

WOMEN AND CANCER: MORE THAN 12 MILLION REASONS FOR ACTION!



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EXECUTIVE SUMMARY OF RECOMMENDATIONS

To better address the challenges associated with the topic of women and cancer, the authors call for:

1. Prevention and screening

- An end to irresponsible and harmful gendered marketing by the tobacco and alcohol industries.
- Expand free HPV vaccination to all individuals up to age 25 through national health insurance systems, regardless of gender.
- Access to breast and gynaecological cancer screening, conducted according to EU guidelines, to be recognised as an undisputed women's right.
- Any guideline produced at an EU level such as the European Commission Initiatives on Breast Cancer and Cervical Cancer should be subject to EU supported implementation activity and review.

2. Women experiencing cancer

- In light of the now well-developed understanding of genetic risk, breast cancer services in every country should offer access to genetic testing and counselling for all women diagnosed with breast cancer.
- Genomic tumour testing should be used to guide the use of systemic therapy in women according to the latest clinical evidence.
- Harmonised European standards in care should be adopted, across a breadth of treatment and care areas.
- The specific needs and challenges faced by women living with advanced/metastatic cancers must be better addressed, through access to comprehensive management.
- All women diagnosed with cancer should be counselled on fertility preservation, most particularly when undergoing therapy that may lead to premature ovarian failure.

3. Women caregivers

- State pension schemes and social security arrangements in all countries must better reflect the invaluable role of informal care provided to cancer and other patients.
- A continuous progression of employees' social rights to flexible working arrangements should also be progressed, especially in cases where an individual has significant care responsibilities.

4. Women in the workforce

- National health ministries, professional societies and universities should establish targets and strategies to achieve gender equality within health systems, including in respect to leadership positions.
- Pregnancy and maternity discrimination within health systems should be combatted through well-formed and communicated flexible working arrangements.
- The power of data to bring attention to, and open new insight on, unmet needs related to women and cancer, should be unleashed. This could include the establishment of national and European population-specific registries, such as but not limited to Metastatic Breast Cancer and cancer vaccination and screening registries.
- Accentuate the need for equal representation and access of women from associated minorities (i.e. young women and older women) in clinical trials, to ensure optimal cancer treatment.

INTRODUCTION

Foreword from Dr Isabel Rubio

This publication is the reflection of the unique challenges that women face when dealing with cancer, whether with a diagnosis, as a caregiver or when working in cancer. Ensuring equitable access to cancer diagnosis and treatment – regardless of socio-economic status, race, age or country of residence is a must. It is crucial to support women throughout the cancer pathway.

This paper is also a reflection on other aspects that impact women in the workforce, such as the need to promote gender equality, and to develop policies to foster an inclusive culture in the workplace.

In the end, the paper is a recognition of the challenges but also an advocate for a voice in policy-making to ensure that women's specific needs and concerns are addressed in all the areas related to cancer.

Foreword from Prof. Paola Erba

Analyses reveal persistent health differences between men and women across the leading causes of disease burden, with limited progress in bridging these health gaps over the past 30 years. Such differences emerge during adolescence and continue to develop with age, leaving women with higher levels of illness and disability throughout their lives as they tend to live longer than males. Early interventions are, therefore, crucial. However, their success depends on the proper understanding of the biological and social peculiarities that fluctuate and, sometimes, accumulate over time, resulting in a unique experience of health and diseases at each stage of life and across different regions and member states.



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Prof. Paola Erba
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12 million reasons for action: the cancer burden for European women

Every year, more than 1.2 million women are diagnosed with cancer in the European Union, with nearly 600,000 losing their lives. As of right now, 12 million women in Europe are living with cancer (1). 12 million reasons for policy action!

Cancer presents numerous multifaceted challenges, extending beyond the realms of healthcare. Women interact with the disease in many different manners, as citizens taking part in screening activities, and as patients, encountering unique and gender-related physical, emotional, and economic obstacles, impacting their quality of life.

Women globally experience disparities in access to cancer screening, diagnosis, and treatment due to socio-economic, geographic, and systemic factors. Above all, the psychological impact of a cancer diagnosis and treatment is significant, as women may face additional stress related to family care responsibilities, societal expectations, and stigmatisation (2).

Another set of issues to consider are economic disparities. On average in the EU, women's gross hourly earnings are on average 12,7% below those of men (3). Women consequently tend to earn less than men and are more likely to be financially dependent on others, which may limit their access to health care. In those countries without universal healthcare, such a financial burden will make them forgo screening and treatments. As a consequence, cancer is the leading cause of premature death and disability worldwide, and most particularly in women.

In addition, women healthcare professionals, researchers, caregivers, and women in leadership and advocacy positions experience their own sets of challenges and systemic struggles, which are also under-recognised and under-addressed. Gender-related disparities in wages and positions, as well as limited access to resources and opportunities may impede the realisation of women's potential in addressing the cancer burden.

Despite the urgency to act, such issues tend to be forgotten, understated and even overlooked at the European level. Acknowledging this situation implies implementing immediate actions, raising awareness, and educating both men and women.

Driven by the creation of its <u>Inequalities Network</u> in 2020, the European Cancer Organisation has dedicated part of its Research and Policy work to the fight against all forms of inequity in cancer and cancer care (4). Guided by its European Cancer Pulse, a digital tool enabling to track inequalities and following the success of the Men & Cancer work, ECO launched the Women & Cancer Workstream in April **2024** (5–7) The latter looks to address the unique inequities faced by women who experience a cancer diagnosis, women working in the cancer sector, and women who provide care to persons with cancer. The European Cancer Organisation, its members and community want to play a key role in advocating for systemic changes, in the wake of the new European legislative cycle for 2024-2029. It is time to accelerate for women and cancer!

WOMEN & CANCER PAPER STRUCTURE

I - The importance of prevention, screening & early detection policies

II - Women experiencing cancer

III - Women caregivers

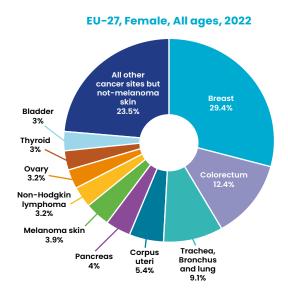
IV- Women in the workforce

Mapping the data: women & cancer

Data from the European Cancer Information System (ECIS) from 2022 shows that the three cancers with the highest incidence among women are breast, colorectal and lung, followed by endometrial, melanoma skin, pancreatic and thyroid cancers. Breast, lung and colorectal cancers are the deadliest for women, based on data from 2021.

Cancer type	Incidence in women (ASR/100,000)	Incidence in men (ASR/100,000)
Breast cancer	147.6	2.0
Colorectal cancer	58.2	92.7
Cancer of trachea, bron- chus and lung	44.1	94.5
Cancer of corpus uteri	26.6	NA
Melanoma skin cancer	19.5	24.1
Pancreatic cancer	18.1	23.4
Thyroid cancer	16.4	5.3

Figure 1. Cancer incidence in Europe by gender and age-standardise rate (ASR), EU-27, ECIS, 2022 (1)



Graph 1: Incidence of Cancers, Females, 2022, EU-27 (ECIS) (1)

Cancer type	Mortal- ity in women (ASR/100,000)	Mortality in men (ASR/100,000)
Breast cancer	30.55	0.47
Cancer of trachea, bronchus and lung	29.46	69.9
Colorectal cancer	20.45	35.97
Pancreatic cancer	15.14	20.18
Ovarian cancer	9.34	NA
Cancer of the uterus (other than cervix uteri)	6.34	NA

Figure 2. Cancer mortality in Europe by gender and age-standardised rate (ASR), 2021 (8)

Since Europe's Beating Cancer Plan, much progress has been made in the primary, secondary and tertiary prevention of breast, colorectal, and cervical cancers. However, their incidence and mortality data highlight the need to organise initiatives focusing on lung cancer, other gynaecological cancers and thyroid cancer. For instance, while thyroid cancer is the 7th most common cancer in women, it does not even figure in the 10 most common cancers in men (1).45

An inclusive definition of gender and an intersectional approach

This paper does not restrict its scope of analysis to people assigned a female sex at birth, also including people who define themselves as women, although they may have been assigned a different sex at birth. Trans women (9) may face additional hurdles in their cancer journey, which need to be acknowledged, discussed, and addressed at policy level. For further information, see ECO's Action Report 'Cancer Care for the LGBTIQ Community: Addressing Inequalities (10).

Consequently, it is of prime importance to clearly differentiate 'sex' and 'gender': whereas, according to the WHO, sex refers to 'the different biological and physiological characteristics of males and females, such as reproductive organs, chromosomes, hormones'(11) gender is a complex and intricate term, referring to the socially constructed characteristics of women and men, such as norms, roles and relationships, varying from society to society and which all must be taken into consideration in one's healthcare journey.

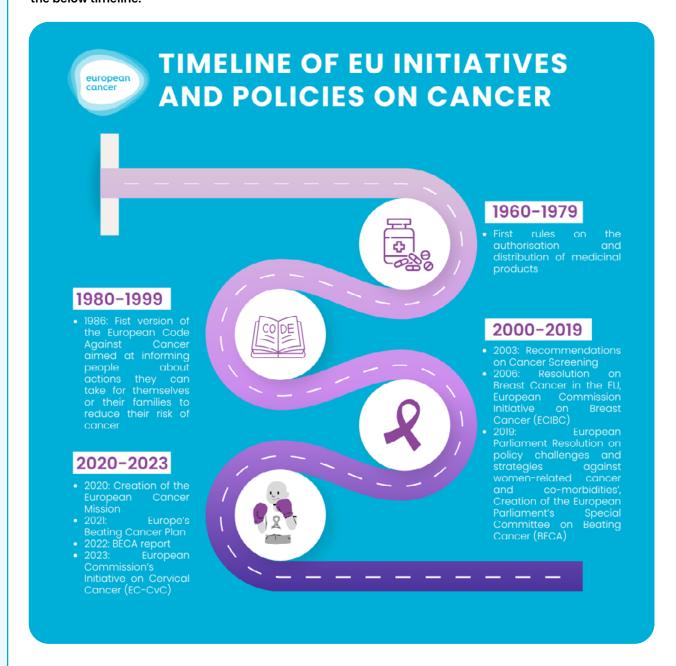
With this inclusive definition in mind, this paper aims to embrace a feminist intersectional approach, for each range of topics that it addresses. Intersectionality is a lens for seeing how different forms of inequalities

exist together and how they can have a cumulative impact (12). Based on this understanding, an individual has multiple social identities: for instance, a Roma woman has her gender identity and ethnic identity. These social positions relate to each other and can exacerbate the discrimination that the person faces, such as women living in extreme poverty face specific healthcare challenges due to their gender and economic position.

This paper acknowledges the full complexity and depth of the challenges that women living with or working in cancer face, considering their complex social statuses. Elements that will be considered include a woman's socio-economic situation, ethnicity, sexual identity, religion, disability (13) status and age. An intersectional approach should inherently be transformational: it takes a critical look at the existing power structures and proposes ways to change these structures (12). Thereby, this paper underlines the need to tailor policies and support schemes for women who face additional setbacks, whether in their cancer journey or in their health-related career, yet also to refresh and extend previous policy commitments.

Overview of cancer-related policies and initiatives at the European level

Over the past decades, the European Union has extended its competences in different fields, and notably in the field of healthcare. It for instance introduced rules on the authorisation and distribution of medicinal products in the 1960s, revamping its framework in 2004 and 2023 to reflect the evolution of competences. In parallel, the EU has gradually taken a range of **political actions to address cancer-related issues, which are captured in the below timeline:**



Finally, it is of note that the European Union has also taken strides in addressing gender equality in the past 15 years, firstly with the 2011–2020 European Pact for Gender Equality (14) and more recently with the von der Leyen's Commission's **EU Gender Equality** Strategy 2020-2025. It is also of note that the European Union has taken strides in addressing gender equality in the past 15 years, firstly with the 2011–2020 European Pact for Gender Equality (14) and more recently with the von der Leyen's Commission's EU Gender Equality Strategy 2020–2025. The latter notably led to the creation of the European Care Strategy (2022), the Proposal for a Pa Transparency Directive.

The European Cancer Organisation salutes the creation of this Strategy and **recommends its renewal** in 2025, as such a policy programme can help alleviate some of the issues addressed in the paper. On 8 March 2025, the European Commission is set to announce its **new Roadmap for Women's Rights**. It appears of utmost importance that this crucial and timely commitment should take health into consideration, including cancer, which affects all women, at all ages and for all social groups. This may for example take the shape of a long-awaited EU Strategy for Women's Health, and for increased funding on the topic.



Purpose of the paper

This paper was greatly influenced by the essential work carried by the Lancet's <u>Women</u>, <u>Power and Cancer Commission</u> (15) and its 2023 publication, which sheds a global picture of the effects of cancer on women.

Despite commendable efforts and steps in the right direction, one can still observe that significant gaps and challenges persist for ALL women undergoing cancer, having survived cancer, taking care of someone with cancer, treating someone with cancer, advocating for cancer and researching cancer. This Paper aims to explore and discuss the latter, striving to identify areas for improvement towards achieving gender-sensitive cancer care across the 27 European member states, paving the way for a stronger health-resilient Europe, and acting as an example to the rest of the world.

This Paper issues a set of policy recommendations, which the authors aim to promote at a high institutional level, including:

- To the new College of EU Commissioners, including the new Commissioner for Health and the new Commissioner for Equality
- To the European Parliament's Health Sub-Committee (SANT)
- To the European Parliament's Committee on Women's Rights and Gender Equality (FEMM), which the European Cancer Organisation believes should be consulted as a matter of procedure on health-related files
- To national governments, including health ministers and the Permanent Representations' health attaches of all 27 EU member states; as well as associate countries

PART ONE: THE IMPORTANCE OF PREVENTION, **SCREENING AND EARLY DETECTION POLICIES TARGETING WOMEN**

This section covers all issues which may prevent a woman from being properly informed on cancer risks, as well as from being diagnosed in a timely manner. Indeed, a woman's socio-economic background, ethnical background and country of residence may affect her cancer risk, yet also her access to appropriate diagnosis and care, affecting her survival chances.

I.1 Recognising and responding to womenrelated dimensions of cancer prevention policies

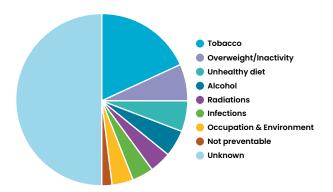


Nela Hasic Think Pink

'In the Balkans, we have to invest in cancer prevention and early detection that can save countless women's lives, and most particularly in underserved communities, where women often face barriers to healthcare access, exacerbating the impact of risk factors such as tobacco, alcohol, and obesity. By addressing these disparities, we can improve health outcomes and societies as a whole.'

The importance of prevention policies to reduce the cancer death toll in women

Of the 2:3 million women who die prematurely from cancer each year in the world, 1.5 million of these premature deaths could be averted through primary prevention or early detection strategies, while a further 800.000 deaths could be averted if all women everywhere could access optimal cancer care (15). In 2020, 1.3 million women from all age groups died worldwide due to three of the major risk factors for cancer - tobacco, alcohol, and infections (15)'. This dramatic figure calls for immediate attention and action, not only on these three major risks but also on all others which must be communicated about and addressed (See Graph below).



Graph 2: Attributable factors of known causes of cancer International Agency for Research on Cancer (16)

Cancer is the leading cause of mortality in women, with breast, colorectal, lung and cervical cancers being the most diagnosed among women worldwide. Nevertheless, many of these deaths could have been averted through primary prevention or early detection strategies, but also if more research in these under-recognised issues had been conducted. For instance, there is a strong misperception that lung and colorectal cancers are more frequent in men. however rates are similar and on the rise form women (see data box). Prevention remains the most cost-effective option that a national system can stimulate and invest in. Improved cancer prevention involves modifying these unhealthy behaviours, as well as and taking part in cancer screening and vaccination programmes (17). However, some inequalities in access to health promotion and protection are increasingly challenging for certain societal groups, including immigrants, refugees and asylum seekers, women with (intellectual) disabilities, and can have a disproportionate negative impact (17). This may be caused by a low level of education - sometimes due to language barriers - as well as a lack of socio-cultural inclusion.

Risk n.1 - Tobacco

In addition to having less time to participate in prevention policies, women are exposed to many cancer-inducing products, including in the tobacco industry.

Specific gendered marketing strategies apply to tobacco-products, despite the fact that lung cancer is the second most diagnosed cancer among women, also increasingly exposed to second-hand smoke (18). These targeted marketing techniques may particularly be seen in the advertising of new products containing tobacco (19), such as e-cigarettes and vapes. Tobacco industries rely on sleek designs and a traditionally feminine colour scheme of products to attract a new customer base also sponsoring events (20) in an attempt to associate smoking with an upscale lifestyle, consequently targeting the upper middle class of society.







Figure 3: Images of tobacco marketing publicities targeting women

To tackle such issues, it is recommended to:

- Promote gender-responsive and gender sensitive policies to reduce tobacco consumption;
- Ban flavours in both tobacco and vaping products and prohibit flavour accessories and additives, which can contribute to gendered marketing;
- Strengthen packaging rules by introducing mandatory plain standardised packaging, with graphic health warnings covering 80% of the front and the back of all tobacco products;
- Every World No Tobacco Day to be marked by an annual report from the European Commission on the progress of the EU towards achieving a tobacco free generation, including with data on gender.

Risk n.2 - Alcohol

Although alcohol was classified as a Group 1 carcinogen by the International Agency for Research on Cancer decades ago (21), Europe remains the continent with the highest alcohol consumption in the world (22). As advised by the WHO, there is no safe level of alcohol intake, the latest available data indicate that half of all alcohol-related cancers in the WHO European Region are caused by 'light' and 'moderate' alcohol consumption (21). This applies to all types of alcoholic beverages, including beer, wines and spirits.

Nevertheless, alcohol companies have recently elaborated alcohol marketing strategies (23), **developed** to target the emergent market dedicated to women.

If alcohol and cigarette use were traditionally associated with masculine behaviours (24), new products have been introduced to European markets: 'Mommy wine', 'pink gin', 'light sangria', featuring pink labelling and cursive writing. These harmful commercials and lifting of societal taboos notably contribute to the surge of heavy drinking and binge drinking episodes, in a spirit to 'keep up with the boys'.

The European Cancer Organisation consequently salutes initiatives such as the 'Don't Pink My Drink' Campaign, launched by academics working in the field of substance misuse in 2018 (25), calling out abuse of marketing stereotypes by the industry.





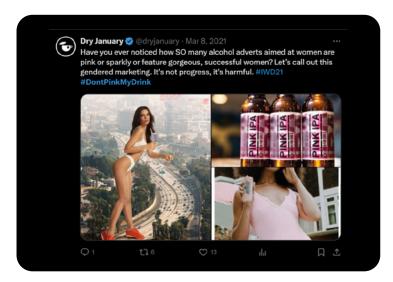




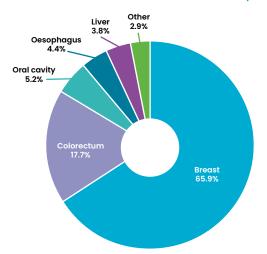
Figure 4: Extracts of the #Don'tPinkMyDrink Campaign, X.



Figure 5: Images of alcohol marketing publicities targeting women

More specifically, alcohol consumption causes 7 out of every 100 new breast cancer cases in Europe (26) (27), and remains the primary risk (28). It also causes an increase in the risk of developing benign breast lumps in teenage girls, which may later lead to heighten risks of breast cancer. In the WHO European region in 2018, 25% of new cases of breast cancer were attributed to drinking a maximum of 2 drinks (20 g pure alcohol) per day, and 46% were attributed to 3 to 6 drinks (60 g pure alcohol) per day. Nevertheless, women and younger women as well as teenage girls tend to be unaware of this link (29), which should be addressed at European policy level as a priority.

Total number of attributable cases: 58,000



Graph 3: New cancer cases attributable to alcohol drinking in Europe, for women (IARC) (16)

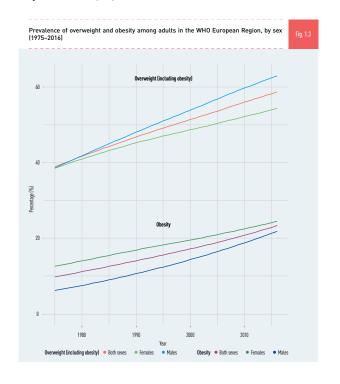
To tackle such issues, it is recommended to:

- Promote gender-responsive and gender-sensitive policies to reduce alcohol consumption, including targeted awareness campaigns in schools, public transports, etc;
- Develop a Code of Conduct on responsible alcohol marketing, in consultation with stakeholders;
- Introduce mandatory health warning labels on alcoholic beverages, to help inform consumers of the association between alcohol intake and cancer risk, most particularly on breast cancer.

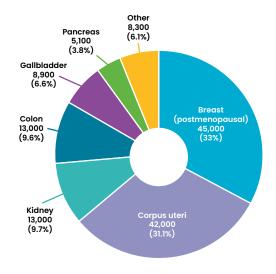
Risk n.3 - Diet & lifestyle

The World Health Organisation points out in an alarming report that in the European Region, 59% of adults and almost 1 in 3 children (29% of boys and 27% of girls) are overweight or living with obesity, a trend on the rise since 1975 (30). Women notably tend to suffer more from obesity – defined by the WHO as a chronic disease- than men. For instance, women in the lowest income group are 90% more likely to be obese than those with the highest incomes, while for men, this likelihood is 50%, thus exacerbating gender-specific social inequalities (31).

Figure 6: The evolution of overweight and obese adults in Europe, WHO European Regional Obesity Report, 2022 (30)



Obesity increases the risk for many non-communicable diseases and is currently considered a cause of at least 13 different types of cancer (32), such as breast, ovary, kidney, liver and colon for women (33). Sedentary lifestyles and weight gain also have an impact on cancer incidence, and not just obesity (34).



Graph 4: Cancer cases attributable to excess body mass index in Europe, for women (IARC) (16)

The **European Code Against Cancer**, referenced in the introduction of this Paper, recommends having a healthy diet to prevent cancer (35), and the International Agency for Research on Cancer also points out that a third of breast cancer cases in Europe can be prevented by maintaining it (36). Research from the World Cancer Research Fund International notably highlights the strong evidence that being physically active decreases the risk of breast cancer (37), also extending to all forms of cancer. It notably recommends keeping a healthy weight, limiting fast foods, cutting down on sugary drinks and limiting alcohol consumption (38). Alcohol indeed represents a source of 'empty calories, which may also increase the risk of obesity, which itself may disrupt the production of hormones and estrogen. Additionally, certain food types such as red meats of processed foods have been linked to increased risks of certain types of sugar, such as colon cancer (39). Due to their caregiving and family responsibilities, further explored in the paper, and often unbalanced when compared to men -, women may sometimes have less time to exercise or cook healthy meals, which requires time. Healthy and balanced food also represent a certain budget, and women are more likely to be exposed to poverty than men.

- Introduce mandatory front-of-pack nutrition labelling for food products, using an intuitive colour-coded scheme;
- Incorporate women's health education from a younger age and the key role of cancer prevention into school health programmes to educate girls about the importance of healthy habits and healthy foods.

Risk n.4 - Infections

Human papillomavirus (HPV)



Prof. Margaret Stanley

International Papillomavirus Society, University of Cambridge

'HPV-related cancers affect women the hardest, yet widespread vaccination, early detection and the use of new techniques such as self-sampling can help change that. Every woman deserves the chance to live free from these preventable diseases, and it is a collective responsibility to implement best practices.'

Human papillomavirus is one of the most widespread sexually transmitted infections worldwide, commonly acquired after the onset of sexual activity, both in girls and boys. Women who have been diagnosed with cervical or vulvar cancer are **at increased risk of developing additional HPV-related cancers** (40), yet there often are missed opportunities for early detection, which could however improve patient outcomes (41). Current healthcare systems are falling short in preventing second cancers, in spite of the existence of effective tools for cancer prevention and early detection (42).

1. Vaccination

Vaccination is key to the prevention of a range of cancers caused by HPV, the vaccination of young girls against HPV types 16 and 18 being notably known to have reduced the incidence of infections, cervical pre-cancer and cancer (43). It is expected that, in time, it will also impact significantly on the incidence of cancers caused by HPV in other sites, including the vulva, vagina, anus, penis, head and neck. Europe's Beating Cancer Plan recommends eliminating cervical cancer and other cancers caused by human papillomavirus by vaccinating at least 90% of EU target population of girls, and to significantly increase the vaccination of boys by 2030 (44). The European Cancer Organisation stresses the importance of increasing vaccination rates for all genders and recommends the adoption of a gender-neutral uptake target of 90% across member states. Gender-neutral vaccination protects everyone against all cancers and actively contributes towards achieving herd immunity, including in countries with lower female uptake (45).

Vaccination rates in Europe currently vary widely.

Data for the European region shows that only two countries achieved a 90% uptake of girls receiving all their vaccine doses, with at least two currently vaccinating fewer than 10% of girls (46). There are also in-country variations linked to socio-economic status, ethnicity and religious beliefs. For instance, a study shows Dutch girls with parents born in Morocco are only half as likely to have received the HPV vaccine as those whose parents were born in the Netherlands (47).

While all countries in the European Union have a vaccination implementation policy, three countries have not implemented gender-neutral vaccinations: Bulgaria, Estonia, Romania (48). Nevertheless, several countries in Europe have made significant steps towards improving their HPV vaccination coverage for all genders, such as the Nordic countries, thanks to their comprehensive national immunisation programs (48).

Additionally, Portugal and Spain have made significant strides in increasing their HPV vaccination rates (49), supported by **strong governmental policies and widespread public awareness efforts**. These countries' success is largely attributed to effective public health strategies, including free or subsidised vaccination programs, strong healthcare infrastructure, and concerted efforts to educate the public. These efforts should be seen as best practices for many member states, but also neighbouring regions, such as for the Eastern Europe & Central Asia (EECA), where policy synergies should be built.

2. Screening

To achieve this ambitious goal, the European Cancer Organisation also stresses the importance to promote use of new tools and techniques such as self-sampling to women and people with a cervix. Self-sampling is a self-care intervention (50), particularly suitable for those who find it hard to access standard screening facilities, because they live in countries with less provision or in remote areas or have a disability, or where there are cultural barriers or previous traumatic experiences.

¹ For more resources on the topic, the authors recommend the Regional Alliance for Cervical Cancer Prevention, lead by the United Nation Population Fund for Eastern Europe and Central Asia: https://eeca.unfpa.org/en/regional-alliance-cervical-cancer-prevention#:~:text=The%20Alliance%20is%20a%20regional, Eastern%20Furope%20and%20Central%20Asia.

Moreover, primary HPV screening can be further improved by **using an HPV test that offers extended genotyping.** Optimising clinical decision making based on extended genotyping results can improve immediate risk stratification and better identify those with high risk for cervical precancer, so that physicians can better manage patients based on their level of risk for disease progression.

To conclude, HPV registries, screening and vaccination, should be an integral part of effective cervical cancer elimination programs and they are vital tools

to support the effective implementation and execution of national elimination efforts. In particular, the registry can be used as a unique identifier and record all vaccination, all screening, and all histopathology and other outcomes. Ideally, the registry should be accompanied by a biorepository – allowing a lookback at a residual sample with a well-characterised outcome. Tracking details of HPV genotypes identified in the population may aid in public health research and further optimisation of both screening and vaccination programs.

To tackle such issues, it is recommended to:

- Expand free HPV vaccination to all individuals up to age 25 through national health insurance systems, regardless of gender;
- Pursue strategies that leverage both HPV vaccination and screening through awareness building, education and access initiatives;
- Actively track and monitor progress towards the achievement of HPV cancers elimination goals, including the implementation of HPV screening and vaccination registries which would support tracking details of HPV genotypes identified in the population;
- Enhance EU level action against misinformation and disinformation about vaccination on social media, as well as multi-stakeholders' educational campaigns;
- Commit Member States to further facilitate access to vaccination and to implement coordinated vaccination catch-up programmes among the population, particularly targeting underserved population (e.g. Roma, inmates, sex workers);
- Include self-sampling kits as a complementary option to cervical cancer screening to address vaccination gaps;
- In the context of primary HPV screening, include HPV tests that offers extended genotyping, to optimise clinical decision making based on the risk level for disease progression.

Hepatitis

Hepatitis B vaccination is crucial for women, due to the significant health risks posed by the Hepatitis B virus (HBV), leading to chronic liver diseases, including cirrhosis and liver cancer. Women who contract HBV are not only at risk of developing these severe complications themselves but can also unknowingly transmit the virus to their sexual partners and, if pregnant, to their newborns during childbirth (51). There is currently limited data on the number of women living with viral hepatitis, as well as on how it impacts women differently to men (52). As advised by the WHO and the ECDC, vaccination is particularly important for women of childbearing age, as it provides a safe and effective way to prevent vertical transmission from mother to child. Additionally, widespread vaccination among women contributes to broader community immunity, helping to protect those who are unvaccinated or at higher risk of infection, such as healthcare

workers, homeless women, women who use drugs, women migrants and women living with HIV. In addition to vaccination, screening and treatment may also prevent the disease from progressing to liver cancer, yet they are not free of charge in every European health system.

Given these benefits, promoting hepatitis B vaccination amongst women is a **critical public health strategy to control the spread of HBV and reduce the burden of liver disease globally.** Several European countries, including Belgium, Greece, Norway, Serbia, and the United Kingdom, advise hepatitis B vaccination for pregnant women who are at high risk of infection or severe disease, **such as individuals with multiple sexual partners, intravenous drug users, and those with chronic liver conditions.** Spain recommends vaccination for pregnant women either at risk of infection or following exposure to the virus. In

countries like Portugal, Estonia, and Italy, the vaccine is indicated for pregnant women if the potential benefits outweigh the risks (53).

Moreover, stigma against women with liver disease can present itself in various ways, most particularly manifesting itself in the most vulnerable groups. Studies have found that among people who inject drugs, women are for instance less likely than men to receive direct-acting antivirals, and access healthcare services. Pregnant women often also fear sharing their

hepatitis status, as the fear of infection has led to nurses and midwives refusing to assist in the labour and delivery of hepatitis-positive women. Additionally, because the Model for End-Stage Liver Disease (MELD) scores are often underestimated in women, they **also have lower chances of receiving a liver transplant**. It is important that equitable and affordable women-specific, community-based, culturally safe services are available to reach different groups of women, yet also that education about hepatitis is made available to prevent disinformation and combat discrimination.

To tackle such issues, it is recommended to:

- Ensure the EU formally commits and invests in achieving the WHO goal for the elimination of mother-to-child transmission (EMTCT) of HBV by 2030;
- Integrate hepatitis vaccination, testing, and treatment into national cancer prevention and control strategies;
- Make hepatitis vaccination, testing and treatment free of charge within national health insurance systems;
- Enhance EU level action against misinformation and disinformation about vaccination on social media, as well as multi-stakeholders' educational campaigns;
- Invest in research and data collection that focuses on the burden of hepatitis in women to better understand gaps in care.

Risk n.5 - UV exposure

Even though sunbeds have been classified as a carcinogen and growing evidence link sunbeds to skin melanoma, or cell carcinoma especially when the first exposure is at a younger age (54), their use is still prevalent in Europe, especially in Northern countries (55) and amongst young people. While people of all genders use sunbeds, women are reported to be two to three times more likely than men to use them (56). Moreover, women start indoor tanning earlier in life, use sunbeds for more sessions and longer periods of time, all of which enhance their negative health impacts

(57). The exposure to ultraviolet (UV) radiation used to elicit the tanning of the skin is a health threat and can increase the risk of developing cutaneous melanoma by up to 27% (55). The main motivation to use sunbeds is the beauty standard of tanned skinned, which is further enhanced by the advertisements from tanning companies (57). Adolescent and young women are especially vulnerable as they have higher rates of use, possibly due to influence from peers and parents who engage in the behaviour, as well as targeted advertising (66).

- Regulate sunbeds as medical devices, gradually phasing out their use for aesthetic purposes;
- Develop European wide public awareness campaigns on UV exposure risk, including placing an emphasis on women and younger women;
- End irresponsible and harmful gendered marketing by the cosmetics industry, which promotes harmful beauty standards.

Risk n.6 - Hereditary risk

5 to 10% of breast cancers are hereditary (58): a woman may inherit faulty genes increasing her risks of developing cancer. For instance, hereditary Breast and Ovarian Cancer syndrome (HBOC) is an autosomal dominant inherited cancer predisposition, characterised by an increased risk of breast and ovarian cancers. It represents about 10% and 25% of all breast and ovarian cancers, respectively. The identification of pathogenic variants in high-risk individuals of developing breast and ovarian cancer is key and

diagnosing a mutation carrier will direct the decision about screening and risk reduction strategies. **Genetic health testing should consequently be performed in national health services, with access to genetic counselling** (58). As best practice, researchers involved in BRIDGES and B-CAST – EU-funded research initiatives – have made huge advances in showing how BRCA 1 and 2, lifestyle and environmental factors influence the risk of breast cancer.

To tackle such issues, it is recommended to:

- Address the so-called 'fear of diagnosis' by, increasing efforts on health literacy and the importance of genetic testing;
- Organise educational cancer prevention campaigns to raise awareness, focusing on high-risk groups such as women with a family history of cancer;
- Promote awareness in researching a woman's family history of cancer;
- Promote risk-assessment and risk-counselling, particularly for breast and ovarian cancer, which
 are the most prevalent for women.

Risk n.7 - Occupational cancers

Occupational cancers in women remain poorly investigated, with the association between work-related carcinogens and women-dominant work environments being complex to adequately measure (59). The immense increase in employed women in the past decades urges the need to bring more attention to the matter, both on a scientific and political level. Women for instance represent the biggest share of employees in healthcare and in the beauty and cosmetic field which have all been associated with the use of carcinogenic chemicals (68). On the one hand, chemotherapy agents, radiation and anaesthetic

waste gases subject healthcare workers to risks of developing cancer. Exposure to cytotoxic drugs may for instance increase the risk of bladder cancer, to which women have a lower survival rate than men (60). Data points out that 11% of all bladder cancers in women are a result of work exposure (69). On the other, products such as bleach and nail care products have been recognised as possible carcinogens, and women hairdressers have witnessed an increase in lung cancer rates (68). This evidence puts forward the need to bring more research and awareness on the topic among policy and decision makers.

To tackle such issues, it is recommended to:

 Acknowledge the impact of occupational cancers among women by encouraging further research on the topic, and developing adapted preventative cancer policies related to the exposure of work-related carcinogens.

I.2 Breaking social barriers: Achieving equal access to cancer screening and early detection for all women

Beyond risk factors, research has shown that women are often more stressed and burdened when it comes to household responsibilities, caring for the family including children and older family members -. In addition to bringing more stress and mental health toll, such activities may prevent the participation of women in national screening programmes - including breast and cervical screening -. This results in a lack of information about the risk factors associated with cancer

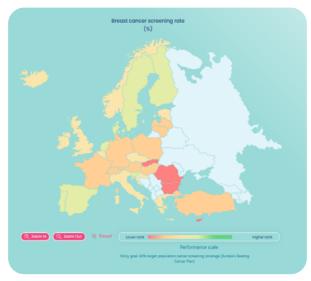


Figure 7. Breast cancer screening rates (European Cancer Pulse, 2024). (61)

The importance of educating all citizens on the use of screening

Breast and cervical cancers (62) are among the most common cancers affecting women. In fact, breast cancer accounts for 25% of all cancer cases in women and cervical cancer for 7.5% of all cancer deaths in women (63). Nevertheless, "only 54% of women in lowand middle-income countries have ever received a mammogram and less than 30% have had a cervical cancer test in the past three years, resulting in a significant burden of late diagnosis and mortality." Among the major barriers limiting access to early testing and diagnosis are cost, lack of awareness and insufficient health infrastructure, yet also a lack of education. Addressing these issues requires coordinated efforts to enhance accessibility, education, and quality of care, ensuring all women have the opportunity for early detection and effective treatment of cancer.

Cancer screening choices and strategies: the impact of a minority and vulnerability status on women's health

'Gender norms imply that women often have to prioritise family needs at the expense of their own health, which sometimes leads to postponing seeking healthcare'. This quote from Professor Nirmala Bhoo-Pathy, from the University of Malaya and Queen's University Belfast may be extended to all women belonging to vulnerable and/or minority groups. In Europe, women indeed face significant disparities in cancer screening and early detection, crucial tools for improving survival rates and outcomes. Despite advancements in medical technology and health care systems, access to innovative services is still not fully available particularly for those in lower socio-economic groups, living in rural areas, and/or belonging to marginalised communities. As of today, only seven countries in the European Union provide the possibility of self-sampling (Denmark, Finland, France, Germany, Netherlands, Portugal, and Sweden), as an additional option to improve cervical cancer screening coverage (48).

A specific example of a vulnerable group is incarcerated women, who have further intersected vulnerabilities, due to a higher prevalence of substance use, risky sexual behaviours, mental health issues and experiences with abuse (64). Therefore, they encounter a higher risk and prevalence of cervical cancer, coupled with lower screening and vaccination rates due to their context-specific barriers (65). The organisation of screening for detained women is often not systematic and does not provide adequate reach. As an example, a study of detained women in Italy showed that none of them have received vaccination against HPV and less than 15% had ever had a screening test in the prison's screening programme (65). Another highly underserved group is sex workers, as they have among the highest rates of cervical cancer and among the lowest uptake of screening. Sex workers - men or women - have specific characteristics that impact how they engage with the healthcare system, such as stigma and discrimination and difficulties in terms of geographical access. To tackle these issues and improve access, the European Union has recently funded a project entitled CBIG-SCREEN, which focuses on how to provide cervical cancer screening to vulnerable and underserved populations across ten European countries (66), shedding a light on policy actions which may be undertaken.

Another example of disparities is seen in the lower screening rates among **LGBTIQ women**, a group facing heightened vulnerabilities due to non-conforming characteristics. Only 10% underwent mammography in the past year compared to 36% of the general population. Similarly, 27% had a cervical smear test, and 12% had a colonoscopy, compared to 36% and 4% of the general population, respectively (67). Concerning the route to diagnosis, people of other ethnic backgrounds (not Black, Asian, nor White) have a lower proportion of diagnosis via screening (68), while Caribbean, African and Asian women are more prone to late-stage diagnosis for breast, ovarian, uterine and colon cancer (69).

Finally, women with intellectual and developmental disabilities may encounter challenges in accessing cancer screening services. Research indicates that individuals with intellectual disabilities demonstrate

lower rates of cancer screening compared to the general population globally (70) (71). Notably, women with severe intellectual disabilities exhibit significantly lower participation rates in breast and cervical cancer screenings in comparison to the general population, while no significant disparity in screening participation rates exists between the general population and individuals with mild intellectual disabilities. This underscores the imperative for a targeted approach to facilitate the support of women with severe intellectual disabilities in accessing screening services. Educating their families and caregivers about the necessity of aiding these women in participate in national screening programmes is of paramount importance in addressing this issue.

- Ensure that access to breast and cervical cancer screening in every European country is a undisputed woman's right;
- Establish mobile clinics to provide cancer screening services in remote and underserved areas, making screenings more accessible to all women - devoting particular attention to Roma women and women from ethnic minorities:
- Provide grants specifically for research on female cancers such as breast, ovarian, and cervical cancers, with a focus on early detection, innovative treatment and age;
- Increase public funding/or ensure access to public health programmes that offer free or lowcost screening and diagnostic services, such as mammograms, cervical cancer screening, and general health check-ups - in cooperation with insurance coverage mandates, especially for young women;
- Implement targeted education initiatives on screening, through accessible information to support marginalised group to engage in cancer screening.

PART TWO: WOMEN EXPERIENCING CANCER

This section addresses many of the issues and unique challenges a woman may face both during and after a cancer diagnosis, encompassing both their medical journey and daily life.

Breast & gynaecological cancers² in spotlight

Breast Cancer

- Breast cancer is the most common cancer in women and a rare cancer for men, accounting for only 0,3% of newly diagnosed cases (72). For women, the incidence of breast cancer in 2022 in the EU was 147.6 new cases per 100 000 people, the mortality was 30.55 per 100 000 people in 2021 (1,8).
- 1 in 11 women in the EU-27 will develop breast cancer before the age of 74(72), with an estimated 23% of cases in the WHO Europe Region occurred in women and men younger than 50 (73).
- Triple-negative breast cancer accounts for 15-20% of cases, with the worst prognosis (74).
- Approximately 5 to 10% of breast cancers are metastatic at diagnosis (75). It is overrepresented among specific ethnic groups such as black women and pre-menopausal women (74).
- There are large differences in breast cancer screening, unavailable in some EU countries (72).

Miriam de Baets

Breast cancer survivor and member of the **HungerNdThirst Foundation**



'When I was diagnosed with breast cancer in 2018, it felt like being thrown into a vortex—questions swirling about life, 'Why me?' and 'How will I deal instead of losing my breasts, the fragmented to my distress. A cancer diagnosis has a huge psychological component which adds a lot offering the care and guidance my husband and I needed. It wasn't just my fight; it was much

Endometrial Cancer

- Endometrial cancer is the most common type of uterine cancer and develops in the innermost lining of the uterus (the endometrium) (76).
- The incidence for endometrial cancer in Europe was 26.6 new cases per 100 000 people in 2022 (1), mortality was 6.34 per 100 000 people in 2021 (8).
- It is the 4th most frequently diagnosed cancer among women in Europe, with the highest incidence in Central Europe and mortality in Eastern Europe (2). Risk factors include age, family history, and obesity.
- There are currently no preventive or early detection endometrial cancer screening.

² This choice of wording is explained by the fact that these cancers affect women with female primary sex characteristics

Ovarian Cancer

Ovarian cancer is the 8th most common cancer for women (1).



- The incidence of ovarian cancer in Europe was 15.7 new cases per 100 000 people in 2022 (1), the mortality was 9.34 per 100 000 people in 2021 (8)
- Ovarian cancer mortality is decreasing in Europe, yet with significant disparities between countries due to late diagnosis and disease recurrence (81). There are many gaps in understanding the development, progression, diagnosis, treatment and care of women with ovarian cancer (2).

Cervical Cancer

- Cervix is the lower third of the womb (uterus) reaching into the upper part of the vagina (2) (76).
- The incidence was 11.7 new cases per 100 000 people in 2022 (1), the mortality was 3.6 per 100 000 people in 2021 (8). Cervical cancer ranks 13th among the most frequently occurring cancer in women. (1) The highest incidence in Central and Eastern Europe (2).
- The major risk factor for cervical cancer is infection with Human Papilloma Virus (HPV) (77). Vaccines and screening are highly effective, yet rates differ widely across countries.

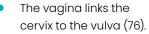
Vulvar Cancer

Vulva is the labia majora, labia minora, clitoris and the opening of the vagina and the urethra (76).



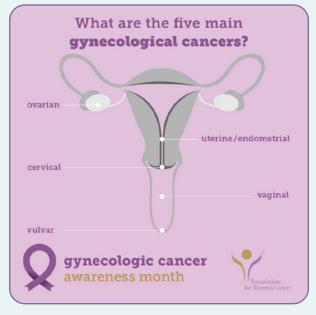
- Vulvar cancer is rare, responsible for around 4% of genital cancers in women (76).
- Women over 65 years old are most at risk, yet there has been an increase in cases among younger women (linked to tobacco consumption and HPV) (76). Risk varies widely in Europe, with higher rates in Eastern and Northern countries compared to West and South (2).

Vaginal Cancer





Vaginal cancer is a rare type of cancer, which makes up less than 1-2% of genital cancers in women (76). Risks factors are HPV infection, smoking and immunosuppression. More typical in older and postmenopausal women, younger women are increasingly affected (2).



Source: <u>UT Health Austin | Gynaecologic Cancer Aware-</u> ness Interview on KXAN

II.1 A diversity of cancers requiring adequate and fit-for-purpose treatment options

Equating the diversity of cancers: the imperative for personalised treatment

With the evolution of research, medicine, technologies and artificial intelligence, the personalisation of treatment has become intrinsic to the therapeutic management of cancers and should be further standardised, being of primary importance for the most common women's cancers, such as breast and lung cancer (78).

For instance, using precision may be highly beneficial, as each cancer patient receives the most appropriate diagnostics and targeted therapies, based on the genetic profile of cancer. Precision medicine requires the selection of suitable biomarkers to predict the efficiency of targeted therapy in specific groups of patients. For example, in breast cancer therapy, several possible mutations identified in breast tumours that may be utilised for therapy design (79).

As in women with early breast cancer, those with advanced or metastatic breast cancer should be treated by a multidisciplinary team, according to

the Advanced Breast Cancer guidelines (80). The treatment approach may involve hormone therapy, anti-HER2 therapy or chemotherapy, depending on the tumour characteristics (58). Novel approaches based on biomarkers are now available and this area continues to evolve.

In cervical cancer, combining targeted therapy, such as immunotherapeutic agents, with conventional agents may mitigate disease progression (81). In endometrial and ovarian cancers, agents targeting specific biomolecules such as hormone receptors, epigenetic regulators and immune-suppressive regulators show great promise. In such cases, nonsurgical treatments are also crucial to make fertility preservation in younger patients possible (82).

For nonreproductive cancers, accounting for sex differences in therapy is essential to minimise harm when sex is a biological variable in the development and progression of cancer, which is not always addressed in early clinical investigation (78). As mentioned above, lung cancer, traditionally identified as a 'men-disease', is influenced by oestrogen levels and genetic variations. Further research on the topic is imperative to enable adapted treatment (83).

- Breast cancer services in every country should offer access to genetic testing and counselling for all women diagnosed with breast cancer;
- Genomic tumour testing should be used to guide the use of systemic cancer therapy in women;
- Incentive structures to bring forward innovation and improvements in treatment for women experiences of cancer could be improved. This relates especially, but not solely, to gynaecological cancers. The range of unmet medical needs associated with female experience of cancers should be more fully addressed within available legal and regulatory structures, such as Regulation 726/2004 and Directive 2001/83/EC, and Regulation (EU) 2021/2282. Guidance and decision-making protocols associated with these regulations should be highly mindful and reflective of the wide range of unmet needs associated with women's experience of cancer, many of which are described in this paper;
- Relevant stakeholders should be involved within consultative mechanisms, such as the EU HTA stakeholder forum and EMA's patient and healthcare professional working groups.

Bridging the gap: ensuring equal cancer treatment for all women

Access to the best suited treatment and care should be a right for all patients (84) (85). However, inequalities in access to cancer treatment and supportive care persist (84). Socio-economic and education levels notably play a central role in the unfair access to cancer care. Inequalities in care are also reported among marginalised communities, with ethnic and sexual minorities reporting poorer outcomes in terms of treatment access (86). "Studies show that ethnic and sexual minorities face a 25% lower likelihood of receiving recommended cancer care and experience a higher rate of treatment delays, highlighting the critical need to address these disparities to improve cancer management (87). These gaps need to be addressed in a systemic manner in the future, to optimally improve management of women-associated cancers.

To tackle such issues, it is recommended to:

Implement comprehensive policies to ensure equitable access to cancer treatment, particularly targeting socioeconomic, educational and systemic barriers affecting marginalised communities and minority groups.

The underrepresentation of women in clinical trials

Ethnic minorities, women, and older people tend to enrol less in cooperative group cancer trials, particularly when compared to white people, men, and younger patients (88). Studying only one sex or one group when developing new treatments risks missing a whole spectrum of information on how a drug works. Considering the progress of precision oncology, as well as the reported sex-based differences in responses to treatment, ensuring equal representation of women in oncology trials is key (89). To date, women are still, for example accounting for 39% of participants in therapeutic lung cancer trials for lung cancer.

This represents an issue, as differences in severity of adverse effects and immune response have been reported between men and women. Women indeed

tend to show higher immune responses during cancer, but also experience greater severity of adverse effects

These factors need to be considered by healthcare professionals, in terms of dose adjustment, toxicity and impact on the quality of life of the patient. Another issue to be addressed is the lack of minority representation in clinical trials for breast or gynaecological cancers, given the need to consider biological differences between ethnic groups, as well as different medical needs among the LGBTIQ community (90). A woman's age is also an important factor in research, as there are for instance biological differences in young women, but also in pre- and postmenopausal women. Although breast cancer in commonly diagnosed in older women, they currently tend to be underrepresented in clinical trials, and evidence on the best treatment are insufficient.

To tackle such issues, it is recommended to:

Accentuate the need for equal representation and access of women and/or women from associated minorities in clinical trials, to ensure optimal cancer treatment.

II.2 The exposure to gender-related psychological and sexual hardships

A cancer diagnosis, medical journey and survivorship will psychologically and emotionally affect each individual, regardless of their background. Symptoms for instance range - and are not exclusive to - anxiety, depression (91), post-traumatic stress-disorder (PTSD), or fear of recurrence. Nevertheless, adding to the daily life obstacles they encounter, stemming from the gender-based discrimination they may face, women with cancer from any social group can be exposed to another intersecting layer of gender-related psychological and sexual hardships.

Understanding the intersectional impact of social determinants on mental health



Prof. Dr Csaba Dégi

President of the European Cancer Organisation

'Women with cancer face not only the physical distress and toll of the disease but also the interconnected obstacles of gender-based discrimination and socio-economic barriers. too-often silent and overlooked needs.'

The intersection of socio-economic determinants such as age, ethnicity, sexual orientation, gender identity, income and geographic location impacts the cancer experience in all aspects, including mental health. The European Cancer Organisation wishes to shed a light on these factors, often under-regarded.

Firstly, patients with poorer socio-economic status tend to have a sub-optimal adjustment to cancer, with acute psycho-social reactions (92). At the intersection of age, ethnicity and socio-economic status, younger individuals and those from minoritised ethnic groups predominantly reported poorer care experiences after a breast cancer diagnosis (93). For example, literature suggests that women presenting breast cancer at younger age report more psychological distress, higher anxiety, more unmet needs, display more concern about finances and loss of time at work, more childcare problems, and decreased self-image when compared with older women (94). It also highlights that women belonging to a marginalised community are at a greater risk of receiving improper care, bringing additional stress to an already psychologically and physically overwhelming situation (95). Often, several myths, taboos and stigmatising behaviours (96) are not being properly addressed, leaving them isolated.

Besides, the LGBTIQ community faces its own set of psychological challenges in cancer care, the effects of discrimination on healthcare being notably theorised by the minority stress model (97). For instance, transgender individuals, along with young queer people and LGBTIQ individuals living in rural areas reported experiencing lower levels of quality of life and increased levels of psychological distress when navigating the cancer care continuum (98).

Psycho-social needs often are silent needs, not addressed enough by clinicians nor brought on the table by patients, especially from marginalised or discriminated communities. Avoiding retraumatisation (99) is central, as it allows to provide quality and equitable care for individuals coming from disadvantaged backgrounds, without further adding to their distress.

- Develop psycho-oncology services, social support networks, peer-support, group-therapies and survivorship programmes which properly address the psychological needs of women affected by cancer, tailoring them to their needs;
- Employ a trauma-informed approach in cancer care, in which professionals must be aware of existing stigma towards historically marginalised communities, as well as of the inequal cancer burden women, of all ages and all background, face.

The pitfalls of cancer treatment: poor body image, low self-esteem and physical pain

Cancer and cancer treatment may lead to physical changes such as hair loss, skin alterations, swelling, weight gain or loss. However, women with cancer and individuals with female characteristics may also be exposed to different physical alterations. Surgery and nonsurgical treatments may expose women to brutal physical changes, often seriously impinging on their self-esteem, perception of the self, body confidence and overall mental health. Poor body image consequently is amongst the most reported outcomes by women patients, who, because of their gender, may already be affected by the societal pressure to fit into beauty norms.3 For example, Mastectomy in breast cancer patients can lead to self-esteem issues due to a disruption in the woman's body image, breasts being culturally seen as essential parts of femininity. In the specific case of breast cancer's conservative and reconstructive surgery, patients are often found to be dissatisfied with the results. In this context, strategies can be implemented to address body image and distress issues. Initiatives like the EU-funded Cinderella project (100) for example aim to develop an Al-based tool for improved prediction of aesthetic outcomes in breast surgery. Ultimately, this would enhance patient satisfaction, reduce anxiety and depression levels, as well as prevent potential revisional surgeries (100).

Additionally, irregular and painful menstrual cycles, as well as bleeding after sexual intercourse, constipation, prolaxus, incontinence, and pelvic pain may be symptoms of gynaecological cancers, often under-regarded and under-addressed, when it should be thoroughly discussed with the treating **physician**. Despite being one of the most common symptoms that people with cancer experience during treatment and post treatment, pain in women is a frequently disregarded side-effect (101). Research indeed reveals significant gender disparities in cancer pain management (102). Women tend to endure pain alone, which sometimes may also affect their sexual life, as discussed in the following section. The International Standard of Quality Cancer Care, dating from October 2014, nevertheless clearly stresses that quality cancer care must integrate the psychosocial domain into routine care, pain being measured as the 6th vital sign after temperature, blood pressure, pulse and respiratory rate (103) (104).

Increasing psycho-oncology and psycho-oncological body image research should not just confined to breast and gynaecological cancers (105). Access to psycho-social care should be considered a social right – for all women but also for all men – and distress-screening should be regularly addressed during critical periods of time such as surgery or systemic therapy.

To tackle such issues, it is recommended to:

 Use distress screening tools routinely such as the Distress Thermometer and its Problem List, to assess patients' psychosocial, physical (including sexual), family/social, financial, spiritual and practical needs and concerns.

³ The topic of beauty standards and pressure imposed on woman delves into another topical societal issue, widely addressed by the dedicated literature. Some reading suggestions on the topic may include – but are not limited to –: Simone De Beauvoir 'The Second Sex' (1949), 'Naomi Wolf's 'The Beauty Myth' (1990), Mona Chollet 'Beaute Fatale' (2012)

Sexual health with a cancer diagnosis – addressing the infertility burden



Fertility Europe

'As cancer evolves into a long-term condition, fertility care must become a core part of treatment. With rising survival rates, fertility concerns, especially for women, are increasingly important but often overshadowed by preservation should be integrated into care plans for both men and women, enabling informed decisions about reproductive futures, even within time-sensitive treatment protocols.'

A specific way in which cancer impacts women's psychological wellbeing and quality of life is through sexual health. One of the most significant effects of cancer on sexual health is the onset of infertility and early menopause, which greatly reduces reproductive potential and affects overall health. Cancer treatments such as systemic therapy, radiotherapy and surgery can for instance damage the reproductive organs and disrupt hormone production. Thereafter, the loss of ovarian function may be permanent, affecting the physical ability to conceive, but also having a long-lasting psychological impact.

The effects of going into premature menopause include not only infertility but also a higher risk of osteoporosis, uneven temperature regulation, muscle and joint pain, fragile mucous membranes, and mood swings. These symptoms and signs typically developed following natural menopause in older women may be difficult to manage in women of young age, and affect negatively their quality of life (106). Due to this fear, around 30% avoid undergoing treatment, afraid they might lose the chance to conceive (73) (107). Menopause also has a major impact on mental health and, in general, fertility-related psychological distress adds to the stress of cancer and persists from diagnosis through to survivorship (108). One significant challenge for women with a history of breast cancer is the risk of recurrence, which can rise to considerable anxiety and depression and render the decision-making process surrounding the family planning more challenging (73).

In recent years, the offer for fertility preservation options has significantly progressed, notably including tissue shielding to reduce radiation damage, fertility-sparing surgery, and the application of fertility preservation using cryopreservation methods prior to cytotoxic treatments (109,110). Nevertheless, these remain available to selected cancers, particularly early-stage ones, when options should be available for all and individualised considering factors such as the patient's pubertal status, relationship status and urgency of treatment (109) The safety and efficacy of fertility-sparing surgery has been evaluated in young women with early-stage ovarian cancer, indicating that this practice is safe, and fertility is preserved (111).

Following cancer treatment, patients may need assisted reproduction techniques, such as in vitro fertilisation (IVF) or intrauterine insemination (IUI), to achieve pregnancy, especially if their reproductive functions are impaired post-treatment. In this sense, uterus transplantation is an emerging but not yet common therapy for absolute uterine factor infertility, which was previously untreatable. The below figure maps current options for fertility preservation.

If cancer treatment includes:

The following options should be considered:

Oncologic surgery

Fertility-sparing surgery to preserve at least part of one ovary and the uterus. Use of cryopreservation (oocytes/embryos/ovarian tissue) may also be considered prior to surgery if the risk of gonadal damage is high

Radiation therapy to pelvic organs and gonads Shielding aiming at reducing damage of reproductive organs and surgical ovarian transposition. Use of cryopreservation (oocytes/embryos/ovarian tissue) may also be considered prior to pelvic radiotherapy

Cytotoxic treatment with high risk of gonadal damage

Fertility preservation before initiation of gonadotoxic treatment should be considered. The methods include cryopreservation of oocytes, embryos and ovarian tissue

Hormone therapy for estrogensensitive breast cancer

Cryopreservation may be considered in women >33 years of age when being planned for a 5-year tamoxifen treatment and >28 years if a 10-year treatment is planned, as natural fertility diminishes with age.

Modified from: Rodriguez-Wallberg and Oktay. Options on fertility preservation in female cancer patients. Cancer Treatment Reviews, 2012.

Nevertheless, combining infertility treatment with cancer treatment places a significant additional physical and psychological burden on patients who are already suffering from the overwhelming nature of their life-threatening situation and the associated psychological distress (112). It is consequently vital that comprehensive fertility counselling programmes should be established and standardised in Europe, preferably prior to treatment with follow-up, entailing adequate training of oncology healthcare professionals (112,113). The involvement of multidisciplinary teams, including reproductive medicine specialists or gynaecologists, can greatly improve the provision of fertility counselling and access to treatment (114,115).

In addition, **patients face economic, legal and availability barriers**, as access to fertility preservation

techniques varies widely across Europe. These inequalities exist both between and within countries, for example single women or female couples in Hungary do not have access to IVF with sperm donation. A recent study from the European Society of Human Reproduction and Embryology shows that, of the 43 European countries, only 5 permit ART and IUI for single women and all same-sex couples (116). In total, 33 countries offer treatment to single women and 19 offer treatment to female couples. Surrogacy as a potential option after hysterectomy remains controversial in many countries and there is a lack of consistent regulation to guide its practice. Furthermore, in instances where compensation or reimbursement is available for these treatments, the scopes vary considerably, potentially constituting an additional economic burden and contributing to existing inequalities (117).

To tackle such issues, it is recommended to:

- Counsel all women diagnosed with cancer on fertility preservation, most particularly when undergoing therapy which may lead to ovarian failure;
- Ensure fertility becomes a central issue in guaranteeing quality of life, by introducing the topic in the European Health Agenda and the next phase of Europe's Beating Cancer Plan;
- Develop funding for the development of fertility preservation options, also allowing for each
 European woman to receive proper counselling and guidance;
- Ensure comprehensive insurance coverage for fertility preservation treatments, to alleviate
- socio-economic barriers this could be promoted by an EU recommendation;
- Conduct studies on the feasibility and effectiveness of sexual health interventions for women with cancer across cancer types and across the life span.

The impacts of cancer on a woman's sexual experience

Cancer can have an influence on all elements of sexual function, through changes in desire, arousal, sexual pleasure and orgasm, and pain during intercourse (118), including during survivorship. Sexual dysfunction is also very common in women, with an average 60% prevalence rate across different cancer types and the highest prevalence of over 70% for gynaecological cancers (118,119).

Hormonal changes triggered by therapy can result in **poor sexual health, especially in reduced vaginal lubrification and low mood**, further worsening the patient's experience during and post-treatment (120). Gynaecological cancer treatments can also affect bowel, bladder and pelvic floor function. Pelvic floor atrophy can have a significant impact on sexual health, causing recurrent infections such as fungal and urinary tract infections, as well as difficulty achieving orgasm (121).

In addition, negative mood and body image issues can reduce a patient's motivation to engage in sexual activity. Cancer also disrupts relationship dynamics, often leading to reduced intimacy and avoidance of sexual contact. As cancer is a shared stressor in a relationship, it is recommended that the partner is involved in the treatment process whenever possible.

Sexual health issues are often overlooked and untreated (118), a gap that urgently needs to be addressed. Patients frequently report a lack of information on these concerns, as well as insufficient referral pathways and screening, which can delay treatment. However, clinicians may be reluctant to address sexual health issues due to concerns about patient embarrassment or their own lack of training

and skills (118). Improving educational curricula is crucial, as integrating simple tools and protocols into routine care can further facilitate these discussions and screenings, ultimately improving patient outcomes. To address such issues, tailored care also is essential, including interventions such as moisturisers, lubricants and hormone therapies, which can be used locally or systemically (122). Integrating specialised professionals into the care pathway from the outset is essential to improving women's sexual health after, but also during, cancer treatment, as sexuality can be a source of comfort and intimacy that improves overall quality of life. **Identifying and referring patients** to specialised professionals - including physiotherapists, cognitive behavioural therapists, nutritionists, dieticians, couples counsellors and sex educators can provide comprehensive support to effectively address complex sexual health issues (122,123). In particular, physiotherapists play a key role in the prevention and rehabilitation of pelvic floor problems, which are often weakened or traumatised by cancer. Sexual rehabilitation programmes should also be considered to help patients relearn and rediscover their sexual needs, which may have changed after cancer.

Additional shortcomings include **the very limited prospective data**. A recent prospective study of women with early ovarian cancer treated with fertility-sparing surgery showed that women who conceived during a two-year follow-up period presented with better indicators of sexual health than women who did not have children (124).

Another barrier is access to and affordability of sexual health care, as access to certain professionals is not covered by all health insurance schemes, while devices to restore sexual health, are difficult to find in pharmacies.

To tackle such issues, it is recommended to:

- Train healthcare professionals on the psycho-social and sexual health impacts of cancer diagnosis and treatment;
- Provide comprehensive support and tailored care throughout the cancer journey and survivorship, particularly through identification and referral to specialist services;
- Assess the endocrine therapy effects on sexuality and follow clinical guidelines to address it and support the patient to achieve a satisfactory sexual life.

The impact of cancer on a woman's romantic relationship



Dr Luzia Travado

International Psycho-Oncology Society

'As healthcare professionals, we need to be aware early on, so that they can prepare themselves, and learn ways to help them improve communication and intimacy. Psycho-oncologists can and should

A Norwegian study found out that women with cervical cancer were 40% more likely to get divorced, and men with testicular cancer 20% more likely (125). When a woman is diagnosed with cancer, it can significantly disrupt her relationship, whether of heterosexual, lesbian or queer nature. For instance, hormone therapy, commonly used in breast cancer treatment, can cause side effects such as mood shifts, irritability, hot flashes, but also vaginal dryness and pain during intercourse (126), which may strain the romantic and/or sexual relationship. Partners need to understand these challenges and be equipped with strategies, such as using lubricants or improving intimate communication, to navigate these changes together.

Unfortunately, the topic of partner involvement in cancer care is under-addressed, and many partners experience anxiety and helplessness due to being excluded from the conversation. Regarding sexual topics often culturally and socially considered 'taboo', addressing these issues in an informal and discrete

manner, such as through brochures could be considered a solution. A partner is often the best source of emotional support for the patient, making their inclusion – upon patient consent – in treatment discussions and decisions crucial. This sense of involvement not only empowers the partner but also enhances the emotional well-being of the patient, as the partner becomes a key part of the care team. Early engagement of partners consequently is essential to the patient's coping process and emotional resilience during treatment. Healthcare clinicians need to be educated on the added value to include, involve, engage partners at an early stage, making it a standard practice.

Furthermore, women with cancer are more likely to experience intimate partner violence (IPV) as a result of the diagnosis, which may affect daily life and the balance in the relationship. The types of IPV may range from restrictions on behaviour, such as clothing or visiting family, to verbal and physical violence., which has direct negative impact on treatment decisions, quality of life and health outcomes (127). Nevertheless, screening for IPV in clinical centres is still underdeveloped, and healthcare professionals are not trained to tackle this issue. A 2022–2023 study in France found that only 14% of women had been asked about their relationship by their GP, and only 3% had been asked directly about IPV, whereas 96% believed systematic questioning would be beneficial. It is consequently recommended to raise awareness and train HCP on these issues, as well as to develop an appropriate screening programme with readily available referral sources, yet also materials such as clinical standardised guidelines (128,129). Some guidelines have already been developed as examples of best practices to build upon, including NCCN clinical guidelines on survivorship (130).

To tackle such issues, it is recommended to:

- Include the partner in the clinical consultations so as to have him/her/them engaging in supporting the patient and collaborating with the team in the treatment and recovering process;
- Raise awareness and train Health Care Professionals to recognise and manage Intimate Partner Violence, in particular with appropriate screening programme and resources.

II.3 Recognising the disproportionate financial burden and workplace toxicity faced by women with cancer



Extract from a Video Testimonial from <u>The</u>

<u>Ending Discrimination Against Cancer Survivors</u>

<u>Initiative</u>, created by Prof. Dr Françoise Meunier

Marianne Massart

'My cancer story kicked back six years after end of treatment, when trying to buy a house. I felt like I had to pay twice for being sick, in addition to fighting twice as hard to do everything everyone else seemed to be doing so easily.'

An increased exposure to poverty

The total **economic loss to the EU** due to lost working days as result of cancer is estimated at **€9.5 billion** in 2009, for both men and women (131). In Europe, **women are on average more exposed to poverty and financial hardships than men**. In 2020, the risk of poverty or social exclusion in the EU was of 22,9% for women, compared to 20,9% for men (132), and this gap might worsen by 2050, due to severe climate deterioration (133).

On average, 29,5% of women with disabilities are at risk of falling victim to poverty and social exclusion, compared with 27,5% of their male counterpart. The

same applies to women from more vulnerable groups, such as young women, women with a migrant background, Roma women, women from religious or ethnic minorities, incarcerated women, and LGBTIQ women, who all face intersecting forms of discrimination when accessing societal advantages (134).

Women battling cancer often find themselves grappling not only with the physical and emotional toll of their illness **but also substantial financial hardships and challenges**. A 2023 Lancet study indicates that 'women are more likely than men to risk financial catastrophe due to cancer, with dire consequences for their families, even if quality cancer care is available (15)'

Cancer treatment incurs **substantial financial costs** (135), such as direct medical and treatment expenses, but also private transportation. These often represent out-of-pocket spendings, which when combined with a potential loss of income due to an incapacity to work, represent a form of financial distress. Research points out that women from vulnerable groups may also face additional layers of financial toxicity, such as women living in rural areas (136). Women may also face additional financial distress relating to their caregiving and family responsibilities, which are addressed in the following section of this paper.

- Expand and enhance existing financial assistance programmes, who must cover essential medical expenses and include provisions for costs incurred by transportation, childcare and homecare services;
- Create financial patient navigation programmes dedicated to helping women patients and women patient from different marginalised communities benefit from assistance, taking example from the <u>EU-Navigate</u> or <u>CancerLess</u> programmes.

Workplace discrimination – a right to be treated equally

Cancer treatment and side effects already make returning to work harder, physically, cognitively and emotionally. The end of active treatment for early cancers does not imply an easy and speedy return to work. Women with advanced/metastatic cancers often experience symptoms and/or side effects which may prevent them from carrying professional activities, or from retrieving the full range of their capacities. Despite these impairments and the need for adaptation, their disability status often is not recognised, or recognised only in the short-term, despite the long-lasting nature of their condition. This is particularly important for women with advanced/metastatic cancers, which are still incurable.

The transition period towards new normality and the stressful situation of living with cancer or metastatic cancer is a time of struggle, where a woman patient needs to be supported by her employer and colleagues. A toxic workplace culture may not only exacerbate financial distress, but also undermine a woman's sense of dignity, autonomy and well-being.

Additionally, women affected by cancer may experience discrimination and stigma in the workplace, creating a sense of double penalty. This discrimination may particularly affect career responsibility, stability and advancement, as well as concerns about job security. Yet again, young women with cancer, often at

the onset of their career and more exposed to instability, low wages and age-based discrimination, may be all-the-more affected. Many women, in particular those living with metastatic cancer, are pressured to early retirement of long-term sick leave, even if they wish and are able to pursue their professional life and societal contribution.

The UK set a best-practice example by protecting cancer patients and survivors from work discrimination under the 2010 Equality Act (137), three forms of discrimination (direct, indirect and arising from disability) being prohibited. Nevertheless, such a scheme does not exist in the EU. This profound lack of legislation but also of awareness concerning mechanisms, arrangements and tools needs to be addressed at policy level, as recommended in this paper.

With the development of new technologies, many concrete solutions exist to allow women with cancer and post cancer to work or return to work. Employers should make changes or adjustments to the workplace environment where suitable, whether in the actual 'physical' workplace or by implementing principles, guidelines and strategies. Loss of strength, and loss of vision may require ergonomic furniture and keyboards. Artificial Intelligence softwares and speech recognition softwares may for example allow to work on a computer without hand-typing. Arranging a buddy system or mentoring may also offer some additional distress-support.

- Raise awareness for women to understand their recovery and return-to-work rights, for employers to allow a successful reintegration, and for health professionals who need to understand the positive impact of return to work;
- Encourage and facilitate the training and education of managers and co-workers in all workplaces, to mainstream cancer-related issues and foster a culture of empathy, understanding and support in the workplace;
- Help create flexible working environments for those with cancer. This could be supported by the production of workplace and work-environment, including, but not limited to:
 - Creating scaled return-to-work plans, if and when necessary;
 - Implementing flexible scheduling, allowing for medical appointments, treatments and sick leave;
 - 0 Modifying workload and/or office equipment;
 - Development and/or strengthening of anti-discrimination policies;
 - Setting up buddy and/or mentoring systems;
 - Allowing for teleworking, when appropriate.

PART THREE: WOMEN CAREGIVERS

This section focuses on women providing decisive and crucial caregiving activities for someone with cancer, either formally or informally. According to the WHO, 32 million European women currently provide care to a family member, friend, or neighbour (138). Often forgotten despite bringing experience and resources, women caregivers must be better recognised, acquire additional knowledge and influence, and be included as part of the solution to keep on performing their duties.



Eurocarers

'Cancer carers form an integral part in the management of this devastating disease. They must be recognised and supported! Women are overrepresented among informal carers. They deliver more personal care, as well as frequent and high-intensity care. A better gender balance in care must be achieved!'

III.1 Understanding the impact of caregiving on societies and economies – valuing the invaluable

Defining and quantifying caregiving

Despite difficulties in precise quantification given the complex nature of caregiving, it is estimated by the 2017 European Quality of Life Survey that there are 100 million caregivers in Europe. It has also been established that informal carers across the EU provide over 80% of all care, with women providing approximately two thirds of care, mainly as daughters (in law) and wives/partners (139).

Caregiving involves time spend on performing daily chores, looking after children and taking care of the ill (15), as well as counselling them. Eurocarers – the European Network representing informal carers and their organisations, defines carers as 'a person who provides usually unpaid care to someone with a chronic illness, disability or other long-lasting health or care needs outside of a professional or formal framework (139)'.

A crucial yet under-acknowledged role in societies and economies

In many cultures, caregiving has also **essentially been** feminised and intersectionally associated with ethnical minorities, such as black women or Eastern-European women. This implies an under-recognition of the time spent on performing such tasks, in spite of the economical value for societies. Unpaid care work contributes in essential ways to society and economies, a study for instance highlighting that in 2016, the economic value of this work was estimated at 576 000 million euros, accounting for 3,63% of Europe's Gross Domestic Product (GDP)(140). Women undertaking caregiving activities acquire new transferable skills, help states save millions, help keeping cancer inflicted families running and they frequently take on the roles of several professionals, consequently reducing the burden of HCPs. Despite these substantial contributions, caregiving activities still tend to be under-acknowledged. The 2022 European Commission's European Care Strategy for caregivers and care receivers has paved the way for policy action, including a set of recommendations for member states.

- Conduct new studies with updated data on caregiving across Europe and emphasising the crucial role played by women caregivers;
- 'Value the invaluable' by recognising and accounting for the monetary and societal value of caregiving in economic analysis tools';
- Allow for the recognition of skills acquired during caregiving, to allow for potential professional reconversion.

III.2 Women caregivers' exposure to poverty risks

The financial repercussions of caregiving

Unpaid caregiving work is **majoritarily and disproportionately undertaken by women**, who often are mothers engaging more childcare activities than their partner or co-parent. A 2023 European Institute for Gender Equality study for instance highlights that 49% of women living with a partner report assuming primary responsibility for essential childcare tasks, compared to 6% of men (141). Equalising the men and women caring responsibilities needs to be further addressed, for instance by empowering to conduct such roles, notably via improving workplace rights in respect to conducting caring roles.

Women undertaking caregiving activities for cancer patients may have to reduce their working hours or readapt their work patterns, leave their jobs, or face being laid off due to the hours spent executing care

activities. In all cases, this will result in a loss of income and may cause repercussions on pension schemes.

Women caregivers are consequently more exposed to poverty risks. According to Eurofound's European Quality of Life Survey, 42% of non-working carers are in the lowest income quartile (compared to 24% of non-carers) and 59% of non-working carers have difficulty making ends meet (compared to 46% of non-carers).

Properly addressing caregiving and caregiving induced hardships

The below graph produced by Eurocarers (142) shows the great disparity in legal status of carers, available support and protection that each member states offers. If some like Luxembourg provide legal recognition and identification, training and financial compensation leave, as well as pension credits, others like Poland or Romania differ greatly in their support.

	OFFICIAL NUMBER		UNOFFICIAL NUMBER					SUPPORT TO CARE			9 - SOCIAL INCLUSION /PROTECTION		
EURO	Number of carers	% of population with caring responsi- bilities	Number of carers	% of population with caring responsibil- ities	1 - Legal recognition of carers	2 - Identifi- cation	3 - Needs Assess- ment	5 - Access to informa- tion	7 - Respite care	8 - Training	Financial compensa- tion (direct or indirect)	Carers' leave	Pension credits
AT 😄	700.083	8,10%	1.519.940	17,00%	V	٠	0	0	V	V	V	4	V
BE ()	1.307.320	11,60%	2.597.515	22,50%	V	V	×	0	~	~	4	V	V
BG 🥃	437.858	6,10%	2.070.622	29,90%	×	×	×	×	0	0	0	0	×
CH O	600.000	7,00%	1.047.168	10,80%	0	×	×	0	0	0	0	V	×
CA 🤏	60.372	5,20%	187.954	21%	×	×	×	0	4	0	×	×	×
CZ 🍉	485.300	4,60%	2.141.871	20,00%	0	0	×	0	×	0	V	V	×
DE 🖱	5.554.920	6,80%	15.810.476	19%	w/	0	0	V	4	~	4	V	w/
DK 🛟	863.816	15,20%	1.313.555	22%	×	0	×	V	~	~	V	V	V
EE 🖷	176.210	13,40%	210.764	15,80%	×	×	×	V	×	4	0	0	×
EL 🎂	724.940	6,70%	3.148.764	29,50%	V	0	×	0	×	0	x	V	×
ES 🖺	5.340.600	11,50%	10.901.700	23,00%	0	0	×	V	4	¥.	V	4	0
FI 🖶	657.600	12,00%	968.745	17,50%	4	0	V	4	~	4	4	4	×
FR ()	9.383.550	14,10%	10.148.502	15,00%	4	0	0	4	4	4	4	4	4
HR 🏗	269.056	6,40%	1.535.945	38,10%	×	×	×	×	0	×	0	0	0
HU 🚍	816.969	8,30%	1.412.978	14,50%	×	×	×	×	~	×	0	4	×
IE()	441.988	9,40%	1.352.215	27,00%	4	V.	~	4	4	4	4	4	4
IT ()	8.502.200	14,00%	14.231.729	24,00%	4	×	×	4	4	4	4	0	0
LT 🐷	241.115	8,30%	769.654	27,50%	×	×	×	×	4	~	4	0	×
LU 👄	35.315	6,20%	50.778	8,00%	4	4	4	4	4	4	4	4	4
LV 👄	144.394	7,30%	380.072	20,10%	×	×	×	4	4	~	0	0	×
MT O	40.945	9,20%	84.890	16,40%	×	×	×	×	4	×	0	0	4
NL 😄	6.216.980	36,70%	4.543.608	26,00%	0	~	0	V	~	~	4	4	×
NO 🌐	N/A	N/A	800.000	15,40%	×	×	×	٥	٠	×	4	٥	٥
PL 🕳	3.874.980	10,20%	8.141.725	21,50%	×	0	×	×	×	×	0	V.	×
PT 💿	1.274.280	12,30%	2.623.150	25,50%	V.	×	×	0	~	0	~	V	×
RO ()	455.860	2,30%	4.996.697	26,00%	×	×	×	×	٥	0	0	٥	×
SE 🛟	2.155.780	22,00%	2.179.652	21,00%	4	~	~	4	· ·	٥	V	4	×
SI 🍅	220.848	10,70%	474.574	22,50%	×	×	×	0	×	Ó	0	O	×
SK 🌚	428.496	7,90%	1.258.286	23,00%	×	0	×	×	O	×	0	V	×
UK #	6.500.000	10,40%	N/A	N/A	V	~	V	4	~	V	4	0	V

The unofficial data concerning the proportion of the population with informal caring responsibilities emanates from the 2022 EIGE survey of Gender Gaps in Unpaid Care, Individual and Social Activities

Figure 8: Number of carers and existing support measures across the EU

The European Union has only very recently addressed caregiving, first in its Gender Equality Strategy for 2020–2025, where the European Commission promotes an equal sharing of home responsibilities and a focus on ageing population (143). Nevertheless, it only marginally addresses health-related caregiving. The 2022 European Commission's European Care Strategy (144) has paved the way for policy action, including a set of

recommendations for member states. It for example touches upon the issue of balancing care and work responsibility. This paper nevertheless represents an opportunity to present stronger policy recommendations to the New Commissioner for Equality for 2024–2029, and in view of future assessments of the Care Strategy.

To tackle such issues, it is recommended that:

- State pension schemes and social security arrangements in all countries better reflect the invaluable role of informal care provided to cancer and other patients, for example by covering for out-of-pocket expenses;
- A continuous progression of employees' social rights to flexible working arrangements should also be progressed, especially in cases where an individual has significant care responsibilities;
- Addressing the 'gender-care gap' by promoting the involvement of men in caregiving, starting in the workplace.

III.3 Recognising the hardships faced by women caregiving for cancer patients

The psychological repercussions for women caregivers and families

Undertaking caregiving activities for a family member or loved one with a cancer diagnosis will have multifaceted physical, emotional and mental health impacts for women, complicating their caregiving tasks. Cancer brings incertitude to the table, which can for instance imply a decreased quality of life, induced by a stressful environment and additional working hours, worsened when the person with cancer approaches end-of-life. This may as well prevent an active social life, career advancements, development of relationships, but also capacity to pursue personal medical appointments.

The caregiving experience may also be negatively affected by different factors. For instance, women living in rural or economically disadvantaged areas may spend additional hours performing caregiving tasks, with travel time representing an additional

burden. On the other end, women caring for a child with cancer also face a unique and stressful experience of balancing work and family responsibilities (145), differing from traditional maternal schemes.

Being a caregiver may additionally induce **adopting a detrimental lifestyle**, for instance by taking anxiety medication, adopting or re-adopting smoking and/or alcohol habits, eating unhealthy foods and pursuing bad sleep habits; all are considered trigger causes for cancer (146).

Cancer also has **consequences on family structures and dynamics**, given the central role played by women. A 2022 study estimates that the 4 million cancer deaths in women in 2020 resulted in 1 million new maternal orphans worldwide, amongst which 60,000 were in Europe (147). Orphans will need to be taken care of by a family member, creating a new toll for the latter. In a nutshell, not only do women caregivers play a central role for the nuclear family, yet their role extends to healthcare systems and societies as a whole.

Calling for an integrated model of care

Carers need to see their burden alleviated, through an improvement of European services, since care should not stop directly after treatment. Rather, it should integrate follow-up assistance, to prevent caring families and partners from embarking in an 'obstacle race' to book appointments in different facilities

More concrete examples include offering more ambulances to access treatment, rather than relying on carers acting as transporters. In the same manner, psycho-oncology should be provided directly at the treating hospital.

To conclude this section, recognising women caregivers as vital contributors to society is crucial for valuing their work and economic impact. Supporting them is key to fostering more equitable policies and support systems that truly reflect the importance of their caregiving roles.

To tackle such issues, it is recommended to:

- Ensure adequate counselling and therapy for caregivers such as cognitive behavioural therapy or family therapy;
- Promote access to support groups notably supporting with the understanding of grieving, or survivorship.

PART FOUR: WOMEN WORKING IN CANCER



Dr Mirjam Crul

European Society of Oncology Pharmacy

'No woman should accept to do a job where men who are doing the same job, earn more.'

IV.1 The representation of women in oncology

The way towards gender equality in oncology

Oncology, like many other medical fields, used to be dominated by men. However, great strides have been made with pioneering women paving the way and men colleagues who have supported progress (148). The representation of women in various fields is increasing, as they currently make up around 70% of the health and care workforce (148).

While more and more women are choosing the medical field, especially certain fields like obstetrics, gynaecology, and paediatrics, many cancer-focused professions such as surgical oncology continue to be dominated by men (149). The remaining underrepresentation in certain fields is due to historical biases, cultural stereotypes and systemic barriers hindering women's access to education and career advancement in medical disciplines. These elements lead to a significant difference in average gross hourly earnings between men and women, referred to as the gender pay gap. According to a WHO report, women in the health and care sector earn approximately 20% less than men, pointing to an urgent need to address inequalities (150). To further facilitate progress, fields where equality has been achieved can serve as examples.

Gendered differences between sectors

Overall, more women are employed in the lowest-paying fields and the highest-paying sectors are dominated by men. To illustrate, 90% of nursing and midwifery staff in Denmark are women, and two thirds of surgeons are men (149). Alarmingly, the more women are working in a specific sector, the lower the average pay in that field is (150).

Differences across sectors are due to conscious and unconscious discrimination against women, as well as beliefs that men are a better fit for higher pay and status (151). All these elements combined result in a disadvantaged position of women in the healthcare workforce, exacerbated by the lack of sex-segregated data, especially for women from minority groups who can face additional barriers and discrimination. Improving the representation of all genders at the workplace can have practical, positive impacts on workplace productivity, innovation and decision-making (152).

Mothers in the oncology workforce

Nikolina Dodlek

European Oncology Nursing Society



'Barriers to career advancement for mothers in the European workforce include limited access to flexible working arrangements, persistent gender biases that undervalue caregiving roles, and insufficient support for returning to work after maternity leave, all of which can hinder career progression in competitive sectors.'

Women face specific barriers due to their social roles. For example, women in academic medicine who are in a relationship are more likely than men to make changes in their work to support their partner's career, for instance, by working less hours and relocating (153).

Career progression is also affected by motherhood. In a study conducted by ESMO, over one third of women reported that having children impacted their career progression (154). Women tend to be primary caretakers; hence, early and late shifts can pose an issue. Additionally, women are also more likely to take up household chores, which makes it difficult to balance the professional and personal life, especially in oncology where long hours and overtime are common. Measures that improve work-life balance, such as flexible working arrangements and sufficient support in returning to work can help address these issues (155). Some countries, for instance in Scandinavia and Eastern Europe offer more affordable and available childcare, which can facilitate return to work and continued career progression as women depend on the availability of childcare (156). Progress can already be seen in certain areas, as women reported less difficulties with managing their work life and personal life in 2021 compared to data from 2016 (154).

To tackle such issues, it is recommended that:

- National governments, professional societies and universities across Europe should establish gender equality targets and strategies, as well as promote the participation of girls and women in STEM education, with support especially to marginalised women (e.g. Job fairs, internships, career counselling);
- Ensure that employers publish transparent career paths and salary structures with clear salary
- Employers should provide flexible working conditions for women with children, as well as paid parental leave;
- National governments across Europe should collect and analyse data to monitor the gender pay gap in the oncology workforce and thereby underline priority areas for action.

IV.2 The representation of women in advocacy, research and leadership positions

Women in leadership positions and barriers to career advancement

While more and more women take up positions in cancer-related disciplines, gender-specific barriers are still present and limit access to medical education, career advancement, mentorship opportunities, and leadership positions (157). Across disciplines, women healthcare workers are less likely to be promoted to leadership or higher management positions and have less access to decision-making opportunities, which is often referred to as vertical segregation (158). For instance, in the field of obstetrics and gynaecology in Germany, over 60% of all physicians are women, however, they only make up 25% of chief physicians (157).

The lack of career advancement opportunities is often due to gendered expectations and stereotypes around what leaders in the oncology workforce should be like (149). One such factor is the perception that traditionally masculine traits like authority and rationality are more valuable in a leader than typically feminine traits like compassion. When a woman is promoted to a leadership position, she contributes to breaking down these barriers and addressing these stereotypes. Women in leadership also serve as mentors and role models for younger women and can provide support in their career development (148). Highlighting their achievements can further increase their positive impact. For instance, the newsletter OncoDaily

presents "100 influential women in oncology" each year, spotlighting women who are driving the field forward (159). Other good approaches are to establish mentorship, networking and training programmes to connect women at the start of their careers with people who are leaders in the field to help them build their careers.

Women in academia

When it comes to the scientific field, meaningful advances have been made in authorship with over half or more of the authors being women in 17 European countries in 2019 compared to only five countries in 2009 (156).

In academic positions, even though progress has been made, women are still underrepresented, especially in higher-ranking positions. In academic oncology, including medical oncology, radiation oncology and surgical oncology, only around 35% of staff are women and less than 25% are chairs (160).

Other inequalities remain in access to research funding, as women are not only less likely to receive grants but also receive lower amounts of funding (15). In terms of gender balance on the editorial board of journals, women only make up around a quarter of the boards of leading oncology journals (161), raising an important issue.

Women in societies and congresses

Impactful developments can be seen in the representation of women in cancer-related societies and congresses, as the number of women members of oncology societies has been increasing (162). Some societies have created task forces and committees focused on improving gender equality, such as the Women for Oncology Committee (W4O) in ESMO and the Women's Empowerment Initiative from the European Association of Nuclear Medicine (163,164).

While women continue to be better represented in societies, areas for further improvement remain especially in involving women as presidents and speakers. As an example, less than a third of speakers at European oncology conferences are women (based on data from 2015–16) (162).

All these factors point to a gender gap in the scientific field that needs to be addressed. Involving people from all genders and backgrounds in conferences and as board members is most importantly a question of equity, while it also improves the quality of discussions and academic outputs (165). Moreover, it can have positive spillover effects; having women in leadership positions and as board members is associated with an increased representation of women in conferences (162).

To tackle such issues, it is recommended that:

- Professional societies should strive to improve the representation of women in oncology society boards and speaker panels at conferences;
- Professional societies and universities should aspire to have women in minimum 45% of cancer research leadership positions by 2028;
- Professional societies and universities should provide training and mentorship opportunities for women (through the support of women leaders);
- Professional societies and universities should ensure equitable access to research resources, leadership and funding opportunities for women;
- Employers should ensure working conditions policies are gender-sensitive by including women, especially from minority groups in the design of policies.

IV. 3 Challenges in the workplace: harassment and discrimination

Harassment against women in the workplace



Prof. Dr Françoise Meunier

Director General of the European Organisation for Research and Treatment of Cancer for 27 years

'A woman cannot choose her parents nor her background. But she can choose a mentor who inspires her and also a partner who supports her professional and private life. These choices are crucial for her to live a fulfilling life and realise her full potential.'

The gender inequalities in oncology, such as the gender pay gap and underrepresentation of women in leadership positions create a male-dominated working culture, which in turn facilitates gender-based harassment and discrimination (15). While there have been significant improvements with reductions in sexual harassment and discrimination, these issues should be further examined and addressed, and harassment remains present at all levels of the medical field (15).

Sexual harassment has different types, including receiving unwanted sexual attention, sexual coercion and behaviours that objectify, exclude or discriminate against someone based on their gender (166). Harassment can take both psychological and physical forms (167). Within the cancer workforce, women often report experiences of gender-based discrimination such as bullying and sexual harassment (15), however, there is a lack of research on the impact of gender on healthcare workers' working conditions. One of the biggest challenges is that women are more likely than men to experience harassment through inappropriate sexual advances or sexist remarks (154).

Harassment is a structural problem, often independent of status or position, as it can come from any level of employee and even from patients (149,168). Sexual harassment is believed to be more prevalent in fields where there is an overrepresentation of men, which illustrates how gendered differences are interlinked. Harassment is further facilitated by certain factors specific to the medical field, such as the strong hierarchy, domination of men in the workforce, long working hours and access to private spaces (168).

While women are more likely to experience harassment than men, they face difficulties in reporting as they fear repercussions or do not believe that the event will be taken seriously (149,169). Therefore, **not only the** prevention of harassment should be addressed but also what happens after harassment occurs, such as ensuring safe reporting, protection of those who report and adequate accountability measures (170).

Implicit biases and discrimination

Apart from explicit harassment, implicit biases can also lead to discrimination and create challenges for women (168). Some examples of biases include that women are less likely to receive recognition for their work and are often misidentified as non-professional staff or not introduced by their professional titles. From an intersectional perspective, women from ethnic or racial minority groups are even more likely to report microaggressions and discrimination in the workplace (171).

Already during training, women face gender-based discrimination. A study on women in postgraduate surgical training shows that they face discrimination in the form of inappropriate jokes or comments and hostile or humiliating behaviours from nursing staff, colleagues and patients (172). Women also reported having to fight harder than men just to be respected in their positions. Therefore, there is an urgent need to address all forms of workplace discrimination and harassment, as it has grave impacts on mental and physical health, job satisfaction, turnover intentions and safety in the workplace. One such impact is that more women report burnout (171).

To address the crucial issue of gender-based violence, harassment and discrimination, international organisations and societies have created guidelines and frameworks. For instance, UN Women published a handbook on "Addressing violence and harassment against women in the world of work" and the European Institute for Gender Equality (EIGE) has a handbook on combatting sexism in the workplace with specific steps to be taken by managers and decision-makers (173,174). These, among other guides, can serve as essential resources for policymakers and employers and outline direct actions to be taken.

To tackle such issues, it is recommended that:

- National governments across Europe should create and implement standardised policies for addressing harassment and discrimination;
- Professional societies and universities should incorporate sex and gender education into medical training, including - and not limited to- gender stereotypes and equal opportunities;
- Professional societies and universities should provide training in bystander intervention and other types of harassment prevention;
- Employers should use transparent and fair metrics for recruitment, job retention, promotion and salary considering gender balances and potential quotas;
- All professional societies and universities should integrate education on gender-based harassment and discrimination into medical training with an intersectional feminist perspective;
- Employers should create safe reporting pathways and protection against retaliation against reporters of harassment, also allowing for employees to feel safe when whistleblowing;
- Employers should ensure support services are available and accessible for people who experience harassment and discrimination.

CONCLUSIONS

The 12 million European women living with cancer in Europe deserve better. Our paper, having interrogated the data and the issues, identifies a range of immediate opportunity areas for improvement. From tackling irresponsible marketing by health-harming industries, to fully achieving Europe's HPV and HBV cancer elimination targets. From educating and informing women belonging to different social groups to educating all European citizens on the benefits of cancer prevention. From delivering the full promise of breast and cervical cancer screening, to ensuring the full promise of precision oncology delivers for female cancers. From building a full policy response for those women living with metastatic and advanced cancer, to enhancing mental health, fertility and reproductive rights. From supporting women as caregivers, to promoting women leaders in cancer care and research.

Everyone has a role to play in promoting the women and cancer agenda laid out in this paper. From WHO breast and cervical cancer strategies to European cancer policies and equality initiatives. From national adoption of best practices from elsewhere, to changes in cancer care cultures and practices at the national level.

Women and Cancer: 12 million reasons for action provides a mandate for change. We invite you to join the European Cancer Organisation and partner organisations in bringing the agenda promoted by this paper to life. We owe Europe's women nothing less.



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As the not-for-profit federation of member organisations working in cancer at a European level, the European Cancer Organisation convenes oncology professionals and patients to agree policy, advocate for positive change and speak up for the European cancer community.



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