community around molecular testing and the critical role it plays in selecting the right cancer treatment and empowering personalised medicine, and raise a joint call for increased access to such testing.

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

During Personalised Medicine Awareness Month, ECPC and its members will unite to call for:

- Increased access and decreased waiting times for high quality molecular testing to make personalised healthcare more of a reality across Europe;
- More information to educate and empower patients and caregivers around the potential of molecular testing and its availability across Europe;
- A harmonised and more efficient regulatory framework across Europe which could increase access to, and potentially reduce the cost of, molecular testing.

	Patients	HCPs	Policymakers	
What audiences need to know about molecular testing	<p>Cancer biomarkers are molecules that are usually produced by cancer cells, which can be detected in bodily tissues or fluids. They can be patient-specific, rather than tumour-specific, which means they can help to identify people who have cancer or who are at risk of cancer, and help to select or predict those people who are likely to derive therapeutic benefit from specific treatments.</p> <p>Molecular testing – analysis of various cancer biomarkers – is already available for many types of cancer. However, its use in Europe varies by country, because in many countries diagnostic tests are not integrated into clinical practice and are therefore not reimbursed or available to all people with cancer. This needs to change.</p> <p>In clinical terms, molecular testing supports better decision-making by healthcare professionals, who can treat people with cancer using new and existing drugs in a way that does the most good and causes the least harm.</p>	<p>Cancer biomarkers are molecules that are usually produced by cancer cells, which can be detected in bodily fluids or tissues. They can be patient-specific, rather than tumour-specific, which means they can help to identify 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, reducing treatment-related toxicity, and potentially paving the way for a more efficient and personalised system of healthcare.</p> <p>Molecular testing – analysis of various cancer biomarkers – is already available for many types of cancer. However, its use in Europe varies by country. In many countries diagnostic tests are not integrated into clinical practice and are therefore not reimbursed or available to all people with cancer. This needs to change.</p> <p>In clinical terms, molecular testing supports better decision-making by healthcare professionals, who can treat people with cancer using new and existing drugs in a way that does the most good and causes the least harm.</p>	<p>Molecular testing improves the sustainability of healthcare systems by ensuring the right people get the right treatment at the right time. It can help to reduce the risk of people receiving ineffective cancer treatment for their condition.</p> <p>Many payors view molecular testing as a commodity and may not understand the added value from investing in its implementation. However, molecular testing is a key part of personalised treatment planning and its use in addition to existing treatments should be supported and harmonised through a robust regulatory framework.</p>	

an initiative of

PATIENT CASE STUDIES – PERSONAL STORIES

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."

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

Click images to download

Barbara, colorectal cancer survivor

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

I was diagnosed with stage IV colon cancer 11 years ago and given a prognosis of just 3 months. Treatment could only be palliative: conventional chemotherapy treatment gave me a 50/50 chance of surviving. The first treatment didn't work so I was given another, meanwhile the secondary tumour in my liver grew to 15 cm.

When the side effects became too hard to manage and positive benefits were diminishing, I felt that there was not much hope for me. There were no biomarkers available in 2006 and personalised medicine was not being talked about. However, I did not give up. Together with my family, we researched two new treatments being used in Europe and America, and I asked my health team about them.

I was told that they were available but not via the NHS. I would have to apply for them as an exceptional patient. I sat in my jeans, with no hair and suffering the effects of chemotherapy, to a dozen suited representatives from my Primary Care Trust while they made decisions on my life. They told me that I was not seen as an exceptional case, so I decided to pay for treatment. It cost £21,000 as, at that time in the UK, you lost all NHS entitlement if you added a private drug to your present regime. Cancer does not wait for bureaucracy.

The drug worked dramatically and after only 4 months I was in hospital and my ascending colon and entire left liver were removed in one operation. But adjuvant treatment brought the same complications, I was ignored, but I wanted to be an active participant in my treatment. I was told that I was not exceptional and I was denied funding.

My cancer did return in the lymphatic system but I underwent another course of chemotherapy. I have been in remission for 9 years. It cost only £4,000 extra, on top of my existing regime, to pay for the treatment that shrank the tumour, allowed resection and enabled my recovery.

I went to the press. I felt that I had to do something. It just cannot be right that others may not have the chance that I had. My story was used as a case study by Prof. Sir Mike Richards to change the law in England. Thankfully, patients can now be administered a private drug without losing their NHS

an initiative of

Christine S., living with breast cancer (Original in French)

When I was diagnosed with early-stage breast cancer, my gynaecologic oncologist told me about the possibility of a diagnostic test that could provide more information about my tumour.

For several reasons, I followed the advice of my surgeon and chose to undergo surgery and take the test. The aim was to avoid chemotherapy, which initially seemed to be a likely treatment option. When 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 surgeon at length, and he explained all the risks and benefits of chemotherapy. Subsequently, my surgeon also contacted the Orleans hospital team in charge of my radiotherapy. In my case, everyone agreed that the right course of action would be to adapt my treatment to radiotherapy and hormone therapy only. The radiotherapy treatment is tiring, and I had to reduce my working time to 60%. But I am happy to be able to continue working because it helps me feel better.

Like so many women who have experienced this, my life has really changed. I appreciate everything much more than before and I do everything I can to try to get better. I am very happy that I do not have the extra burden of chemotherapy, which I believe would have made my life more difficult. I am a mother of 5 children and so I already have a lot of responsibility resting on my shoulders.

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

Before I was diagnosed with breast cancer, I had never heard of diagnostic tests. It is very important that women know that molecular testing exists and that it allows people to obtain additional information on certain types of tumours. This can help to avoid, in certain cases, unnecessary treatment through chemotherapy or other treatments. In addition to the savings in terms of treatment, I am convinced that this test helps to give women a comfort of life when they need it the most.

**The test was OncoType DX. ECPC does not endorse any particular company or brand of molecular test.*

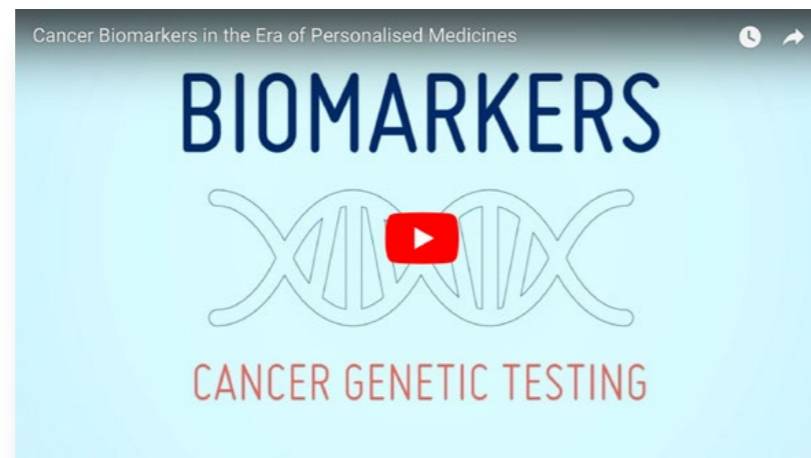
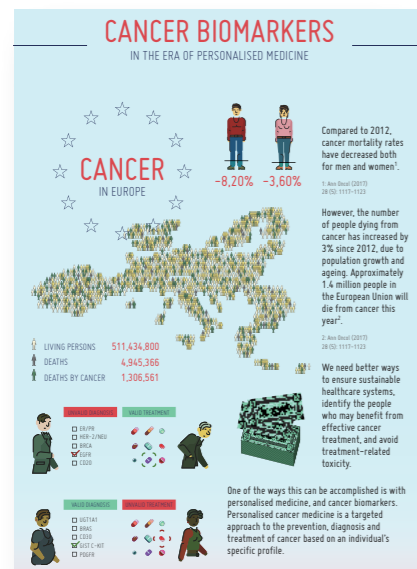
an initiative of

ECPC INFOGRAPHIC AND VIDEO ANIMATION

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.

Click images or scan QR code to download

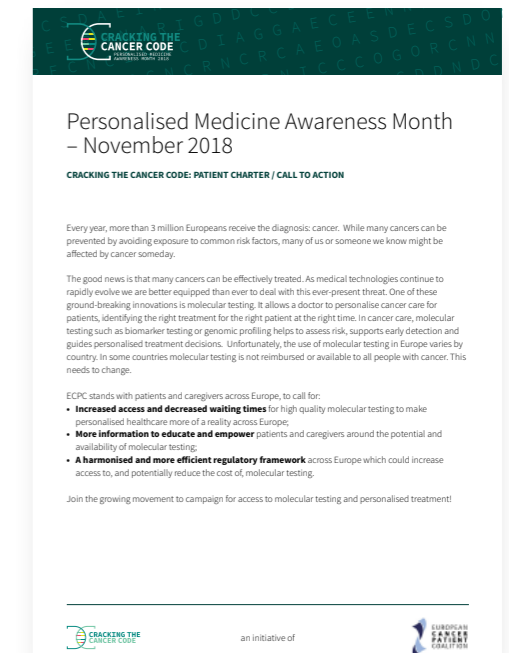


PRESS RELEASE TEMPLATE

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.

Click image to download



an initiative of

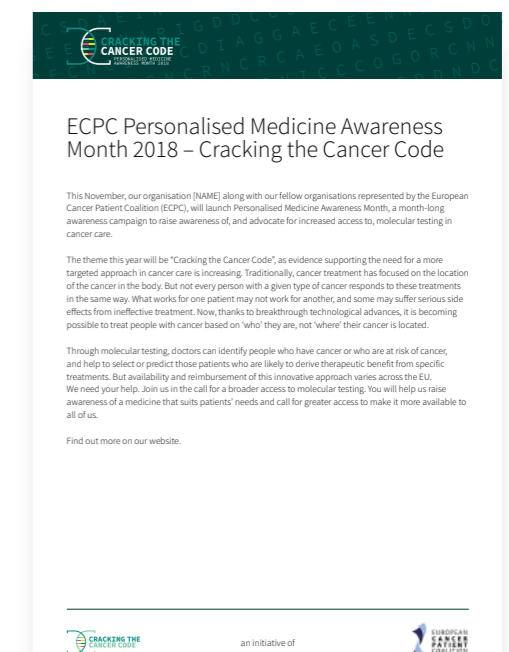


NEWSLETTER TEMPLATE

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.

Click image to download



an initiative of



PATIENT CHARTER/CALL TO ACTION

How to use Patient Charter/Call to Action

The ECPC Personalised Medicine Awareness Month presents an opportunity to raise awareness and garner commitment for the cause across Europe and individual member states. The template Patient Charter/Call to Action 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.

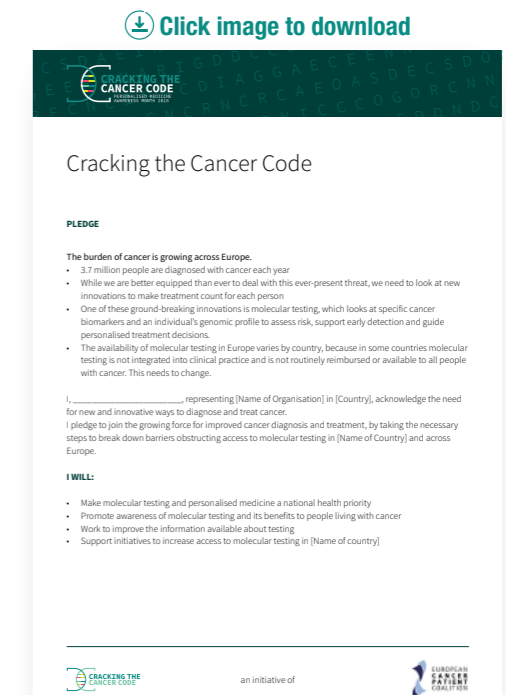


POLICYMAKER PLEDGE TEMPLATE

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 access to 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.

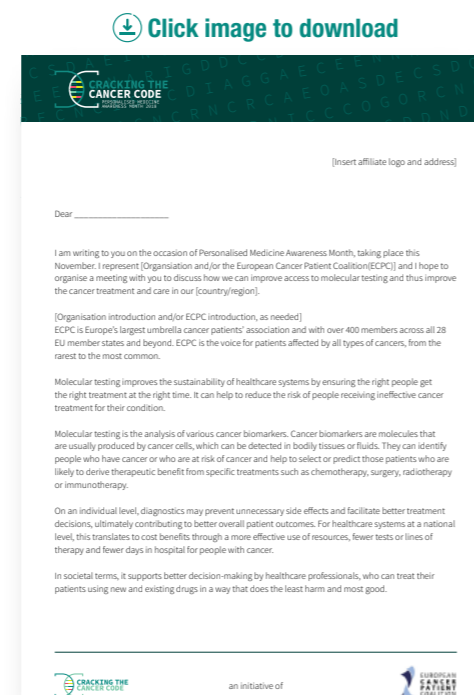


POLICYMAKER OUTREACH LETTER

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 access to molecular testing and personalised medicine.

This template outreach letter can be used to contact policymakers to ask for a meeting and is available in several languages.



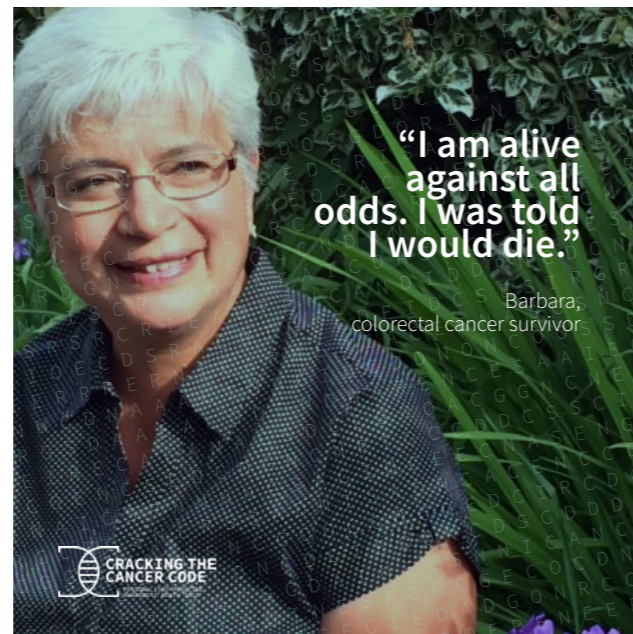
SOCIAL MEDIA MATERIALS

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!

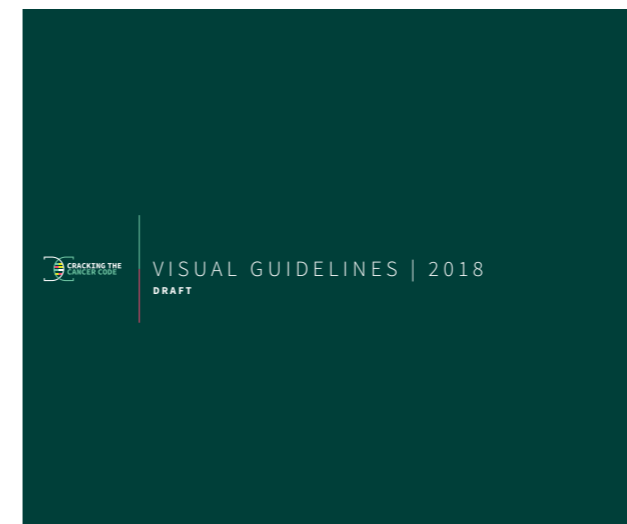
Please remember to tag ECPC @cancereu and use relevant hashtags so we can track levels of conversation: #CrackingTheCancerCode and #PMAM18

[Click image to download](#)



CAMPAIGN LOGOS & DESIGN GUIDELINES

[Click images to download](#)



[Click image to download](#)

CONTACTS AND DISCLAIMER

For press enquiries:

Anna Rek
Senior Communications & Partnerships Manager

+32 (0) 2 342 01 04
anna.rek@ecpc.org

For all PMAM enquiries:

Alex Filicevas
Head of EU Affairs
European Cancer Patient Coalition

+32 (0) 2 342 01 04
alex.filicevas@ecpc.org

Lydia Makaroff
Director
European Cancer Patient Coalition

+32 (0) 2 342 01 04
lydia.makarof@ecpc.org

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.





AN INITIATIVE OF THE EUROPEAN CANCER PATIENT COALITION

ecpc.org/personalisedmedicine2018

 |  **Cracking the Cancer Code**