Women as Change Agents in Oncology
Foreword

Throughout time women have played a significant role in the health of individuals and communities, often playing roles closest to those who are ill. From early pioneers, such as Marie Curie succeeding in the male dominated world of science, to the rise of leaders in patient advocacy of today, such as Jana Pelouchova and Tasha Westerman, women have held and continue to hold important roles in advancing the cancer agenda. This publication, while focusing on some of the individual women who have been agents of change in oncology, is a celebration of women’s contribution to science, practice, advocacy and care – all critical elements in tacking cancer.

Women’s leadership has some important features that are reflected in the stories featured here. Each of these women demonstrates the important ability to see a gap in knowledge, treatment or care and to set and reach goals associated with closing that gap. Their work shows a remarkable lack of self-interest or desire for personal reward, but rather focuses on what can be achieved for the greater good. This is not to suggest that any of these women should be under-estimated as each is a forceful character with a strong sense of self and the courage to break the rules when needed. I am sure that anyone who dared stand in the path of these women, with the intent of blocking the achievement of their goals, intimately understands that they are strong, persuasive and not easily shifted from their path.

Central to each of the stories represented in this publication is each woman’s clear understanding of the impact of cancer on individuals, families and communities and a desire to lessen that impact in tangible ways: improving understanding of how cancer occurs, finding cures, advancing treatment approaches, reducing the impact of cancer on physical, psychological, social and economic wellbeing, mobilising communities towards changing the face of cancer or changing the system to improve outcomes for people affected by cancer. Much of the work they undertake transcends any paid role they may have in cancer; making a difference involves significant voluntary contribution, passion and commitment over time. Their stories are inspirational, compelling and motivational, hopefully mobilising a call to action in us all. However, their stories are not unique, rather they are representational. In celebrating the contribution of these women we celebrate the significant and growing contribution of women everywhere to reducing the burden of cancer.

Professor Sanchia Aranda, RN, PhD
President-elect, UICC
CEO, Cancer Council Australia
Why ‘women’ as change agents in oncology?

The hypotheses

Although recent decades have seen great progress in the battle against cancer, there is still much work to be done. Projected incidence and mortality rates provide an important forewarning of the growing burden it will have on individuals; families; communities; societies and economies worldwide, unless more is done to prevent it. Roche, as part of its ongoing commitment to exploring new and effective ways to tackle cancer, developed this report to further investigate the following three hypotheses:

1. Women are disproportionately impacted by cancer, both directly and indirectly, increasing the burden cancer places on society

2. Women are a valuable source of positive change in efforts to reduce the global cancer burden

3. Maximizing the potential of women can help to advance the fight against cancer

Women as a source of positive change

Women have been making significant contributions to cancer treatment and care for decades. Whether as scientists; healthcare professionals; patient advocates; caregivers or patients, women have undeniably played a vital role in reducing the devastating impact cancer has upon individuals and societies across the globe.

This report reflects on some of the extraordinary achievements made by women through history to the present day. It also examines the disproportionate impact cancer continues to have on women and broader socioeconomic development, as well as perspectives on the most effective ways to rectify this now and into the decades ahead.
The disproportionate impact of cancer on women today

Women as patients
In societies across the globe, gender inequalities remain deeply entrenched in many aspects of life, including health. This has recently been highlighted by the Lancet Oncology / The Lancet Cancer Campaign, which considers women’s cancers a neglected area.

The International Agency for Research on Cancer (IARC) predicts a substantive increase of new cancer cases per year by 2025. It also highlights ‘striking patterns’ of cancer in women and suggests that particular priority should be given to cancer prevention and control measures for breast and cervical cancers globally.2

Breast cancer is the most common cancer in women, accounting for one in four cases and is the second most common cancer overall worldwide2. The next most common cancers in women include colorectal, lung and cervical, with slight variations between developed and developing countries (see table 1)3. Despite being largely preventable4, cervical cancer remains a significant problem in developing countries, which account for almost 70% of the global cervical cancer burden5. In fact, deaths from breast cancer and cervical cancer combined already outnumber maternal deaths in developing countries6.

There are also issues to be addressed in terms of stigma and the consequences of cancer treatment, such as infertility and disfiguration following invasive breast cancer surgery.

“Access to affordable and relevant health services and to accurate, comprehensive health information are fundamental human rights. Yet, gender-based discrimination, lack of access to education, poverty, and violence against women and girls can all prevent these rights from being realized for women and girls - challenges that are often particularly acute when it comes to sexual and reproductive health rights and safe motherhood.”

Amnesty International

<table>
<thead>
<tr>
<th>Worldwide</th>
<th>Developed Counties</th>
<th>Developing countries</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast (1,676,600)</td>
<td>Breast (793,700)</td>
<td>Breast (882,900)</td>
</tr>
<tr>
<td>Colon &amp; rectum (614,300)</td>
<td>Colon &amp; rectum (338,000)</td>
<td>Cervix uteri (444,500)</td>
</tr>
<tr>
<td>Lung, bronchus, &amp; trachea (583,100)</td>
<td>Lung, bronchus, &amp; trachea (267,900)</td>
<td>Lung, bronchus, &amp; trachea (315,200)</td>
</tr>
<tr>
<td>Cervix uteri (527,600)</td>
<td>Corpus uteri (167,900)</td>
<td>Colon &amp; rectum (276,300)</td>
</tr>
</tbody>
</table>

Table 1: Estimated new cancer cases in women according to, GLOBOCAN, 2012
Women as caregivers

Across the world, women and girls commit substantially more time than men to unpaid care care. It is most often mothers, wives, sisters and daughters caring for a family member living with cancer. With informal caregivers providing an average of 35-50 hours per week, this can have a detrimental impact on their health, wellbeing and finances. For example, one study on women and caregiving found that:

- 33% of working women decreased working hours
- 29% missed a job promotion, training or assignment

In some cases, it may be necessary to significantly reduce or even leave paid work entirely, with very little or no financial support. Even in a high income country such as the UK, a person that has left work due to caregiving responsibilities may receive as little as £1.70 an hour in caregiver benefits.

Global NGOs are beginning to acknowledge the disproportionate impact of caregiving on women and are encouraging positive action to address it. For example, UN Sustainable Development Goal 5: Gender Equality, includes the target to ‘recognize and value unpaid care and domestic work through the provision of public services, infrastructure and social protection policies and the promotion of shared responsibility within the household and the family as nationally appropriate’.

The consequences for healthcare systems and broader societies

As the cancer burden worsens for women as patients and caregivers, the strain it puts upon already stretched healthcare systems in nations across the globe will also get worse. However, the consequences of the cancer burden reach far beyond healthcare systems into many aspects of a society’s ability to develop and prosper. For example, the further a woman’s quality of life is impaired as a patient or caregiver, the less she will be able to continue with her paid and unpaid work. With women accounting for more than 40% of workers worldwide and their unpaid work estimated to have a monetary value of between 10% and 39% of GDP, the implications for society are substantial.

The wider economy is affected by loss of productivity from patients and their caregivers and correspondingly, the wider economy would benefit from interventions that enable people to get back to work. Investment in improvements in prevention, treatment and system efficiencies, could reduce the burden of cancer on women and therefore also healthcare systems and broader societies.

“It is estimated that if women’s unpaid work, for example as mothers and housewives, were assigned a monetary value, it would constitute between 10% and 39% of GDP.”

United Nations Research Institute for Social Development. Why care matters for social development, 2010
Throughout history, whether as scientists; healthcare professionals; patient advocates; caregivers or patients, women have played a vital role in the fight against cancer. Here, we celebrate two such women, who have made outstanding contributions in science.
Professor Marie Curie

Marie Curie

Marie Curie (1867 -1934) was a double Nobel Prize-winning physicist and chemist who helped shape modern chemistry and physics at a time when women were rarely acknowledged as having any standing in professional life, science or academia. Her work led to the discovery of radioactive elements, opening the way for treating many types of cancer, as well as wider advances in radiology and x-ray techniques.

Achievements at a glance:

• Discovery of the radioactive elements polonium and radium

• Publication of 32 scientific papers, including one proposing that diseased tumor-forming cells were destroyed faster than healthy cells when in contact with radium

• First female faculty member at the École Normale Supérieure to be awarded a doctorate

• Given a professorship in physics at the Sorbonne, the first time such a prestigious Sorbonne professorship had been awarded to a woman

• Awarded a Nobel Prize in 1911 in a different scientific field, chemistry, for discovering a way to measure radioactivity
  – This breakthrough led the University of Sorbonne to build the world’s first radium institute with two laboratories; one for study of radioactivity under Marie’s direction and the other for biological research into the treatment of cancer

• With the outbreak of World War I, Marie applied her expertise as a pioneering scientist to humanitarian work for the war effort. The International Red Cross appointed her to head of its radiological service and she organized training courses for medical staff in the new techniques. This included equipping the world’s first X-ray vans, which she drove to the front lines, and became famously known as Petites Curies (Little Curies). The vans enabled battlefield surgeons to treat the wounded at the front, saving thousands of lives.
“Not only did she do outstanding work in her lifetime, and not only did she help humanity greatly by her work, but she invested all her work with the highest moral quality. All of this she accomplished with great strength, objectivity, and judgment. It is very rare to find all of these qualities in one individual.”
Albert Einstein

“I have frequently been questioned, especially by women, of how I could reconcile family life with a scientific career. Well, it has not been easy.”
Marie Curie

Continued legacy
Despite the scale of her achievements, Marie faced prejudice from sections of the French press and some male scientists for being a woman and an immigrant and never received significant financial benefits from her work. She died on 4 July 1934 from leukaemia, possibly caused by exposure to high-energy radiation from her research at a time when the risks were not fully known.

In 1948 The Marie Curie International Memorial was formally established and shortly afterwards became the Marie Curie Memorial Foundation which was the beginning of the charity that is known today as Marie Curie. For her scientific achievements alone, Marie Curie’s reputation would put her in the top league of 20th Century scientists, but for a woman to achieve such recognition was unheard of in her time.
Professor Janet Rowley

Professor Janet Rowley was the first person to discover the link between genetics and cancer. Her breakthrough came in 1972, when she proved that certain types of cancer could be caused when chromosomes abnormally swapped place. Her discovery and future work helped to revolutionize cancer science and lead to the development of life saving targeted cancer treatments.

Achievements at a glance

- Discovered a swapping of two chromosomes evident in all patients with a form of leukemia known as AML (acute myeloid leukemia). This was the first identification of what is now known as ‘chromosomal translocation’
- Discovered a second and third chromosomal translocation in patients with two other types of leukemia: chronic myelogenous leukemia, or CML and acute promyelocytic leukemia
  - Her discoveries were so departed from current scientific thinking that it wasn’t until the third translocation was identified that her discoveries were widely accepted
  - Since that time, researchers have identified hundreds more translocations linked to specific cancers, which have allowed the development of therapies which target the genetic defects known to have caused the cancer
- Appointed to the National Cancer Advisory Board (1979 - 84) by President Jimmy Carter
- Awarded the National Medal of Science (1998) by President Bill Clinton
- Served on George W. Bush’s President’s Council on Bioethics (2002 to 2009)
- Stood next to President Barack Obama when he lifted the federal moratorium on funding for stem cell research (2009), and received the Presidential Medal of Freedom later that year

“I’ve never regretted being in science and being in research. The exhilaration that one gets in making new discoveries is beyond description.”

Professor Janet Rowley
"I have a research project started in England that I’d like to continue with. Could I work here part time? All I need is a microscope and a darkroom. And by the way, will you pay me? I must earn enough for a baby sitter."

Professor Janet Rowley describing her request to continue her research during an interview with the New York Times, 7 February 2011

- Awarded the Lifetime Achievement Award from the American Association for Cancer Research (2010), Japan Prize for Healthcare and Medical Technology (2012) and Albany Medical Center Prize (2013)
- Received honorary doctor of science degrees from 14 institutions, including Oxford, Harvard University, Yale University, the University of Pennsylvania and Dartmouth College

Continued legacy
Dr. Rowley died from ovarian cancer at the age of 88. Her contributions to increased understanding of cancer and our ability to treat it are without question. Some of the additional challenges she faced as a woman, such as having to wait to enroll for her medical degree at the University of Chicago as its quota of three women per year had already been reached and managing her research around raising four children, make her accomplishments all the more impressive.
Although gender inequalities remain, women are now rightly being afforded increased influence in today’s world. Here, we profile five women who are making remarkable contributions to the fight against cancer.
We have seen throughout history the ability of women to drive change. Here, we profile and celebrate three women who have made extraordinary contributions to the fight against cancer.

Taking co-ordinated action in the fight against breast cancer

I started IMAMA 23 years ago in a city called Porto Alegre in the very south of South America, with a group of people passionate about providing education, physical and emotional rehabilitation and social mobilization towards early breast cancer diagnosis. Today, the group has grown to a nation-wide organization, which is proud to be a member of the Union for International Cancer Control (UICC). FEMAMA was founded in 2006 with a simple but vital aim: to reduce the number of women dying from breast cancer in Brazil. Thanks to the hard work of the dedicated team, FEMAMA now incorporates 59 NGOs in Brazil, with partners in Latin America and Mexico and represents the largest NGO member of the UICC.

The need for improved access to timely breast cancer diagnosis and treatment

One of the most pressing problems when it comes to breast cancer in Brazil is the time that it takes for women to be diagnosed and receive treatment. Too many women are losing their lives to breast cancer in Brazil, not because they have a more aggressive form of the disease than women in other parts of the world, but because they are not receiving screening, referrals, specialist care and adequate treatment quickly enough. Improving this situation has been the main focus of our health policy work at FEMAMA.
Ensuring women can continue their personal and societal responsibilities

Too often there is a focus on just treating the disease, not the person. Cancer is complex, so there is a habit of seeing just the disease or the body part, not the human being whose life it has become part of. When a women is diagnosed with breast cancer the healthcare process and society expects her life to be put on hold. But the reality is that life continues, as do its everyday demands, particularly as breast cancer often hits women in their most active phase of life, when they are working and have family commitments. However, this is not well enough considered when it comes to their treatment. There are too many different appointments at different times, creating a significant added burden. I believe that if we were able to reduce the number of appointments by providing single multi-disciplinary support sessions with experts from across the board, e.g. clinical, psychological and legal, there would be a less traumatic impact on a woman and her ability to continue with her life. We should not just provide a woman with treatment, but also help get her through it.

Ironing out inequalities

I think access to cancer treatment is still a problem, not only in Brazil but globally. Many countries have good treatment facilities but the waiting times are long and most cancers are time sensitive. More personalized treatment options are needed, and patients should be provided with more information and access to them, as they can make such a huge difference. For example, after I returned to Brazil, I had to quickly realize that women with the same diagnosis I had seen in the USA or the UK had a smaller chance of being cured. It gave me nightmares, so this is when I started to more intensively devote my time to ensuring that these things were improved. The very restricted Brazilian health system is my biggest frustration, but at the same time my biggest motivation to continue fighting for women’s health. Breast cancer does not have to be a death sentence.

Dr. Maira Caleffi
To educate people about the disease, their rights, their power and how they can change other people’s lives is a magical feeling. This is something that women should embrace, their actions could not only help their own plight, but that of others in the decades ahead.

Cancer as a catalyst for positive change

I would say the majority of the women I see as patients are submissive. Often they have lived their lives trying to please or care for others, not sharing their own feelings or pushing for action or changes that will help themselves. It is very important that this changes when it comes to women’s healthcare. One thing this advocacy crusade has taught me is the true value of empowerment. It is not about being a role model, I would never consider myself as that, as I don’t feel my own life is perfect! However, to educate people about the disease, their rights, their power and how they can change other people’s lives is a magical feeling. This is something that women should embrace, their actions could not only help their own plight, but that of others in the decades ahead. It can bring an enormous sense of satisfaction. Often a cancer diagnosis is the first time a person is forced to think in depth about their own mortality, but this may also be the first time a woman thinks about what she wants for her own life and can be a catalyst for positive change.

An active role for women in the fight against cancer

Women already play a big role in family care and education, as well as within their immediate communities. This is where they can share their knowledge and be a driving force for change. Even in terms of prevention, they can play a role, engaging and educating others on risk factors and the importance of lifestyle changes. I see great possibilities in terms of what women can potentially achieve if they are empowered to play a more active role. There is nothing more important. When it comes down to it, health is the only thing that matters.

I see great possibilities in terms of what women can potentially achieve if they are empowered to play a more active role. There is nothing more important. When it comes down to it, health really is the only thing that matters.
We have seen throughout history the ability of women to drive change. Here, we profile and celebrate three women who have made extraordinary contributions to the fight against cancer.

Cancer misconceptions and fear

There remains a lot of stigma and misinformation around a cancer diagnosis, so it is still greatly feared. Even when patients present with early stage curable cancer, the amount of fear that exists is astounding. This stigma has a huge impact and can really turn a person’s life upside down, even in developed countries like Canada. There’s a blurry boundary between stigma and fear and it’s not just about the reaction of the person who is diagnosed, but also those around them, such as their co-workers or community.

The need for better support and inclusion for people living with cancer

There’s still a lot of work to be done in terms of ensuring support and inclusion for cancer patients, for example support in returning to work. In my institution, we have combined psychosocial oncology, supportive care and volunteer services in one big department under single leadership and this has helped tremendously. However, many institutions don’t have the resources to put these programs in place and in the majority of countries around the world, struggles remain around access to basic cancer care. So the needs and impacts really differ from country to country.

Dr. Mary Gospodarowicz

Immediate-Past President, Union for International Cancer Control (UICC) and Medical Director of the Princess Margaret Cancer Centre at the University Health Network in Toronto

Dr. Gospodarowicz received her medical degree from the University of Toronto and holds specialty certifications in internal medicine, medical oncology and radiation oncology. She is currently Medical Director of the Princess Margaret Cancer Centre at the University Health Network in Toronto, where she and her team treat patients with malignant lymphomas and genitourinary cancers.

Aside from her hands-on work in treating cancer patients, Dr. Gospodarowicz has been proactive in helping advance scientific and clinical progress in her field. She has authored more than 250 peer-reviewed articles, book chapters and letters and has been at the forefront of clinical trials evaluating the role of radiation therapy in lymphomas, prostate cancer, bladder cancer and testis cancer.

In addition, she has been a Member of the Board of Directors at the Union for International Cancer Control (UICC) since 2006 and played a key role in its work on cancer staging. Dr. Gospodarowicz is the immediate past-President of UICC and continues to work with the UICC in its mission to unite the cancer community ‘to reduce the global cancer burden, to promote greater equity and to integrate cancer control into the world health and development agenda.’
Taking faster and more definitive action on cancer

Cancer is complex. It is not one disease. Diagnosis is complicated, treatment is complicated. There is still so much to be done that requires faster and more definitive action. The achievements made by the HIV community are a testament to the value of advocacy and making it clear the current situation isn’t tolerable. Also, the cancer community is not united. It is important that the community comes together and much of the work at UICC has focused on this.

Harnessing women’s qualities in the fight against cancer

I think women are much more open to admitting that the situation is far from perfect and we need to collaborate. Many executive boards of companies greatly value and recognize the attributes women can bring. Most people observe that when women are included, the conversation changes. It becomes more caring, more considerate and more inclusive. Women in their caregiving roles are part of a culture that promotes acceptance. It’s interesting how you can harness these experiences and apply them to broad aspects of cancer.

“There is gradually more consideration of the value of broader contributions to society when it comes to investing in health. There is increasing evidence to show that improving life expectancy and quality of life is good for a country’s economy.”
The socio-economic value of investing in health

There is gradually more consideration of the value of broader contributions to society when it comes to investing in health. There is increasing evidence to show that improving life expectancy and quality of life is good for a country's economy. Ultimately, women who live well longer can continue to contribute to society for longer. If we invest in healthcare, then there is good return on investment.

Making progress through engagement, altruism and business

First and foremost we must engage in order to successfully tackle the growing global cancer burden. There's a huge need to engage young people. In medicine, we are very traditional. There is a belief that you are not ready to lead until you are a senior physician, department head or hold a position of authority and I think it's wrong. We need to harness the energy of people when they're in their 30s as the fight against cancer is going to be a long one.

Each country's needs and situations differ but this is something we should embrace. Countries that are less developed don't want to be told what to do. Instead, they look for partnerships and solidarity, particularly as even the most developed countries don't have cancer control completely right yet. It is important this is acknowledged in order to make progress.

I feel it’s important to combine altruism and business acumen in healthcare. In my department, healthcare is frequently considered as a higher calling and people do not like to think that it is an industry, but business skills help us to ensure there is value in health investments. We can be more effective that way, allowing for better progress and sustainability.

Women in their caregiving roles are part of a culture that promotes acceptance. It’s interesting how you can harness these experiences and apply them to broad aspects of cancer.

Satisfaction of playing an active role in tackling the cancer burden

Of all the work I have done, one aspect that makes me proud is my trainees. Those who worked with me who have gone on to bigger and better things in their own careers and are now a force of their own, I feel like a mother proud of her children! Also, I am just so pleased to be able to say I have participated in the fight against cancer, in all aspects – care delivery, research, innovation, progress. It’s very exciting to be part of all that.
Providing much needed patient information and empowerment

After I received my cancer diagnosis and while I was undergoing treatment, I was surprised by how little information and support were available to patients like me. This moved me to set up Diagnoza CML, a Czech language information portal on CML, to educate patients on new treatment options and help them understand how to take their medications correctly and manage the side effects. As I built relationships with patient advocates in other countries, I was particularly inspired by colleagues from the United Kingdom who had established online forums in which patients could share medical information and best practices on advocacy. This showed me a totally new world – one in which patients weren’t limited to mutual support, but instead could obtain practical and reliable information they could use to become active participants in their own care, as well as more effective advocates in dealing with healthcare decision makers.

When she was diagnosed with chronic myeloid leukemia (CML) in 2002, Jana experienced firsthand many of the challenges faced by people living with CML. Astounded by the lack of information available in the Czech language, Jana took action and established Diagnoza CML, a national society providing much-needed practical support for people diagnosed with CML in the Czech Republic. The organization has since transformed to support patients with all types of leukemia, starting with chronic lymphocytic leukemia (CLL).

Since then, she has worked tirelessly to improve access to expert care, novel therapies and clinical trials for patients worldwide. In 2007, she co-founded CML Advocates Network, a worldwide network of non-profit organizations supporting CML patients and their relatives by sharing knowledge and best practices, running joint campaigns, and educating advocates on how to build and grow their own patient organizations.

In addition, Jana is President of the Swiss-based Leukemia Patient Advocates Foundation and a member of the Steering Committee for CML Horizons. In 2013, she was also elected Secretary of the European Cancer Patient Coalition (ECPC).
Connecting and growing CML patient support groups around the world

I became a co-founder of CML Advocates Network to help people in other countries set up and grow their own national CML groups. This global advocacy network has been a tremendous resource for my own organization and many others like it. Since it was founded, the network has grown to include more than 100 member organizations on all continents. It has demonstrated the power of networking to help small grassroots organizations grow into really effective patient support groups.

Making the patient voice heard

In the past, many patient groups have focused on giving care and emotional support to individual patients. This is very important, but there’s so much more we can do. Patient advocates need to ensure that cancer patients have access to useful information that will help them become active partners in their own care. We can also ensure that payers, regulators, reimbursement authorities and other healthcare decision makers hear the patient’s voice and understand the many complicated needs that cancer patients have.

This is a particular challenge for us in the Czech Republic, because the healthcare system doesn’t yet offer many opportunities for including patients’ perspectives in the decision-making process. Even though the patient community here is small, we have considerable first-hand experience and expertise that we want to share with the healthcare authorities, to help them develop policies that address adequately the full range of patients’ needs.

Enabling people with cancer to remain productive members of society

Especially among younger cancer survivors, much of the unmet need centers on job-related concerns. Cancer can take people out of the workforce for several years, and many survivors face discrimination and other barriers when they try to return to work. Employers are sometimes reluctant to hire cancer survivors, thinking they might be more prone to infection, get tired more easily, take more time off, and be less productive while on the job. We need to do more to change society’s perceptions about cancer, and this will become even more urgent as more people survive cancer thanks to effective new treatments. We should encourage
employers to view cancer survivors as individuals – they have the same professional qualifications and skills they had before they got sick, and they deserve a fair chance to remain productive and contributing members of society. Stigmatization often causes cancer survivors to hide information about their condition from potential employers, and that’s not right. As patient advocates, we can help raise awareness of these challenges and find solutions.

**The importance of improving quality of life**

Quality of life is very important, but it varies from patient to patient since each one is unique and experiences side effects differently. Some patients manage major side effects quite well, while others struggle a lot with things that we might be consider rather mild. How well patients can tolerate the side effects of treatment has a great bearing on their overall quality of life, including the ability to pursue hobbies, work and stay socially engaged. I’m excited about the prospect of more personalized treatments that can be targeted to the particular needs of individual patients and help them cope more effectively with treatment.

**Women as caregivers**

Women face special challenges relating to cancer, since they are often patients and caregivers at the same time, managing their own health as well as caring for their partners and children both materially and emotionally. The women I’ve known and worked with in supporting cancer patients haven’t been driven by ego or desire for fame. They’re motivated simply by the satisfaction of seeing the positive impact of their work on other patients. It’s not just women’s responsibility though, we need to engage everyone in society, including men, to be passionate and effective advocates for people living with cancer.

**A message of hope**

If I were to have one message to other women who want to make a difference in the fight against cancer it would be ‘don’t lose hope’. We’ll succeed over the long run, even though positive change might not come soon enough to benefit patients who need help right now. But whatever we can do to help patients today, even if its impact feels limited, will build a foundation for big improvement for people living with cancer in the future.

“We need to do more to change society’s perceptions about cancer, and this will become even more urgent as more people survive cancer thanks to effective new treatments.”
We have seen throughout history the ability of women to drive change. Here, we profile and celebrate three women who have made extraordinary contributions to the fight against cancer.

**Leading the way for the integration of psycho-oncology**

I was trained in clinical psychology and soon developed a passion for helping people mitigate the psychological impact of their illness and learn to cope with the consequences of treatment. However, at that time, there were no official jobs as a health psychologist. My career started at Hospital de São José in Lisbon, where I was needed to support a group of young patients and their families following an explosion at a high school which had caused them to suffer severe burns. Gradually, the types of patients I saw grew to include those affected by cancer.

Dr. Luzia Travado is a clinical health psychologist and psychotherapist. When she began her career in the 1980s, psycho-oncology was still developing and was poorly understood. Now a specialist in psycho-oncology, Dr. Travado has unequivocally demonstrated the value of psychosocial support for patients with cancer, and has advocated for early patient access to this highly effective and necessary element of mainstream care. In 2013 she was awarded her doctoral degree (PhD) in Health Psychology for her dissertation ‘The Role and Challenges of Psycho-Oncology in Improving Cancer Care’.

Taking inspiration from her patients and with a determination to influence care in cancer, Dr. Travado was initially involved in raising the profile of psycho-oncology at a local level. As her career progressed, her span of influence increased to policy change at the national level, serving as an adviser to the Portuguese Cancer Program Director, Ministry of Health and representing Portugal in the European Partnership for Action Against Cancer (EPAAC), under which she led the Psychosocial Oncology Action. With the aim of bringing improved care to a wider reach of patients with cancer, she has been involved in various European Commission initiatives, contributing to the inclusion of psychosocial care into key policy documents and recommendations (e.g. the European Guide for Quality National Cancer Control Programmes). Currently, she is collaborating with the Cancer Control in Europe Joint Action (CanCon 2014–2017) and is a member of the Quality Assurance Scheme Development Group of the European Commission Initiative on Breast Cancer (ECIBC). Moreover, she is President of the International Psycho-Oncology Society (IPOS).

Dr. Luzia Travado

*Head of Psycho–Oncology Unit, Champalimaud Clinical Centre, Champalimaud Foundation, Lisbon, Portugal*
In the beginning, as the only psychologist in an under-recognized field and as a female doctor in a traditionally male environment, I had to work hard to defend my role by showing the value of attending to patients’ emotions and helping them to cope more adaptively with their clinical situations. For example, helping them to comply with difficult treatments and adjusting to physical changes in a more positive way. As my practice grew, my colleagues and patients began to see the value of my work. It was a win-win situation, as I not only supported patients once they had been diagnosed but I also supported the doctors and the clinical team with the tough task of communicating the bad news of a diagnosis to their patients. Over the years, we have managed to integrate psycho-oncology more and more into the multi-disciplinary cancer treatment teams.

**Proving the value of psycho-oncology as part of a multi-disciplinary approach**

A cancer diagnosis is a cause of great distress to patients. We know that about 50% of cancer patients suffer from severe distress. If this is not adequately managed, the impact on quality of life can be severe. Some patients may experience longer hospital stays or reduced treatment compliance. Others may show a decreased benefit from chemotherapy. Psychosomatic complaints may increase and patients may have a shorter survival expectancy or inclination towards suicide. This burden often extends to caregivers.

There is substantial evidence to support the positive impact of psychosocial interventions on patients’ quality of life and clinical outcomes. Slowly, we are seeing psychosocial cancer care being recommended as mandatory for quality cancer care within treatment guidelines and standards. Yet, there is still much debate amongst health professionals, patients and policy makers about the importance of addressing these needs. I am determined to contribute towards closing this gap through my role as President of the International Psycho-Oncology Society (IPOS) and participation in European Commission projects. I aim to help ensure that psycho-oncology training, clinical practice guidelines and standards for psychosocial cancer care are disseminated, and that cancer policies include psycho-oncological care. It is essential that we ensure psychosocial care is available to help ease cancer suffering for as many people as possible across the globe.
We know that about 50% of cancer patients suffer from severe distress, which may develop into a psychological condition with a negative impact on their clinical outcomes.

Reducing patient distress to help tackle the cancer burden
There is so much still to be done in all aspects of improving the cancer burden, from prevention to diagnosis and treatment, ensuring that patients have access to high-quality services throughout their journey. I would like to see patient distress universally accepted as the sixth vital sign, and psychosocial care recognized as a universal human right, which is included in routine cancer treatment and care, as part of a multi-disciplinary approach to whole patient care, standards and cancer policies.

Ensuring the inclusion of psychosocial care in national and European cancer plans
In 2007, I was invited to act as an adviser to the National Coordinator for Oncological Diseases, who was in charge of developing the Portuguese National Cancer Plan within the Ministry of Health. I made it my personal objective to help ensure that psychosocial care was included in the program. I was also given the opportunity to represent Portugal in the European Partnership for Action Against Cancer (EPAAC), which was launched in 2009 by the European Commission. This aimed to develop core multi-disciplinary areas and share expertise and successful strategies to reach our common goal of reducing the cancer burden across Europe. We worked closely with experts from all EU Member States to reduce inequalities and ensure that all Europeans affected by cancer have access to high-quality treatment and care. In particular, I was appointed to lead the Psychosocial Oncology Action which I had proposed as part of the healthcare work package of the Joint Action. This action supported by EPAAC and IPOS, had three main objectives: to map the psychosocial needs and infrastructure in the different EU Member States; to develop an educational training tool for psychosocial care and communication skills that could be replicated throughout the EU; to pilot the educational training tool in an underserved EU Member State. Romania was the recipient of this pilot training.

It has really been my key objective all throughout these various activities to ensure that psycho-oncological care becomes available to all affected patients from the very moment of diagnosis and onwards.
A vision for better integrated cancer care

My vision for the future is better integrated care. We need to build bridges and communicate more effectively within the cancer community at all levels and across all disciplines. Psychosocial care must be recognized as a human right and should be fully integrated into the treatment plan. It should not be considered a luxury nor only made available once the patient shows symptoms of depression or severe distress. To ensure the best clinical outcomes, we need to ensure patient access to psychosocial treatment right from the start, from the moment they are given their diagnosis. I also would like to see patients playing a more active role in all aspects of their care, but for that they need to be empowered and equipped with the right tools – most importantly comprehensive treatment and rehabilitation plans that address all dimensions of the illness (psychosocial, physical, neurocognitive, sexual, nutritional, etc.) to encourage self-management. It is so important to think about rehabilitation alongside treatment and to seek to minimize and address damaging side effects of treatment as early as possible to safeguard patients’ right to quality of life. Psychosocial support plays an integral part in this and is required along every step of the patient journey as a way to prevent or reduce unnecessary suffering.

“
I, like others, want to live a happy and positive life and with the right support we can do that, we owe it to ourselves.
”

Taking inspiration from other women

There are two women who have been a particularly strong inspiration to me: One is Dr. Jimmie Holland, Wayne E. Chapman Chair in Psychiatric Oncology at Memorial Sloan Kettering Cancer Center in New York and founder of IPOS; the other is the mentor of my doctoral studies, Dr. Julia Rowland, Director of the National Cancer Institute’s Office of Cancer Survivorship in Bethesda, Maryland. These two strong and dedicated women have served as true ambassadors for our discipline and pioneers of psycho-oncology, having co-authored the first Handbook of Psycho-Oncology in 1989 which opened the doors of psycho-oncology to the world.

The role that women can play in the fight against cancer

I believe that women should be encouraged to take a much more active role in managing their health. Through provision of relevant information, they should have the confidence to take action and engage in healthy lifestyles. Daily exercise is fundamental to staying in good health both physically and mentally. I wish more women understood the value of walking, dancing, using the staircase, having good dietary habits, sleeping a sufficient number of hours and generally taking good care of themselves by leading a happy and positive life, making time for their family and friends, and quitting tobacco or excessive alcohol consumption. I exercise regularly and really try to lead by example on this as I don’t think I could tell my patients to take good care of themselves if I didn’t have a balanced lifestyle and positive attitude myself. I, like others, want to live a happy and positive life and with the right support we can do that, we owe it to ourselves.
Facing cancer as a patient and a caregiver

My husband and I were both battling cancer at the same time while trying to raise our young son. Thankfully, I got through my second bout of breast cancer, but then Ryan’s brain tumor became terminal. I think the hardest thing for both of us was how to tell our son, Talyn, that his Dad was going to die. We had nobody to turn to for advice. After Ryan passed away, my top priority was keeping things as stable as possible for Talyn. He had suffered the tremendous blow of losing his father, but I was determined that everything else stay the same. At just 35 years old and recovering from cancer myself, I kept him in the same school and home, which was very difficult to do on my single income. It was a very stressful and challenging period, financially, emotionally and physically. Facing all of these challenges all at once was very difficult, but it really fueled my passion to work as an advocate.

The impact of cancer on women

Women with cancer are trying to be the best wives, mothers, and daughters they can be, on top of all their other responsibilities, also while dealing with the tremendous physical toll that the disease and its treatment take. The fact that many women with cancer can’t work poses additional challenges, especially for those at a stage in their career when they must work hard to keep pace with their male counterparts. For me personally, I felt at times as though everything important in life had been taken from me: my husband, my health, my son’s childhood and my ability to work.

Newly married and with an infant son, Tasha Westerman was diagnosed with aggressive breast cancer at the age of 32. Despite initial treatment, her cancer later returned and, simultaneously, Tasha’s husband Ryan experienced a recurrence of brain cancer that ultimately claimed his life. While caring for Ryan and raising their son, Tasha carried on and fought off her own cancer.

In the midst of her struggle, Tasha started the Calgary chapter of Rethink Breast Cancer, originally a Toronto-based non-profit that promotes breast cancer awareness among women under 45. For her work, Tasha was named one of Avenue magazine’s annual Top 40 Under 40 in November 2012. She is also one of nine women who describe their own battles against breast cancer in the documentary About Her. Today, Tasha also volunteers with the Brain Tumor Foundation of Canada, in the hope of ensuring that all families receive the support they need throughout their cancer journeys.

Tasha Westerman
Two-time breast cancer survivor, caregiver and volunteer
Cancer and fertility
Fertility is an issue I’ve seen affect many women with cancer and I don’t mind speaking from my personal experience on this topic. After my cancer returned, I remember talking with my oncologist about the impact of chemotherapy on my ability to have more children. Ryan and I wanted to have another child. My physician referred me to a fertility clinic, where I was given one day to decide whether I wanted to move forward with fertility treatment to preserve eggs. The doctor explained that my cancer was fueled by estrogen, and that fertility treatment would mean giving my body more than it had ever had before at a time when I least needed it. That made the decision easy for me: I needed to focus on living for the sake of my son, rather than try to have more children. It’s hard for Talyn to understand, he still tells me he wants a brother or sister. I’m grateful to be here, but part of me still struggles with that loss.

Women in the fight against cancer
Many women I’ve met who have been touched by cancer directly or indirectly feel empowered. They want to make a difference, and they choose to dig in and fight. Women have made a huge difference in every aspect of cancer, including research, awareness education and support. I’ve seen a tremendous amount of energy; even women who haven’t been through it themselves want to do all they can to make sure no other woman ever has to face this situation.

Taking inspiration from other women
I’ve been inspired by so many women, it’s hard to single out just one or two. I’m inspired by every selfless woman who chooses to help others, to generate change, to push forward a bold idea to make things better for someone else. I’m inspired by every woman who chooses to do this simply for the sake of helping another person.
Many women I’ve met who have been touched by cancer directly or indirectly feel empowered. They want to make a difference, and they choose to dig in and fight. I’ve seen a tremendous amount of energy; even women who haven’t been through it themselves want to do all they can to make sure no other woman ever has to face this situation.

Positivity despite adversity
I’m tremendously proud of my son, who has faced all of these wrenching changes with such bravery. He’s passionate about helping others, about trying to create change, and make a difference in the world. He and other kids in his situation have had a very challenging childhood. We need to include our kids in the search for a solution; they’ll be a huge force driving for change and it’s exciting to think about everything they will accomplish.

Choosing to be a force for positive change
One of the hardest realities in dealing with cancer is the need to face your own mortality and consider what legacy you will leave. Every individual can make a difference, and collectively, we can be a huge force for change. Everyone has a choice. You can ignore the issue, or you can work to bring about positive change, find the gaps, push forward solutions and help make the road easier for women who will have to walk it in the future.

Everyone has a choice. You can ignore the problems posed by cancer, or you can work to bring about positive change, find the gaps, push forward solutions and help make the road easier for women who will have to walk it in the future.
Professor Julia Downing is an experienced palliative care nurse, educationalist and researcher. She has been working within palliative care for 25 years, with 15 of those working internationally in Uganda, Africa, in Eastern Europe and throughout the world, developing palliative care services for adults and children.

She is an Honorary Professor at Makerere University in Kampala, Uganda and the Director of Education and Research for the International Children’s Palliative Care Network (ICPCN). She is also a Visiting Professor at Edge Hill University and the University of South Wales in the UK, and the University of Belgrade in Serbia. Professor Downing has also recently worked as the Team Leader on an EU-funded project to develop palliative care in Serbia. She is on the editorial board of the International Journal of Palliative Nursing (IJPN) and has been involved in a number of local, national and international research studies.

She also serves on the Boards of several NGOs including the International Association of Hospice and Palliative Care, Hospice in the Weald, African Palliative Care Association UK, the Palliative Care Association of Uganda and the Palliative Care Research Society. She is also an Honorary Research Fellow with the Cicely Saunders Institute of Palliative Care, Policy and Rehabilitation, King’s College London and is a Patron of Hospice23.

Professor Downing was the recipient of the IJPN’s Development Award in 2006, the Robert Tiffany Lectureship from the International Society of Nurses in Cancer Care in 2014, and the Pearl Moore “Making a Difference” International Award for Contributions to Cancer Care from the Oncology Nursing Society in 2015.

Developing palliative care in Africa and Eastern Europe

I moved to Uganda in 2001, where I have been working with different organizations such as Mildmay, the African Palliative Care Association, and Makerere University, to develop all elements of palliative care across the continent. This has included everything from technical palliative care and knowledge sharing, to health policy development and educational research. I also spent four years working in Serbia as the Team Leader on an EU project to develop palliative care in Serbia. Working with the Ministry of Health, we were tasked with creating a complete model for palliative care, so this was an enormous challenge. This included the initiation of clinical services, ensuring access to medicines, training existing doctors, nurses and social workers and getting palliative care into the undergraduate curriculum.
Unfortunately cancer can have particularly devastating implications for women in some parts of the world. In Africa, I am aware of situations where women and children have been chased out of their homes after losing a husband to cancer, particularly if there is no will.

Inequalities across the cancer care spectrum

The more I travel, the more I see enormous inequalities across the entire cancer care spectrum. In Uganda, over 70% of patients present with advanced disease because they haven’t had access to diagnostic facilities, so they are diagnosed too late. Even once diagnosed, resources and access to treatment are extremely limited. For example, in Uganda we have one cobalt radiotherapy machine for the entire country. Recently we were trying to help a young boy from one of the internally displaced camps access chemotherapy, and we managed to get him to Kampala, but it was hard to access medication. In the end at least we were able to provide palliative care, so his pain could be well-managed and he died peacefully. Inequality is particularly noticeable for the poorest and most vulnerable, who may struggle to afford even the transportation to medical facilities. In terms of palliative care, there is great inequality in care for children, something I am trying to address through my work with the International Children’s Palliative Care Network.
Women and the cancer burden

Unfortunately cancer can have particularly devastating implications for women in some parts of the world. In Africa, I am aware of situations where women and children have been chased out of their homes after losing a husband to cancer, particularly if there is no will. So these women have not only lost their husbands and their only source of income, but also their homes. Yet, I have also seen the power that women can have when they work together. In Uganda, the National Community of Women Living with HIV and AIDS has done great work advocating for improved access to care and treatment for women. I am proud to be a nurse and have the privilege of working with other incredible women. I believe as nurses, we could make a significant impact by coming together and collaboratively advocating for positive change across all aspects of cancer care.

Ensuring integrated care and equity of access to what we have already achieved

I strongly believe there needs to be a more integrated approach across the entire cancer control contingent and an urgent need to work together to diminish existing inequalities. Cancer not only has a devastating impact on patients but also the individuals and communities that surround them. Poor quality of life through sickness might mean the sole bread-winner is unable to work, and can have a negative impact for generations, particularly if school fees can no longer be afforded. In terms of palliative care, I believe there is a vital need to ensure its value is better understood, not just for end of life care but for the entire cancer journey, and for this to be reflected in cancer strategies. We have come so far in all aspects of cancer care. Although there is always more we can learn, and always more treatments needed, we could make a vast difference to many people’s lives just by ensuring integrated care and improved equity of access to what we have already achieved.

We can make a difference

I believe that each one of us can make a difference, no matter where we are working or what we are doing. Whether it’s a difference for the one individual person with cancer that you come across, or whether it’s for all of those with cancer in a hospital, a nation or the world. In Africa we have a saying, ‘if you think you are too small to make a difference, try going to bed with a mosquito’. One of my biggest inspirations is Dame Cicely Saunders, who I was fortunate enough to work with and get to know during my time at St Christopher’s Hospice. At her memorial service Dr. Robert Twycross said: ‘we too must not just talk the talk, but, like her, we must walk the walk, and stay the course, and continue the task of changing the world’. To me it’s about pressing on. It may be challenging and we may need to step outside of our comfort zones, but we can achieve great things when we work together and persevere.

“In Africa we have a saying, ‘if you think you are too small to make a difference, try going to bed with a mosquito’.
Conclusion

This report celebrates just some of the incredible contributions that women have made and are continuing to make in the fight against cancer. However, it also highlights the disproportionate impact cancer has on women directly as patients and indirectly as caregivers, as well as the substantial consequence this has for healthcare systems and broader societies worldwide. The stories and perspectives of some of today’s inspirational women provide a real-world insight into some of the greatest areas of need and ways in which they could be addressed. Whether it be as patients, caregivers, patient advocates, policy makers, doctors, surgeons or scientists, women can play a powerful and effective role in tackling the growing global cancer burden. And with the cancer burden set to worsen in the decades ahead, it is more important than ever for this change to take place.

This all reaffirms the hypotheses which first inspired this report:

1. Women are disproportionately impacted by cancer, both directly and indirectly, increasing the burden cancer places on society
2. Women are a valuable source of positive change in efforts to reduce the global cancer burden
3. Maximizing the potential of women can help to advance the fight against cancer

If women as individuals can make a positive change, then collaborative efforts could harness even greater power. Not only in reducing the health burden cancer inflicts, but also in mitigating the cost it has on broader societies and economies across the globe. In today’s interconnected world, it is also important to think more broadly about the opportunities that can lead to meaningful change.

Partnerships that look beyond traditional boundaries or approaches should be a major part of ongoing discussion and action amongst a wide range of stakeholders in the endeavour to defeat cancer.

In light of this, Roche is committed to collaborating with others who see potential in this approach, whether they be from industry, patient advocacy, women’s rights organizations, public policy or academia, to:

- Generate evidence to illustrate the direct and indirect burdens of cancer on women and the impact this has on societies across the globe
- Explore and implement initiatives with the goal of reducing the direct and indirect burdens of cancer on women
- Increase awareness and recognition of women’s contributions to the cancer field as a tremendous source of advancement
- Support health policies and programs that advance women’s role in the fight against cancer
- Inspire and empower women around the world to activate their own powers as change agents to further accelerate positive change

Roche believes that a broader set of criteria needs to be considered when assessing the impact of cancer on society, and the resulting benefit that innovation in healthcare provides. The cancer burden concerns all of us and should be addressed by more than just the medical profession. Instead, commitment and collaboration from a broad range of stakeholders is required, including those outside the traditional cancer community. Roche hopes that this report will spur such collaborations, with the goal of reducing the direct and indirect burden of cancer on women, and further enhancing women’s potential as agents of change in the fight against cancer.
Acknowledgements

Roche would like to thank the following women for taking their time and sharing their inspiring stories with us:

- Dr. Maira Caleffi
- Professor Julia Downing
- Dr. Mary Gospodarowicz
- Jana Pelouchova
- Dr. Luzia Travado
- Tasha Westermann

We further wish to thank Dr. Sanchia Aranda for her inspiring words in the foreword as well as the Union for International Cancer Control (UICC) for the opportunity to present the initial findings of this report to an expert audience at UICC Partners’ Day in 2015.
References


