

WHITE PAPER

Awareness of Genomic Testing in Breast Cancer

A Call to Action
Across Europe



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What is Cancer Patients Europe (CPE)?

CPE is a pan-European cancer patient organisation whose vision is to reduce the burden of cancer on patients and survivors, their carers, the healthcare systems, and society as a whole. More specifically, CPE is missioned to represent and empower cancer patients and survivors in their communications with policymakers and other stakeholders.

Overview

What is the prevalence of breast cancer today?

Breast cancer is the most common cancer among adults with more than 2.3 million cases occurring worldwide each year.¹ In the EU, it is estimated that one in seven women is at risk of developing breast cancer during her lifetime.² Thankfully, the five-year survival rate for breast cancer has increased due to major progress in the oncology field, including the growing role of precision medicine.^{2,3} Furthermore, initiatives which focus on early detection, fast diagnosis, rapid treatment decisions and ongoing patient management are key to this upward spiral to improve breast cancer outcomes and save lives.¹

What is precision and personalised medicine?

According to the US National Institute of Cancer, **precision medicine** is a form of medicine that uses information about a person's own genes or proteins to prevent, diagnose, or treat disease.⁴ In cancer, precision medicine tools such as genomic testing provide specific information about a person's tumour that can help doctors better tailor diagnostics and therapeutics to each patient.

When doctors initiate treatment plans that consider a patient's individual cancer and personal lifestyle choices, this is called **personalised medicine**. In literature, the terms precision medicine and personalized medicine are often used incorrectly. Simply speaking, it could be said that precision medicine is 'what happens to the patient' and personalized medicine is 'what matters to the patient'.

When brought together, precision medicine and personalised medicine can foster shared-decision making that can positively impact patient outcomes.

Genomic testing as a part of precision and personalised medicine

Genomics marks a new age in precision medicine and personalised breast cancer treatment, yet it is often confused with genetics.

Genetics is the study of inherited traits and genes that may predispose a person to a particular health condition whereas genomics is the study of complex sets of genes and how they interact and function in the body. When applied to tumour tissue from cancer patients, **genomic tests can assess how likely the cancer is to return (prognostic)** and some tests can **predict whether a tumour is likely to respond to treatment (predictive)**.

In early-stage hormone-receptor positive breast cancer, a genomic test can provide invaluable insights unique to a patient's individual tumour biology. With this knowledge, the physician and the patient can choose a more tailor-made treatment path that can decrease the risk of over or undertreatment. For many patients this means the possibility of avoiding chemotherapy and the associated side effects.



Cancer Patients Europe (CPE) in the fight against breast cancer

Unfortunately, there is a lack of awareness of precision medicine tools such as genomic testing especially among patients. This makes it difficult for patients to be a part of the decision-making process in their disease management. Cancer Patients Europe (CPE), a pan-European cancer association, has chosen to focus its attention on genomic testing through the my Cancer my Concern (myC) initiative.

With the continued growth of breast cancer cases, it was decided that the first project under the myC banner would be in this area.

The myC Genomics and Breast Cancer European Patient Survey

myC (my Cancer my Concern) is a CPE initiative that aims to raise awareness of the value and benefits of genomic testing in cancer, educate patients and stakeholders, and improve accessibility to genomic testing across Europe. A survey focusing on breast cancer was carried out in 2022 as the first step of the myC initiative to better understand the level of patient knowledge about genomic testing, specifically in terms of awareness, available information, and delivery of the test. The results of this survey, presented below, have been extremely enlightening and brought attention to the need for more information for patients, and action by healthcare professionals and policymakers.

The myC Advisory Committee

The myC Advisory Committee was established to design and disseminate the results of the myC Genomics and Breast Cancer patient survey. Below is a list of members and their respective countries or international association:

Oncologists

Dr. Fatima CARDOSO
(Portugal)

Prof. Francesco COGNETTI
(Italy)

Prof. Dr. med. Michael Patrick LUX
(Germany)

Dr. Ana SANTABALLA
(Spain)

Prof. Richard SIMCOCK
(UK)

Dr. Johanna WASSERMANN
(France)

Patient Associations / Societies

Ms. Dany BELL
Macmillan Cancer Support (UK)

Ms. Conchi BIURRUN
FECMA (Spain)

Dr. Alba DI LEONE
Susan Komen (Italy)

Ms. Rosanna D'ANTONA
Europa Donna (Italy)

Dr. Csaba DEGI
International Psycho-Oncology
Society (IPOS)

Ms. Laure GUÉROULT-ACCOLAS
Patients en Réseau (France)

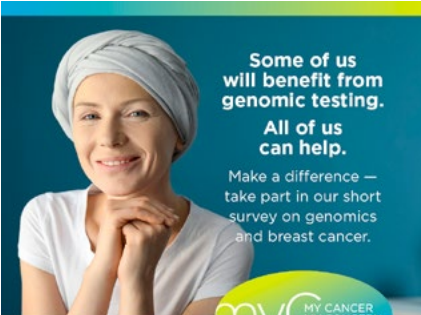
Dr. Isabel RUBIO
European Society of Breast Cancer
Specialists (EUSOMA)

Method

How was the survey developed and distributed?

The 42-question digital survey was developed by CPE with input from the myC Advisory Committee members.

The survey was distributed by CPE, cancer patient associations, and individual advocates across five countries (France, Germany, Italy, Spain, UK), in English and in the local language, during a six-week period in September and October 2022.



Some of us will benefit from genomic testing.
All of us can help.

Make a difference — take part in our short survey on genomics and breast cancer.



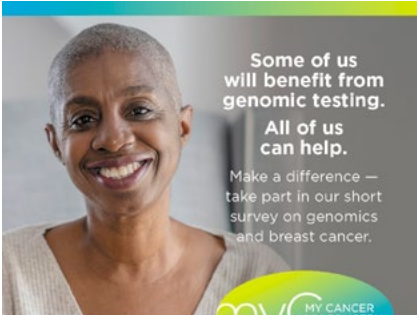
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Who were the targeted survey participants?

The survey was structured to accommodate feedback from the general population, cancer patients, breast cancer patients and breast cancer patients eligible for genomic testing.

All respondents answered general questions concerning their awareness and understanding of genomic testing.

The respondents who were eligible for genomic testing were asked specific questions regarding information received about genomic tests at the time of diagnosis and whether or not they actually took a test.

Eligible respondents were those whose tumours were hormone receptor/ estrogen receptor-positive (HR+/ER+) and human epidermal growth factor receptor 2-negative (HER2-). In other words, they had been diagnosed with early breast cancer which was sensitive to hormone treatment'.

Results

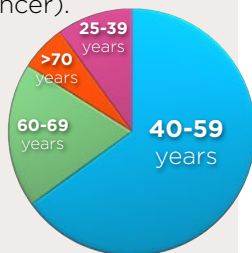
Over the six-week period, **1,383** respondents from five countries completed the survey with the following country breakdown:

France	633
Germany	249
Italy	146
Spain	146
UK	209



83% of the respondents were breast cancer patients, **50%** of whom were eligible for genomic testing (HR+/ER+ and HER2-type breast cancer).

65% of respondents were in the 40-59 age group.



Key findings

The data demonstrated an acute lack of awareness and understanding of genomic testing amongst both the general population and cancer patients as well as a lack of communication on the topic by healthcare professionals.

63% of respondents reported that they had never heard about genomic testing in cancer. Given that genomic testing is an important example of precision medicine, they were also asked if they had heard of the concept.

59% stated that they had never heard of personalised or precision medicine.

Patients eligible for genomic testing

The lack of awareness and communication was particularly evident in the findings concerning breast cancer patients who were eligible for genomic testing.

4 out of 5 (78%) breast cancer patients eligible for genomic testing were not told it was available to them.

In addition, **84%** said they did not have enough information to make a decision, and **75%** of breast cancer patients who could have taken a test did not do so.

When specifically asked why they did not take a test, **32%** stated that they did not have enough information about it. Interestingly, **49%** answered “Other” to this question. Upon analysis of these answers, the majority of them were found not to have received any information at all.

A further **16%** stated that their healthcare professional did not think it was necessary for them to take the test.

Country variations

The key findings were fairly consistent from country to country. Below are the specific results per country regarding the breast cancer patients eligible for genomic testing.

	Patients who were not told that genomic testing was available to them	Patients who did not have enough information to make a decision to take a test	Patients who did not take a test
France	82%	88%	81%
Germany	73%	81%	65%
Italy	61%	68%	58%
Spain	83%	93%	76%
UK	78%	78%	77%
Average	78%	84%	75%

Call to Action

The results of this in-depth survey strongly highlight the need to raise awareness and understanding about the value and benefits of genomic testing in breast cancer among different stakeholder groups. Based on this compelling data, CPE is leading an urgent call to action to ensure that breast cancer patients across Europe benefit from genomic testing and the latest progress in precision and personalised medicine. This will improve the management of patients and breast cancer outcomes, ultimately reducing the burden of breast cancer on both patients and healthcare systems.

For policymakers

In this environment, it is important that policymakers add genomic testing to their agenda of healthcare concerns that need to be addressed. They have a key role in formulating policies to ensure access to genomic testing especially through reimbursement and insurance coverage. Furthermore, increased investment in education and awareness campaigns to reach physicians and patients at the local level could greatly impact the situation.

For healthcare professionals

Healthcare professionals are also key to improving the gap in genomic testing for breast cancer patients by keeping themselves abreast of the availability of genomic tests locally and any current and future progress in the field. Likewise, they should be encouraged to better communicate with their patients about genomic tests and provide information in their clinical practice. This will ensure that each individual has a clear understanding of the option of a genomic test when appropriate. At the same time, improved communication will favour shared decision-making which is vital to achieving the best breast cancer outcomes.

For patient associations

Cancer patient associations should be a portal for patient information about genomic testing in breast cancer. The better informed patients become about the role genomic testing can play in their outcomes, the more prepared they will be to discuss it with their healthcare professionals and become advocates for themselves, friends, carers, and other patients. Furthermore, patient associations can play an important role in representing patients at a higher level to help gain access to tests.

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This White Paper and the Call to Action are endorsed by



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