

Insights into the unique challenges faced by women living with cancer and identification of actions that may help to improve their experiences and outcomes

Findings from a 23-country research initiative September 2019

Merck KGaA, Darmstadt, Germany, a leading science and technology company, operates its biopharmaceutical business as EMD Serono in the US and Canada

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### we can do better on behalf of women



Cancer is one of the greatest health burdens that women face today. It is the second leading cause of death globally and the number of cancer cases continues to rise year-onyear,2 indicating the vast scale of the problem.

Overcoming the unique challenges that can stand in the way of women's potential matters to me, as it should to all of us. At Merck KGaA, Darmstadt, Germany, we focus on developing and implementing solutions for health conditions and diseases that disproportionately affect women, and cancer is high on the list.

Cancer affects an increasing number of women and this growing global burden constitutes one of the most significant health challenges of the 21st century.3 In 2018, an estimated 8.6 million women were diagnosed with cancer around the world, with breast, colorectal and lung cancers accounting for 44% of these cases.4,5 Cancer prevention and the support of women living with cancer should be a global priority. It is for Merck KGaA, Darmstadt, Germany.

According to the International Labour Organization, 865 million women across the globe are not reaching their full potential to contribute to society.6 Many of the causes are preventable. There are enduring obstacles women must overcome, including health challenges that impact economies around the world.

This is why I personally, and Merck KGaA, Darmstadt, Germany as a company and a community, are committed to the global Healthy Women, Healthy Economies initiative, which brings together patients, governments, healthcare professionals. employers, academics and other stakeholders to improve women's health — so that they can thrive in all aspects of their lives and communities.

The Healthy Women, Healthy Economies Policy Toolkit\* provides guidance and support to a variety of stakeholders who can implement policy change. The Toolkit is built on the premise that reliable data and research are necessary to determine the prevalence and risk factors of diseases that impact women and ensure that effective, transformative health programs and interventions are developed and operationalized.

This report is a core part of the *Healthy* Women, Healthy Economies evidence base. 'Supporting Women With Cancer' presents a new 23-country survey designed to shed light on the challenges faced by women diagnosed with cancer. The survey provides data that are key to strengthening policies and programs, highlighting the need for greater multi-stakeholder action to address significant unmet needs in the areas of education, cancer screening and access to support services.

Merck KGaA, Darmstadt, Germany sees the bigger picture of how health and prosperity are intertwined for women, and we will do our part to advance the *Healthy* Women, Healthy Economies initiative to improve the potential of women living with cancer globally.

### Belén Garijo

Member of the Merck KGaA, Darmstadt, Germany Executive Board CEO Healthcare

\*The Healthy Women, Healthy Economies Policy Toolkit can be accessed at: http://healthywomen.apec.org/policy-toolkit/

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# How we should respond as a community



For the last 10 years we have seen a growing global understanding of the impact cancer has and will have on future generations.

There have been three United Nations High Level Meetings on non-communicable diseases (NCDs), agreements to global targets to be achieved by 2025, a Resolution on cancer at the World Health Assembly in 2017 and the inclusion of NCDs in the Sustainable Development Goals for 2030. If we act collectively on all these global agreements and commitments, then we will make great progress in reducing the numbers of premature deaths from cancer and the other NCDs by a third by 2030. This ambition, however, is not without its challenges.

At the Union for International Cancer Control (UICC), we strive to build a global community which works collectively to ensure that evidence-based solutions to reduce cancer incidence and increase cancer survival are in place around the world. We expect all countries to have a robust and funded national cancer control plan, to develop information systems so they understand their cancer burden today, and in the future, and that the pathway to effective action involves the active participation of players from all sectors—governments, civil society, academia and the private sector.

As others have said in this report, despite the advances in reducing exposure to risk factors, the existence of more vaccination and screening programs and breakthroughs in treatment and care, we face a growing number of cancer cases and deaths from cancer each year. The main driver being an aging and growing population and not making the progress at the pace we would like to see in reducing the world's exposure to cancer risk factors.

Today, more than 70% of cancer deaths occur in low- and middle-income countries. The International Agency for Research on Cancer (IARC) suggests that more than two thirds of new cancer cases will occur in lower-middle income countries in the coming decades—countries which are least able to respond to such a seismic change in the health of their population.

In this report, EMD Serono highlights some of the challenges faced by women as the cancer burden grows.

The numbers speak for themselves but let me contribute my own thoughts on how we should respond as a community to some of the headlines in this report.

- 1. "Only 45% of women surveyed reported they were aware of cancer signs and symptoms before receiving their diagnosis" — we must deploy every tool we have at hand to increase women's awareness of cancer symptoms. Not just of cancer types which are unique to women, but also of others like lung, colorectal and stomach cancers. The UICC calls on the global cancer community to help women better understand the signs and symptoms of cancers and ensure that they present to their healthcare practitioner at a stage which improves their chances of survival.
- 2. "Nearly half of women surveyed had never attended a cancer screening program" we must encourage governments around the world to implement national screening programs which also raise the profile of cancers, encourage women to seek advice and help identify more cancers earlier than we do today. We must increase the awareness of national programs and ensure outreach to the most vulnerable communities.
- 3. "Only 42% of women surveyed had accessed support services" this is a challenge complicated by a lack of information, poor education, poverty, the existence of myths and misconceptions and, in some cases, hindered by cultural norms. Despite these barriers, we know that great progress can be made if medical institutions, doctors and service providers work more closely together so that cancer patients receive the holistic support they need.

I thank Merck KGaA, Darmstadt, Germany for their continuous commitment to global cancer control. This report broadens our understanding of the specific challenges faced by women with cancer and helps us shape a sustainable and effective response.

#### **Dr. Cary Adams**

Chief Executive Officer Union for International Cancer Control

### **Executive summary:**

## We must act now to improve education, screening programs and support services for women living with cancer

At EMD Serono, we see the bigger picture of how health and prosperity are intertwined for women and are committed to making a positive contribution to improving both.

Merck KGaA, Darmstadt, Germany is the founding private sector partner of *Healthy Women*, *Healthy Economies*, a global initiative that brings together governments, the private sector and other stakeholders such as non-governmental organizations (NGOs) and patient advocacy groups to address women's health so women—and by extension their families—can live better lives.

Bringing these significant commitments together, EMD Serono, with input from the UICC, implemented the *Supporting Women With Cancer* survey across 23 countries and more than 4,500 women who had received a cancer diagnosis and undergone treatment. The survey was undertaken to better understand the unique challenges women diagnosed with cancer face and where more societal support is needed.

The survey identified three core areas where there is a greater need for multi-stakeholder action.

### 1. Continued education to promote awareness of all cancers and their risk factors amongst women

Regardless of a woman's socio-economic demographic, the research showed a greater focus is needed to improve knowledge and understanding of the signs, symptoms and risk factors of cancer, in particular those not widely considered 'women's cancers' such as lung and colorectal cancer.

### 2. Increased awareness of, and access to, cancer screening programs for all women to support earlier diagnosis

The survey findings highlighted the need for increased access to, and awareness of, cancer screening programs for all women, particularly those with a lower level of formal education, to support potential earlier diagnosis.

Additionally, the survey results critically highlighted that improving women's understanding of the benefits of early cancer detection could help to remove some barriers to accessing screening programs.

### 3. Improved awareness and access to support services, plus the further identification of where unmet needs persist

According to the research, women clearly require improved awareness of and access to financial, emotional, employment and fertility support to ensure they can maintain their daily lives following a cancer diagnosis. A perceived greater stigma was also experienced by women diagnosed with cancer compared to men, with women feeling burdened financially and across their work and family responsibilities.

Many women of childbearing age with cancer were not offered family planning support and related guidance from their healthcare professional—despite the fact that half of those who did not receive this would have welcomed the support, in retrospect. The research highlighted that in some regions there is significant opportunity to improve access to such advice.

Furthermore, the research showed an opportunity for employers to better demonstrate, and in some cases improve, how employees are supported following a cancer diagnosis to help reduce related job security fears.

This report highlights and recommends seven specific areas for further consideration and action. Should interested stakeholders be able to work together to affect change in these areas, meaningful progress will no doubt be made towards the goal of improving support for women throughout their cancer journey. Experience indicates that public-private partnerships are key to addressing challenges, due to a mutual objective of business and governments to generate sustainable growth to benefit their communities.

### **Survey methodology:**

### An overview of the 23-country research initiative

The Supporting Women With Cancer survey was conducted by Cello Health, a thought-leading health advisory firm, to ensure that findings were an accurate representation of women's experiences. Women in the

following 23 countries were surveyed: Argentina, Australia, Brazil, Canada, China, Colombia, France, Germany, Ghana, India, Indonesia, Italy, Japan, Jordan, Kazakhstan, Kenya, Mexico, Poland, Spain, South Africa, South Korea, the United Kingdom and the United States.

The research methodology was tailored across countries as needed to meet local requirements.

- 15-minute online quantitative interviews were conducted across 16 countries (Argentina, Australia, Brazil, Canada, China, Colombia, France, Germany, Italy, Japan, Mexico, Poland, Spain, South Korea, the United Kingdom, and the United States).
- 15-minute face-to-face quantitative interviews were conducted across five countries (Ghana, Jordan, Kenya, Kazakhstan and South Africa).

· 15-minute face-to-face and online interviews were conducted across two countries (India and Indonesia).

Across the entire survey globally, the sample was 4,585 women, with 200 participants per country except in Kazakhstan (n=201), Jordan (n=204) and South Korea (n=180). The sample sizes were chosen to collect a representative sample in each country and allow robust analysis and comparison across countries. The sample sizes were also selected to adequately allow for sub-analyses to take place, looking at country income level, region, age, education level, dependant status and diagnosis delay status.

Survey participants were required to be female, should have received a diagnosis and treatment for cancer and be aged between 18 and 80 years old, with a minimum quota for women living with cancer aged 18-40 years to aid analysis.

The research did not explore topics qualitatively and as a result, certain topics were not captured in great detail.

The topic of conversation was also sensitive for some respondents, therefore, there may have been inherent differences in those who chose to partake in the survey compared to those who were less comfortable and opted out. The decision was also taken not to ask or screen out respondents based on their date of diagnosis, to ensure that a wide population was reached without restrictions.

There is a small risk that variation in research recruitment and data collection per market may have influenced the results. All markets had the exact same quantitative questions asked using the same script.

This research was unable to collect information on resource availability as this varies considerably depending on socioeconomic status, geography, and changes over time.

The Supporting Women With Cancer survey explores the unique challenges faced by women affected by cancer and identifies areas where knowledge and understanding may be increased, and areas where more support may be beneficial.



### **Action Point 1:**

### **Education**

### The need to improve women's knowledge and understanding of cancer signs, symptoms and risk factors

Across countries and demographics, there is a need to improve women's knowledge and understanding of the risk factors, signs and symptoms of cancer, in particular those that are not widely considered to be 'women's cancers', regardless of income and level of education.

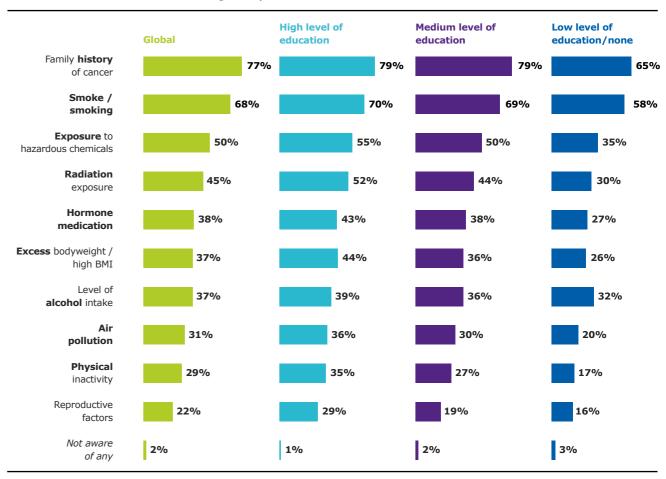
The education of both women and men on cancer remains a key health promotion priority in most regions around the world. However, the Supporting Women With Cancer initiative highlighted that only 45% of the women surveyed were aware of cancer signs and symptoms before receiving their diagnosis.

- · Women with a lower level of formal education had lower awareness of risk factors associated with cancer compared to those with higher levels of education. The issue of female education is complex and, in many countries, tightly connected to gender equality and the alleviation of poverty.7 The research further compounds the need to ensure women's access to education is a continued global priority, in support of improved women's health and the health of their economies.
- The older a woman was, the less likely she was to be aware of cancer signs and symptoms before a diagnosis. With cancer incidence increasing with age, education efforts that are specifically

tailored for older women can be considered important.

• Women in lower- and upper-middle income countries were less aware overall of the signs and symptoms of cancer, compared to those in high-income countries. While this disparity was anticipated due to potentially limited resources dedicated to public health awareness campaigns, it highlights the need to approach education efforts in accordance with country Gross Domestic Product (GDP). Public health and cancer advocacy resources will vary country-tocountry and there is a potential need to be even more targeted across geographies.

#### Women with a low level of education were generally less aware of cancer risk factors



The possible consequences of such low awareness of cancer risk factors, signs and symptoms are significant. This finding begs the question of how we can better tailor resources to achieve the needed degree of health education and empowerment.

One area identified by the research warranting additional attention is the focus on female cancers versus cancers that directly impact both genders. The women surveyed perceived predominantly female or female-only cancers—such as breast, cervical and ovarian cancer-to have the highest mortality, while significantly underestimating cancers with the highest mortality amongst both genders—for example lung, colorectal and stomach cancer.

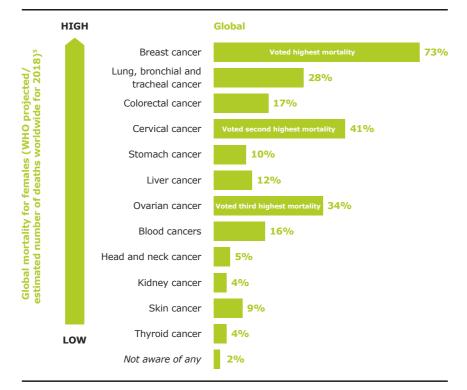
- Awareness of high mortality cancers was below average in women with a lower-level of formal education (people who had some schooling or no schooling) for the majority of cancer types.
- Awareness of cancers with high mortality that affect both genders (except for colorectal cancer), and not just women, was low across all education levels.

The cancers with the highest mortality in women according to the World Health Organization (as of 2018) are breast, lung and colorectal, and they have estimated that 30-50% of cancer cases diagnosed every year are preventable.<sup>5,8</sup> The women surveyed as part of the Supporting Women With Cancer research initiative perceived the cancers with the highest mortality to be breast cancer (73%), cervical (41%) and ovarian cancer (34%).

It could be fair to hypothesize that this awareness situation is a result of highly impactful female cancer advocacy and education.7 This is encouraging, but it also suggests there remains work to do in the extension or creation of education programs for women that address all cancers, not just those that only women are typically diagnosed or linked with.

Other research has highlighted the importance of educating women specifically on weight management as it relates to cancer risk. According to some predictions, cancer rates will increase nearly six times faster in women than in men over the next 20 years, with obesity partly to blame.9

Awareness of cancers with high death rates that affect both genders (except for colorectal cancer) was low



Several types of obesity-related cancer only affect women, so even though there is a growing number of people of both genders who are severely overweight, this is likely to have a greater effect on the incidence of cancer among women than men.<sup>10</sup>

Merck KGaA, Darmstadt, Germany in partnership with the American Cancer Society released a report at the 2016 World Cancer Congress focusing on the increasing impact of cancer in low- and middle-income countries, both on women's health and their economic participation. The report emphasized that while the societal and economic costs of cancer are considerable and even catastrophic, the burden of disease, loss of life, and economic hardship is not inevitable. For more information, visit https:// www.cancer.org/research/cancerfacts-statistics/global-burden-ofcancer-in-women.html.

Low awareness of cancer symptoms has been shown to be associated with longer delays in seeking medical help in multiple countries, especially for those living in rural and remote areas.11 Although access to, and the quality of, cancer treatments are important determinants of outcomes, some studies have observed higher delays in the presentation of rural patients to a healthcare professional.11

Via the Find Cancer Early campaign, researchers in Australia were able to show that by taking a very local, community-based approach they could successfully improve knowledge of cancer symptoms in remote areas, possibly leading to changes in behavior. More than a quarter of those who were aware of the campaign reported seeing a general practitioner as a result of their exposure.11

Simple community-based education interventions, in rural areas and specific urban populations, hold significant potential for the improvement of understanding cancer signs and symptoms.

### **Action Point 2:**

### Screening program awareness and access

### The need to increase awareness of, and access to, cancer screening programs for all women, to support the potential of earlier diagnosis

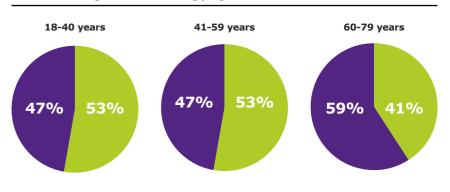
Cancer screening program access and awareness must be increased for all women, especially for those in lower-middle income countries or with a lower level of formal education, in order to support the potential for earlier diagnosis.

Of those women surveyed in the Supporting Women With Cancer initiative, nearly half (47%) had never attended a cancer screening program.

· Women with lower levels of formal education were less likely to access a screening program, irrespective of country GDP, with 54% having never attended one. The issue of female education, as it correlates to awareness and recognition of cancer signs and symptoms and the uptake of screening, is significant and will require sustained major international efforts to continue its improvement. In the short-term, the research shows that female public health initiatives must be increasingly focused on how to reach women, in order to be effective and resonate with women across all levels of formal education. • Age does not appear to be a significant influencing factor in women accessing cancer screening programs (47% of women aged 18-59 had attended a screening program, compared to 59% of women aged 60-79). This finding shows women of all ages must be better informed and encouraged to access screening programs in their areas. Undoubtedly, the availability of screening will be a barrier for women in some countries, however the findings also suggest more needs to be done to increase participation in screening initiatives already established.

• For women 60 and over, the most often cited reason for having never attended a cancer screening program was being unaware of such programs in their area (33%), while women aged 41-59 and 18-40 cited that they did not think they needed to attend (33% and 29% respectively). These findings hint at the potential to do more to promote screening initiatives at a local community level. It's vitally important that opportunities are capitalized on to improve this older age group's uptake of screening availability.

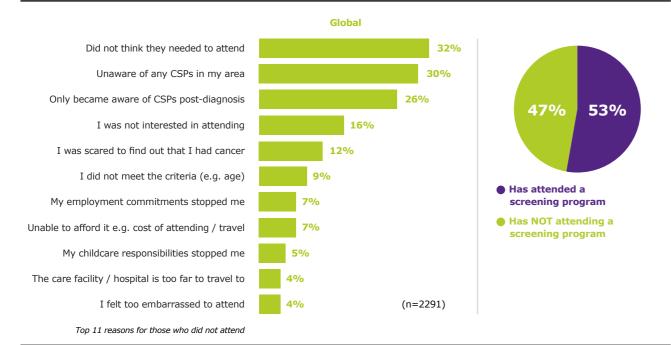
There was no significant difference between younger and older generations of women attending a cancer screening program



Has attended a screening program

Has NOT attending a screening program

#### Reasons women did not attend a cancer screening program (CSP)



### Awareness of cancer screening programs must be improved to support earlier diagnosis of cancer in women.

Women who did not attend cancer screening programs were significantly more likely to report thinking their cancer diagnosis had been delayed (38%). The barriers to accessing screening services included lack of awareness and understanding of the role of screening, fear of diagnosis or embarrassment around the procedure and logistical challenges related to attending tests and cost.

Correlation between women who had not attended a screening program and perception around delays in diagnosis

Has NOT attended a screening program



- Report cancer diagnosis was delayed
- Report cancer diagnosis was NOT delayed
- Does not know if cancer diagnosis was delayed

While screening programs differ country-to-country and by cancer type, too high a number of women are not participating in the screening initiatives that are available. More can always be done to increase screening efforts but equally, if not more importantly, increasing uptake must be a priority.

The barriers to participating in existing screening initiatives will also vary, not only across countries but across areas within them. It is crucial that uptake is continuously monitored, evaluated and assessed, with consideration given to what more could be done at regional, national and community levels. For example women in some parts of Asia may be concerned about revealing parts of their body to a healthcare provider. 12 Measures to help address such reservations might include always matching the gender of patients and healthcare providers to ease potential embarrassment.12

Delays in diagnosis were more common for women in lower-middle income countries. The three most significant reasons included higher rates of women in these countries not taking their symptoms seriously (52%), fearing a diagnosis (38%) and delaying a visit to their healthcare professional due to the cost involved (29%).

Nearly half of the women (49%) aged 18–40 were more likely to face delays in diagnosis compared to other age groups, mainly due to not taking their symptoms seriously (43%).

Other research has shown that women who were aware of the merits of early cancer detection were more likely to take proactive control of their susceptibility.<sup>12</sup>

All of these statistics point to the need to improve understanding of the importance of early detection, specifically what it can mean for outcomes as well as treatment

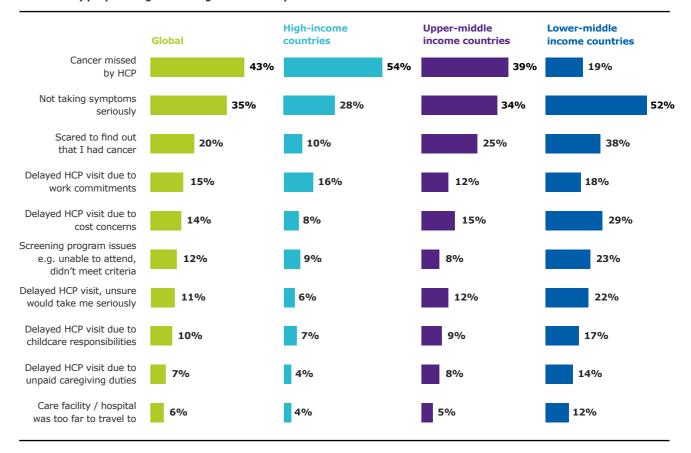
The Journal of Medical Screening studied the impact that British reality TV star Jade Goody's death from cervical cancer in 2008 had on screening attendance. Jade's diagnosis and ultimate death as a result of the disease was the subject of significant media coverage.

About half a million extra cervical screening attendances occurred in England between mid-2008 and mid-2009, the period during which Jade was diagnosed and died.<sup>13</sup> Among these screenings, suspected neoplasia was identified in 370 women.<sup>13</sup>

The pattern of increased screening attendance mirrored the pattern of media coverage related to Jade's diagnosis and death. It is likely that the increased screening resulted in a number of lives being saved.<sup>13</sup>

As time has passed though, the effect has diminished, and current reports suggest that screening is now at a 20-year low, indicating that just as awareness can dramatically rise, it can also fall, despite the risk, and potential repercussions.

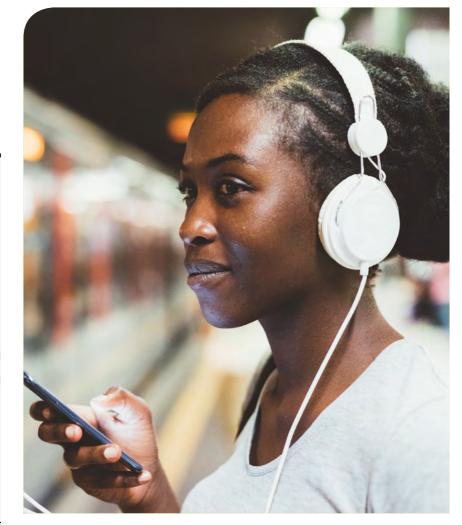
#### Reasons why people thought their diagnosis was delayed



management approaches. With the research showing that the barriers to screening are vastly different across demographics, it is critical that behavior change efforts are focused at a community level. Simple health promotion efforts to highlight where and how screening opportunities can be accessed also have a meaningful role to play.

I started working in colorectal cancer (CRC) 20 years ago and I have been dedicated to building and working alongside patient advocacy groups to educate the public and policymakers on CRC. Despite my experience and understanding of the disease, I, like many other people worldwide, delayed screening. However, last year I started feeling under the weather and I was concerned I had developed CRC. Deciding to face my fears, I visited a gastroenterologist to have a colonoscopy. The colonoscopy changed my life. Three transitioning polyps, one in the advanced stage, were found and removed. Now under surveillance, I will attend regular screenings to reduce my risk of developing CRC. I can't stress enough how important it is to get screened and, if there is a risk, attend a colonoscopy!"

Jolanta Gore-Booth Chief Executive Officer, Digestive Cancers Europe



### **Action Point 3:**

### Access to support services

### The need to improve women's capacity to maintain daily life via better access to support services tailored for their circumstances

All women should have access to healthcare solutions and be aware of the options available to them to protect their health and well-being. Further tailored services are needed for women looking for financial, emotional, employment or fertility support to ensure they can maintain their daily lives following a cancer diagnosis.

Only 42% of women surveyed had accessed support services. Those who had, mostly stated that one-toone counseling and support group attendance were the services they most used.

Differences were seen across the types of services that women were more likely to access. Those aged 18-40 were more likely to access a broader range of support service types, while older women were least likely to access most forms of support, especially group counseling or online help.

It was also noted that younger women were more likely to access support services compared to older women (60-79 years).

Those with caregiving responsibilities, including those caring for elderly / sick relatives, children or other members of the community, were much more likely to use support services versus those who did not, highlighting that these women likely feel a greater need for support in general.

Only one-in-five women believed they receive enough support to manage family responsibilities or fit work around their cancer. Those with a delayed cancer diagnosis were significantly more likely to report their lives had been impacted overall.

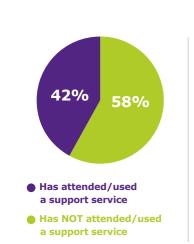
The need to look carefully at the pressures felt by women with caregiving responsibilities following a cancer diagnosis further was evident —those with dependants were less likely to have attended a screening

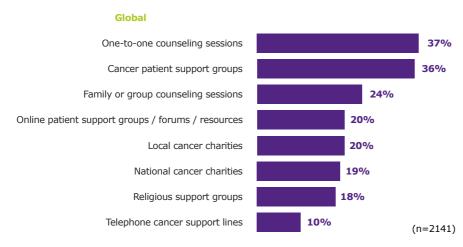
program and were significantly more likely to experience treatment cost burden. They were also more likely to have to leave formal employment because of their diagnosis.

Unsurprisingly, the financial burden was most felt in lower-middle income countries, with 74% of women believing that cancer and its treatment had impacted their personal finances.

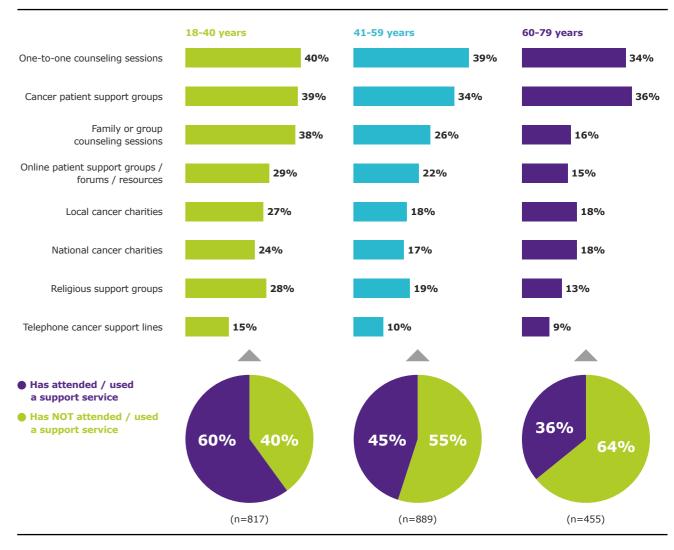
In order to enhance and improve the lives of women diagnosed with cancer, we must reduce the severe detriments to women's health caused by trying to balance family and workplace responsibilities. It is critical that as a global society we support women who work—both paid and unpaid—and create supportive work environments and health systems that can help women achieve greater work-life integration and improve their overall health and well-being.

#### Women's use of support services

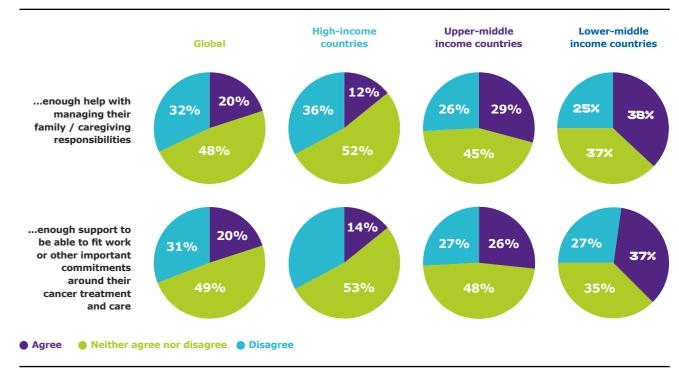




#### Age impacts the support services that women typically access



### Women's perceptions around the support available to manage family and work following a cancer diagnosis



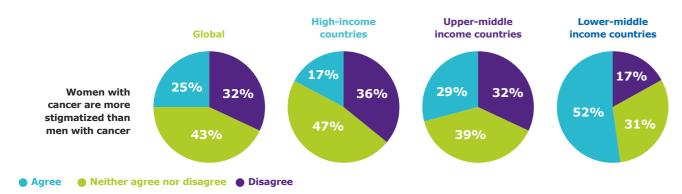
Parenting concerns also have a significant impact on the mental and emotional health of women living with cancer, particularly advanced cancer. 14 With cancer being a leading cause of death for parenting-age women in some of the world's most developed countries, it's not a surprise that parenting concerns have proven to have a negative influence on quality of life.14

A mother's emotional well-being has been found to be significantly linked with whether she had communicated with her children about her illness and her concerns about how her illness will financially impact her children.14

The pressures evidently felt by mothers following a diagnosis suggest part of the solution is helping them learn how to communicate with their children, promote resilience in them and plan for their family's future, especially if their illness worsens.

Perceived stigma also impacts how women are able to manage their daily lives following a cancer diagnosis. Women noted feeling burdened financially and across their work and family responsibilities. A quarter of all women felt they were stigmatized more than men as a result of their cancer. In lowermiddle income countries more than half felt that stigma was more acute for women.

Women living with cancer believe they are more stigmatized than men with cancer



The research showed that family planning support and fertility advice needs to be proactively offered by healthcare professionals to all women of childbearing age living with cancer.

Among those women of childbearing age, only 45% were offered family planning advice by a healthcare professional. High-income countries were revealed to be the least likely to offer family planning advice (as recognized by 55% of women) and 48% of women of childbearing age who were not offered fertility or family planning advice across geographies stated they would have liked to receive the advice.

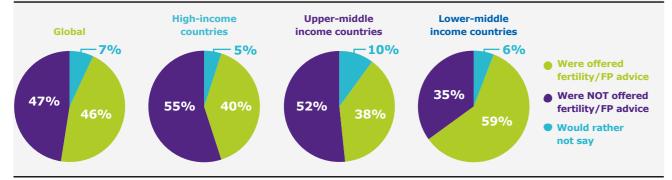
Those who were offered family planning and fertility advice from healthcare professionals found it helpful, importantly with the information impacting treatment choices for more than 57% of women overall and 74% of women in lower-middle income countries.

These findings suggest there is a real need for standardizing the offer of family planning and fertility advice across the healthcare professional community. As an interim measure, other less formal approaches can be considered at the national and community levels, including the encouragement of oncology nurses to play a more active role in directing women to family planning and fertility advice.

In July 2019, Merck KGaA, Darmstadt, Germany launched a support website with the intent to provide the latest scientific information to healthcare professionals in the advancing field of fertility, while also supporting women, men and couples who are looking for information about fertility and / or undergoing fertility treatments.

For more information see www.fertility.com

Less than half of the women living with cancer of childbearing age were offered fertility or family planning (FP) advice by a healthcare professional



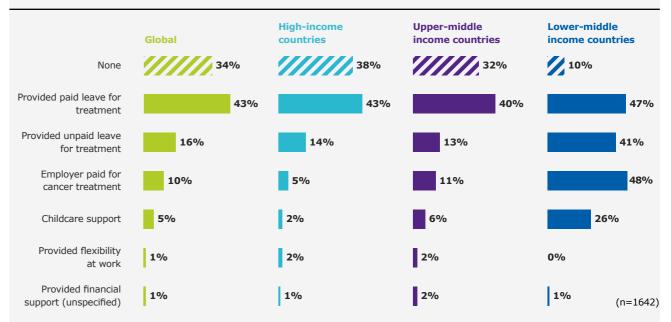
There is more that could be done to empower employers to better demonstrate, and in some cases improve, how employees are supported following a cancer diagnosis—especially to help alleviate job security fears. All public and private organizations have a role to play in creating equitable environments where women and men can work, without sacrificing their health. National policies and programs (new and existing) should also be championed to ensure those living with a cancer diagnosis receive support.

Most women were worried about the negative impact of informing their employer of their diagnosis, being particularly concerned about potential changes being made to their employment status or how they are perceived at work.

One-in-five women (20%) chose not to inform their employer of their cancer diagnosis, further cutting them off from potential support that could have been provided. However, one third of women (34%) who did inform their employer received no support from their workplace following their diagnosis.

Women in lower-middle income countries were the most concerned about changes being made to their employment status once their employer knew of their diagnosis. Additionally, more than half of women (52%) in lower-middle income countries employed part time were unable to work full time due to their cancer, compared to one third of women citing the same in uppermiddle income countries.

Extent and types of support provided by employer (% of women living with cancer who informed employer about cancer diagnosis)



Persistent pain and the fatigue mean that you have to take more and more time off work, the risk of losing your job increases which in itself is very stressful, either you go and not feel well and not be focused but that would be noticed, or if you take sick leave which would put ideas in their head that you'd be laid off"

Survey participant from France

I had to change job. I worked as a teacher before. I am very tired. I have to go to clinic very often. I need money for treatment of thyroid because they don't treat thyroid diseases here in Kazakhstan"

Survey participant from Kazakhstan



### Recommendations for change

### What more can we do for women living with cancer?

Improving the understanding of the challenges faced by women who are impacted by cancer is the fundamental first step to address and deliver the changes needed to drive better societal outcomes.

This report highlights several critical areas that warrant careful and immediate multi-stakeholder discussion, further assessment and most importantly-action.

#### Healthy Women, Healthy Economies

Originally conceived in 2015 within the Asia-Pacific Economic Cooperation and in collaboration with the governments of the United States and the Philippines, Healthy Women, Healthy Economies aims to identify and implement policies that advance women's health and well-being to support their economic participation.

Merck KGaA, Darmstadt, Germany is the founding private sector partner of Healthy Women, Healthy Economies and is expanding and making it part of its commitment by supporting research to quantify the impact and forming collaborations to advocate for change.

The Healthy Women, Healthy Economies initiative strives to unleash the economic power of women by bringing governments, employers and other interested stakeholders such as NGOs and patient advocacy groups together to help to improve women's health so women—and by extension their families—can join, thrive and rise in their communities and live better lives.

These areas include short and long-term recommendations:

#### Short-term

- 1. Promote wide-scale education to improve women's understanding of the benefits of early cancer detection and existing screening programs, specifically to support increased uptake of screening.
- 2. Ensure women of childbearing age living with cancer have access to fertility and family planning advice, due to the potential impact of cancer treatments on their fertility. For example, training nurses on the role they can play to advise patients to make informed decisions on fertility preservation, or other options that may be available.

#### Long-term

- 3. Review existing awareness programs and adapt as necessary to support more women identifying the risk factors, signs and symptoms of all cancers, in particular those associated with high incidence and / or mortality, and those that are incorrectly perceived to be of greater risk to men than women.
- 4. Advance multi-stakeholder engagement to consider how government health promotion resources can be leveraged and targeted at different audiences, with particular emphasis on influencing women with low levels of formal education, recognizing it is this demographic with the greatest need for improved awareness of cancer risk factors, signs and symptoms.
- 5. Consider how the healthcare community and stakeholders can be called upon to provide women of childbearing age with family planning and fertility advice, as an essential part of the cancer management pathway, or direct women to reliable resources and support structures to obtain this information.
- 6. Explore a further tailored approach to support services, based on an analysis of uptake, recognizing that different demographics of women need and want different support options. In some cases, provide different levels of support, and prioritize services accordingly. For example, focus on providing services needed by the prevailing demographic, such as tailoring services to older women in areas where there is a higher need.
- 7. Create employer education programs that equip workplaces with the tools and resources to support women through and beyond a cancer diagnosis.

### Conclusion

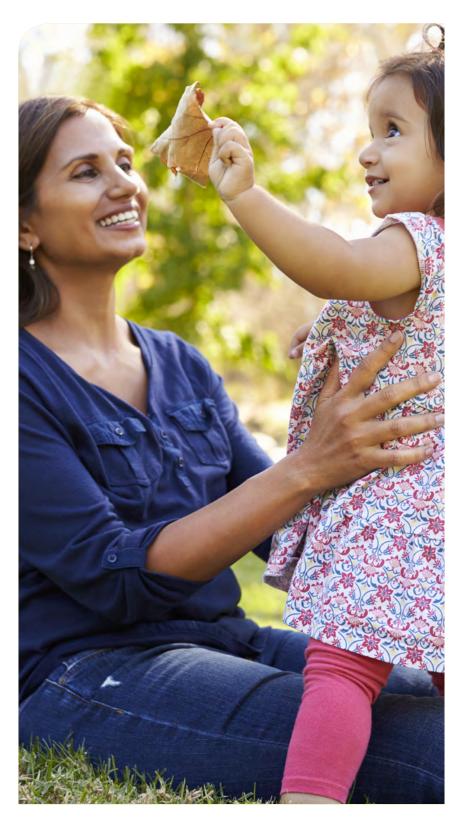
### There is always an opportunity to do more on behalf of women, but we can improve their support systems with the resources we already have

Cancer is a huge burden for men and women everywhere with health and prosperity clearly intertwined, but there are unique factors impacting women that need to be addressed.

Understanding the unique challenges that women face when living through cancer provides interested stakeholders great opportunity to lessen the weight of a diagnosis via the provision of tailored societal support.

The findings of the extensive Supporting Women With Cancer research initiative provide insights to inform meaningful discussion and subsequent action on how we can collectively support women impacted by cancer to live their lives as best as possible.

EMD Serono is committed to working with diverse stakeholders to find solutions to help turn insights into meaningful outcomes for women living with cancer.



### **About Merck KGaA, Darmstadt, Germany**

Merck KGaA, Darmstadt, Germany, a leading science and technology company, operates across healthcare, life science and performance materials. Around 52,000 employees work to make a positive difference to millions of people's lives every day by creating more joyful and sustainable ways to live. From advancing gene editing technologies and discovering unique ways to treat the most challenging diseases to enabling the intelligence of devices — the company is everywhere. In 2018, Merck KGaA, Darmstadt, Germany generated sales of €14.8 billion in 66 countries.

The company holds the global rights to the name and trademark "Merck" internationally. The only exceptions are the United States and Canada, where the business sectors of Merck KGaA, Darmstadt, Germany operate as EMD Serono in healthcare. MilliporeSigma in life science, and EMD Performance Materials. Since its founding 1668, scientific exploration and responsible entrepreneurship have been key to the company's technological and scientific advances. To this day, the founding family remains the majority owner of the publicly listed company.

For more information, visit www.emdgroup.com

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